Exploring mental health support for people with communication access needs:
Learnings from lived experience.

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ABSTRACT

People with communication access needs are known to face elevated risk factors for poor mental health. Existing research and reports from the Australian Disability Royal Commission identify that this group are frequently exposed to events that negatively impact mental health and wellbeing. Consequently there are social and legislative imperatives to improve the communication accessibility of mental health supports.

Research Question. This study explored mental health support for people with communication access needs with the objective of identifying potential improvements to promote inclusion in mental health care. The researcher sought the perspectives of three populations: people with communication access needs, their everyday communication partners (ECPs), and mental health workers (MHWs) to respond to the following research questions:

1. What strategies and resources for promoting the inclusion of people with communication access needs in psychoeducational support have previously been tried? Refer to the published scoping review (E. Watson et al., 2022).
2. What do people with communication access needs and their ECPs know, or want to know, about mental health and related supports and services?
3. What are the barriers and facilitators to mental health help-seeking for people with communication access needs?
4. What are the experiences, perceptions, and skills of MHWs relating to the provision of mental health care to people with communication access needs?
5. How can mental health care be adapted to improve access to systemic resources that promote the mental health of people with communication access needs?

Method. A participatory-social justice mixed methods design, underpinned by a transformative paradigm and the Human Rights Model (Degener, 2016; Mertens, 2007), was utilised to promote the inclusion of stakeholders throughout the research process. Online surveys and interviews were designed in collaboration with lived-experience research advisors and delivered to stakeholder groups: people with communication access needs (*n=9 survey, n=6 interview*), their ECPs (*n=9 survey, n=6 interview*), and MHWs (*n=24 survey, n=9 interview*). Framework Analysis (Ritchie et al., 2014) was used to analyse the interviews and survey data was analysed using descriptive statistics. Quantitative and qualitative data were integrated using the Framework approach. Levesque et al.'s (2013) Conceptual Model of Access to Health Care was applied to contextualise the findings among the empirical research, legislation, and contemporary social policy.

Findings. The scoping review revealed a range of communication access strategies (for example, using communication partner skills, providing accessible written information, and incorporating AAC) that have been utilised in research and practice to promote participation in psychoeducational interventions. Additionally, analysis of interview and survey data from the three groups yielded two key themes:

1. Experiences: Informing mental health knowledge and practice.
2. Factors that influence access to mental health care: Barriers and facilitators.

Within key theme one, data revealed that experiences informed the mental health awareness of people with communication access needs and ECPs, rather than proactive education. People with lived experience and ECPs desired more information about mental health and support pathways. MHWs' accounts revealed a lack of pre-service education to prepare them to provide communication access, they had learned on the job to accommodate communication diversity. Data yielded insights into positive and negative influences on mental health in people with communication access needs. Social connectedness had substantial positive impacts, while loss of autonomy presented negative impacts for lived-experience participants. In key theme two, barriers and facilitators occurred across five sub-themes: Communication Access Factors, Systems Factors, ECP Supporter Factors, MHW Practitioner Factors, and Environmental Factors.

Conclusions. Mental health support can benefit people with communication access needs, and a range of strategies are available to enhance communication access. Research that prioritises the perspectives of lived-experience stakeholders provides rich information about the barriers to engaging with mental healthcare. Applying the Conceptual Model of Access to Health Care (Levesque et al., 2013) clarified the pinch-points encountered by people with communication access needs across the mental health system. Recommendations for ECPs, MHWs, and disability and mental health service providers have been developed to improve inclusivity in mental healthcare for people with communication access needs.

DECLARATION

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university

2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and

3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: Eleanor Watson

Date: 02/06/2024

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ACRONYMS

3DN	Department of Developmental Neuropsychiatry, University of NSW
AAC	Augmentative and Alternative Communication
AHRC	Australian Human Rights Commission
AIHW	Australian Institute of Health and Welfare
CA	Communication Assistant
CALD	Culturally and Linguistically Diverse
CGF	Calouste Gulbenkian Foundation
CRE-DH	Centre for Research Excellence in Disability Health
CRPD	United Nations Convention on the Rights of Persons with Disability
CTPRG	Clinical Trials Project Reference Group
DIRC	Disability Inclusion Resource Centre, South Australia
ECP	Everyday Communication Partner
GCAPP	Global Consortium for the Advancement of Promotion and Prevention in Mental Health
GP	General Practitioner
HREOC	Human Rights and Equal Opportunity Commission
MHW	Mental Health Worker
NHMRC	National Health and Medical Research Council
NMHC	National Mental Health Commission
NSW	New South Wales
PBS	Pharmaceutical Benefits Scheme
SA	South Australia
UDHR	Universal Declaration of Human Rights
WHO	World Health Organization

GLOSSARY OF TERMS

Accessibility: Accessibility refers to the extent to which a person with disability can use or access services, environments, and information on an equitable basis to others without disability.

Augmentative and alternative communication: Augmentative and Alternative communication (AAC) refers to a range of unaided (facial expressions, gestures, manual signs, speech, vocalisations) and aided (assistive technologies for communication) communication modes. These strategies can be used in combination to comprise a multimodal system of communication.

Better Access to Mental Health Care: The Better Access to Mental Health Care initiative facilitates access to funds to subsidise psychological services through the Medicare health insurance scheme.

Communication Access: Communication access refers to the ability of people to understand information and to be understood by other people. The United Nations Convention on the Rights of People with Disability (UNCRPD, 2006) refers to the right of people with disability to seek, receive and impart information on an equal basis with other people.

Communication Access Needs: People with communication access needs are described as individuals who “cannot rely on speech alone to be heard and understood” (Communication First, 2023). People with communication access needs use adaptations to assist in meeting the everyday demands of communication, such as expressing or understanding spoken or written information.

Disability: In this thesis the UNCRPD definition of disability has been adopted, recognising the interaction between an individual’s physical, intellectual, cognitive, sensory, and psychosocial functioning and elements in the environment, including attitudes, which may inhibit equitable participation and access.

Disability Royal Commission: The Disability Royal Commission refers to the Australian Royal Commission into the Abuse, Neglect and Exploitation of People with Disability, which was established in April 2019, with final recommendations delivered in September 2023.

Everyday Communication Partners: Everyday communication partners (ECPs) are those people who have a supportive relationship and frequent contact with a person with communication access needs. ECPs include natural supports such as family members, spouses, and friends, as well as paid people such as disability support workers.

Medicare: Medicare is the Australian universal health insurance scheme. Funds from the scheme is contributed to cover the full or partial cost of eligible health services.

Mental Health: Mental health refers to the health of one's mind, it includes the emotions, thoughts, behaviour, and capacity to cope with stressors. An interaction of biological, psychological and social factors contributes to an individual's state of mental health.

National Disability Insurance Agency (NDIA): The National Disability Insurance Agency (NDIA) is the statutory agency that administers the funds and operation of the National Disability Insurance Scheme (NDIS).

National Disability Insurance Scheme (NDIS): The National Disability Insurance Scheme (NDIS) provides funding for individualised supports for Australians with disability who are eligible to access the scheme.

NDIS Independent Review: The NDIS Independent review was established in October 2022 with final recommendations released in December 2023. The purpose of this review was to examine the design, operations and sustainability of the scheme.

Wellbeing: Wellbeing is a positive state that includes quality of life and personal autonomy in the matters that influence one's life. Wellbeing is determined by a complex interaction of social, economic, and environmental factors. Emotional wellbeing refers to a person's capacity manage feelings constructively and maintain a sense of purpose or meaning.

CHAPTER 1. INTRODUCTION

1.1 Background

Mental health is a foundational factor in human engagement, societal contribution, self-determination, regulation of emotional states, and personal satisfaction with life. The World Health Organization (WHO) provides the following conceptualisation of mental health:

> … a state of wellbeing in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to contribute to their community.
> (World Health Organization & Calouste Gulbenkian Foundation [WHO & CGF], 2017)

This conceptualisation does not infer an absence of mental illness, rather it recognises that people who experience mental illness have the capacity to live fulfilling lives (Keyes, 2005; WHO & CGF, 2017). It makes the multi-dimensional connection between mental health and wellbeing.

The social and economic consequences of poor mental health are experienced collectively at individual, familial, and societal levels (Global Consortium for the Advancement of Promotion and Prevention in Mental Health [GCAPP], 2009). However, people who experience social inequality are often disproportionately affected by the impacts of poor mental health (GCAPP, 2009; WHO, 2021a). Access to the conditions that promote optimum mental health and wellbeing is a fundamental right to be afforded to all citizens of all nations, during all stages of life (WHO & CGF, 2014). Consequently, where a population experiences a greater prevalence of risk factors for poor mental health, access to the means to mediate and promote positive mental health and wellbeing must be provided (GCAPP, 2009; WHO, 2021a). Access to education, housing, employment, financial security, as well as meaningful social connections are determining factors in mental health and should be considered in mental health promotion strategies (WHO & CGF, 2014). As such, when individuals experience decreased mental health, they have the right to access support to restore mental health and improve wellbeing (National Mental Health Commission [NMHC], 2023; WHO, 2021a).

People with intellectual and developmental disability are persistently identified as a population under-served in mental health care delivery in Australia (Human Rights and Equal Opportunity Commission [HREOC], 1993; NMHC, 2014; New South Wales [NSW] Department of Health, 1983; Weise et al., 2021). While concerted efforts have been made to examine the mental health care help-seeking experiences of people with intellectual disability (Lake et al., 2021; Weise et al., 2018, 2021; Whittle et al., 2018), there is a lack of empirical research focused on the mental health help-seeking experiences of people with disabilities who experience significant communication difficulties unrelated to diagnoses of intellectual disability.

1.1.1 Communication and Mental Health

Communication is an underpinning factor in all human interaction (Light, 2003). It facilitates social connectedness (Callus, 2017; Therrien, 2019), the sharing of knowledge and the pursuit of information (Donaldson et al., 2023; Turnbull et al., 2022), and allows the expression of desires, preferences and identity (Sellwood et al., 2022; Williams et al., 2009). As such communication is a defining aspect of mental health. Communication allows individuals to express emotions, seek support from others and address concerns that impact mental health and wellbeing (E. Watson et al., 2021). Communication is foundational in developing and maintaining the interpersonal relationships that remediate psychological distress. This human connectedness has protective benefits for mental health and is important in sustaining wellbeing by upholding intrinsic personhood and human-value of persons with disability (Petroutsou et al., 2018; J. Watson et al., 2017). These human connections rely upon the communicative awareness of the people involved to identify and resolve misunderstandings, fostering trust, reciprocity, and friendship (Therrien, 2019).

Communication is a key factor in sharing one’s feelings and experiences, developing coping strategies, and managing stressors (Hagiliassis, Gulbenkoglu, et al., 2005; Hagiliassis & Di Marco, 2017; E. Watson et al., 2021). Dialogical processes which are heavily dependent on speech to facilitate a deeper understanding of the thoughts and behaviour of oneself and of others. Sharing the narratives of our lives enables us to make meaning of our experiences and integrate achievements and challenges into a positive conceptualisation of self (Averill et al., 2013). While psychotherapeutic relationships rely on both verbal and non-verbal models of communication, speech is by far the dominant mode of expression (Del Giacco et al., 2019; Noyes & Wilkinson, 2022). When speech is unavailable or unreliable, communication requires an intentional approach to ensure that the skills to reconcile distressing emotions and seek mental health care are conveyed in a manner that is useful and effective (Hagiliassis, Gulbenkoglu, et al., 2005; E. Watson et al., 2022). In some instances, non-verbal cues or behaviour may provide a better understanding of mental health status than spoken words (Bowring et al., 2019; Painter et al., 2018). The connection between communication and mental health is multifaceted, consisting of protective and remediating benefits. As such, approaches to mental health support require intentional consideration of the challenges faced by individuals with communication access needs.

1.1.2 People with Communication Access Needs

People with communication access needs are described as individuals who “cannot rely on speech alone to be heard and understood” (Communication First, 2023). People with communication access needs use adaptations to assist in meeting the everyday demands of communication such as sharing information, expressing wants and needs, and establishing and maintaining social relationships (Beukelman & Light, 2020; Light & McNaughton, 2014). Some people with communication access needs also use adaptations to assist them in understanding spoken and/or written information (Solarsh & Johnson, 2017). Communication access needs may originate from motoric, cognitive, sensory, psychological, or environmental factors (Beukelman & Light, 2020). They may be temporary (e.g., resulting from intubation for a surgical procedure), acquired (e.g., due to a brain injury or progressive neuromuscular condition), or lifelong (e.g., occurring alongside a developmental condition such as cerebral palsy, intellectual disability, or autism) (Light et al., 2019). The population of people with communication access needs is diverse; comprising people across a range of ages, and social, cultural, and linguistic groups (Amery et al., 2022; Beukelman & Light, 2020). Accordingly, the amount of support required to manage communicative participation is varied (Blackstone et al., 2007).

Terminology. With diversity among the population of people with communication access needs, there are diverging opinions regarding the terminology used to describe this group, though strengths-focused and anti-ableist terminology is preferred (Donaldson et al., 2023; Zisk & Konyn, 2022). There is a growing movement towards terminology that is defined by lived-experience perspectives (Communication First, 2023; Speech Pathology Australia, 2024; Zisk & Konyn, 2022) and the social model of disability (Dee-Price et al., 2021). Many people with communication access needs are multimodal communicators, using augmentative and alternative communication (AAC); a combination of unaided and aided communication strategies to meet their communication requirements. Throughout the thesis, terminology that reflects current community preferences (Communication First, 2023) has been used and conforms to academic conventions of person-first language. The terms *people with communication access needs*, *people who use AAC*, *person,* and *lived experience* have been used throughout this thesis. These terms are not abbreviated in the thesis. Some documents that were developed earlier in the project used the term complex communication needs as this was the term used in the AAC field and the AAC journal, and was the preferred terminology of the research advisors and community at the time (Speech Pathology Australia, 2024). This shift in terminology demonstrates a commitment to representing the perspectives of people with communication access needs.

1.1.3 Augmentative and Alternative Communication (AAC)

People who experience communication access needs often use AAC to circumvent the challenges that may arise in communicative interactions (Beukelman & Light, 2020). AAC refers to a range of communication strategies that aim to enable greater communicative participation and self-expression, broadening the scope of potential communication partners (McNaughton et al., 2019). AAC comprises aided and unaided strategies to facilitate more effective communication. Unaided strategies do not require the use of an external aid or assistive device, such as speech, pointing, gesturing, vocalising, and facial expression (Beukelman & Light, 2020). An extensive range of aided communication systems also exist, from low-tech graphic symbol boards and books to higher-tech computerised speech-generating systems that enable the user to communicate unlimited messages via a keyboard (Beukelman & Light, 2020; Ripat et al., 2019).

In most instances, people with communication access needs will use a range of strategies to get their message across, depending on the communicative task, environmental demands, and familiarity of the communication partner (Williams et al., 2009). The use of a combination of aided and unaided methods of communication is referred to as multimodal communication (Beukelman & Light, 2020). People who use AAC identify the importance of having multiple modes of expression that are received and respected by communication partners, as no singular approach to communication is sufficient to fulfil all communicative requirements (Williams et al., 2009).

1.1.4 Everyday Communication Partners

Communication partners are those people who interact with people with communication access needs. They are referred to as partners because communication is a two-way process, requiring collaboration to co-construct a jointly understood meaning (Beukelman & Light, 2020). *Everyday communication partners* (ECPs), the term used throughout this thesis, are those who have a supportive relationship and frequent contact with a person with communication access needs. ECPs include natural supports such as family members, spouses, and friends, as well as paid people such as disability support workers. ECPs play an important role in facilitating communication with unfamiliar people and demonstrating multimodal communication strategies, including AAC (Beukelman & Light, 2020). Due to their close affiliation with the person, ECPs are likely to have deep knowledge about their communication styles and are well positioned to notice changes in physical and emotional states. Many people with communication access needs rely on ECPs to provide information, assistance, and advocacy to promote their health and wellbeing (Brolan et al., 2012; Halmetoja et al., 2023; Nicholas et al., 2017). ECPs can, through their approach and responsiveness to communication, empower the person in making choices relating to health and wellbeing (Paynter et al., 2022; J. Watson et al., 2017). However, ECPs may lack awareness of mental health issues, resulting in apprehension about referring to mental health care services for additional help (Costello et al., 2007; Holub et al., 2018; Rose et al., 2007; E. Watson et al., 2021).

1.1.5 Communication Access

Communication access has been summarised as the ability to understand and to be understood (Solarsh & Johnson, 2017). The communication access movement seeks to enshrine and protect communication rights with similar legislation and standards as exist for physical access (Speech Pathology Australia, 2018). The case for improved communication access has been propelled by the recognition of communication and access to human rights. The United Nations Universal Declaration of Human Rights ([UDHR], 1948) in Article 19 first identified the right of all people to freedom of opinion and expression, to hold opinions and share information. The United Nations Convention on the Rights of Persons with Disability ([CRPD], 2006) expanded upon the Universal Declaration to specify actions for State Parties to promote communication accessibility. Article 21 of the CRPD states that people with disability have the right to seek, receive, and impart information and ideas on an equal basis to all other persons, using communication methods of their choosing (CRPD, 2006). Specific actions to promote communication access are: a) providing information intended for the general public in accessible formats; b) accepting and enabling the use of AAC, braille, sign languages, and other modes of communication in official dealings; c) imparting the responsibility of service providers to offer information and services in accessible formats; d) supporting and promoting accessibility of online platforms (CRPD, 2006). Communication accessibility measures also promote access for people with low literacy, culturally and linguistically diverse populations, as well as Deaf and hard-of-hearing communities (McLeod, 2018; Mitchell, 2021; Solarsh & Johnson, 2017). Taking action to preserve and promote communication rights facilitates the participation of people with communication access needs in the community (Taylor et al., 2021). To date, there is limited evidence of efforts to improve communication access in mental health support provision (Dew et al., 2018; Newman et al., 2022; E. Watson et al., 2022).

1.1.6 Mental Health of People with Communication Access Needs

People with disabilities report mental health problems and psychological distress at a greater prevalence than the broader Australian community (Australian Institute of Health and Welfare [AIHW], 2022). In a recent Australian survey of health, 40% of respondents with severe and multiple disabilities, including those with communication support needs, reported high or very high levels of psychological distress (AIHW, 2019). This statistic does not represent those who were unable to self-report and therefore the percentage is likely to be higher. Previous research finds that people with communication disability face additional susceptibility to risk factors for poor mental health, such as experiences of discrimination and stigma, physical health concerns, challenges to developing close relationships, and reduced engagement in employment and education (Di Marco & Iacono, 2007; Hagiliassis, Gulbenkoglu, et al., 2005; Richardson et al., 2019; Sellwood et al., 2022; Therrien, 2019). Increased risk of poor mental health is further implicated by increased levels of exposure to trauma and abuse for people with communication access needs (Bell & Cameron, 2003; Centre of Research Excellence in Disability and Health [CRE-DH], 2021; Collier et al., 2006; Ottmann et al., 2017; Powers et al., 2002), reduced self-determination (Di Marco & Iacono, 2007; J. Watson, 2023), loneliness (Balandin et al., 2006; Cooper et al., 2009; Petroutsou et al., 2018), and challenges to establishing approaches to convey and regulate emotions (Hagiliassis, Gulbenkoglu, et al., 2005; Hsieh et al., 2012; Kneebone, 2016).

In the Australian context, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) highlights the breadth of disadvantage experienced by many people with disabilities (CRE-DH, 2021; Commonwealth of Australia, 2020). A further risk to wellbeing is presented when a person with communication access needs is not equipped with the necessary vocabulary to broach issues that impact mental health and wellbeing (Bell & Cameron, 2003; Collier et al., 2006; Johnson & Yee, 2020; E. Watson et al., 2021) and when they lack trusted or skilled communication partners with whom to discuss issues such as grief and loss (Dark et al., 2011). Additionally, progressive communication loss related to both acquired and developmental conditions may place further pressure on mental health and wellbeing (Aoun et al., 2015; Baker et al., 2021; Dark et al., 2011; Northcott et al., 2017). Despite this heightened exposure to risk factors for mental ill-health, people with communication access needs are under-represented in their use of services and programs that aim to address issues pertaining to reduced mental health and wellbeing (Foley & Trollor, 2015; Holub et al., 2018; Howlett et al., 2015; Weise, Cvejic et al., 2020; Weise et al., 2021).

1.1.7 Imperatives for Access to Mental Health Care

In Australia, there is a legislative and social imperative for the provision of accessible mental health support for people who experience disabilities and mental health problems. This imperative is driven by statistical data indicating a high prevalence of severe psychological distress among people with communication access needs (AIHW, 2019), as well as, legislation (Disability Discrimination Act, 1992; CRPD, 2006), policy (Australian Government, 2010; Commonwealth of Australia, 2021; SA Health, 2019; WHO, 2021a), and systemic inquiries (Commonwealth of Australia, 2023a; HREOC, 1993; NMHC, 2014; NSW Department of Health, 1983). However, these various drivers have not positively influenced the quality or quantity of services required to assist people with communication access needs to address issues of mental health and wellbeing (Howlett et al., 2015; NMHC, 2023; Weise et al., 2021).

The Australian Government ratified the United Nations CRPD in 2008, heralding the commencement of a period of reform and commitments to strategic action to promote the human rights of people with disabilities (Commonwealth of Australia, 2011; McCallum, 2020). Endorsement of the CRPD required the Australian government to commit to action toward the promotion of a human rights orientation in policy, legislation, and service provision (CRPD, 2006). Two of the critical strategic commitments underpinning the provision of services to people with disability in Australia are the *National Disability Strategy* (Commonwealth of Australia, 2011, 2021) and the *National Disability Insurance Scheme* (National Disability Insurance Scheme [NDIS] Act, 2013). The Disability Strategy and NDIS Act make specific provisions for the social and economic resources that enable greater participation of people with disabilities in Australian society. The NDIS, under the direction of the federal National Disability Insurance Agency, delivers individualised supports to eligible Australians with disability, including psychosocial disability. However, the recent independent review of the NDIS indicates shortcomings in the delivery of service to people who experience co-existing disability and mental ill-health (Commonwealth of Australia, 2023e). The Disability Strategy also highlights the need for improvements in the mental health system, with a key health and wellbeing policy priority being dedicated to improving accessibility of mental health care for people with disability (Commonwealth of Australia, 2021).

1.2 Theoretical Overview

Communication stands at the intersection of mental health and human rights. The journey to mental well-being is inextricably connected to the ability to convey the emotions, thoughts, and concerns that impact upon wellbeing, and to be understood in return. For people with communication access needs, this fundamental aspect of human experience can present significant barriers. In this theoretical overview, we delve into the Transformative Paradigm (Mertens, 2007) and the Human Rights Model of Disability (Degener, 2016) and the implications of these theoretical perspectives for mental health care provision. The theoretical foundation of the research project is congruent with Levesque et al.'s (2013) Conceptual Model of Access to Health Care, which guides the discussion of research findings in Chapter six. The Conceptual Model of Access to Health Care offers a lens through which we can conceive a more inclusive and equitable system of mental health care for people with communication access needs, and form recommendations for policy and practice.

1.2.1 Transformative Social Justice Paradigm

A paradigmatic approach was adopted to ensure a cohesive theoretical underpinning for the study and methodology clearly oriented towards the purposes of social justice and meeting the objectives of people with lived experience of communication access needs. Theories and models are integrated within the study to ensure that the exploration of the phenomenon is consistent with the transformative paradigm (Mertens et al., 2010), which provides a philosophical scaffold that encompasses axiology, ontology, and epistemology comprising a cohesive worldview. This enables researchers to address systemic inequity and make methodical decisions that are attuned to the requirements of communities involved in the research (Mertens, 2007).

1.2.2 Human Rights Model of Disability

The Human Rights Model of Disability (Degener, 2016), embedded in the principles of dignity, equity, and inclusion, posits that every individual possesses rights to accessibility, autonomy, and full participation in society. The study applies the Human Rights Model of Disability to demonstrate the imperative for accessibility measures in mental health care, and because the assumptions of the transformative paradigm intersect with the endeavour to promote human rights through formal channels such as the CRPD (Mertens et al., 2010). The Human Rights Model of Disability has developed within the context of the social model of disability (Oliver, 2009), a model with continued relevance in understanding the systemic oppression that people with disability face in structures that are not designed with diversity in mind (Berghs et al., 2019; Lawson & Beckett, 2021; Shakespeare, 2018). The Human Rights Model extends upon the social model as a tool to implement the rights codified by the CRPD; in civil and political, as well as economic, social, and cultural life (Degener, 2017). In the context of this study, the Human Rights Model attends to both the entitlement to equal access to health care and denial of human rights as a contributing factor in psychological distress leading people to seek mental health support.

The CRPD provides the framework for Australian legislation regarding equitable access to civil, political, economic, social, and cultural entitlements (CRPD, 2006). Although Australia became a signatory of the CRPD 2008, some articles are believed to be in breach or are yet to be fully implemented in Australian law (McCallum, 2020). Presently action is underway to develop a federal Australian Human Rights Act, which would further progress the implementation of human rights legislation (Australian Human Rights Commission [AHRC], 2022). Multiple articles from the CRPD incite the right to access mental health care, key among which are: Article 9 - Accessibility; Article 21 – Freedom of expression and opinion, and access to information; Article 25 – Health; and Article 26 – Habitation and rehabilitation (CRPD, 2006). The literature review in Chapter 2 will expand upon the rights pertinent to people with communication disability in seeking mental health care and maintaining optimum mental wellbeing.

1.2.3 Conceptual Model of Access to Health Care

To examine the accessibility of mental health support for people who experience communication access needs, a Conceptual Model of Access to Health Care was utilised (Levesque et al., 2013). This dynamic model of access has been used across a variety of health care settings with a multitude of populations, including mental health care (Cu et al., 2021; Davy et al., 2016; Haggerty et al., 2020; Schwarz et al., 2022; Song et al., 2019). This model has utility as it examines service and system factors, as well as personal and community factors that may impact access. The authors of the model propose six stages in the trajectory of health care practice that can impact access: 1) emergence of mental health care needs; 2) perception of mental health support needs and desire for care; 3) mental health care seeking; 4) mental health care reaching; 5) mental health care utilisation; and 6) mental health care consequences (Levesque et al., 2013). The underpinning assumption of the model is that access to quality health care is a human right to be afforded to all populations.

1.3 Purpose of the Study

The purpose of this study was to explore the intersecting perspectives of three groups – people with communication access needs, their ECPs, and Mental Health Workers (MHWs) – to better understand issues impacting access to mental health supports for people with communication access needs. The overarching objective was to identify how mainstream mental health supports can be adapted to improve access to the resources that promote the mental health of people with communication access needs.

1.4 Research Aims

The aims of the research project were:

- To conduct a comprehensive scoping review of literature on the inclusion of people with communication access needs in psychoeducational mental health support.
- To explore the issues that impact the mental health help-seeking of people with communication access needs, such as mental health literacy among support networks.
- To investigate the current skills, experience, and perceptions of MHWs regarding working with people who experience communication access needs.
- To examine the ECP and MHW practices that help or hinder mental health care access for people with communication access needs.
- To establish an understanding of the systemic resources that improve access to services and promote the mental health of people with communication access needs.

1.5 Research Questions

This study explored mental health support for people with communication access needs with the objective of identifying potential improvements to promote inclusion in mental health care. The researcher sought the perspectives of three groups – people with communication access needs, their ECPs, and MHWs – to respond to the following research questions:

1) What strategies and resources for promoting the inclusion of people with communication access needs in psychoeducational support have been tried already?
2) What do people with communication access needs and their ECPs know, or want to know, about mental health and related supports and services?
3) What are the barriers and facilitators to mental health help-seeking for people with communication access needs?
4) What are the experiences, perceptions, and skills of MHWs relating to the provision of mental health care to people with communication access needs?
5) How can mental health care be adapted to improve access to systemic resources that promote the mental health of people with communication access needs?

1.6 Rationale

This research builds upon the researcher’s previous Honours study which explored the views and perceptions of people with communication access needs regarding mental health and wellbeing (E. Watson, 2018; E. Watson et al., 2021). The previous study found that while participants experienced events that impacted their mental health, they encountered significant barriers to obtaining mental health care. A possible component of this issue was suggested as a lack of awareness among people with communication access needs and their ECPs about the indicators of poor mental health and help-seeking pathways. Additionally, some MHWs may not have been aware of the adaptations required to include a person with communication access needs in psychotherapeutic programs and other mental health services.

There are social, legislative, and policy-based imperatives to improving the communication accessibility of mental health support (Disability Discrimination Act, 1992; Commonwealth of Australia, 2021; CRPD, 2006; WHO, 2021b). Existing research (CRE-DH, 2021; Collier et al., 2006; Ottmann et al., 2017; Petroutsou et al., 2018; Powers et al., 2002; E. Watson et al., 2021) and government inquiries (Commonwealth of Australia, 2023a) highlight frequent exposure to events that negatively impact the mental health and well-being of people with communication access needs. However, mental health care remains inaccessible to much of this population.

1.7 Significance of the Study

Current research has not yet provided an in-depth exploration of access to mental health support as perceived by people with communication access needs. While there are practice guidelines available to support access to mental health services, these have been generated by experts in the field rather than those with lived experience (Department of Developmental Disability Neuropsychiatry [3DN], 2014, 2016, 2017; Hagiliassis et al., 2006). Engaging with the populations who experience access issues directly can establish a deeper understanding of the factors that inhibit or enhance access (Mertens, 2007; Seekins & White, 2013; Walmsley et al., 2018). Additionally, incorporating the perspectives of practitioners who deliver mental health care to the general population may provide insight into some of the systemic barriers and facilitators. Solutions to access issues gain salience when they are generated by the populations concerned (Mertens et al., 2014).

The findings of this study advance the body of knowledge currently guiding mental health practitioners in their interactions with people with communication access needs. This PhD research project drew upon existing evidence to inform the study design, building upon the current understanding of what contributes to good mental health care for people with communication access needs.

1.8 Thesis Synopsis

This thesis consists of eight chapters. ***Chapter 1*** has introduced the research project, presenting the background to the study, problem statement, and significance of the research project, concluding with this overview of the thesis chapters.

The literature review in ***Chapter 2*** introduces central issues related to mental health service provision for people with communication access needs. Key aspects include the historical basis for the provision of mental health care provision, the connection between human rights and mental wellbeing, a review of human rights related to the accessibility of mental health care, and a framework to explore access to mental health care.

The scoping review in ***Chapter 3*** is a pre-print version of the scoping review titled *Improving communication access in psychoeducational interventions for people with complex communication needs: A scoping review and stakeholder consultation* (E. Watson et al., 2022) which was published in the journal *Disability and Rehabilitation*. The scoping review was developed in response to research question one and explores the communication access strategies that have been used in psychoeducational interventions with people with communication access needs.

Chapter 4 details the design of this research project, including detailed descriptions of the underpinning theoretical framework and methodology. This chapter also explains the research methods, recruitment approaches, data collection strategies, and analysis of data. An overview of the characteristics of each of the three groups is included.

The research findings are presented in ***Chapters 5*** and ***6***. Chapter 5 examines the key theme Experiences: Informing Mental Health Knowledge and Practice. The chapter explores the perspectives of each group to define mental health, and the connection between experience and knowledge about mental health supports. Chapter 6 explores the second key theme of the study, Factors That Influence Access to Mental Health Care: Barriers and Facilitators.

In ***Chapter 7,*** the findings are discussed, with the Person-centred Conceptual Model of Access to Health Care (Levesque et al., 2013) providing a scaffold to organise the discussion along a trajectory of mental health care help-seeking. Further, this chapter provides key recommendations for policy and practice in mental health care provision for people with communication access needs.

Chapter 8 provides concluding statements, emphasising the significant contributions of this research to the field of knowledge about how to improve access to mental health care for people with communication access needs.

CHAPTER 2. LITERATURE REVIEW

Communication is an essential component in the maintenance of mental health and wellbeing (Hagiliassis & Di Marco, 2017; E. Watson et al., 2021). Speech is the dominant mode of contemporary mental health support provision (Del Giacco et al., 2019). Previous studies have examined access to mental health care, directed toward understanding and addressing challenges faced by various populations across the lifespan (Cu et al., 2021). While this field of inquiry acknowledges and addresses the mental health needs of various populations, the experiences of adults with communication access needs remain under-explored. This often-overlooked demographic comprises individuals who encounter significant difficulties in the use of speech for expressive and/or receptive communication. The intersection of mental health and communication access needs presents a unique juncture characterised by unacknowledged accommodations, barriers to support, and under-servicing. This literature review explores the existing body of research to elucidate the key issues relating to mental health care provision among adults with communication access needs. To develop a thorough understanding of the mental health care landscape for people with communication access needs it is essential to explore the history of mental health care, the role of human rights, challenges to accessing services, and communication access in mental health care. The literature review concludes with an examination of a model that supports the analysis of health care barriers, with a view to enhancing access and inclusion. The literature has been continuously updated and synthesised throughout the course of the research project to provide a contemporaneous summary of the evidence regarding mental health support for people with communication access needs.

This literature review builds upon the researcher’s previous pilot study which explored the views and perceptions of people with communication access needs regarding mental health and wellbeing (E. Watson, 2018; E. Watson et al., 2021). The previous study found that while participants experienced events that impacted their mental health and wellbeing, they encountered significant obstacles in obtaining mental health support. The threats to their mental wellbeing included experiences of discrimination and stigma, physical health concerns, challenges to developing close relationships, and reduced engagement in employment and education (Hagiliassis, Gulbenkoglu, et al., 2005; Hagiliassis & Di Marco, 2017; Richardson et al., 2019; E. Watson et al., 2021). Furthermore, mental wellbeing was impacted by reduced self-determination (Di Marco & Iacono, 2007; E. Watson et al., 2021), loneliness (Balandin et al., 2006; Petroutsou et al., 2018), and elevated exposure to trauma and abuse (Bell & Cameron, 2003; Collier et al., 2006; Commonwealth of Australia, 2023c; CRE-DH, 2021; Ottmann et al., 2017; Powers et al., 2002). Despite elevated exposure to risk factors for mental ill-health, Australians with communication access needs are under-represented as consumers of mental health care services (Di Marco & Iacono, 2007; Howlett et al., 2015). Many of the threats to mental wellbeing confronted by people with communication access needs relate to infringements upon human rights. Additionally, access to mental health care is a human rights issue (CRPD, 2006; WHO & CGF, 2014), which governments throughout Australia have sought to ameliorate with legislation and policy (Australian Government, 2010; Disability Discrimination Act, 1992; NDIS Act, 2013; Commonwealth of Australia, 2021). These legal and ethical imperatives exist to ensure equitable access to mental health care for people with communication access needs. However, people with communication access needs continue to experience marginalisation and exclusion from services. This literature review will examine the relationship between human rights and access to mental health care, identifying the conditions that underpin optimal mental health and wellbeing.

This chapter provides an overview of the historical context of mental health care provision for people with disabilities and explores the association between human rights and mental health, including an analysis of legislation and policy associated with the provision of mental health care. The chapter also establishes the basis for the scoping review in Chapter 3, which explores strategies to improve communication access in mental health psychoeducation for people with communication access needs.

2.1 The History of Mental Health Care for Australians with Disability

Historical information does not provide a meaningful distinction between disability and people with communication access needs, instead focusing on the perceived capacity of individuals to contribute to society (Jolly, 2022). Therefore, in the following section on the history of mental health care, people with communication access needs represent a subgroup among the broader population of people with disability. The provision of mental health services for people with disability in Australia has shifted from routine institutionalisation of people with disability alongside those with mental illness, to a system of mental health care that divides services among these groups with limited recognition of co-existing support needs (Hallahan, 2021; Weise et al., 2021). This historic overview of mental health care focuses on more recent models of service provision, from the devolution of institutional care from the 1970s to 1990s, to present day models of funding and support provision. Accounts of the early history of mental health service provision for people with disability are focussed on South Australia, the state where this research was undertaken. However, these practices are broadly reflective of those throughout Australia (Gerrand et al., 2012). The purpose of providing an overview of the historic approaches to mental health care for people with disability is to better understand the legacy of these practices on current barriers to mental health care access for people with communication access needs.

2.1.1 Institutional Care: A Persistent Legacy

From the occupation of Australia by British colonists in 1787 through to the 1970s the dominant model of services for people with physical, intellectual, or psychosocial disability deemed unable to contribute to the betterment of the colony, according to the views of the time, was segregation in state-run institutions, asylums and hospitals (Bell, 2003; Goldney, 2007; Hallahan, 2021). The South Australian Lunacy Act was passed in 1846, in the first decade of the colony (Goldney, 2007). Under the Lunacy Act, there was little distinction between the impacts of poverty, aging, mental illness, and disability (Goldney, 2007). People with disability were commonly admitted to the Adelaide Destitute and Lunatic Asylum on the basis that their families were unable to care for them (Bell, 2003; Lunacy Act, 1847). In 1858, long-term accommodation in the form of specialised hospital wards was established for adults and children with lifelong disability (Jolly, 2022; Piddock, 2011). In subsequent years several institutions were opened to house people with disability; the Home for Incurables, Minda Home for Weak-Minded Children, and Magill Old Folks' Home (Disability Information & Resource Centre [DIRC], 2014; Jolly, 2022; Piddock, 2011). People with mental illness continued to be housed in a succession of asylums until the establishment of the Enfield Receiving House. This institution operated between 1922 and 1982, housing and treating people with intellectual disability and psychosocial disability together under the Mental Deficiency Act (George, 2014).

This account of South Australian disability and mental health services highlights a history of congregate treatment, confining people with disability and those with mental ill-health in institutions, with little distinction of individual support requirements (Bell, 2003). The greater objective of the institutions was to educate and contain people with disability under a social policy that enforced the eugenics agenda (Hallahan, 2021; Lewis, 1988). To the current day, most of the mental health legislation is dedicated to outlining conditions of involuntary detainment and treatment, rather than promoting and mandating inclusive mental health care systems (Mental Health Act, 2009; Pandos et al., 2023).

2.1.2 Deinstitutionalisation and the Emergence of Rights Movements

In the 1950s, the separation of services for individuals with intellectual disability and psychosocial disability commenced in Australia (DIRC, 2007; Lewis, 1988). However, the model of large institutional care for people with disability and mental illness was prevalent until the 1970s and 1980s when the disability and mental health consumer rights movements emerged. Increasing awareness of the human rights of people with disability and people with mental illness was provocation for Australian constituencies to examine disability and mental health policy and service provision (Disability Royal Commission, 2021; HREOC, 1993; NSW Department of Health, 1983). Inquiry and subsequent reform of the Australian mental health system coincided with the release of the United Nations Principles for the Protection of Persons with Mental Illness (United Nations, 1991). The changes in Australian policy to deinstitutionalise disability and mental health services reflected the global movement to improve the treatment of people experiencing mental ill-health and their supporters (Weise et al., 2021). The National Inquiry into the Human Rights of People with Mental Illness, also known as the Burdekin Report, was a pivotal moment in mental health care in Australia (Gerrand et al., 2012; HREOC, 1993). As a result of the inquiry the mental health system was centralised and Australia's first federal mental health strategy was released in 1993 (Gerrand et al., 2012; Rosen, 2006).

The National Inquiry into the Human Rights of People with Mental Illness formalised the process of deinstitutionalisation of people with disability and mental ill-health with a greater focus on community-based supports (HREOC, 1993). The emerging distinction between the differing requirements of these populations was welcomed by MHWs and service users (Weise et al., 2021). The inquiry recommended that people with disability experiencing mental health problems should be treated by community-based, disability-specific services. However, under this model of separated mental health care, services became siloed resulting in poor MHW awareness of the various specialists and a lack of integration of services (Weise et al., 2021). Separation of specialist disability services resulted in a lack of choice regarding service providers and treatment options, as well as extensive wait times for assistance.

Australia's Disability Strategy (Commonwealth of Australia, 2011, 2021), the National Disability Insurance Scheme (NDIS) Act (2013) and the Contributing Lives, Thriving Communities Report (NMHC, 2014) provide the direction for mainstream agencies to develop inclusive, accessible approaches to mental health service provision. Implemented in 2006, the Better Access to Mental Health Care initiative represented major reform to public funding for mental health services under Medicare, intending to make private mental health services more financially accessible (Council of Australian Governments, 2006; Gerrand et al., 2012). The systemic reforms to mental health care of the 1990s and 2000s set the underpinnings of the current Australian mental health system.

2.1.3 Contemporary Mental Health Care Provision

As introduced in the previous chapter, Australia's Disability Strategy (Commonwealth of Australia, 2011, 2021) and NDIS Act (2013) direct social and economic resources to improve the inclusion of people with disability. The NDIS has consolidated funding and policy directives for two of Australia's largest and most complex systems of social support, the disability and mental health systems. The NDIS Act (2013) informs a model of service provision that aspires towards the self-determination of people with disability and responsive action by service providers to support autonomy and participation in society. With the NDIS roll-out, the historically siloed disability and mental health services began to combine resources and offer services to people with persistent mental ill-health alongside other populations of people with disability (NMHC, 2017b). However, there are persistent limitations to the collaboration of the disability and mental health care systems under the NDIS (Commonwealth of Australia, 2023e), resulting in a lack of accessibility for people with disability and mental ill-health (NMHC, 2022; Weise et al., 2021).

In national reporting, Australians with intellectual disability have consistently been identified as a population facing a greater burden of mental ill-health and discrimination in mental health care provision (NMHC, 2014, 2017a). From 2017, NMHC reporting begins to consider the intersectional experiences of people with disability, describing a diverse population requiring particular attention from the mental health care sector (NMHC, 2017b, 2022). Women with disability (NMHC, 2022) and survivors of abuse, neglect, and exploitation (NMHC, 2021) are identified as two groups of interest. In more recent reports there is recognition of the challenges faced by people with disability navigating the mental health system (NMHC, 2021) as raised by the Disability Royal Commission (Commonwealth of Australia, 2023c). The need for improved collaboration between the disability and mental health sectors to enable major systemic reform is highlighted in multiple service reviews (Commonwealth of Australia, 2023b; NMHC, 2017b, 2022). However, disability and mental health services remain poorly integrated (NMHC, 2018). This summary of the NMHC's reports on mental health service provision indicates increasing recognition that people with disability have an entitlement to equitable treatment in the mental health system. Notably, there is an absence of recognition of the requirements of individuals with communication access needs from mental health reporting. Bridging the gaps between the disability and mental health service systems calls for an investigation from multiple perspectives: lived-experience perspectives of people with communication access needs who seek mental health care and their ECPs, as well as MHWs with insider knowledge of the mental health system.

2.2 Human Rights and the Mental Health of People with Disability

Access to the circumstances to live a fulfilling life on one's own terms, with equal conditions to all other citizens are the underpinnings of optimum mental health and functioning (WHO & CGF, 2014). Realisation of social, economic, and environmental rights can determine one's capacity to attain good mental health and wellbeing. These conditions are referred to as social determinants of mental health (WHO, 2021a; WHO & CGF, 2014). As previously identified, the right of Australians with disability to equal participation in social, cultural, economic, and political life is protected by legislation and policy. However, existing legislation does not guarantee human rights (AHRC, 2022; McCallum, 2020). The Disability Royal Commission brought to focus the systemic and individual abuses of the rights of Australians with disability (Commonwealth of Australia, 2023a). It is apparent that the realisation of human rights impacts both the psychological wellbeing of people with communication access needs, as well as their capacity to access mental health care. This section will explore the role of substantive human rights in the realisation of optimal mental health and wellbeing.

2.2.1 Everyday Rights and Mental Health

The disability rights movement has been driven by the resolve of disabled people to gain control of the conditions that govern their everyday lives on an equal basis with all citizens (Clifton, 2020; Disability Royal Commission, 2021; Hallahan, 2021). The CRPD was born of the disability rights movement (Kayess & Sands, 2020). Substantive rights refer to those human rights that involve the everyday circumstances of our lives – where we live, who we spend time with, where we learn and work, and how we make choices. These substantive rights are detailed in the CRPD Articles five through thirty, and reinforced by the fundamental principles of CRPD; 1) respect for inherent dignity, individual autonomy and independence, 2) non-discrimination, 3) full participation and inclusion in society, 4) respect for human diversity and acceptance of person's with disability, 5) equal opportunity, 6) accessibility, 7) gender equality, and 8) respect for children with disability to discover capabilities and identities (CRPD, 2006). Notably, these principles are factors that are generally protective of mental health and wellbeing (GCAPP, 2009; WHO & CFG, 2014). The introduction chapter outlined the issues that impact the mental health and wellbeing of people with communication access needs. Here, these issues are brought into line with the CRPD. Accessibility, health, and communication access rights are addressed alongside the systemic issues related to access to mental health care later in this section.

2.2.2 The Social Determinants of Mental Health

It is well accepted that social factors play a significant role in shaping the mental health and wellbeing of people with communication access needs (Compton & Shim, 2015). These social factors, referred to as social determinants, include: access to education and health services, employment opportunities, social support networks, and economic resources, and all influence mental health outcomes (Shim & Compton, 2015; WHO & CGF, 2014). Additionally, there is a cross-disciplinary body of research that identifies stigma as a fundamental determinant of health inequity (Hatzenbuehler et al., 2013; Holub et al., 2018). Stigma in mental health care is compounded by legacy issues of institutionalisation, historical mistreatment, over-medicalisation, lack of access to equal education, and systemic discrimination.

Social determinants are closely connected to human rights and therefore require intersectoral responses to address disadvantage and promote equity across the lifespan. Strategies to tackle the social determinants of mental health must draw upon lived-experience perspectives to produce solutions that are relevant to the group with communication access needs (Shim & Compton, 2015; WHO & CGF, 2014). However there is a lack of research into the social determinants and how they influence the mental health of people with communication access needs (Friedman, 2021). Further research is required to clarify the influence of social determinants on the mental health and help-seeking capabilities of people with communication access needs.

2.2.3 The CRPD and People with Communication Access Needs

Access to the conditions for optimum mental health is aligned with the rights detailed in the CRPD. While attaining each of the rights detailed in the CRPD is important, there are articles pertinent to people with communication access needs. These articles are: equality and non-discrimination (Article 5), accessibility (Article 9), equal recognition before the law (article 12), freedom from violence, abuse and exploitation (Article 16), living independently and community inclusion (Article 19), freedom of expression and access to information (Article 21), respect for the home and family (Article 23), education (Article 24), health (Article 25), habilitation and rehabilitation (Article 26), work and employment (Article 27), the equitable standard of living and social protection (Article 28), and participation in cultural life and recreation (Article 30) (CRPD, 2006).

The connection between the absence of these everyday rights and impacts on the mental health and wellbeing of people with communication access needs has been explored in the following research. Negative implications for mental health and wellbeing have been linked to exposure to discriminatory microaggressions (Kattari, 2020), lack of autonomy and respect for personal choices (Di Marco & Iacono, 2007; E. Watson et al., 2021), access to safe places to live with good support (E. Watson et al., 2021), exposure to heightened rates of exposure to trauma and abuse (CRE-DH, 2021; Collier et al., 2006; Powers et al., 2002), and access to employment (Richardson et al., 2019). Social connections are imperative to maintaining mental health; however, people with communication access needs often experience loneliness due to isolation (Balandin et al., 2006; Petroutsou et al., 2018), and a lack of trusted communication partners to share wellbeing concerns with (Dark et al., 2011).

The realisation of human rights will have tangible impacts on the mental health of many people with communication access needs. However, the stalled implementation of CRPD in Australian legislation leaves many people with communication access needs reliant on the will of others to obtain these rights (McCallum, 2020). Mental health legislation is predominantly focused on the terms of involuntary detainment of people in crisis rather than the conditions for providing early access to mental health care (Mental Health Act 2009, 2009; Pandos et al., 2023). Furthermore, anti-discrimination legislation has been demonstrated as ineffective in changing persistent access issues, leading to a recent push towards a national Human Rights Act (AHRC, 2022; Commonwealth of Australia, 2023a), and the Disability Royal Commission recommendation for the implementation of a Disability Rights Act (Commonwealth of Australia, 2023b). Integration of the CRPD principles into legislation and policy requires action from state signatories to advance access to the conditions to attain and preserve optimum mental health and wellbeing.

2.2.4 The Communication Bill of Rights

Article 21 of the CRPD addresses communication access and has resulted in legislation that has supported the movement for improved communication access in the community (Solarsh & Johnson, 2017). The Communication Bill of Rights offers people with communication access needs, and also the public, concise guidelines regarding the communication rights of all people in contemporary legislative contexts (Brady et al., 2016). In the context of mental health and wellbeing, communication access means greater inclusion in the community, as well as improved access to services that support the mental health and wellbeing of the broader population (Collier et al., 2012; Solarsh & Johnson, 2017). Mental health services in Australia are required by legislation and industry standards to consider the needs of diverse populations (Australian Government, 2010; Disability Discrimination Act, 1992; NMHC, 2014, 2022). The implementation of communication access strategies can contribute to efforts toward increased inclusion of people with disability, as well as other communication-diverse populations (Solarsh & Johnson, 2017). Exploring experiences of engaging with mental health support may clarify the role of human rights in achieving an equitable standard of mental health and wellbeing among people with communication access needs.

2.3 Challenges to Accessing Mental Health Care

According to the available literature, people with communication access needs confront a unique set of challenges in gaining access to mental health care (Di Marco & Iacono, 2007; Torr et al., 2008; E. Watson et al., 2021; Weise, Cvejic et al., 2020; Weise, Fisher et al., 2020). The systemic barriers to accessing mental health care are threefold: the mental health knowledge of ECPs, the capacity of MHWs to adequately collaborate with people with communication access needs, and diagnostic overshadowing.

2.3.1 ECPs mental health knowledge

ECPs may lack awareness of mental health issues, resulting in apprehension to refer people with disabilities to mental health specialists for additional help (Costello et al., 2007; Holub et al., 2018; Rose et al., 2007; E. Watson et al., 2021). Therefore, a need exists for ECPs to develop basic mental health literacy, including knowledge of referral pathways when additional help is required to address matters of mental health and wellbeing. In mental health care literature ECPs hold an important position in the circle of care in the mental health support team and are uniquely positioned to identify psychosocial risk factors and activate mental health support systems (Costello et al., 2007; Lawn et al., 2017).

Collaborative alliances between MHWs and ECPs may assist in enacting strategies to support mental health, providing observation and giving timely feedback regarding behavioural changes (Dark et al., 2011; 3DN, 2014; Di Marco & Iacono, 2007; Hagiliassis et al., 2006; Kneebone, 2016; Wark, 2012). ECPs may provide MHWs with information about communication preferences and model effective communication partner techniques (3DN, 2014; Hagiliassis et al., 2006). Dark et al. (2011) identified the importance of having skilled and sensitive communication partners to engage in conversations about challenging topics such as grief and emotional distress. This study emphasised the need for support workers to be equipped with skills to discuss issues that impact mental health and wellbeing (Dark et al., 2011).

Few training initiatives have sought to improve the capacity of formal carers to recognise the signs and symptoms of mental health problems in people with intellectual disabilities and provide referrals to mental health support (Costello et al., 2007, 2010; Tsiantis et al., 2004). Costello et al.'s (2007) trial found that exposure to training significantly improved the knowledge, attitudes, and referral decisions of support workers, compared with those who did not receive training. Tsiantis et al. (2004) used the same training package to train support staff based in institutional and community settings in Greece. Although staff from the institutional setting had lower mental health knowledge and attitudes before training, post-training results indicate a significant improvement in these domains, with institutional staff achieving the same results as community-based staff (Tsiantis et al., 2004).

These studies demonstrate that training can positively influence ECPs' capacity to identify and refer people with intellectual disabilities to mental health support. However, there is a lack of studies demonstrating the flow on benefits to people with communication access needs. Additionally, these studies do not include lived-experience perspectives on the efficacy of the mental health support provided by ECPs.

2.3.2 Mental Health Workforce Capability

The capability of MHWs to deliver appropriate and effective mental health support is a critical issue impacting the accessibility of mental health care (Cvejic et al., 2018; 3DN, 2016, 2017; Weise et al., 2016). MHWs' knowledge, skill and attitudes regarding communication influence the efficacy of the mental health care that they provide to people with communication access needs (Morrow-Odom & Barnes, 2019; Rose et al., 2012; Venville et al., 2015; Weise, Fisher, et al., 2020). MHWs identify a lack of pre-service training to equip them to communicate effectively with people with disability (Morrow-Odom & Barnes, 2019; Rose et al., 2012; Whittle et al., 2018). This lack of training and education influences the confidence of MHWs to provide services to people with communication access needs (Morrow-Odom & Barnes, 2019). Additionally, MHWs' lack of knowledge and experience can lead to biases and attitudinal barriers to the person with communication access needs acquiring mental health care (Rose et al., 2007; E. Watson et al., 2021). Knowledge and attitudinal barriers result in people with communication access needs being adversely impacted by diagnostic overshadowing, unequal service provision, lack of early intervention, and limited treatment options (Whittle et al., 2018). All are reflections of deficits in workforce capacity to appropriately service people with communication access needs.

Most research regarding the capacity of MHWs to meet the requirements of people with communication access needs comes from the field of intellectual disability mental health (Costello et al., 2010; Man et al., 2017; Rose et al., 2007; Venville et al., 2015; Weise et al., 2020). Significant work has been undertaken to identify the workforce capacity gaps in serving the population of people with intellectual disability, with communication being consistently identified as an area of deficit among MHWs (Cvejic et al., 2018; Weise et al., 2017). Efforts have been invested in developing a practice framework to develop the capabilities of Australian MHWs to improve the inclusion of people with intellectual disability in mental health care (3DN, 2016, 2017; Weise et al., 2016, 2017). The Intellectual Disability Mental Health Core Competency Framework comprises a practice guide (3DN, 2014), a manual (3DN, 2016), and a toolkit (3DN, 2017) to assist MHWs in their work. A further toolkit has been developed to assist MHWs in adapting communication to support access to mental health services for people with communication access needs (Newman et al., 2020). This toolkit is complemented by previous practice guides such as Beyond Speech Alone:

Guidelines for Practitioners Working with People with Disabilities and Complex Communication Needs (Hagiliassis et al., 2006). Because communication is a focal point for developing the capacity of MHWs, input from lived-experience populations is required to provide information that can guide such development.

Although accessible mental health care has been identified as a policy priority area (Commonwealth of Australia, 2021), there is presently no strategic approach to enhancing service delivery to populations impacted by people with communication access needs (Weise et al., 2021). Data regarding the implementation of the Intellectual Disability Mental Health Core Competence Framework is yet to become available. Further, the implications of the framework for other populations impacted by communication access barriers are yet to be explored. The fact remains that many people with communication access needs are not diagnosed with intellectual disability and do want to access mental health services (E. Watson et al., 2021). There is a need for research that explores the interplay of MHW capability and the implementation of communication access strategies in mental health care beyond diagnostic bounds. Such an exploration will bring to light the communication access strategies that MHWs can employ to benefit people with communication access needs more broadly.

2.3.3 Diagnostic Overshadowing as a Barrier to Access

A component of the issue of mental health access may be attributed to diagnostic overshadowing (Bennett, 2014; Hagiliassis & Di Marco, 2017; Jamieson & Mason, 2019). Diagnostic overshadowing represents practice, skill, knowledge, and attitude barriers that prevent the MHW from integrating disability and mental health care requirements (Holub et al., 2018; Noyes & Wilkinson, 2023; Pinals et al., 2022a, 2022b). Diagnostic overshadowing occurs when behavioural communication of psychological distress is misattributed to factors relating to the person’s diagnosis (Hagiliassis & Di Marco, 2017). People with communication access needs are continually under-represented as users of mental health support services in Australia and this is likely due to inadequate diagnostic processes (Hagiliassis, DiMarco, et al., 2005; Jamieson & Mason, 2019). Few diagnostic assessments are designed having people with communication access needs in mind (Brinkman et al., 2022; Di Marco & Iacono, 2007). For this population, the use of diagnostic assessments that are reliant on spoken responses presents a persistent barrier to mental health care access (Di Marco & Iacono, 2007; Foley & Trollor, 2015; Hemmings et al., 2013). The use of unsuitable assessment tools may lead to underdiagnosis or misdiagnosis of mental health problems in people with communication access needs and may result in ineffective treatment (Di Marco & Iacono, 2007; Hemmings et al., 2013; Noyes & Wilkinson, 2023; Pinals et al., 2022b).

2.3.4 Ableism in Mental Health Care

Ableism influences the mental health and wellbeing of people with communication access needs, as well as their capacity to access mental health care services. Ableism refers to the prejudicial treatment of people with disability, inclusive of attitudes, stereotypes, policies, and practices that lead to disadvantage and discrimination (Bogart & Dunn, 2019; Nario-Redmond, 2020). Ableist prejudice has pervasive impacts on the way that people with disability live, relate, and access human rights, as described by Nario-Redmond (2020, p. 10): “Prejudice, and disability prejudice in particular, can be benevolent and kind, paternalistic, pitying, and inspired by charitable intentions that nevertheless allow for the justification of control, restricted rights, and dehumanising actions”.

Ableism occurs at personal, interpersonal, and group levels, and has both individual and institutional effects. For people with communication access needs ableism presents as the prioritisation of speech over other forms of communication (Donaldson et al., 2023), assumptions regarding personal competence/ incompetence (DeThorne & Gerlach-Houck, 2022), and restricted opportunities for social relationships (Sellwood et al., 2022). The manifestations of ableism in health care provision include lack of practitioner knowledge regarding communication partner skills, discrediting descriptions of symptoms, disparity in treatment options, underservicing of people with disability, and lack of education and accessible information about mental health (Mladenov & Dimitrova, 2023; Nicolaidis et al., 2015). Examples of ablism in mental health care provision include diagnostic overshadowing and the misconception that people with communication access needs do not experience deep emotions or precipitating life events. In the delivery of therapeutic supports, ableism may manifest in practices that reinforce able-bodied characteristics, or normalisation, as the most desirable outcomes (Campbell, 2009; DeThorne & Gerlach-Houck, 2022; Donaldson et al., 2023).

Ableism is fundamentally harmful to people with disability and may result in further harm to one’s self-identity and induce limitations to one’s functioning (Campbell, 2009). Ableist microaggressions are the smaller interpersonal interactions that perpetuate devaluating attitudes towards people with disability in the form of assaults, insults, and invalidations (Kattari, 2020). Recent research reports that ableist microaggressions are encountered by most disabled people, with people with physical disability reporting higher levels of impact on their mental health than individuals diagnosed with psychosocial disability (Kattari, 2019, 2020). This finding indicates the potential for exposure to ableist microaggressions to influence the status of one’s mental health (Kattari, 2020). Further inquiry is required to understand the latent effects of ableism on mental health and its implications for engagement with the mental health care system for people with communication access needs. By centring people with lived experiences of disability and adopting a Human Rights Model of Disability, researchers can recognise and rectify tendencies towards ableist norms in research (Berghs et al., 2016).

2.4 Communication Accessible Mental Health Supports

The prevalent use of “talk therapies” in mental health care support depends upon spoken dialogue to facilitate outcomes that enhance emotional wellbeing (Del Giacco et al., 2019; Hagiliassis et al., 2006). This may lead to the misconception that people with communication access needs will not gain value from mental health services such as counselling and psychology (Hurley et al., 1998). However, there is emerging evidence indicating that with an adapted approach that considers the cognitive and communicative abilities of the person, mental health support is beneficial (Noyes & Wilkinson, 2023; E. Watson et al., 2022).

Literature regarding the inclusion of people with communication access needs in mental health service settings consists of opinion pieces (Bennett, 2014; Hagiliassis & Di Marco, 2017; Trollor, 2014), practice guides (3DN, 2014, 2016, 2017; Hagiliassis et al., 2006; Howlett & Trollor, 2013; Hurley et al., 1998; Newman et al., 2020), and limited intervention research (Bell & Cameron, 2003; Crawford, 1987; Hagiliassis, Gulbenkoglu, et al., 2005; Kneebone, 2016; Wark, 2012). Of the original research, most are case studies that describe adaptions to counselling approaches to enable the inclusion of people with communication access needs using AAC (Bell & Cameron, 2003; Crawford, 1987; Kneebone, 2016; Wark, 2012). Hagiliassis, Gulbenkoglu, et al. (2005) conducted a randomised controlled trial testing the efficacy of a psycho-educational program aimed at equipping participants with skills to manage anger. The anger-management program used pictographic symbols to support written information and resources provided to participants. Some participants used AAC methods such as electronic communication aids, static communication boards, manual signs, as well as facial expressions and gesture. Participants in the anger-management program experienced reduced levels of anger, as measured by the Novaco Anger Scale, sustained over a four-month follow-up period (Hagiliassis, Gulbenkoglu, et al., 2005).

2.4.1 AAC Supports in Mental Health Care

Practice guides for mental health practitioners suggest that the most promising practices for enhancing the inclusion of people with communication access needs come from the field of AAC (3DN, 2014; Hagiliassis et al., 2006; Hurley et al., 1998). The use of AAC to support access to mental health services has been documented for well over thirty years. Crawford’s (1987) case studies provide a basic introduction to the use of early electronic communication aids to enable people with dysarthria to engage in psychotherapy. Crawford

(1987) does not report on the outcomes of psychotherapy, instead suggesting AAC as a tool to assist the therapeutic process; this represents the emergence of AAC as an assistive technology of benefit in psychotherapeutic relationships.

More recent studies have discussed non-electronic communication aids (Bell & Cameron, 2003; Hagiliassis, Gulbenkoglu, et al., 2005; Kneebone, 2016; Wark, 2012). Wark (2012) presents case studies detailing the use of narrative therapy with three people with communication access needs resulting from intellectual disability and autism. Communication aids such as pictographic symbols, photographs and sign language were used assist each person to tell their story and address issues such as anxiety and grief. Bell and Cameron (2003), a psychologist and speech language therapist team, describe using the Talking Mats©[1] picture communication system to enable a young woman with communication access needs to establish a vocabulary to discuss sexual abuse, while Kneebone (2016) describes the use of pictographic symbols and a tablet computer to assist a woman with post-stroke aphasia to communicate as part of a strategy to address symptoms of depression. These studies demonstrate how psychoeducational approaches can be adapted using AAC to ameliorate communication barriers and assist in the promotion and restoration of mental health and wellbeing with people with communication access needs. However, engagement with mental health supports and services remains limited for people with communication access needs (Hagiliassis & Di Marco, 2017). Investigation of the individual and systemic factors that affect MHWs' capacity to incorporate communication access strategies is lacking in the research literature. Further, the benefits of different communication strategies have not been examined through the lens of lived expertise. There is thus a requirement for further exploration of the communication access strategies that have been used in psychoeducational interventions that include the perspectives of people with communication access needs.

2.4.2 Multidisciplinary Mental Health Care

The practice guides and frameworks identified above discuss the value of collaborative practice in promoting access to mental health care for people with communication access needs (3DN, 2014, 2016, 2017; Hagiliassis et al., 2006; Hurley et al., 1998). Previous research provides examples of successful interdisciplinary collaborations between a Speech Pathologist and Psychologist to support a woman with communication access needs to establish a vocabulary to enable her to discuss sexual abuse (Bell & Cameron, 2003). This case study demonstrates how the expertise of professionals from

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different disciplines can work together to establish a therapeutic environment that recognises and values diverse communication. Noyes & Wilkinson (2022) propose a framework and advice to guide collaborations between speech pathologists, therapists, communication assistants and people with communication access needs in psychotherapeutic interventions. However, Northcott et al.'s (2017) survey of speech pathologists working with people with acquired communication access needs identified that funding, time constraints, and the availability of therapists all presented barriers to multidisciplinary collaborations in psychotherapeutic support.

Other collaborative alliances may be formed between mental health professionals and carers or support workers. These collaborations may be beneficial in enacting strategies to support wellbeing, providing opportunities for observation and feedback regarding changes in behaviour, and gaining information about preferred methods of communication (Dark et al., 2011; 3DN, 2014; Di Marco & Iacono, 2007; Foley & Trollor, 2015; Wark, 2012; E. Watson et al., 2021). When engaging in multidisciplinary practice, the primacy of the person with communication access needs must be maintained and consent must be sought before collaboration begins (Hagiliassis et al., 2006).

2.4.3 Learnings from Other Communication Diverse Populations

The Deaf and hard-of-hearing population also experience communication access issues in engaging mental health services (García & Bravo, 2015). Issues experienced by the Deaf community in mental health services (such as a lack of familiarity with communication methods, violations of confidentiality, reduced access to information, and increased risk of misdiagnosis) are common themes among people with communication access needs (Cabral et al., 2013; García & Bravo, 2015). Deaf communities and mental health practitioners have undertaken systemic action to counter exclusion, establishing Deaf mental health care as a discipline (Brice et al., 2013). However, the Deaf community is connected by shared languages and culture (Glickman, 2013). In contrast, people with communication access needs are a heterogeneous group with diverse means and methods of communication (Beukelman & Light, 2020).

Lived-experience perspectives are an established component of the research into the effectiveness and availability of mental health services for Deaf people (Cabral et al., 2013; Sheppard & Badger, 2010; Steinberg et al., 1998). Steinberg et al. (1998) identified that most participants in their qualitative study learned mental health terminology from other Deaf friends. Interestingly, two further qualitative studies identified apprehension among participants to engage with peer mental health support due to perceived stigma and challenges to confidentiality in the Deaf community (Cabral et al., 2013; Sheppard & Badger, 2010). Resoundingly, participants in all studies identified that they preferred their mental health professional to have familiarity with their method of communication (Cabral et al., 2013; Sheppard & Badger, 2010; Steinberg et al., 1998). The above studies have drawn on the lived experiences of the Deaf community and offer essential insights into the barriers and facilitators encountered in seeking mental health support. This lends credence to the inclusion of people with lived experience of communication access needs in the development of knowledge that informs mental health support provision.

2.4.4 Psychoeducation and Mental Health Care

A common and broad-based approach to enhancing community mental health literacy is through psychoeducational interventions that can be delivered in a group format or personalised within 1:1 worker/client interactions to respond to the requirements of an individual (Sarkhel et al., 2020). The aims of psychoeducational intervention include: improving awareness of mental illnesses and mental health; teaching stress management, resilience and coping skills; aiding recovery of optimum mental health; reducing stigmatising attitudes; and identifying sources of mental health care (Sarkhel et al., 2020; Zhao et al., 2015). Because ECPs are critical in providing information about mental health and wellbeing these individuals must be included in these interventions (Brady et al., 2017; Brolan et al., 2012). Existing studies have identified the characteristics of psychoeducational approaches with individuals with intellectual disability and neuromuscular disorders, which may impact upon communication (Dagnan et al., 2018; Walklet et al., 2016). However these studies have not explored the influence of communication access on the suitability of psychoeducational interventions for people with communication access needs. Further investigation is required to identify what strategies have been used to improve communication access in psychoeducational interventions.

2.5 Examining Mental Health Care Accessibility

Access to mental health care is fundamentally rooted in human rights (CRPD, 2006; WHO & CGF, 2014). Reviewing the current body of literature has revealed the interplay between rights and accessibility in mental health care provision. Furthermore, a gap has emerged between existing research and the need for clarity regarding the actions that can improve access for people with communication access needs. Examining the accessibility of health care systems for marginalised groups requires a model that reflects population factors and health care system factors. The Conceptual Model of Access to Health Care provides a framework to examine service and system factors, as well as personal or community factors that impact access and is conducive to the ethos of human rights and mental health care equity (Cu et al., 2021; Levesque et al., 2013). The Conceptual Model of Access to Health Care proposes six stages in the trajectory of health care practice: 1) emergence of mental health care needs; 2) perception of mental health support needs and desire for care; 3) mental health care seeking; 4) mental health care reaching; 5) mental health care utilisation; and 6) mental health care consequences (Levesque et al., 2013). This dynamic model of access has been applied across a variety of health care settings and with diverse populations (Cu et al., 2021; Kourgiantakis et al., 2023; Schwarz et al., 2022; Shady et al., 2022; Shea et al., 2022).

Levesque’s model has been used to examine access to general practice health care incorporating people who experience communication difficulties (Selick et al., 2022; Shady et al., 2022; Shea et al., 2022; Song et al., 2019) These studies included indirect accounts from people with communication access needs via previously published studies (Shady et al., 2022; Shea et al., 2022), and proxy reports from care providers (Song et al., 2019). Selick et al. (2022) qualitative study explored the experiences of people with developmental disability engaging with telehealth during the COVID-19 pandemic. Though direct accounts were collected, the communication access requirements of participants were not specified. The Conceptual Model has been used to examine access to mental health care, albeit not with people with communication access needs directly. Schwarz et al. (2022) used the model to explore service access for older people with mental illness, while Kourgiantakis et al. (2023) studied access to youth addiction services. Levesque et al.’s (2013) model supports the examination of access barriers and facilitators related to mental health care provision with people with communication access needs. Additionally, the model allows for incorporating a range of perspectives including lived experiences, ECPs and MHWs.

2.6 Chapter Summary

To summarise, there are a range of historical and systemic issues that influence the mental health and wellbeing of people with communication access needs. However, this group has been largely excluded from mental health care due to lack of accessibility. Critical factors influencing access to mental health care for this group relate to the mental health knowledge of ECPs, the capacity of MHWs to adequately collaborate with people with communication access needs, diagnostic overshadowing and systemic ableism. Further research is required to clarify the factors that influence the mental health and help-seeking behaviours of people with communication access needs. Exploring experiences of engaging with mental health support may identify solutions that enable access to health care.

There is emerging literature that advances the case for communication access in psychoeducational interventions, such as the use of AAC strategies to enable access to resources that promote and restore mental health and wellbeing (Bell & Cameron, 2003; Crawford, 1987; Hagiliassis, Gulbenkoglu, et al., 2005; Kneebone, 2016). Additionally, there is guidance to assist mental health practitioners in developing more inclusive mental health supports (3DN, 2014, 2016, 2017; Hagiliassis et al., 2006; Hurley et al., 1998; Kneebone, 2016). However, lived-experience perspectives have largely been absent in the development of these strategies. Further, there is a necessity for mental health information for ECPs who can assist in identifying psychosocial risk factors and connect people with mental health care (Costello et al., 2007; Lawn et al., 2017).

Literature highlights the capacity of the Australian mental health system and competencies of MHWs to include and support people with communication access needs (Weise, Cvejic, et al., 2020; Weise et al., 2017, 2021). Current literature and government reports indicate that there is a persistent lack of collaboration between the disability and mental health care systems, resulting in a lack of accessibility for people with disability and mental ill-health (Commonwealth of Australia, 2023c, 2023e; NMHC, 2022; Weise et al., 2021). Much of the research and practice advice for MHWs regarding communication relates to people with intellectual disability (Cvejic et al., 2018; 3DN, 2014, 2016, 2017; Howlett & Trollor, 2013; Newman et al., 2022; Trollor, 2014; Weise, Cvejic, et al., 2020; Weise et al., 2016, 2017, 2018, 2021; Weise, Fisher, et al., 2020). The population of people with communication access needs is diverse and includes many people who are not diagnosed with intellectual disability yet face significant barriers to gaining mental health support (Di Marco & Iacono, 2007; Noyes & Wilkinson, 2023; E. Watson et al., 2021). Because communication is a critical factor in service provision there is a requirement for input from individuals with lived experience to develop inclusive mental health care systems.

Further inquiry is vital to improve understanding of the latent barriers to maintaining emotional wellbeing and obtaining mental health support for people with communication access needs. Bridging the gaps in mental health support calls for the exploration of multifaceted perspectives of people with communication access needs, along with ECPs and MHWs, to better understand the complex factors influencing access to mental health support, and to seek improvements that promote inclusion in mental health care.

The following chapter responds to the first research question and describes a scoping review identifying strategies and resources that have been used to promote the inclusion of people with communication access needs in mental health care (E. Watson et al., 2022). The scoping review responds to research question one. Chapter 4 will present the methodology, drawing together the evidence from the literature, theoretical underpinnings, and research design elements.

CHAPTER 3. SCOPING REVIEW AND STAKEHOLDER CONSULTATION

One of the major outputs of this research project was a scoping review of the literature and stakeholder consultation. The scoping review relates to research question 1: What strategies and resources for promoting the inclusion of people with communication access needs in psychoeducational support have been tried already? The objective was to generate a comprehensive scoping review of the literature on the inclusion of people with communication access needs in mental health interventions. The researchers sought the perspectives of stakeholders; people with communication access needs, everyday communication partners (ECPs) and mental health workers (MHWs). The stakeholder consultation contextualised the literature amid the perspectives of informants with experience of participating in, observing, or delivering mental health care. This chapter contains a pre-publication version of the manuscript: Watson, E., Raghavendra, P., Lawn, S., & Watson, J. (2022). Improving communication access in psychoeducational interventions for people with complex communication needs: A scoping review and stakeholder consultation. *Disability and Rehabilitation*, 1–19. https://doi.org/10.1080/09638288.2022.2127932

The concept for the scoping review was devised in a supervision meeting and the process was led by the PhD researcher with contributions from the supervision team, research advisors and Research Librarian. The role and contribution of each author and advisor are detailed in Table 3.1 in accordance with the Higher Degrees by Research Policy of Flinders University.

Table 3.1
Research Team Member Contributions to the Scoping Review

Author/ Role	Contribution (%)
E. Watson PhD researcher.	• Scoping review research design (85%) • Data collection, review, and analysis (55%) • Writing and editing (80%)
Raghavendra. P. Supervisor.	• Scoping review research design (5%) • Data collection, review, and analysis (15%) • Writing and editing (10%)
Lawn. S. Supervisor.	• Scoping review research design (5%) • Data collection, review, and analysis (15%) • Writing and editing (5%)
J. Watson Adjunct Supervisor.	• Scoping review research design (5%) • Data collection, review, and analysis (15%) • Writing and editing (5%)

Further acknowledgement is made to Shannon Brown, Senior Librarian in the Research Engagement Team at Flinders University, for their valuable instruction, and guidance in developing the literature search strategy. Additionally, research advisors Dr. Darryl Sellwood and Margie Charlesworth are acknowledged for their expertise in reviewing and providing critical feedback on the interview question schedule delivered to stakeholders.

3.1 Background

Australians with disability experience a higher incidence of mental health problems and psychological distress in comparison with the broader Australian community (AIHW, 2019). People with communication access needs are included among this population facing increased risk to mental health (Beukelman & Light, 2020). As a result of multiple physical, cognitive, intellectual, sensory, and psychosocial factors, people with communication access needs experience significant difficulties in meeting the everyday demands of communication such as exchanging information, expression of wants and needs, and establishing and maintaining social relationships (Taylor et al., 2021). Many people with communication access needs employ a range of strategies and assistive technologies referred to as augmentative and alternative communication (AAC) to assist them to communicate with independence in a range of settings (Light et al., 2019; Ripat et al., 2019).

People with communication access needs face mental health risk factors, such as experiences of discrimination and stigma, physical health concerns, challenges to developing close relationships, reduced engagement in employment and education, and fewer community connections (E. Watson et al., 2021). Mental health may be further impacted upon by exposure to trauma and abuse (Collier et al., 2006; Johnson & Yee, 2020), reduced self-determination (Ripat et al., 2019), loneliness (Balandin et al., 2006; Petroutsou et al., 2018) and challenges to establishing approaches to convey and regulate emotions (Hagiliassis, Gulbenkoglu, et al., 2005). Without access to appropriate vocabulary or a means of expression, such as AAC, an individual may be unable to broach concerns pertaining to mental health and wellbeing (Collier et al., 2006). Furthermore, the absence of trusted or skilled communication partners with whom to discuss issues such as grief and loss may compound emotional distress (Dark et al., 2011). Additionally, progressive communication loss related to both acquired conditions, and developmental conditions may place further pressure on an individual's psychological wellbeing (Northcott et al., 2017).

People who require more extensive disability supports have experienced disproportionate mental health challenges resulting from biological, psychological, and social factors associated with the COVID-19 pandemic (Buonaguro & Bertelli, 2021; Rosencrans et al., 2021). People with disabilities have expressed frustration at limited access to suitable mental health services. In responding to the pandemic mental health services have developed novel approaches to support provision, such as the expansion of telehealth services which has benefited some people with disabilities (Lake et al., 2021). However, the communication accessibility of these services has not yet been examined.

Despite this heightened exposure to risk factors for mental ill-health, people with communication access needs are under-represented in their use of services and programs that address mental health and wellbeing (Whittle et al., 2018). Under-representation may be due to lower awareness among people with communication access needs and their ECPs about the indicators of poor mental health and pathways to enable recovery of optimum mental health. People with communication access needs often rely on ECPs, such as family members, friends, and support workers to provide assistance, advocacy and information that promotes health and wellbeing (Brolan et al., 2012; Donley et al., 2012; E. Watson et al., 2021). However, low awareness of mental health supports may result in apprehension to refer people with disabilities to mental health specialists (Holub et al., 2018; Rose et al., 2007).

Psychoeducational interventions for mental health aim to be person-centred and adapt to the requirements of the participant and their supporters (Sarkhel et al., 2020). This flexibility of intervention delivery is important to people with communication access needs who require that mental health practitioners apply adaptive communication strategies. Psychoeducational interventions have the following aims 1) improve awareness of either specific mental illness, or mental health generally; 2) teach stress-management, resilience, and coping skills; 3) aid recovery of optimum mental health; 4) provide information that reduces stigmatising attitudes; and 5) identify help-seeking pathways and foster advocacy (Sarkhel et al., 2020; Zhao et al., 2015). Psychoeducational interventions may include ECPs, acknowledging their role in enabling engagement with information and supports for mental health and wellbeing (Brady et al., 2017; Brolan et al., 2012). Previous systematic reviews have demonstrated the benefit of psychoeducational approaches with individuals with intellectual disability or neuromuscular disorders, which may impact upon communication (Dagnan et al., 2018; Walklet et al., 2016). However, communication access was not explored in these studies.

Communication access is a broad approach which aims to address systemic barriers to the use of speech or writing, and comprehension of information (Parr et al., 2006). Communication access strategies are relevant to all communication formats; face-to-face, written documents, online, as well as communication that is mediated by a human assistant (Solarsh & Johnson, 2017). The CRPD (2006) informs the legislation of signatory nations and includes items relating to communication access and health services. Communication access is addressed in Article 21, access to services in Article 9 and equitable access to health supports in Article 25. Communication access has been examined in the context of health support provision (Hemsley & Balandin, 2014), however, examples from mental health services are lacking.

Literature on the provision of mental health support for people with communication access needs is scarce. Thus, this scoping review seeks to identify the psychoeducational approaches that have been applied with the population of people with communication access needs to promote awareness about mental health, coping strategies and help-seeking for mental health concerns.

3.1.1 Aims

The purpose of this scoping review is to explore the psychoeducational interventions that have been utilised with people with communication access needs. The scoping review has included ECPs where the primary focus of the intervention has been to benefit the individual who experiences communication difficulties. Their inclusion recognises the important role that ECPs play in connecting people with communication access needs with information and supports for mental health and wellbeing (Brolan et al., 2012; E. Watson et al., 2021).

The key objectives of the scoping review are to: 1) Identify the psychoeducational interventions that have been utilised with people with communication access needs; 2) Identify the adaptations used to improve communication access in psychoeducational interventions; and 3) report on the outcomes of psychoeducational interventions for mental health problems in people with communication access needs.

3.2 Method

3.2.1 Study Design

The scoping review methodology allows an overview of the breadth and topography of the existing research, as well as seeking social validation from the populations concerned (Arksey & O'Malley, 2005; Colquhoun et al., 2014). Multiple study designs are accommodated within the bounds of a scoping review, enabling inclusion of diverse literature which is particularly important in an area where literature is scarce such as this one (Arksey & O'Malley, 2005; Levac et al., 2010). The scoping review methodology has relevance among disciplines that are establishing a common ground for research and practice (Daudt et al., 2013), as is the case in the field of mental health support for individuals with disability, where multiple disciplines contribute to intervention.

Arksey & O'Malley's (2005) systematic guidelines for conducting scoping studies consist of six phases:1) Identification of the research question; 2) Identification of relevant studies; 3) Selection of studies for analysis; 4) Charting the data; 5) Collation, summarisation, and reporting of the data; and 6) Consultation and social validation of findings. Arksey & O’Malley (2005) regarded the sixth phase of consultation as optional; however, more recent contributors to scoping review methodology highlight the essential role of stakeholder consultation in asserting relevance of the scoping review’s results (Daudt et al., 2013; Levac et al., 2010). In this review we considered consultation as a means of giving social validation to our findings. An in-depth description of the scoping review process is provided below.

3.2.2 Identifying the Research Question

The PESICO framework was employed to support the development of the research question. Originally developed to enable identification of evidence-based practices pertinent to people who experience communication access needs (Schlosser et al., 2007), PESICO includes the domains “Environment” (E) and “Stakeholders” (S), in addition to PICO; population, intervention, comparison, and outcome model commonly applied in health research. By including these considerations, researchers can attune their literature searches to the influence of both environment and communication partners in the efficacy of interventions as communication requirements frequently vary dependent on the context and partner involved. The PESICO template outlining search terms are presented in Table 3.2.

3.2.3 Identifying Relevant Studies

In consultation with a research librarian, the search terms from the PESICO table were mapped across to a basic search string that was used to perform database searches. The search string was modified as required to meet the specific requirements of each database’s search engine. Database searches were conducted in ProQuest, Scopus, PsycINFO, CINAHL, and Medline. Grey literature was sourced through the following databases: Open Grey; South Australian Health Library Service (SALUS); and Google. Additionally, we conducted a hand-search of the reference lists of systematic reviews, articles included for data extraction, and the professional journal of the Australian Psychological Society. The search was limited to articles published in English, after 1980 until November 2019. Search alerts were created for each database and monitored until February 2022; however, no additional articles met the inclusion criteria.

Table 3.2

PESICO Framework of Search Terms

P Population	E Environment	S Stakeholders	I Interventions	C Comparison	O Outcome
Adults Complex Communication Needs Intellectual disability Physical disability Developmental disability Stroke Aphasia Autism Dual diagnosis Cerebral palsy Multiple Sclerosis Motor Neuron Disease Amyotrophic Lateral Sclerosis Huntington's Disease Traumatic Brain Injury Acquired Brain Injury Muscular dystrophy	Any Community-based	Informal supports Family Parents Spouse Siblings Friends Peers Co-workers Caregivers Informal carer* Natural supports Paid supports Support workers Carer* Personal assistant Personal attendant Disability support workers Care workers Paid supports	Psychoeducation Psycho-education Psycho education Mental Health Literacy Mental health first aid Mental health awareness Mental health education Mental health training Mental health awareness Mental health knowledge Promotion of mental health Mental health promotion Primary prevention Preventative psychiatry Affective awareness Emotional awareness Emotional wellbeing Wellbeing	Nil comparison	Improvement of general mental health literacy. Improvement of awareness of specific mental health problems. Promotion of coping skills and resilience. Recovery of optimum mental health. Identification of mental health support. Pathways. Enhanced advocacy and help-seeking capacities

3.2.4 Study Selection

Articles that were included focused on persons over 18 years of age with communication access needs, or severe communication difficulties resulting from developmental, acquired, or progressive conditions. All studies discussed psychoeducational interventions and their outcomes. For inclusion in this scoping review, psychoeducational interventions had one or more of the following aims: 1) Improve awareness of either specific or general mental health problems; 2) Promote coping skills and resilience; 3) Aid recovery of optimum mental health; 4) Identify of pathways for mental health support; 5) Foster advocacy and help-seeking capacities in mental health. Excluded articles focused on the paediatric population (people under 18 years of age), only described outcomes for ECPs, or included participants experiencing communication difficulties primarily due to hearing-impairment.

As recommended by previous authors (Daudt et al., 2013; Levac et al., 2010), the screening and review of studies was conducted by a multi-disciplinary team, including researchers from disability studies, social work, and speech pathology. The initial screening of titles and removal of duplicates was conducted by the first author. The title and abstract of each article were screened by two authors. The first author (E. Watson) screened all articles with the second screening divided among the three co-authors (Raghavendra, Lawn, J. Watson). Full text review was conducted for the retained articles. Again, all articles were reviewed by the first author with the second review divided among the co-authors. The review process was managed using Covidence software. Where conflicts occurred as to an article’s inclusion, the two reviewers met, discussed the article, and determined its inclusion status.

3.2.5 Charting the Data

Key information such as intervention type, population and location of research was recorded from each article and data were entered into a Microsoft Excel data extraction spreadsheet. The first nine articles were checked by two researchers: the first author and one of the three co-authors. The remaining data extraction was conducted by the first author.

Following the extraction of key information, further thematic analysis was conducted using the six-step process described by (Braun & Clarke, 2006). The first author (E. Watson) was primarily responsible for transcription, initial data coding, and generating themes. The process of data analysis was overseen by the three co-authors through monthly meetings which proved a forum to discuss coding and define themes. NVivo software was used to support the analysis of both articles and consultation data and to promote the transparency of the analytic process.

3.2.6 Reporting the Results

Results are reported in two ways; numerically and thematically. The study designs, key research aims, context of studies, and demographic and diagnostic information about the participant populations are reported numerically to provide an overview of the included studies. The results of the thematic analysis are presented under three theme headings with sub-themes generated through the process of thematic analysis described above (Braun & Clarke, 2006). The key theme headings each responding to one of the research questions stated previously in the scoping review aims.

3.2.7 Consultation

Following preliminary thematic analysis to identify psychoeducational interventions and communication accommodations, consultations were held with stakeholders from three groups: people with lived experience of communication access needs; supporters of people with communication access needs; and mental health workers (MHWs). All stakeholders had experience of participating in, observing, or delivering psychoeducational interventions for people with communication access needs. Stakeholder interviews were conducted with ethical approval from (Flinders University Human Research Ethics Committee, project number 1885).

Stakeholders were recruited via emails containing the study information pack which were sent to professional networks, and disability and mental health service providers in South Australia. Two individuals from each group participated in a semi-structured interview about psychoeducational interventions and communication access accommodations. The stakeholder interviews were audio recorded, transcribed, member checked, and then thematically analysed using the process described previously (Braun & Clarke, 2006). Findings from the stakeholder consultations are reported alongside the results as they provide important contextual information and extend upon the scoping review findings.

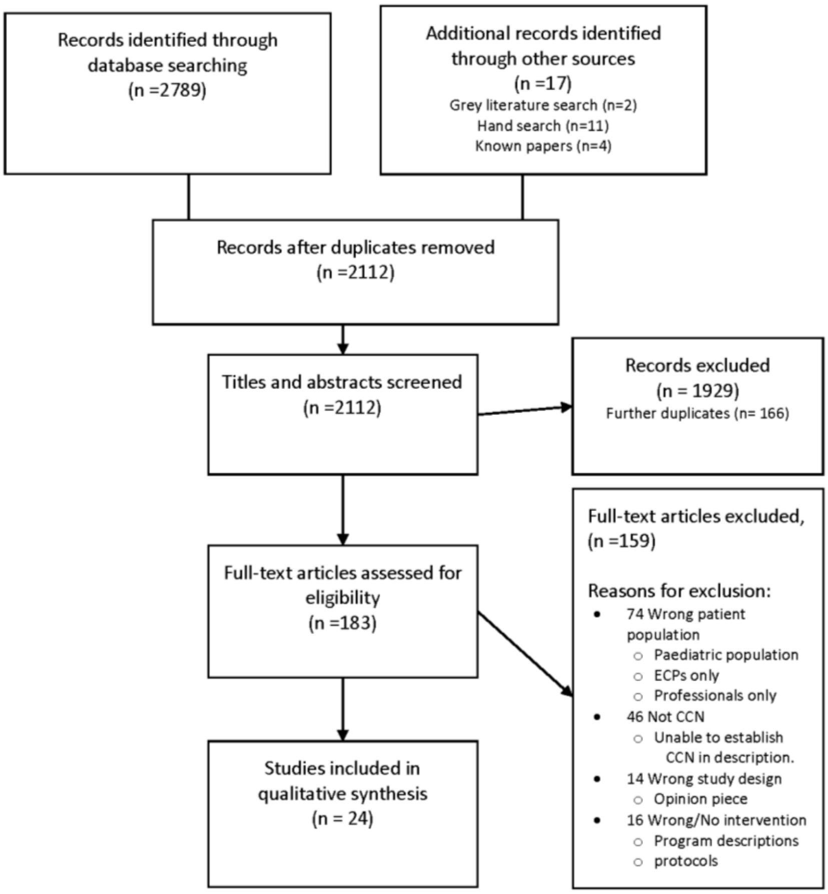
3.3 Results

3.3.1 Numerical analysis

A total of 2112 unique papers were located through searching the literature; of these, 24 papers met the inclusion criteria and were retained for data extraction. The PRISMA flow diagram presents the results of the study selection process (see Figure 3.1). The 24 papers were located from various sources including peer-reviewed database searches (*n=9*), handsearching systematic reviews and journals (*n=11*), known articles (*n=3*), and grey literature searches (*n=1*). The articles retained for data extraction ranged in publication date from 1987 to 2018.

Figure 3.1

Scoping Review PRISMA Flow Diagram



3.3.2 Study Designs

Empirical research comprised 23 articles and one case description sourced from the professional journal of the Australian Psychological Society. The empirical research included descriptive case studies (*n=7*), pre-post studies (*n=6*), randomised controlled trials (*n=4*), single subject experimental design (*n=2*), clinical case study (*n=2*), and a feasibility study (*n=1*). One study described both pre-post and observational design elements (Douds et al., 2014). A further study was described broadly as a qualitative research design and applied focus groups to assess the effectiveness of Multi-Family Group Therapy (Couchman et al., 2014).

3.3.3 Context of Studies

All the research was conducted in high-income countries; the United Kingdom (*n=8*), Australia (*n=7*), the United States of America (*n=5*), Italy (*n=2*), France (*n=1*), and New Zealand (*n=1*). Interventions were delivered in predominantly community-based settings (*n=18*). Most interventions were delivered in affiliation with specialist disability services including public disability support services (*n=4*), outpatient health services (*n=3*), forensic support (*n=2*), recreational day-options (*n=1*), counselling service (*n=1*), and an acute mental health treatment unit (*n=1*). A portion of the interventions were provided in the participants' home (*n=3*). Additionally, intervention delivery related to organisations that provided support to specific populations including those who experience brain injury (n=2), Motor Neuron Disease (MND) or Amyotrophic Lateral Sclerosis (ALS) (n=2), and developmental disabilities (n=1).

3.3.4 Participant Populations

As communication access needs frequently coexist with other conditions, the primary diagnoses of participants were varied. Further detail regarding participant populations can be found in Table 3.3. Most papers focused on a singular, primary diagnostic group (n=20): intellectual disability (n=11), acquired brain injury (n=4), MND (n= 3), autism spectrum disorder (ASD, n=1), dementia (n=1). However, some studies included participants with different diagnoses (n=5), including individuals with diagnoses such as intellectual disability, ASD, brain injury, and/or physical disabilities. Many of the included papers identified that participants had a co-existing psychiatric diagnosis including depression (n=5), specific phobia (n=3), schizophrenia (n=3), post-traumatic stress disorder (PTSD, n=2), bipolar disorder (n=2), or generalised anxiety disorder (n=1). Articles also described broader mental health concerns, such as: trauma (n=8), grief and loss (n=6), dysregulated anger (n=5), emotional distress (n=3), behavioural concerns (n=2), and suicidal ideation (n=1).

In the selected studies, the experience of having communication access needs was identified using various terminology such as 'non-verbal' (Cravero et al., 2016; Magai et al., 2002), 'non-vocal' (Crawford, 1987), 'without functional verbal communication' (Webber & Harkness, 2016), and 'unable to speak' (Palmieri et al., 2012). Participants were described as having very low verbal intelligence quotient (Willner, 2004), speech impairment (Aoun et al., 2015), or significant communication disabilities (McClean et al., 2007). Only one paper used the term 'complex communication needs' (Hagiliassis, Gulbenkoglu, et al., 2005). Determining the presence of communication access needs was more frequently implied by the description of the participant, diagnostic factors, and support requirements (Boso et al., 2007; Cambridge, 2013; Chapman et al., 2006; Couchman et al., 2014; Douds et al., 2014; Douglass et al., 2007; Fernando & Medlicott, 2009; Hsieh et al., 2012; Kay et al., 2015; Kreutzer et al., 2018; Summers & Witts, 2003). Some authors addressed the participants' preferred methods of communication and use of AAC (Aoun et al., 2015; Averill et al., 2013; Hagiliassis, Gulbenkoglu, et al., 2005; Wark, 2012). Most studies did not identify the proportion of participants with communication access needs. Exceptions include McClean et al. (2007) and Wark (2012) who noted that all participants experience significant communication difficulties, and Hagiliassis, Gulbenkoglu, et al. (2005) who provided a detailed breakdown of the communication needs of psychoeducational group members.

Table 3.3

Overview of Psychoeducational Interventions for People with Communication Access Needs

Author/ Year/ Country	Study design	Intervention	Psychoeducational aims	Intervention delivery	Participants and evidence of	Outcomes
Aoun et al. (2015) Australia	Pre-post study	Dignity Therapy (DT)	Test the acceptability and feasibility of DT to reduce distress for people living with MND. Themes: • Enhance coping and wellbeing. • Symptom reduction.	Practitioner: Psychologist 3-7 x sessions. Average12 hours per intervention. Sessions focussed on the Dignity Therapy Questions Protocol	n= 27 people with MND (18 male/ 9 female) n= 18 care givers 11 participants experienced bulbar onset MND, resulting in speech difficulties.	No significant changes to quality of life (ALSAQ-5), spiritual wellbeing (FACIT-sp12), hopefulness (HHI), or distress (PDI). 89% agreed that DT was helpful to them. 70% felt more connected to family and friends. 37% felt reduced sadness/depression
Averill et al. (2013) USA	RCT	Expressive emotional disclosure	Examine the effects of expressive emotional disclosure on the psychological wellbeing in people with ALS. Theme:	Practitioner: Clinical Psychologist Intervention participants wrote or spoke (44%) about their thoughts and feelings related to ALS for 20 mins per day for 3	n=48 participants w. ALS (24 intervention) Participants were able to complete the intervention by writing (56%) or speaking	No increase in negative affect from baseline to 3 months (ABS, GDS). Improvement in wellbeing from baseline at 3 months and at 6 months (McGill QoL Questionnaire).

			• Enhance coping and wellbeing.	days.	(44%), including the use of AAC.	Mode of disclosure (written or spoken) had no further effect on wellbeing.
Boso et al. (2007) Italy	Pre-post study	Music Therapy	Investigate the effects of music therapy on the behavioural profile of young adults with severe autism. Themes: • Education. • Symptom reduction.	Practitioners: Multi-disciplinary Music Therapists and Psychiatrist 52 x weekly 1 hr music therapy sessions. Group sessions consisted of musical activities including drumming, piano, and singing.	n= 8 adults with severe ASD. 7 male/1 female 23-38 years of age Participants experience of communication access needs (CAN) was not stated; diagnosis of severe ASD is associated with communication difficulties.	Significant improvements in psychiatric symptomology (BPRS) from baseline to T2. Non-significant improvement on BPRS from T2 to T3. 88% of participants experienced improvement in functioning (CGI-I) between T1 to T2.
Cambridge (2013) UK - England	Case study (descriptive practitioner reflection)	Individual counselling	Application of a person-centred, rights-based approach to address concerns regarding a sexual fetish. Theme:	Practitioner: Social Worker 1:1 psychoeducation session delivered over a 3-year period. 1hr session followed by	n=1 Adult w. ASD and ID. CAN was not stated; the author described adapting written and spoken information to enable comprehension, as well as the	Concerning behaviours related to the individual’s fetish diminished. The participant displayed greater autonomy in his sexual life, at times ceasing to engage with his fetish.

			• Enhance coping and wellbeing. • Education.	mediated dialogue with service provider.	participant's use of AAC (writing and images).	The participant expressed his rights and wishes with support people through person-centred planning.
Chapman et al. (2006) USA	Clinical case study	Cognitive Behaviour Therapy (CBT)	Demonstrate the use of the Stop-Think-Relax training for people with dual diagnoses; ID and mental ill-health. Themes: • Enhance coping and wellbeing. • Education. • Symptom reduction.	Practitioner: Multi-disciplinary (disciplines not specified). 5x 45 min sessions per week. Group format and 1:1. Training protocol consists of; teaching and review, identifying feelings, listening skills, anger control and relaxation.	n = 3 Adults 1 male, ID, and depression. 1 male ID, panic disorder. 1 female. Foetal alcohol syndrome, anxiety disorder. CAN is not stated; participant descriptions of indicate communication access needs.	All participants experienced a reduction in scores across all domains of the Aberrant Behaviour Checklist (ABC). The greatest reductions were in the irritability and hyperactivity scales related to reduced anxiety and anger.

Couchman et al. (2014) Australia	Focus group evaluation (qualitative design)	Multi Family Group Therapy (MFGT)	Identification of factors that influence the success of MFGT programmes with families impacted by ABI. Themes: • Enhance coping and wellbeing. • Education	Practitioner: Clinical Psychologists 12 sessions over 12 weeks: 2x ‘getting to know you’ sessions. 2 x education sessions. 8 x solutions focussed problem solving sessions.	n=29 adults w. ABI, and n=30 caregivers CAN was not stated; the authors describe communication access strategies to include participants. The researchers also describe communication barriers faced by participants with ABI during interviews.	Results are reported under the following themes: 1. Connectedness – relationships and feeling understood. Connectedness led to reduced feelings of grief, frustration, and despair. 2. Identity - sense of self and identity within the family unit. 3. Knowledge and understanding of ABI.
Cravero et al. (2016) France	Clinical case study	Positive Behaviour Support (PBS)	Describe the approach used to alleviate distress and concerning behaviours in person with multiple coexisting diagnoses in a neurobehavioral support unit. Theme: • Symptom reduction.	Practitioner: Multi-disciplinary Psychiatry, Nursing, Dermatology, Pharmacy Daily support 3 months Neurobehavioral in-patient unit.	n=1 21-year-old Male ID, ASD, Cornelia de Lange Syndrome, Ehlers-Danlos Syndrome Severe behavioural disorder, depressive syndrome. The participant is described as 'non-verbal'.	Reductions in aggressive behaviours, self-injury, and aggression directed at other people/property. Return to supported-living support in the community. Reduced hospital admissions related to distress/behavioural concerns. Description of outcomes were limited.

Crawford (1987) USA	Case studies	Individual Psychotherapy	Descriptions of the use AAC in counselling and psychotherapy to assist adjustment to disability. Theme: • Enhance coping and wellbeing.	Practitioner: Clinical psychologist The author provided dynamic psychotherapy to the individuals described in the case studies.	n=7 adults with anarthria and dysarthria associated with various diagnoses. 4 females Each Participant was able to use an electronic communication aid to engage in psychotherapy.	All participants were able to use electronic AAC in individualised psychotherapeutic support. The period of psychotherapy varied among participants.
Crowley et al. (2008) UK - England	Pre-post study	Group psychoeducation (CBT model)	Test an adapted psychoeducational group for people with ID and psychosis. Themes: • Enhance coping and wellbeing. • Education. • Symptom reduction.	Practitioner: Multidisciplinary Team (disciplines not specified). 6 x 1.5hr weekly sessions. 4 participants per group. Each participant was invited to bring a support person.	n=8 Adults with mild-moderate ID and schizophrenia or manic depression (Bipolar 1 or 2). CAN was not stated; it is indicated by the adaptations applied to the intervention to support communication access.	No significant changes to self-esteem pre and post intervention (Crown Self Esteem Scale). Significant changes to psychosis knowledge measure ($p>0.01$). All participants developed a support plan with pictographic symbols.

Douds et al. (2014) UK - Scotland	Pre-post study	Group psychoeducation (CBT model)	Improve participants understanding of schizophrenia, treatments, early signs, and symptoms. Theme: • Education	Practitioner: Multidisciplinary Team (Psychiatry, Nursing, Social Work, Speech Pathology) 6-7 x 1hr sessions weekly 3-5 participants per group	n=20 people with ID and schizophrenia. CAN was not stated; communication difficulties are implied by the inclusions of communication access strategies for written and spoken information.	All participants completed a 'Staying Well Plan'. Participants could identify early indicators for mental ill-health and strategies to maintain their wellbeing. Participants continued to use the 'Staying Well Plans' two years after completion of the first groups
Douglass et al. (2007) UK - Wales	Pre-post study	Group psychoeducation (CBT model)	Investigate the effectiveness of a psychoeducational group for people with ID and anxiety. Theme: • Enhance coping and wellbeing. • Education. • Symptom reduction.	Practitioner: Multidisciplinary Team (Occupational Therapy, Psychology, Disability Nursing). 12 x 2hr weekly sessions. Homework between sessions. Support workers were available.	n= 6 people with ID and anxiety 4 female, 22-65 years of age. CAN was not explicitly stated; diagnoses indicate that some individuals experienced CAN.	All participants reported using new coping strategies. Three out of six participants experienced reduction in anxiety (GAS-ID). For two participants, the reduction in anxiety was clinically significant. No information about analysis.

Fernando & Medlicott (2009) UK - Wales	Case study Descriptive	Individual psychotherapy (CBT model)	To report on the treatment of a woman with ID and PTSD related for romantic partner violence. Themes: • Enhance coping and wellbeing. • Education. • Symptom reduction.	Practitioner: Clinical Psychologist 9 x sessions with a clinical psychologist.Treatment was comprised of: education, relaxation training, problem solving, cognitive restructuring, and exposure.	n= 1 34-year-old woman with diagnosis of ID and PTSD. CAN was not stated; participant scored below average in the communication skill domains (ABAS-II).	Participant reported a reduced conflict with partner and improved relationship with her mother. Participant reported reduced intrusive thoughts and improved mood.
Hagiliassis et al. (2005) Australia	RCT	Anger Management Group (CBT model)	Examine the effectiveness of an anger management skills program for people with varied communication support requirements. Themes: • Enhance coping and wellbeing. • Education. • Symptom reduction.	Practitioner: Clinical Psychologists 12 x weekly 2hr sessions. Each session follows a standardised format.	n= 29 people with ID and/or CAN. n=14 intervention group Participants with diverse communication support needs, including eight “non-verbal communicators.”	Significant reduction in participants’ Novaco Anger Scale (NAS) scores measuring the cognitive, arousal and behavioural aspects of anger. Improved NAS scores were sustained at 4-month follow-up. Data did not demonstrate and improvement in quality of life.

Hsieh et al. (2012) Australia	Single-subject research design.	CBT	To describe two client cases with moderate/severe TBI demonstrating the benefit of using CBT for anxiety. Themes: • Enhance coping and wellbeing. • Education. • Symptom reduction.	Practitioner: Clinical Psychologist 9x 1hr individual CBT sessions Delivered weekly by a doctoral level psychologist Manual developed for the study	n=2 'Alex' - male 40+ years. Severe TBI and depression. 'Sara' - female 30+ years. Moderate TBI and post TBI anxiety disorder CAN was not explicitly stated; challenges experienced by 'Alex' in accessing written and spoken information imply CAN.	Participants reported using new coping skills to manage anxiety. Alex - statistically significant reduction in distress (SUDS). 'Sara' - statistically significant reduction in anxiety and stress scores, but not depression score (DASS). Participants and researchers recommend access strategies: 1) Include depression and anxiety resources due to high co-morbidity. 2) Use decision-trees for flexible delivery of content. 3) Use visual supports alongside written materials.

Kay et al. (2016) UK - England	Feasibility study.	Psychomotor therapy	Identify adverse behavioural effects resulting from PsyMot treatment. Themes: • Enhance coping and wellbeing. • Symptom reduction.	Practitioner: Multidisciplinary Team Physiotherapist, Clinical Psychologist. 6-8 x 1hr psychomotor therapy sessions	n= 12 adults with intellectual disability and mental health condition. CAN was not stated; three participants were unable to complete the assessment due to severe communication difficulties.	Psychomotor therapy did not increase the number of reported incidents on the day of treatment/ assessment. Further outcomes for psychomotor therapy were not reported.
Kreutzer et al. (2018) USA	RCT	Resilience and Adjustment Intervention Group (CBT model)	Examine the effectiveness of a psychoeducational skill development intervention following TBI. Themes: • Enhance coping and wellbeing. • Education. • Symptom reduction.	Practitioners: Doctoral Psychologists 7x 1hr sessions Facilitated by doctoral level Psychologists	n= 160 n= 83 intervention group 36% of participants had sustained a moderate-severe TBI. CAN was not stated; two sessions focussed on communication skills indicating CAN.	Intervention participants had clinically significant increase in resilience (CD-RISC). Clinically significant improvement in psychiatric symptomology (BSI-18). Improved MPAI-4 scores indicating reduced psychological distress.

Magai et al. (2002) USA	RCT	Non-verbal sensitivity training	Test the effectiveness of non-verbal communication training for caregivers of people with dementia. Theme: • Symptom reduction.	Practitioner: Clinical Psychologist 10 x 1 hr information sessions delivered to caregivers over 2 weeks. Sessions covered facial, vocal, and bodily indicators of emotion; distinguishing emotions; responding to emotional expression; and validating emotions.	n= 91 people w. mid to late-stage dementia n=41 intervention 93% female CAN was not stated; participants' diagnoses, and the researchers' use of non-verbal communication training is indicative of CAN.	Significant improvement in positive affect (joy), subsiding by 12 weeks post intervention. Reduction in depression, agitation, behavioural and psychological symptoms (BEHAVE-AD, CMAI, CDS).
McClean et al. (2007) UK - Ireland	Single case design.	PBS	Evaluate the implementation of PBS for five individuals with severe challenging behaviours. Themes: • Enhance coping and wellbeing. • Symptom reduction.	Practitioner: Multidisciplinary Team (Psychology, Psychiatry, Behaviour Therapy, support staff and family). Personalised PBS plans were developed. Caregivers were supported to implement PBS by the multi-disciplinary team.	n= 5 adults with intellectual disability and psychiatric diagnosis. n= 3 male All five participants experienced significant communication difficulties.	Four participants experienced a reduction in PAS-ADD scores. Three participants had significant increases in quality of life (QoLQ) from baseline to 24 months. All participants experienced a reduction in the use of behaviours of concern.

Palmieri et al. (2012) Italy	Pre-post study. Pilot study.	Hypnosis-based treatment	Investigate the effectiveness of hypnosis-based psychological wellbeing intervention for people with ALS. Themes: • Enhance coping and wellbeing. • Education. • Symptom reduction.	Practitioner: Clinical Psychologist 4 x weekly 2hr sessions. Sessions included personalised hypnotic suggestion tailored to symptoms. Participants used an audio recording of the hypnosis to practice every day.	n=8 adults with ALS (4 male) One participant is described as having 'no speech', and two participants had bulbar onset ALS more commonly associated with CAN.	Participants experienced reductions in anxiety and depression (HADS) Participants experienced reductions in negative emotion subscale scores (ALSQoL-r).
Summers & Witts (2003) UK - England	Case study Treatment description.	Individual psychotherapy	Provide a case study illustration of the theoretical underpinnings in providing support for grief and loss in people with ID. Theme: • Enhance coping and wellbeing.	Practitioner: Clinical Psychologist 12 x sessions of psychotherapy	n=1 Adult female with ID. CAN was not explicitly stated; the participant's lifelong difficulties with language and comprehension are described.	Support staff reported that the participant experienced fewer angry outbursts, was no longer distressed and tearful, no longer incontinent, and her cough had ceased. 12 months post-treatment, the participant was able to demonstrate understanding of her father's death.

Walker et al. (2010) Australia	Pre-post study	Anger Management Group (CBT model)	Evaluate the effectiveness of a group anger management programme for individuals with TBI. Themes: • Enhance coping and wellbeing. • Education. • Symptom reduction.	Practitioner: Multi-disciplinary Team Clinical Psychologist, Brain Injury Case Manager 12 x 2hr group sessions +1 follow-up session 4-8 participants per group	n= 52 adults with anger control difficulties following a severe TBI. CAN was not stated; strategies were used to improve access to written and spoken information indicating communication support requirements.	Significant decreases in anger (trait and expression) and an increase in anger control post treatment (STAXI). Participants who had the support of a friend or family member were more likely to complete the follow-up session.
Wark (2012) Australia	Case studies. Descriptive	Narrative Therapy	Explore the use of narrative therapy with people with ID, ASD, and/or CAN. Theme: • Enhance coping and wellbeing. • Education.	Practitioner: Clinical Psychologist The intervention is highly personalised to meet individual requirements.	n= 4 adults All participants experience complex communication support needs and/or use AAC.	Participants worked with the therapist to create resources to address specific phobia, anger, grief and loss. Resources were shared with support people.

Webber & Harkness (2016) Australia	Case studies. Descriptive	PBS	Describe clinical psychologists work with people with complex support needs. Theme: • Enhanced coping and wellbeing	Practitioner: Clinical Psychologist No description of the intervention delivery.	n= 1 adult with ID and complex support needs ('James'). James is described as having no functional verbal communication.	James' support people were able to apply PBS practices. James ceased self-harming and mechanical restraints were withdrawn.
Willner (2004) UK - Wales	Case study	Individual psychotherapy (CBT model)	To describe a brief intervention for recurrent nightmares. Theme: • Symptom reduction	Practitioner: Clinical Psychologist 1 x 1hr session w. psychologist	n= 1 adult male 29 years old with ID. The author refers to the participant as 'a man with a very low verbal IQ.'	No subsequent recurrence of the nightmare during treatment. The participant reported that the nightmare had only occurred once more at 6-month follow-up.

3.4 Thematic Analysis

Thematic analysis was conducted with a specific focus on the scoping review aims. The key themes explored were:

- Types of psychoeducational interventions that have been trialled with people with communication access needs;
- Adaptations used to include people with communication access needs in psychoeducational interventions; and
- The effectiveness of psychoeducational approaches as reported by people with communication access needs and their ECPs.

3.4.1 Types of Psychoeducational Intervention

Cognitive Behavioural Therapy (CBT) was the most prevalent intervention, with seven interventions described as such (Chapman et al., 2006; Douglass et al., 2007; Fernando & Medlicott, 2009; Hsieh et al., 2012). Group anger management interventions (Chapman et al., 2006; Hagiliassis, Gulbenkoglu, et al., 2005; Walker et al., 2010) were based upon a cognitive-behavioural approach. However, these interventions are identified separately due to their very specific objectives, particularly stress reduction and self-management. An overview of the objectives of each intervention can be found in Table 3.3.

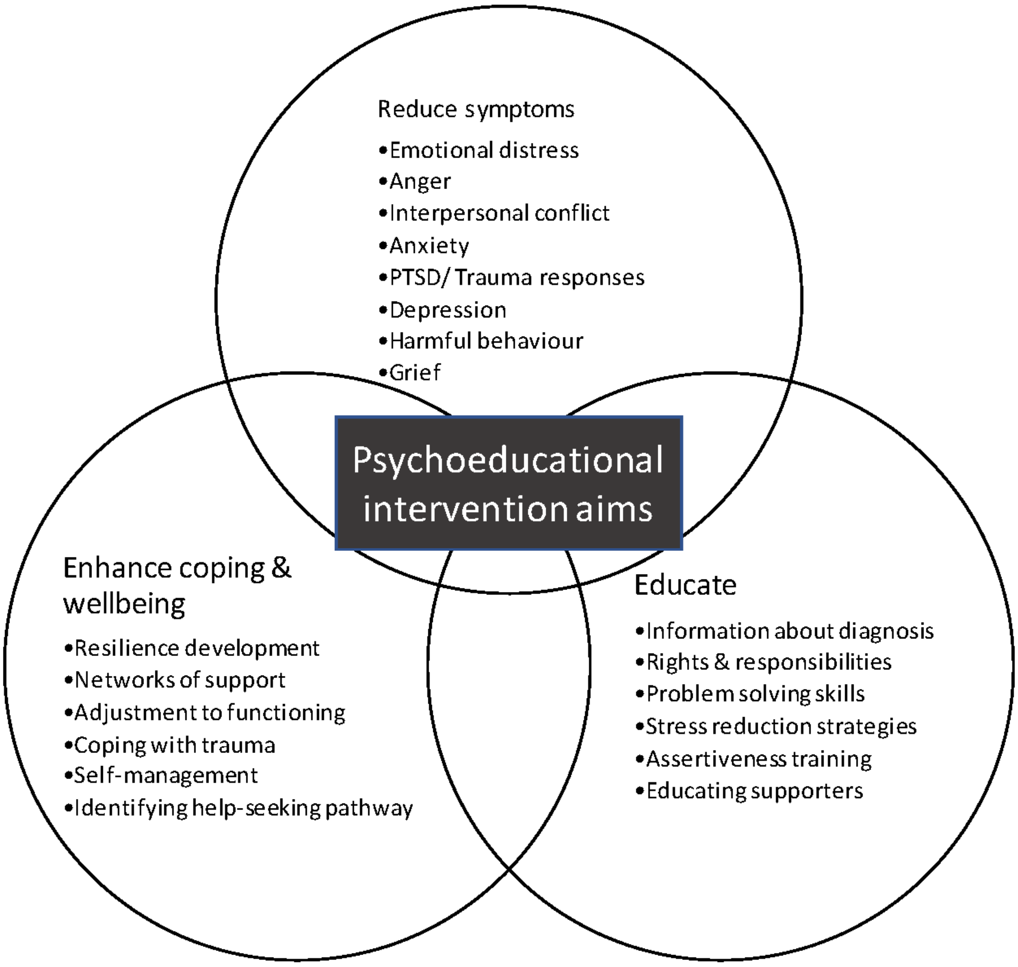
Eight interventions were delivered in a group format (Boso et al., 2007; Couchman et al., 2014; Crowley et al., 2008; Douds et al., 2014; Douglass et al., 2007; Hagiliassis, Gulbenkoglu, et al., 2005; Magai et al., 2002; Walker et al., 2010). Chapman et al. (2006) applied a mixed delivery approach whereby content is partially delivered in group sessions and supported by individual skill development sessions. The objectives of interventions delivered in groups settings were predominantly educational. Some focused on addressing mental health issues for a specific diagnostic group (Couchman et al., 2014; Walker et al., 2010). Other interventions provided education and skills training to enable management of mental health problems generally (Douds et al., 2014), or specific concerns such as anger (Hagiliassis, Gulbenkoglu, et al., 2005; Walker et al., 2010), psychosis (Crowley et al., 2008), or anxiety (Douglass et al., 2007). One intervention sought to educate ECPs in non-verbal communication of emotions to benefit wellbeing and reduce agitation in individuals living with dementia (Magai et al., 2002). A final intervention taught music to participants with ASD and communication access needs with the aim of reducing psychiatric symptomology (Boso et al., 2007).

3.4.2 Aims of Psychoeducational Interventions

Psychoeducational interventions may form a broad category defined by some common aims (Sarkhel et al., 2020; Zhao et al., 2015). Through the process of thematic analysis, the aims of selected studies were grouped based upon three overarching themes: 1) Education; 2) Enhancing coping and wellbeing; and 3) Reduction of symptoms. Figure 3.2 specifies the characteristics of each theme. Outcomes of the interventions are addressed using these same thematic groupings

Figure 3.2

Aims of Psychoeducational Interventions for People with Communication Access Needs



3.4.3 Adaptations to Psychoeducational Interventions

All articles described adaptations to improve the accessibility of the intervention for people with communication access needs. Key adaptations related to personalisation of the intervention, utilisation of communication access strategies, and the inclusion of ECPs. Table 3.4 identifies the adaptations applied in each study.

Table 3.4

Summary of Adaptations to Promote Access in Psychoeducational Interventions

Author/ Year	**Intervention**	Use existing AAC	Use new forms of AAC	Assess behaviour	Environmental adjustments	Inclusion of ECPs	Memory Aids	Multi-disciplinary team	Reduced use of speech	Personalise intervention	Recap information	Simplify language	Teaching strategies	Increase time	Visual aids	Total adaptations per paper
Aoun et al. (2015)	Dignity Therapy													✓		**2**
Averill et al (2013)	Expressive emotional disclosure	✓														1
Boso et al. (2007)	Music Therapy			✓				✓								2
Cambridge (2013)	Individual counselling	✓				✓										2
Chapman et al. (2006)	Cognitive Behaviour Therapy (CBT)						✓	✓		✓		✓			✓	5
Couchman et al. (2014)	Multi Family Group Therapy					✓				✓			✓		✓	4
Cravero et al. (2016)	Positive Behaviour Support		✓	✓				✓								3
Crawford (1987)	individual psychotherapy	✓												✓		2
Crowley et al. (2008)	Group Psychoeducation (CBT model)					✓	✓	✓		✓	✓	✓	✓		✓	8
Douds et al. (2014)	Group Psychoeducation (CBT model)							✓				✓				3
Douglass et al. (2007)	Group Psychoeducation (CBT model)					✓				✓	✓	✓	✓		✓	7
Fernando & Medlicott (2009)	Individual psychotherapy (CBT model)					✓							✓		✓	3

Author/ Year	Intervention	Use existing AAC	Use new forms of AAC	Assess behaviour	Environmental adjustments	Inclusion of ECPs	Memory Aids	Multi-disciplinary team	Reduced use of speech	Personalise intervention	Recap information	Simplify language	Teaching strategies	Increase time	Visual aids	Total adaptations per paper
Hagiliassis, Gulbenkoglu, et al. (2005)	Anger Management Group (CBT model)	✓				✓				✓			✓		✓	5
Hsieh et al. (2012)	Cognitive Behaviour Therapy					✓	✓			✓	✓	✓		✓		8
Kay et al. (2016)	Psychomotor therapy				✓			✓	✓	✓						4
Kreutzer et al. (2018)	Resilience and Adjustment Group (CBT model)						✓				✓					2
Magai et al. (2002)	Non-verbal sensitivity training	✓				✓			✓							3
McClean et al. (2007)	Positive Behaviour Support		✓	✓		✓		✓								4
Palmieri et al. (2012)	Hypnosis-based treatment								✓		✓					3
Summers & Witts (2003)	Individual psychotherapy					✓						✓			✓	3
Walker et al. (2010)	Anger Management Group (CBT model)					✓		✓			✓	✓			✓	6
Wark (2012)	Narrative Therapy	✓										✓	✓		✓	4
Webber & Harkness (2016)	Positive Behaviour Support		✓	✓		✓			✓							4
Willner (2004)	Individual psychotherapy (CBT model)					✓					✓	✓				3
Total adaptations by type		7	3	4	1	13	4	8	4	7	7	9	7	3	9	

Personalisation. Personalisation, or person-centredness, requires mental health practitioners to respond to the unique requirements of the individual, working collaboratively in goal setting and intervention implementation (Neale et al., 2019). Hsieh et al. (2012) noted the importance of striking a balance between manualisation for consistency, and personalisation of content to ensure that it met the participant's capabilities. Personalisation of resources occurred both in the planning phase (Douds et al., 2014; Hagiliassis, Gulbenkoglu, et al., 2005; Hsieh et al., 2012; McClean et al., 2007; Palmieri et al., 2012), and during implementation in response to participants' reactions and feedback (Chapman et al., 2006; Couchman et al., 2014; Crowley et al., 2008; Douglass et al., 2007; Kay et al., 2015). In responding to personal factors, researchers tailored their approaches to meet individuals' mobility (Crowley et al., 2008; Hagiliassis, Gulbenkoglu, et al., 2005), cognitive capacities (Chapman et al., 2006; Douglass et al., 2007; Hsieh et al., 2012), and fatigue levels (Palmieri et al., 2012). In their psychomotor therapy intervention, Kay et al. (2015) responded to participants' previous exposure to traumatic events, adopting a trauma-informed approach to intervention. Adaptations were made to levels of competition and physical contact dependent on the participants' comfort and security. Personalisation of specific communication access requirements is addressed in the following theme: communication access strategies.

Communication Access Strategies. All included articles discussed strategies that improved communication access within the psychoeducational intervention. Key communication access strategies are identified in Table 3.4. Interventions described as having a CBT approach applied the most adaptations (*n=5*), these studies applied over 50% of the adaptations categories identified. Of these CBT interventions, the majority were delivered as group psychoeducational programs (Crowley et al., 2008; Douglass et al., 2007; Hagiliassis, Gulbenkoglu, et al., 2005; Walker et al., 2010), with one manualised program delivered to individuals (Hsieh et al., 2012). The exception was Wark's (2012) case studies of narrative therapy delivered in individual counselling sessions; the only study to use over half of the adaptations that did not apply a CBT approach.

Communication access strategies fell into the following categories: changing mental health practitioner communication behaviours, incorporating individuals' AAC, inclusion of other stakeholders, reduced requirement for speech in the intervention delivery, and time.

Inclusion of ECPs. Inclusion of ECPs was the most frequently cited adaptation to intervention delivery (*n=11* studies). ECPs' involvement in intervention varied, ranging from inclusion as participants in the study (Aoun et al., 2015; Couchman et al., 2014; Douglass et al., 2007; Magai et al., 2002; Palmieri et al., 2012; Walker et al., 2010) to incidental supporters in the implementation of the intervention and providing observations of participant functioning (Cambridge, 2013; Crowley et al., 2008; Douds et al., 2014; Fernando &

Medlicott, 2009). One training intervention was delivered to support workers to promote their capacity to respond to non-verbal communication from people with advanced dementia (Magai et al., 2002). ECPs were also included to support attendance of groups, assisting participants' uptake of information, and promoting implementation of strategies beyond the group (Crowley et al., 2008; Douglass et al., 2007; Hagiliassis, Gulbenkoglu, et al., 2005; Walker et al., 2010).

Changing practitioner communication behaviours. Authors discussed the communication behaviours adopted by mental health practitioners to better include individuals experiencing communication difficulties. These changes in behaviour related to improving accessibility of spoken and written materials, incorporating memory aids, and employing teaching strategies.

The key strategies for improving accessibility of written information in psychoeducational interventions were: 1) using plain language documents (Crowley et al., 2008; Douds et al., 2014; Douglass et al., 2007; Summers & Witts, 2003); and 2) using visual aids or pictographic symbols with simplified text (Chapman et al., 2006; Crowley et al., 2008; Hagiliassis, Gulbenkoglu, et al., 2005). In addressing adjustments to spoken communication researchers noted the benefit of using the participant's existing vocabulary to explain unfamiliar terms (Hsieh et al., 2012), using simultaneous visual cues when providing instruction (Chapman et al., 2006; Wark, 2012), repetition or rehearsal of coping statements (Douglass et al., 2007; Willner, 2004), and using concrete explanations of concepts rather than metaphors (Summers & Witts, 2003; Walker et al., 2010).

Teaching new skills to support coping is a core element of psychoeducational interventions (Zhao et al., 2015). Researchers who sought to teach participants new skills used strategies to promote engagement, such as multi-media content (Crowley et al., 2008), peer-presentations (Couchman et al., 2014), boardgames (Douglass et al., 2007), roleplay (Hagiliassis, Gulbenkoglu, et al., 2005; Hsieh et al., 2012), and drawing or painting (Fernando & Medlicott, 2009; Wark, 2012). These teaching strategies enabled participants to practice skills such as conflict resolution, distress management, and challenging intrusive thoughts.

To support the inclusion of participants experiencing cognitive difficulties, researchers utilised memory aids such as frequent recaps of content (Couchman et al., 2014; Crowley et al., 2008; Hsieh et al., 2012), visual prompts with short written cues (Chapman et al., 2006; Fernando & Medlicott, 2009; Hsieh et al., 2012; Wark, 2012), and collated, hardcopy resources to be retained by the participant (Kreutzer et al., 2018; Walker et al., 2010). Hardcopy resources included written plans to assist self-management of mental health problems (Crowley et al., 2008; Douds et al., 2014; Douglass et al., 2007).

Use of AAC modes. AAC refers to the range of multimodal expression employed by people with communication access needs and their communication partners. Seven papers identified that participants had pre-existing AAC strategies which were incorporated into psychoeducational support. Participants in these studies utilised a range of AAC methods including simplified manual signs (Wark, 2012), electronic communication aids (Crawford, 1987), writing or typing (Averill et al., 2013; Cambridge, 2013), human assistance (Aoun et al., 2015), as well as communication boards, gesture, and facial expression (Hagiliassis, Gulbenkoglu, et al., 2005; Magai et al., 2002). In these examples, AAC was employed to supplement speech and was integral to individuals' participation in the intervention.

A further seven papers discussed the introduction of a new form of AAC. Four interventions included the provision of alternative modes of expression employed within the intervention sessions. Examples include the use of drawing, painting, and photographs to enable participants to communicate a message or demonstrate their new skills and knowledge (Crowley et al., 2008; Fernando & Medlicott, 2009; Summers & Witts, 2003; Wark, 2012). A further cluster of interventions introduced new AAC systems to be used in the individual's everyday life, beyond the intervention. These were all PBS studies delivered by multi-disciplinary teams in which the researchers equipped participants with AAC to enable choice-making and alleviate distress (Cravero et al., 2016; McClean et al., 2007; Webber & Harkness, 2016).

Inclusion of other stakeholders. The stakeholders included in the psychoeducational intervention fell into two sub-groups: 1) ECPs (discussed previously), and 2) professionals. Professional stakeholders were included in multi-disciplinary teams, with professionals from two or more disciplines providing perspectives on psychoeducational intervention delivery. Multi-disciplinary professionals included behavioural therapists, case managers, nursing staff, pharmacists, physiotherapist, psychiatrists, psychologists, social workers, and speech pathologists (Boso et al., 2007; Chapman et al., 2006; Cravero et al., 2016; Crowley et al., 2008; Douds et al., 2014; Kay et al., 2015; McClean et al., 2007; Walker et al., 2010). In one example, a speech pathologist informed the team about communication adaptations, ensuring that psychoeducational content was accessible to all group members (Douds et al., 2014). A speech pathologist was also engaged to support the implementation of an AAC systems within a PBS intervention (Cravero et al., 2016). Although communication access was considered in other studies, the inclusion of speech pathologist in the team was not specified.

Interventions that reduce the requirement for verbal communication. Four interventions reduced participants' requirement to use to speech for participation; these were: psychomotor therapy (Kay et al., 2015); hypnosis (Palmieri et al., 2012); music therapy (Boso et al., 2007); and expressive disclosure, where writing was the person's chosen form of communication (Averill et al., 2013). Although most interventions used speech as the primary mode of delivery; alternative modes of communication were offered to enhance communication. For example, participants were able to select writing (Averill et al., 2013; Cambridge, 2013) or drawing (Crowley et al., 2008; Fernando & Medlicott, 2009; Summers & Witts, 2003), rather than speech.

Time. Time provision required personalisation to meet individual requirements. Time referred to duration of sessions, as well as the time taken to exchange information within sessions. Increased time was required within sessions for individuals using AAC devices (Aoun et al., 2015; Crawford, 1987). For some participants' cognitive processing required a reduced pace of information delivery in the sessions (Hsieh et al., 2012; Wark, 2012). Some participants using AAC required longer sessions to enable them to get their message across without time pressures. Conversely, Wark (2012) provided shorter sessions to maintain participants' energy and attention. Each of the interventions that considered time were delivered on an individual basis.

3.4.4 Effectiveness of Psychoeducational Interventions

Effectiveness of the interventions is discussed thematically, grouped under three primary outcome themes: 1) Enhanced coping and wellbeing; 2) Reduction of symptoms; and 3) Education (see Figure 2). Most interventions reported outcomes across all three domains (*n=12*), with the remainder reporting on two domains (*n=10*) or one domain (*n=2*). The three themes provide a framework to better understand the outcomes of psychoeducational interventions for people with communication access needs.

Enhanced coping and wellbeing. Twenty-three studies reported on outcomes related to coping and wellbeing. Outcomes in this category related to quality-of-life measures such as wellbeing (Averill et al., 2013), hope (Aoun et al., 2015), self-esteem (Crowley et al., 2008), resilience (Kreutzer et al., 2018), affect (Magai et al., 2002), and spirituality (Palmieri et al., 2012). Participants reported changes to feelings of connectedness (Couchman et al., 2014), adjustment to disability (Crawford, 1987), and engagement in employment and training (McClean et al., 2007). Additionally, participants developed specific skills which enabled them to cope with stressors (Douglass et al., 2007; Hagiliassis, Gulbenkoglu, et al., 2005; Kay et al., 2015; Wark, 2012; Willner, 2004), self-manage symptoms and identify pathways for mental health support (Chapman et al., 2006; Crowley et al., 2008; Douds et al., 2014). In some cases, these new skills and coping strategies resulted in reduced use of crisis services (Chapman et al., 2006; Cravero et al., 2016; McClean et al., 2007).

Developing new coping skills had flow-on effects for participants' social and occupational engagement. This was indicated by strengthened familial relationships and friendships (Couchman et al., 2014; Fernando & Medlicott, 2009) and participation in community-based activities (Cravero et al., 2016; Wark, 2012).

Reduction of symptoms. Twenty studies reported on reduction of symptoms experienced by participants. Reduced symptoms included anger (Hagiliassis, Gulbenkoglu, et al., 2005), anxiety and agitation (Chapman et al., 2006; Douglass et al., 2007; Wark, 2012), depression (Hsieh et al., 2012), flashbacks and nightmares related to PTSD (Fernando & Medlicott, 2009; Willner, 2004), and psychological distress (Aoun et al., 2015). Further studies reported decreased concerning behaviour or self-injuring as indicative of reduced symptoms (Cambridge, 2013; Cravero et al., 2016; McClean et al., 2007). Two studies measured reductions in general psychiatric symptomology (Boso et al., 2007; Magai et al., 2002). Further studies spoke of improvements in physical wellbeing (Cravero et al., 2016; Palmieri et al., 2012), reduced reliance on psychoactive medications (McClean et al., 2007) and decreased restrictive practices (Webber & Harkness, 2016) as being indicitive of symptom reduction.

Reduced psychiatric symptomology had benefits for participants' functioning, leading to increased community participation, particularly where restrictive measures were previously implemented to manage the person's behaviour (Cambridge, 2013; Cravero et al., 2016; McClean et al., 2007; Webber & Harkness, 2016; Willner, 2004).

Education. Fifteen studies reported outcomes that related to education. Some studies with aims related to education did not report on participants' uptake of knowledge, rather they reported on participants' use of new coping strategies or reduced distress (Fernando & Medlicott, 2009; Hagiliassis, Gulbenkoglu, et al., 2005). For example, Hagiliassis, Gulbenkoglu, et al. (2005) applied pre-post measures to identify participants' capacity to manage anger before and after participation in an anger management skills program. Alternatively, Boso et al. (2007) used pre-post measures to test participants' uptake of musical knowledge, as well as psychiatric symptomology throughout the music therapy intervention. Further studies used participant self-reports to assess the uptake of information relating to human rights (Cambridge, 2013) or self-management of mental health (Chapman et al., 2006; Crowley et al., 2008; Douds et al., 2014). Researcher observation was used to describe the uptake of communication and self-regulation skills taught within a highly personalised psychoeducational program (Cravero et al., 2016).

The effectiveness of psychoeducational program presentation was also explored. Group psychoeducational interventions discussed the benefits of peer-to-peer learning (Couchman et al., 2014; Crowley et al., 2008; Douds et al., 2014). Participants with brain injury described peer presentations, scaffolded with evidence-based content, as a more accessible from of information delivery (Couchman et al., 2014). Through education, some participants developed capacities for self-advocacy, enabling them to exercise greater influence over systems of support (Cambridge, 2013; Willner, 2004), and in relationships (Couchman et al., 2014; Fernando & Medlicott, 2009). In summary, studies that reported educational outcomes placed their findings alongside improvements in symptomology, coping and wellbeing.

3.4.5 Stakeholder Consultations

Consultations with people with communication access needs, ECPs, and MHWs offered social validation of our findings and exposed research gaps. Consultations provided perspectives on receiving, observing, and delivering psychoeducational interventions to people with communication access needs. Consultation was conducted via semi-structured interviews that explored the psychoeducational interventions and communication access strategies that participants had encountered in mental health support settings. Stakeholders with communication access needs were invited to use their preferred methods of communication; each selected to have a communication assistant present to help interpret unaided communication (gestures, facial expressions, and vocalisations). Additionally, both participants with communication access needs used communication boards and AAC apps on a tablet. Stakeholder characteristics are provided in Table 3.5.

Table 3.5

Stakeholder and Interview Characteristics

Identifier	Group	Age	Occupation	Mode of participation	Length of interview
LE 1	Lived experience of communication access needs	50-59 years	Student/ individual community-based program	In-person (home)	1hr 59 mins
LE 2	Lived experience of communication access needs	60-69 years	Group and individual community-based program	In-person (home)	44 mins 35 mins 29 mins
ECP 1	Everyday communication partner	40-49 years	Paid supporter	In-person (office)	1hr 14mins
ECP 2	Everyday communication partner	30-39 years	Paid supporter	Video call (office)	1hr 25mins
MHW 1	Mental health worker	50-59 years	Psychiatrist	Video call (office)	57mins
MHW 2	Mental health worker	50-59 years	Counsellor	In-person (office)	1hr 19mins

Interventions. Stakeholders had varied experiences of the interventions described in the literature. Individual counselling and psychotherapy, and PBS were the most frequently experienced interventions. None of the stakeholders had experience of receiving, observing, or delivering dignity therapy, hypnosis, psychomotor therapy, or resilience and adjustment therapy.

All participants had either received, observed, or delivered individual counselling. Stakeholders with communication access needs identified that, overall, they had benefited from counselling and would seek help from a MHWs in the future, if required. MHWs discussed drawing from multiple psychoeducational approaches within counselling sessions to personalise the intervention to individuals' communicative requirements. Consultation interviews revealed the MHWs employ a range of modalities beyond those suggested by the literature, including arts-based and animal-assisted therapies. The objectives of these modalities are to develop emotional awareness and regulation skills.

MHW 2: I think many of the creative arts can be helpful (…) And I think that's probably an issue when you get a Mental Health Care Plan, because I don't think there's much personalisation. They just think CBT, ten sessions, talking therapy, counselling, all the old school stuff.

The lack of referrals for arts-based and animal-assisted modalities may be due to a less robust evidence-base for interventions that require significant personalisation, thus less suited to large cohort trials. However, stakeholders expressed an interest in these types of interventions.

All stakeholders except one were familiar with PBS. Both ECPs and MHWs had been involved in teams that engaged in functional behaviour assessments, development, and implementation of PBS plans. Stakeholders valued the comprehensive approach of PBS and appreciated investigating communication behind the person's behaviour. However, behaviour support practitioners said that they require specific knowledge and resources for identifying when mental health support is required.

Researcher: Do you think PBS adequately acknowledges the impact of mental health problems?

MHW 2: The theory and the vision and the values base does, but I think the implementation might sometimes not, because it doesn't start with the mental health and wellbeing (…) it starts with the behaviours of concern. And I think we don't get enough tools to learn how to measure progress regarding quality of life.

One stakeholder with communication access needs had participated in PBS and subsequently engaged a MHW for counselling when underlying mental health concerns were revealed.

Five stakeholders discussed the inclusion of a Developmental Educator in psychoeducational interventions. Developmental Educators are predominantly employed in South Australia. Their practice is characterised by transdisciplinary, strengths-based, and person-centred approaches to promoting the inclusion of people with disability (Rillotta & Alexander, 2020). Stakeholders stated that Developmental Educators played a role translating mental health resources to improve accessibility for individuals with communication difficulties and their ECPs.

ECP 1: So, we've had support from Developmental Educators to work alongside staff and customers where they've experienced grief or loss. For example, the death of a parent or sibling, and they need help to understand what has happened (…) through the use of social stories.

The role of Developmental Educators in mental health support was not discussed in the literature. Although the multi-disciplinary research teams discussed in the literature did include disability professionals, the paradigms underpinning their practice was not specified. Stakeholders confirmed that in their experience psychologists were primarily responsible for formal mental health support provision of people with communication access needs.

Adaptations. Stakeholders discussed adaptations ranging across the themes identified in Table 3.4 and beyond. The most frequently discussed topics were personalisation, the use of AAC, and the role of ECPs. Most adaptations occurred in individual counselling or psychotherapy sessions.

Personalisation referred to the application person-centred practice; ensuring that the individual seeking mental health support is central to the goals and delivery of the intervention. Aspects of personalisation prioritised by stakeholders were participation in goal setting, physical accessibility of therapy settings, and in-home appointments.

AAC was considered essential for participation in psychoeducational interventions. Stakeholders discussed the need to recognise the multiple modes of communication utilised by individuals experiencing communication difficulties. Stakeholders with communication access needs used a range of AAC strategies including high-tech devices, communication boards, gestures, facial expressions, vocalisations, and human assistance. They expressed a desire to choose among their AAC methods to communicate with mental health practitioners, as demonstrated in the following quote.

> *Researcher: Did you use your iPad with them (MHW)?*
>
> *L.E. 2: 'No' (shakes head)*
>
> *Communication Assistant: No… You haven't always been overly keen on using the iPad, have you?*
>
> *L.E. 2: 'No' (shakes head)*
>
> *Communication Assistant: You're pretty good at using gestures and sound to get your message across and they were also quite person-centred in the way that they communicated with you, using the yes/no answers.*
>
> *L.E. 2: 'Yes' (nods head)*

Incorporating the person's multiple modes of AAC was essential mental health support provision and enabled the individual to remain at the centre of the intervention.

All stakeholders discussed the ways in which MHWs could adjust communication strategies to better include individuals experiencing communication difficulties. Stakeholders stressed the need for MHWs to use clarifying yes/no questions when communication became fatiguing, or when limited vocabulary was available, as demonstrated in the following exchange with a stakeholder experiencing communication access needs.

> *Researcher: So, you feel that (the counsellor) didn't really understand your communication?*
>
> *LE 1: 'Yes' (squints eyes to indicate yes)*
>
> *Researcher: Was (name) your communication assistant then?*
>
> *LE 1: 'Yes' (squints eyes to indicate yes and looks towards assistant to help elaborate)*
>
> *Communication Assistant: Yes. He knew how you said "yes," we showed him that. It's just that, I'm not sure how to describe it… They have to be able to ask the right questions.*

Both stakeholders with experience of communication access needs stressed that using yes/no responses was a necessary part of their communication regime.

Stakeholders described the multiple roles of ECPs in psychoeducational intervention. All interviewees identified that everyday communication partner involvement was important to the success of psychoeducational intervention. However, goodness of fit and consent were essential considerations. As highlighted in the quote below, not just any support worker would be an appropriate communication assistant for appointments with an MHW.

> *Researcher: When do you think that family members or friends or support workers should be involved in your counselling?*
>
> *L.E. 1: (Pauses)*
>
> *Researcher: Would you like me to ask yes/no questions?*
>
> *L.E. 1: 'Yes' (squints eyes to indicate yes)*
>
> *Researcher: Should they always be involved?*
>
> *L.E. 1: 'Yes' (squints eyes to indicate yes)*
>
> *Researcher: So, you think that they should always be involved. (…) would you want any one of your support workers to come along?*
>
> *L.E. 1: 'No' (shakes head)*
>
> *Researcher: No, you wouldn't. (…) Would you want to choose the person to support you for counselling sessions?*
>
> *L.E. 1: 'Yes' (squints eyes to indicate yes)*

Both stakeholders with communication access needs identified the importance of consistent support from a trusted person to read and respond to correspondence from mental health services and control the dissemination of personal information.

Mental health practitioners noted the importance of equipping ECPs to provide real-time mental health support to the individuals with communication access needs in their lives, as described below.

> *MHW 2: Often it's low-level sort of counselling where when you've got a good support worker who just takes the time to have a chat, can do that as well. So, then I feel (…) I could also develop tools or supports or do other things that would actually make a bigger impact on their lives.*

Strengthening the capacity of the ECPs to respond to issues relating to mental health and wellbeing, in preference of long-term mental health service use could ensure that assistance is more readily available.

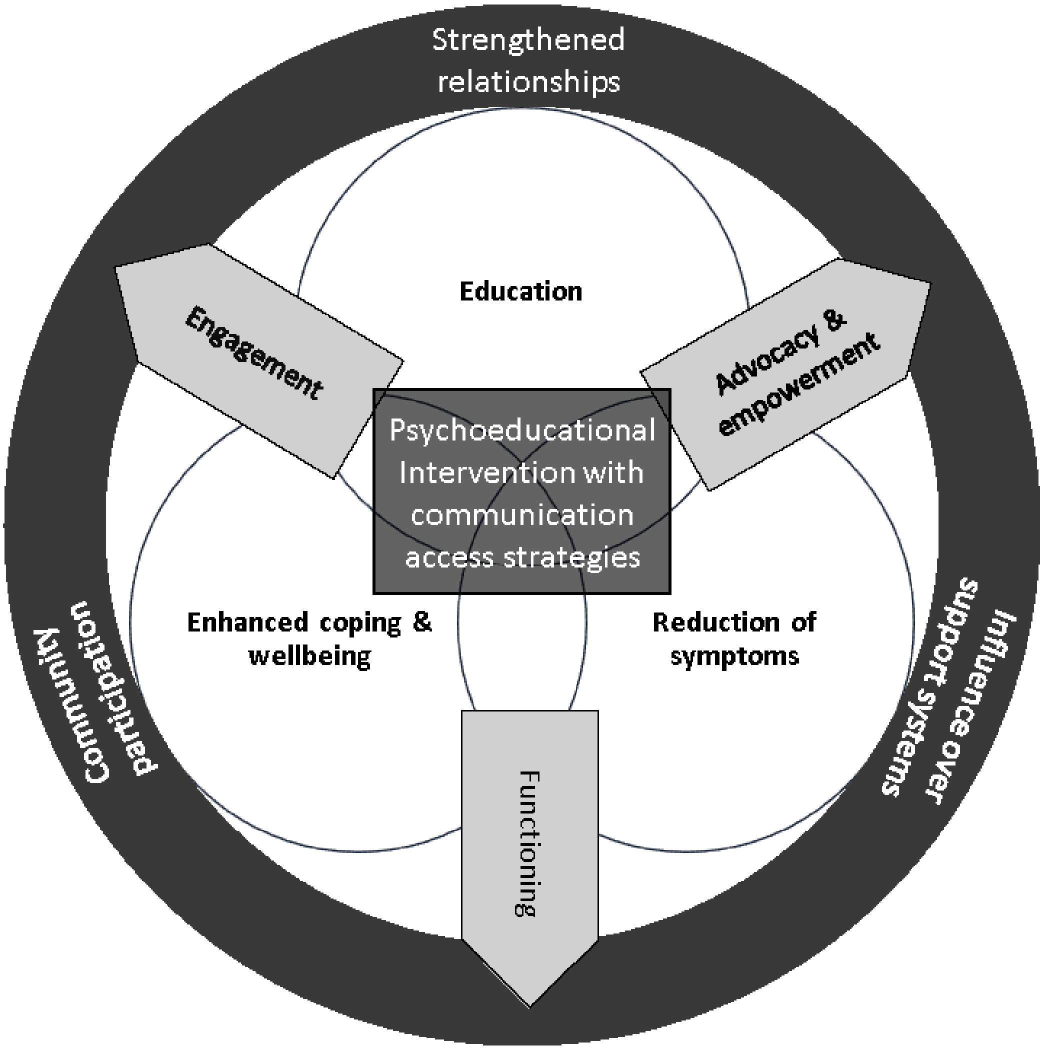
Stakeholder interviews uncovered the practical issues involved in providing psychoeducational support to individuals with communication access needs. These emphasised the need to place communication access at the forefront of interventions for mental health support and psychoeducational interventions.

3.4.6 Placing Psychoeducational Intervention in Context

The secondary outcomes arising from psychoeducational interventions with communication access strategies are consolidated in Figure 3.3. The thematic findings from qualitative data emphasise a range of interrelated secondary outcomes that arose from psychoeducational intervention. These secondary outcomes were increased community participation (Cravero et al., 2016; McClean et al., 2007; Wark, 2012; Webber & Harkness, 2016; Willner, 2004), strengthened relationships (Aoun et al., 2015; Couchman et al., 2014; Fernando & Medlicott, 2009; Summers & Witts, 2003), and influence over support systems (Cambridge, 2013; Chapman et al., 2006; Crowley et al., 2008; Douds et al., 2014; Douglass et al., 2007; Willner, 2004). In drawing together findings from the scoping review and stakeholder consultations, we were able to place psychoeducational interventions context that they are experienced by individuals with communication access needs and their ECPs. Stakeholder consultations emphasised the vital nature of personalised communication access strategies in facilitating both the primary and secondary outcomes of psychoeducational interventions. Qualities of interventions, access strategies and outcomes are further explored in the stakeholder consultations.

Figure 3.3

Outcomes of Psychoeducational Interventions with Communication Access Strategies



3.5 Discussion

People with communication access needs may benefit from psychoeducational interventions, as established by the research included in this scoping review. Stakeholder consultations confirmed the benefits of psychoeducational interventions when appropriate communication access strategies are applied. As a signatory of the CRPD, Australian legislation and health policy requires health services to adopt access strategies which enable equitable participation by people with disabilities (CRPD, 2006). For example, the South Australian Mental Health Services Plan states that services should be underpinned by a human rights-based approach which upholds the principle of access to services and information (SA Health, 2019). However, without specific strategies to address communication access, people with communication access needs are excluded from mental health support services.

The psychoeducational interventions reviewed positively impacted on the mental health of individuals with communication access needs, both directly and indirectly, as demonstrated in figure 3. Indirect benefits included increased community participation (Aoun et al., 2015; McClean et al., 2007; Wark, 2012; Webber & Harkness, 2016), strengthened relationships (Aoun et al., 2015; Couchman et al., 2014; Fernando & Medlicott, 2009), choice and influence in systems of support (Cambridge, 2013; Chapman et al., 2006; Crowley et al., 2008; Douds et al., 2014; Douglass et al., 2007). Interventions that achieved these outcomes were characterised by holistic approaches mental health challenges. These outcomes demonstrate the relevance for people with communication access needs who frequently face challenges to developing relationships, as well as reduced autonomy and access to services (Petroutsou et al., 2018; Taylor et al., 2021).

3.5.1 Communication Access Strategies in Psychoeducational Interventions

Effective participation of people with communication access needs in psychoeducational support is underpinned by practitioners and researchers taking an active approach to including access strategies in intervention delivery. Multiple adaptations to improve communication access were identified through this scoping review, and these adaptations were expanded upon by stakeholder consultations. Inclusion of ECPs was frequently identified as a strategy to improve participation by people with communication access needs. Stakeholders revealed that ECPs can influence the success of mental health support and requires careful consideration. Douglass et al. (2007) noted a participant who received deficient support from ECPs at home struggled to complete intervention activities. Conversely, ECPs who participated psychoeducation interventions were equipped with strategies to better respond to mental health problems (Douglass et al., 2007; Magai et al., 2002). Though stakeholders felt that self-selecting a support person was an important factor, only two studies stated that participants chose their own supporters (Crowley et al., 2008; Walker et al., 2010). Consent to share information with third parties is mandatory in mental health practice settings; however, this was not well explored in any of the included studies.

The issue of third-party reports in preference of self-reporting by people with communication access needs was raised by researchers. Hagiliassis, Gulbenkoglu, et al. (2005) prioritised the collection of data directly from participants and adapted their data collection tools to effectively do this, whereas other research drew on third party reports. Magai et al. (2002) stated that the more labour-intensive approach collecting direct-observation data would be more beneficial than third party reports which may be biased. Hagiliassis, Gulbenkoglu, et al. (2005) drew their justification for direct reporting from a commitment to promoting the autonomy of participants. Receiving direct reports, observations, and evaluations from participants with communication access needs rather than third party reports may address some power imbalances that are prevalent in relationships with support people.

CBT interventions applied a greater number of communication access strategies than other interventions (Crowley et al., 2008; Douglass et al., 2007; Hagiliassis, Gulbenkoglu, et al., 2005; Hsieh et al., 2012; Walker et al., 2010). This was the case in both individual and group interventions (Crowley et al., 2008; Hsieh et al., 2012); however, group interventions generally employed more communication access strategies. CBT requires participants to become active contributors in the process of identifying thoughts, feelings, and behaviours. For people with communication access needs this active approach requires that participants are equipped to receive and express information and ideas. Additionally, group interventions require that facilitators consider the diverse range of communicative capacities among participants (Crowley et al., 2008; Douglass et al., 2007; Hagiliassis, Gulbenkoglu, et al., 2005), and provide opportunities for peer-to-peer learning (Couchman et al., 2014). Neither of the stakeholders with communication access needs had experienced group psychoeducation, raising queries regarding the availability of this type of mental health support for people with communication difficulties in South Australia.

3.5.2 Future Research Recommendations

The purpose of a scoping review is to provide a topography of the existing literature to identify knowledge gaps for future research (Arksey & O'Malley, 2005). Enacting a consultation phase contextualises the research in the lived experiences of stakeholders (Levac et al., 2010). The inclusion of the consultation phase is a strength of the present scoping review and has assisted in prioritizing the recommendations for research discussed below.

PBS as a psychoeducational intervention. PBS is a holistic intervention that considers biopsychosocial domains to skill development to enhance the individual's quality of life by reducing reliance on behaviours of concern (Cravero et al., 2016; McClean et al., 2007). One of the key outcomes of PBS interventions was to reduce behavioural markers of distress, such as self-injuring; however, it is not exclusively a mental health intervention (Cravero et al., 2016; McClean et al., 2007; Webber & Harkness, 2016). While the PBS studies did measure improvements in participants' mental health and wellbeing, the extent to which intervention addressed underlying mental health problems and risk factors, rather than mitigating behavioural effects was not explored. Stakeholder consultations indicated that the provision of mental health support within PBS varied dependent on the practitioner's skill in identifying potential mental health problems and knowledge of psychoeducational resources. While PBS may benefit the mental health and wellbeing of people with communication access needs, more research is required to ascertain the specific impacts upon mental health of individuals with communication access needs.

Communication access and multi-disciplinary teams. There was a prevalence of multi-disciplinary teams working to provide psychoeducational support to people with communication access needs (Boso et al., 2007; Chapman et al., 2006; Cravero et al., 2016; Crowley et al., 2008; Douds et al., 2014; Kay et al., 2015; McClean et al., 2007; Walker et al., 2010). Only three of the studies identified a team member responsible for developing communication access strategies (Cravero et al., 2016; Crowley et al., 2008; Douds et al., 2014). PBS studies included in this review were conducted by multi-disciplinary teams (Cravero et al., 2016; McClean et al., 2007), providing multiple skill sets where both mental health and communication-oriented practitioners are included. Future research would benefit from exploring roles of multi-disciplinary team members in developing communication accessible psychoeducational interventions. Additionally, the contribution of Developmental Educators to mental health support in South Australia is worthy of examining, given the volume of stakeholder feedback regarding this professional group.

Communication access and counselling micro skills. Individual counselling and psychotherapy provided favourable outcomes for people with communication access needs (Cambridge, 2013; Crawford, 1987; Fernando & Medlicott, 2009; Summers & Witts, 2003; Wark, 2012; Willner, 2004). Stakeholder consultations revealed differences between the range of communication behaviours required of MHW practitioners working with people with communication access needs. The use of open questions is a defining skill in counselling (Geldard et al., 2021). However, people with communication access needs may prefer the use of closed, "yes/no" response questions when communication is fatiguing, or vocabulary is limited (Hagiliassis et al., 2006). Closed questions must be used with caution. Practitioners should check the reliability of responses using strategies such as reversing the question to confirm the answer and remaining attuned to signs of confusion, misunderstanding, and production errors (Hagiliassis et al., 2006). Research detailing the counselling micro-skills applicable when working with individuals with communication difficulties would support MHWs to better include this population. Additionally, guidelines for including communication assistants and support people in mental health service provision may address issues related to autonomy, confidentiality, and power imbalances.

3.5.3 Study Limitations

The findings of this scoping review are contingent upon several limitations. Firstly, while communication was a significant factor in the delivery of interventions, the communication support requirements of participants were not expressed consistently. Authors have previously discussed the need for clearer descriptions of participants in interventions that include people with communication access needs (Pennington et al., 2007). The diversity of terms used to describe participants with communication access needs arises from the heterogeneity of the population as well as disciplinary differences (Marshall et al., 2011). In the literature there was a lack of distinction between participants with communication support needs and those without. There were notable exceptions which provided clear descriptions of the participants’ individual communication support requirements and specification regarding AAC use (Hagiliassis, Gulbenkoglu, et al., 2005; Wark, 2012). We attempted to include diverse terminology in our search strings to capture a full array of literature, however some studies may have been missed.

Second, the eligibility criteria focused on articles that reported outcomes, so this may have limited the types of articles that were retrieved. For example, practice guidelines were not included in the scoping review as they did not report specific outcomes. Finally, we engaged a small sample of stakeholders from a single Australian state. This may result in a regional interpretation of the services available, and types of accommodations used by practitioners. The inclusion of stakeholders from other regions may have resulted in different outcomes and areas of focus. Both stakeholder consultants with lived experience of communication access needs possessed similar characteristics in terms of age and occupation, leading to potential biases in the experiences discussed. However, as representatives of a small population who are frequently excluded from research it was essential that their perspectives were included. Both lived-experience participants had a range of experiences of seeking mental health help which provided valuable insight into the types of psychoeducational interventions which may be available to people with communication access needs.

3.6 Scoping Review Conclusion

This scoping review provides an overview of the psychoeducational interventions that have been utilised with people with communication access needs, reported in the empirical literature. An array of communication access strategies is available to practitioners seeking to include people who experience communication access needs to achieve optimum mental health and wellbeing. Rather than a single method to promote communication access in psychoeducational interventions, a range of strategies should be personalised to best address the individual’s communication access requirements. People with communication access needs can achieve a range of outcomes related directly to psychoeducational support, as well as secondary outcomes which are contextualised within the living experiences of this population. The stakeholder consultation phase added valuable insights to the project and confirmed the importance of social validation in prioritising the objectives of participant groups. It is recommended that future scoping reviews in this area seek stakeholder perspectives to ascertain practice issues and research gaps in the field.

CHAPTER 4. METHODOLOGY AND THEORETICAL FRAMEWORK

The methodological approach used to investigate the mental health care experiences of adults with communication access needs is described in this chapter. The research design was guided by a methodology and theoretical framework that served as a map to navigate the processes of data collection, analysis, and interpretation. The theoretical framework used was grounded in the transformative paradigm (Mertens, 2007) and informed by the Human Rights Model of Disability (Degener, 2016). It provided the conceptual foundation for understanding the interactions between communication facility and access to mental health care. The participatory-social justice mixed methods approach in combination with the transformative paradigm provides a philosophical frame to address social justice and human rights issues, such as access to mental health care (Mertens et al., 2016). Informed by these theoretical foundations, this chapter outlines the research design, data collection methods, and analytical strategies utilised to capture the perspectives of participants from three groups: people with communication access needs; everyday communication partners (ECPs); and mental health workers (MHWs).

4.1 Philosophical Assumptions and Theoretical Lenses

Philosophical assumptions and theoretical lenses were integrated throughout the study to ensure that the research design was conducive to exploring the phenomenon (access to mental health care) and aligned with the preferences of the focus population (Mertens et al., 2010). The transformative paradigm provided a philosophical scaffold that encompassed axiology, ontology, and epistemology. It comprised a cohesive worldview, oriented towards human rights and social justice (Mertens, 2007). The theoretical lenses that supported the interpretation of the research were the Human Rights Model of Disability (Degener, 2016) and the Conceptual Model of Access to Health Care (Levesque et al., 2013). The models selected align with the overarching objective of the research project to improve access to mental health care for people with communication access needs. This section outlines the philosophical and theoretical components of this study and connects these to the research design decisions detailed in the following section.

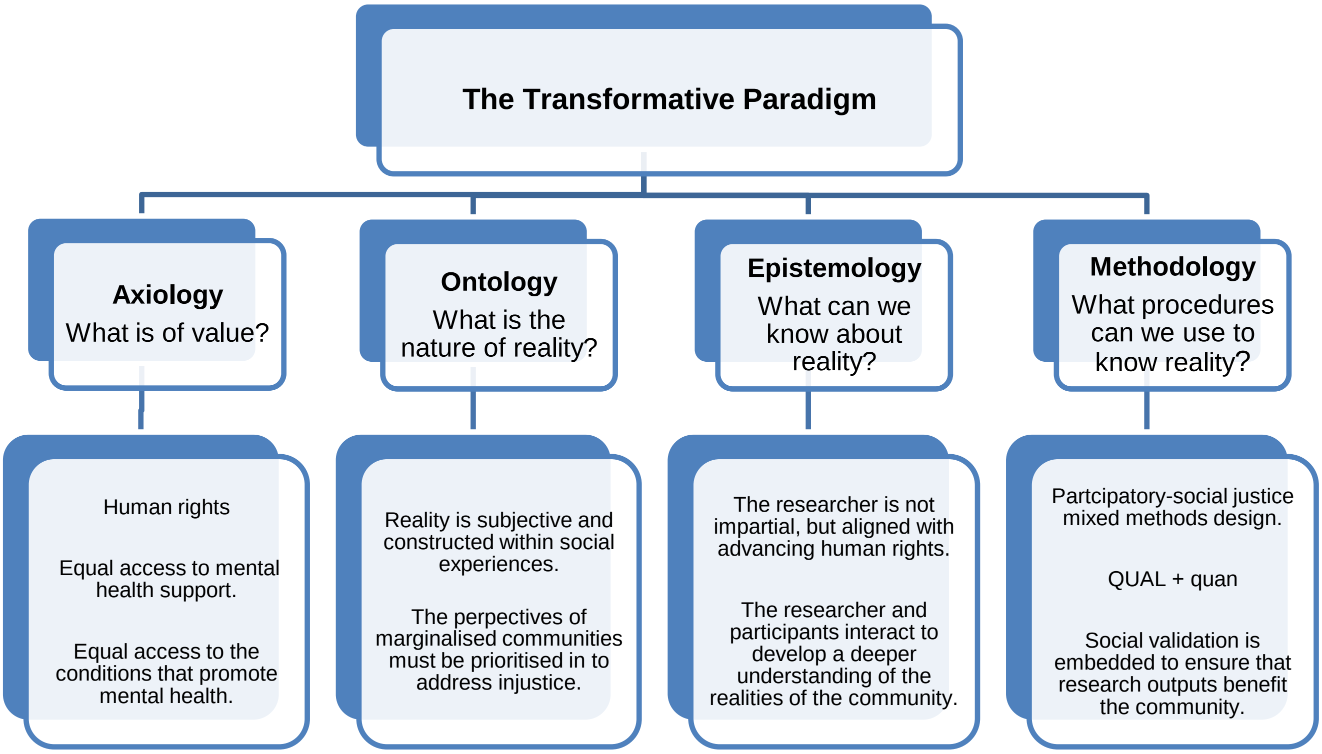
4.1.1 The Transformative Paradigm

The transformative paradigm enables researchers to address systemic inequity and make methodical decisions that are attuned to the requirements of communities involved in the research (Mertens, 2007). The paradigm arose in response to limitations in existing philosophical paradigms to examine power dimensions, include marginalised people, and uphold community knowledge through participatory research practices (Hurtado, 2022;

Mertens, 2015). The paradigmatic approach integrates the axiological, ontological, and epistemological dimensions to inform methodological decisions. This approach was adopted to ensure a cohesive philosophical underpinning for the study and align the research design with social justice purposes (Guba & Lincoln, 2008; Mertens, 2007). The four paradigmatic dimensions are: 1) axiology, referring to ethical assumptions and values; 2) ontology, referring to assumptions about the nature of reality; 3) epistemology, referring to knowledge and the relationship between knowledge-sources and knowledge seekers; and 4) methodology, which refers to the procedures of enquiry that can be used to gain knowledge (Denzin & Lincoln, 2013). Figure 4.1 provides an overview of the four dimensions.

Figure 4.1

An Overview of the Transformative Paradigm



Transformative Axiology. Applying the assumptions of transformative axiology upholds the value of human rights and pursues the enactment of social justice (Mertens, 2015). By adopting the transformative paradigm, the researcher places values at the forefront of research. Being guided by the value of equity, the researcher recognises the power differentials that occur in research and actively seeks to remediate power imbalances, thus enacting an inclusive approach to research and producing evidence and outcomes that are credible to the populations concerned (Mertens, 2013). The transformative paradigm is community-centred and person-centred, which acknowledges both the diversity and strength of the marginalised communities at the centre of the research (Hurtado, 2022; Munger & Mertens, 2011). Espousing the transformative paradigm enabled the researcher to adhere to social justice principles to advance the human rights of people with communication access needs in mental health care.

Transformative Ontology. From an ontological perspective, the transformative paradigm acknowledges that reality is subjective; there are a range of social constructs that shape our realities including cultural, economic, political, gender, and disability (Mertens, 2015). The transformative paradigm assumes the existence of multiple realities, some of which are valued, and others that have been devalued by societal structures (Hurtado, 2022). Additionally, the transformative paradigm recognises the role of privilege in shaping our realities and that the consequences of accepting one version of reality over another can have detrimental effects on populations who experience stigma or exclusion (Mertens et al., 2010). With a transformative ontological lens, the perspectives of people who have experienced marginalisation must be elevated against the perspectives of those who are privileged by their membership in dominant social groups. Throughout this research project, the perspectives of people with communication access needs have been prioritised among other populations in recognition of the systemic discrimination encountered by people with disability in mental health care.

Transformative Epistemology. Epistemology addresses the nature of knowledge and the relationship of the inquirer to sources of knowledge (Denzin & Lincoln, 2013). Transformative researchers must consider their relationship with the individuals and communities impacted upon by the research (Munger & Mertens, 2011). The transformative paradigm distinguishes the need for researchers to comprehend the pervasive and persistent nature of discrimination and marginalization. This knowledge enables researchers to contest the systemic processes that perpetuate barriers to equal participation (Mertens et al., 2010). A collaborative relationship with stakeholders is necessary to facilitate engagement and deepen knowledge sharing (Munger & Mertens, 2011). In the present study, this meant that the perspectives of people with communication access needs were considered first in research decisions. Though the researcher and supervision team have extensive experience working with people with communication access needs, we do not live with any significant communication access requirements. For this reason, the decision was made to include two research advisors with lived experience to provide guidance regarding methodological decision-making for the study.

Transformative Methodology. Methodology deals with the procedures used to gain knowledge of the phenomenon (Denzin & Lincoln, 2013). Extending upon the axiological, ontological, and epistemological underpinnings of the study, the perspective was taken that reality can only be known through deep engagement with people who experience the issue, in this instance people with lived experience of communication access needs. The transformative paradigm is not specifically aligned with a single method of data collection; however the methods selected must adequately reflect the preferences of the communities involved (Hurtado, 2022). For this reason, the participatory-social justice mixed methods design (Creswell & Plano-Clark, 2018) was selected, enabling the researcher to apply a range of data collection methods to best support the participation of people who use diverse means of communication (Mertens, 2007). As stated by Mertens (2013, p. 29), “(researchers) can ensure that all stakeholder groups, especially those from marginalized and less powerful groups, are invited and supported in appropriate ways so that their voices are included throughout the evaluation”. The participatory-social justice mixed methods design (Creswell & Plano-Clark, 2018) is discussed in greater depth under the heading of Research Design.

4.1.2 Theoretical Lenses

The transformative paradigm is a product of social justice and civil rights movements and is therefore linked to the aims of human rights covenants (Mertens et al., 2014). The theoretical models selected for this research project complement the axiological underpinnings of the research project. The models are the Human Rights Model of Disability (Degener, 2016) and the Conceptual Model of Access to Health Care (Levesque et al., 2013). These models draw together access principles adopted by the CRPD (2006) and the objectives of the disability rights movement – eliminating segregation, discrimination, and inequality (Kayess & Sands, 2020). Equitable access to mental health care is a human right and the actions proposed to improve access must be relevant to people with communication access needs. The theoretical models selected enable exploration of the access to mental health care from a perspective that promotes rights and access from both individual and systemic perspectives. The following paragraphs build upon the introductory information provided in Chapter 2 and explain the integration of the Human Rights Model of Disability (Degener, 2016) and the Conceptual Model of Access to Health Care (Levesque et al., 2013) within the research design for this study.

Human Rights Model of Disability. The Human Rights Model of Disability (Degener, 2016) was applied to establish the imperative for access. The assumptions of the transformative paradigm intersect with the endeavour to promote human rights through formal channels such as the CRPD (Mertens et al., 2010). Article 25 of the CRPD (2006) frames access to health care as a fundamental human right for people with disability, and the transformative paradigm focuses on dimensions of diversity that affect access, such as disability, gender identity, ethnicity, and class (Mertens et al., 2014). Thus, the transformative paradigm in combination with the Human Rights Model provided a lens to examine access to mental health care, as influenced by the unique experiences of people with communication access needs.

The Human Rights Model of Disability has developed within the context of the Social Model of Disability (Oliver, 2009), a model with continued relevance in understanding the systemic oppression that people with disability face in structures that are not designed with diversity in mind (Lawson & Beckett, 2021). The Human Rights Model extends upon the Social Model as an instrument to examine the experiences of people with disability against the rights codified by the CRPD – civil and political, as well as economic, social, and cultural (Degener, 2017).

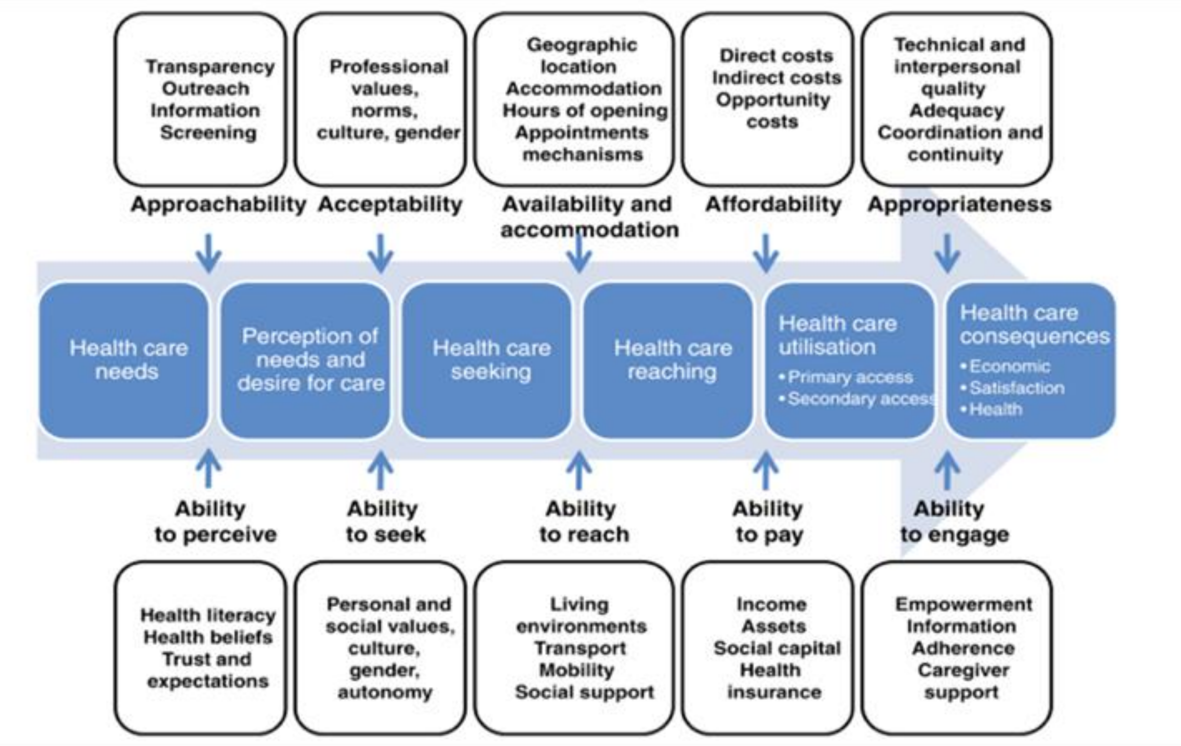
There are human rights issues beyond the right to equitable health care that may precipitate psychological distress in people with communication access needs (CRE-DH, 2021; Kattari, 2020). The Human Rights Model attends to the entitlement to equitable health care, as well as other rights detailed in the CRPD as contributing factors in the mental health and wellbeing of people with communication access needs. The Human Rights Model has previously been used by researchers to examine the efficacy of health care interventions for people with disability that are grounded in rights, respect, and responsibility (Berghs et al., 2016; Feldman et al., 2016). The principles of the CRPD and the Human Rights Model are embedded in this research project. Espousing these in the theoretical framework ensures that the research project is conducive to the attainment of human rights for people with communication access needs.

The Conceptual Model of Access to Health Care. Levesque et al.’s (2013) Conceptual Model of Access to Health Care was introduced in the literature review in Chapter 2. CRPD (2006) Article 25 states that people with disability have the right to quality health care that is responsive to the individuals’ access requirements. The Conceptual Model of Access to Health Care (Levesque et al., 2013) provides a model to investigate the mental health care experiences of people with communication access needs through a human rights lens. The model is well suited to the present study as it identifies service and system factors, as well as personal or community factors that may impact access (Schwarz et al., 2022); it has previously been used in a variety of health care settings with a multitude of populations (Cu et al., 2021).

During the data collection phase of this research project, it became apparent that participants had discussed access barriers and facilitators across the trajectory of mental health help-seeking. Thus a model was sought that would adequately capture experiences across time points in the mental health care journey. The Conceptual Model of Access to Health Care was used to frame the discussion in Chapter 7, integrating findings, policy, and literature to form recommendations that support access to mental health care from primary to tertiary service provision. As identified in Chapter 2, the Model of Access to Health Care proposes six stages in the trajectory of health care practice: 1) emergence of mental health care needs; 2) perception of mental health support needs and desire for care; 3) mental health care seeking; 4) mental health care reaching; 5) mental health care utilisation; and 6) mental health care consequences (Levesque et al., 2013). The characteristics of each stage of the Conceptual Model of Access to Health Care are outlined in Figure 4.2.

Figure 4.2

The Conceptual Model of Access to Health Care (Levesque et al., 2013), reused under Creative Commons Attribution license.



4.1.3 Researcher Positionality

In considering interpretative frameworks, Denzin & Lincoln (2013) discuss the influence of biographical experiences and researcher positionality amidst research design choices. They promote the importance of the researcher providing the reader with an understanding of the motivations and perspectives they personally and professionally bring to the research. Axiology, ontology, epistemology, methodological, and interpretive decisions are configured within the class, gender, and socio-cultural perspectives of the researcher, and researchers require awareness regarding the philosophical assumptions that guide their practice (Mertens, 2007). In the transformative ethos of mutually beneficial research, researchers must convey both the strengths and limitations of their knowledge and experience to build trust with the community (Munger & Mertens, 2011). It is in this ethos of reciprocity that the researcher's subjective position as a scholar on the topic of communication access in mental health support is discussed.

The researcher's philosophical worldview has been reached through research, study, and occupational and personal experiences. The researcher has worked with people with disability for eighteen years, as a disability support worker and following the completion of undergraduate studies, as a Developmental Educator (DE). DEs are tertiary-educated professionals who employ strengths-based and person-centred approaches to promote the human rights of people with disability (Rillotta & Alexander, 2020). DEs work across disciplines, blending approaches to achieve better outcomes and inclusion with people who experience disability and their communities.

Support workers and DEs are often firsthand witnesses to systemic injustice, exclusion, and inequity entrenched in the lives of disabled people. Through their work, the researcher observed both struggle and joy. These encounters sparked curiosity about the way society operates to include people with disability in community life and to ensure that rights are afforded in large and, at times, oppressive social systems. The questions raised in the researcher's previous Honours study were a result of practice-based observations. While working in services for people with coexisting disability and mental health concerns, the researcher noted differential treatment of people with communication access needs compared to those who were readily able to use speech and be understood by MHWs. To attempt to understand the reality of this observation, the researcher undertook an honours project to explore the perceptions of people with communication access needs regarding mental health and wellbeing. That study revealed that people with communication access needs were interested in accessing mental health care but faced significant barriers in gaining access to those supports (E. Watson et al., 2021).

In addition, the researcher recognises the influence of their own mental health help-seeking experiences. Reflecting upon their mental health help-seeking revealed further discrepancies between the researcher's experiences and the experiences of the people they had worked with. Such reflections have influenced the researcher's interest in equable access to mental health support. These experiences underpin the researcher's conviction that access to the conditions that support mental health are human rights to be afforded to all people. These underlying perspectives and experiences necessitated the selection of research methods that seek to understand diverse lived experiences and remain loyal to the accounts of the stakeholders participating in the study. This is a responsibility that requires careful selection of research methods, as well as reflection upon the role of the researcher in the research process (Hesse-Biber et al., 2015). The researcher recognises the comparative power in the position of researcher and supporter.

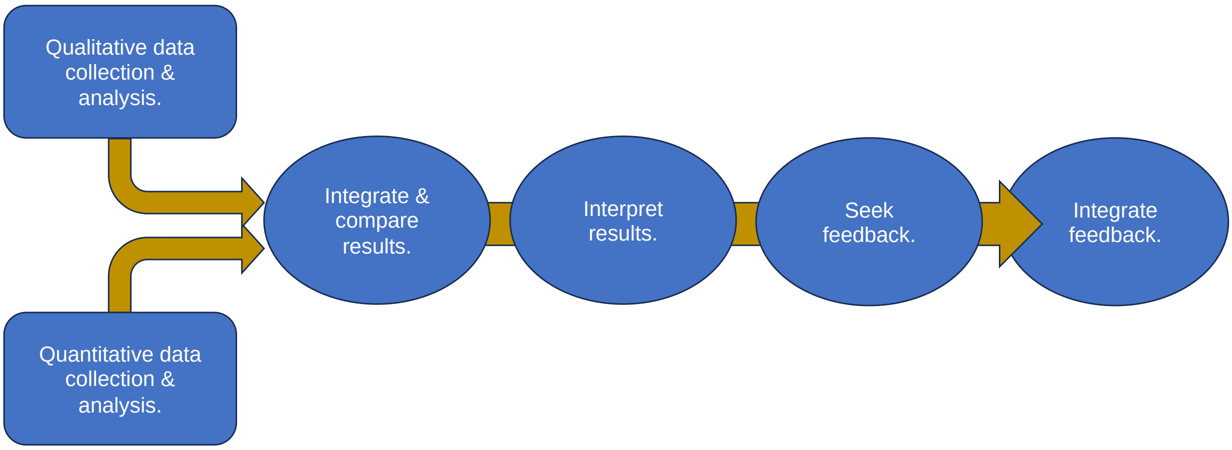
4.2 Research design: Participatory-Social Justice Mixed Methods

This study applied a participatory-social justice mixed methods design. The participatory-social justice design is a complex mixed methods design that promotes the inclusion of lived-experience perspectives in the research at each stage of the research process (Creswell & Plano-Clark, 2018). Mertens (2007) states that neither qualitative nor quantitative methods alone can adequately engage and encapsulate the experiences of heterogeneous, communication-diverse populations who are frequently excluded from research. The participatory-social justice mixed methods design was selected to maintain responsiveness to the requirements of participants with communication access needs as the primary participants in this study. Eminent mixed methods researchers have noted the potential of participatory social justice mixed methods research to inform solutions to contemporary wicked problems such as access to health and education (Creswell, 2015; Mertens et al., 2016).

The core design of this mixed methods study was a convergent approach in which interviews and surveys occurred concurrently, and data were analysed within a single phase of research (Creswell, 2015; Creswell & Plano-Clark, 2018; Mertens, 2015). The intent was to compare data, report upon findings and seek feedback, thus enhancing understanding of the phenomena under investigation (Creswell & Plano-Clark, 2018). A graphic overview of the convergent mixed methods approach is available in Figure 4.3. The data collection, analysis and integration processes are described in-depth in the research design section of this chapter.

Figure 4.3

The Convergent Mixed Method Design



It is important to note that, within the timeframe of the PhD research project, seeking feedback from stakeholders with communication access needs in the final stage was not possible. Feedback was sought from academics with expertise in disability studies and health sciences fields via the final thesis review seminar. Stakeholder perspectives and additional feedback on the findings and recommendations will be sought at a later stage. The section below will provide a rationale for the selection of the participatory-social justice mixed methods design, highlighting its utility and responsiveness during unpredictable research conditions within the overarching transformative paradigm.

4.2.1 Prioritising Access in a Turbulent Research Environment

Several factors influenced the decision to employ a mixed-methods approach, one of which was the advent of the COVID-19 pandemic which required the researcher to reconsider what research participation might look like for a population considered vulnerable to complications from contracting the virus. Ultimately, responsiveness to rapidly changing health directives, and accessibility for participants with communication access needs became the priority in designing the research methods. The participatory-social justice mixed methods approach was selected due to its responsiveness to stakeholder requirements and capacity to incorporate a range of data collection methods. A qualitatively driven mixed methods design was selected to ensure the primacy of lived experience accounts in informing research outcomes. This design regards reality as manifold, requiring the research methods to accommodate the varied perspectives of participants with lived-experience expertise (Hesse-Biber et al., 2015).

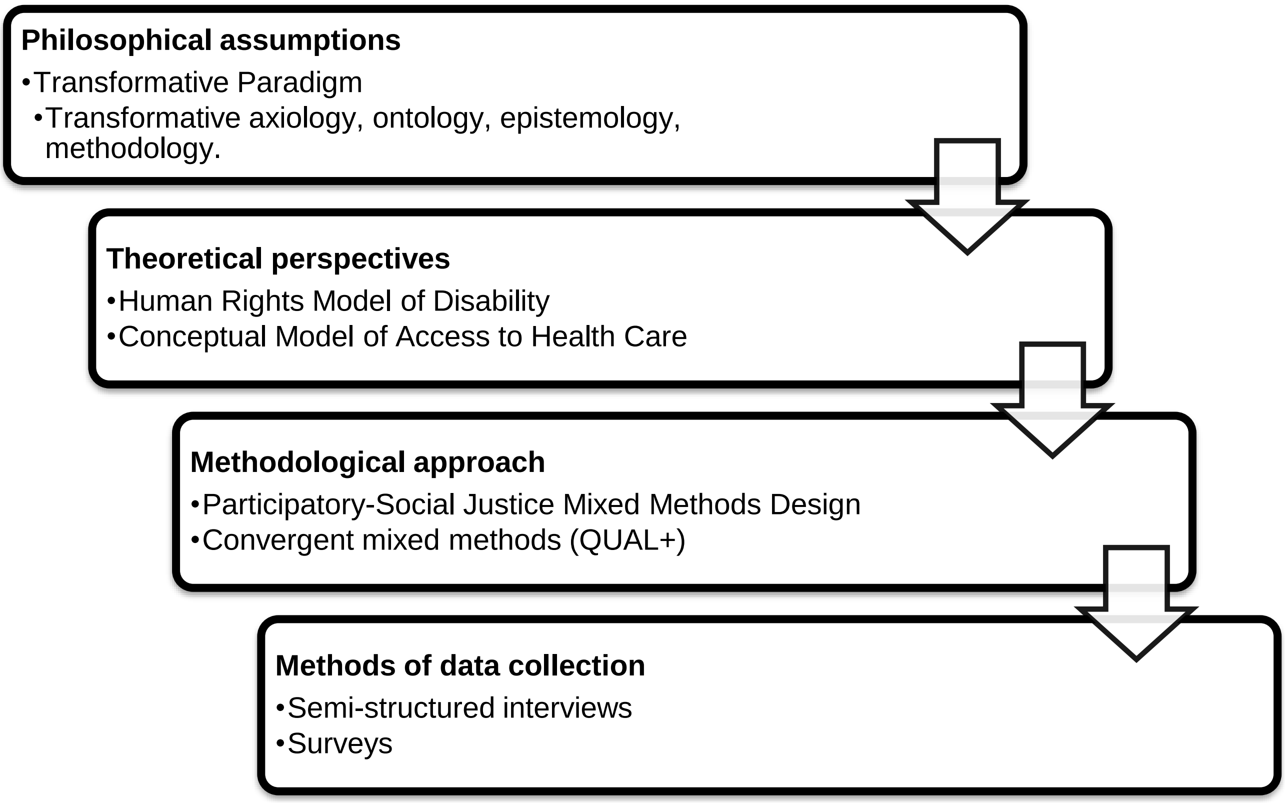
The participatory-social justice mixed methods approach has utility in accommodating participants with communication access requirements by employing a range of data collection methods (Mertens, 2007, 2013). The present study used online surveys and interviews to collect data, and the researcher provided additional support and flexibility in communication methods to ensure participants could convey their messages to the researcher. Including an online survey component made it possible to cast the net wide and include the perspectives of people with communication access needs, ECPs and MHWs, globally (Sue & Ritter, 2012a). The qualitative components of the survey and the interviews yielded detailed accounts of experiences of accessing mental health support that extended the researcher's understanding (Hesse-Biber, 2015). The synergistic integration of interview and survey methods provided a fuller understanding of the mental health help-seeking experiences of people with communication access needs.

In preparing to undertake participatory-social justice mixed methods research, Ponterotto et al. (2013) suggest that research teams consider their competency across five key areas: self-awareness of enculturated viewpoints; knowledge of the historical treatment of minority groups in research; responsibility for consultation with stakeholder communities; ethical research practice; and understanding of the philosophical frameworks and methodologies applied in their discipline. The supervision team had an established record of conducting inclusive research with people who experience marginalisation due to communication difficulties or mental illness. These researchers were committed to advancing social justice in the communities their research served and in their respective disciplines of disability studies, speech and language pathology, and social work. Additionally, the supervision team had experience in using mixed methodological approaches and guided the PhD candidate who had previously conducted qualitative research including people with communication access needs. The knowledge, research experience, ethical orientation, and personal commitment of the research team were compatible with the participatory-social justice mixed methods design (Mertens et al., 2016; Ponterotto et al., 2013).

By collecting data from a range of sources, researchers who use the participatory-social justice model seek to honour the experiences and perspectives of stakeholders, giving priority to those who are at risk of exclusion from change-making processes. The primary aim of the participatory-social justice mixed method approach is to improve conditions through engagement with marginalised populations across the research project. This aim aligned with the overarching objective of improving communication access in mental health support at the forefront of this study. Figure 4.4 displays the levels of philosophical and theoretical consideration at the foundation of our methodological choices. The following paragraphs explore other factors that impacted the decision to select the participatory-social justice approach: 1) inclusive research principles; and 2) the impact of the COVID-19 pandemic.

Figure 4.4

Four Levels of Research Design Considerations



Adapted from Crotty (1998).

4.2.2 Inclusive Research and the Participatory-Social Justice Mixed Methods Approach

Through this study, the researcher aimed to place the perspectives of people with communication access needs at the forefront of research outcomes by applying inclusive research principles across the span of the research project. The principles of inclusive research are: 1) research must address issues that are relevant to people with disability; 2) researchers must seek out and accurately represent the perspectives of people with disability; and 3) people with disability must be respected in the research process (Walmsley & Johnson, 2003). In accordance with these principles, research processes and tools have been deliberately selected to enhance the participation of people with communication access needs (Mertens, 2007; Nind, 2017).

In line with the transformative paradigm and participatory-social justice mixed methods approach, connections with people with lived experience were sought for feedback at each stage of the mixed methods project (Mertens, 2007). Prior to collecting data, two research advisors with lived experience were engaged to provide advice on the research project, notably the suitability of the research questions; data collection methods; and questionnaire and survey tools. Research advisors, when teamed with other structured forms of lived experience involvement, increase the relevance and acceptability of the research methods (Seekins & White, 2013). The field of AAC research has a long history of including consumers in research to contest the social exclusion experienced by many people with communication access needs (Balandin & Raghavendra, 1999). Further strategies to promote lived experience participation and access are discussed in-depth throughout the Research Process section of this chapter.

4.2.3 Recognising the Impact of the COVID-19 Pandemic

The COVID-19 pandemic required a reconceptualisation of the research design to ensure participants' safety. The original research proposal was presented on the 3rd of March 2020. By the end of that month, COVID-19 suppression measures were implemented throughout Australia. In April 2020 the National Health and Medical Research Council released recommendations relating to research with populations that are vulnerable to COVID-19 (Clinical Trials Project Reference Group [CTPRG], 2020). The CTPRG (2020) advised that, wherever possible, research should be moved online to protect participants from exposure to the virus. The original project design was intended to be highly interactive, requiring participants from all populations and the researcher to share physical spaces, collaborate, and engage with one another. This collaborative approach to problem identification and solution-finding was based on participatory action research (Kemmis et al., 2014). As the COVID-19 pandemic progressed, it became apparent that a more researcher-led mixed-methods design with embedded inclusive research principles would be required to navigate the turbulent research environment.

The mixed methods approach allowed data collection via an online survey, followed by in-person interviews when COVID-19 health directives were relaxed. This concurrent approach to data collection enabled adaptability and enriched the contextual depth of the data collected. The decision to collect both survey and interview data met the need to maintain the momentum of the research project and obtain data in an accessible and inclusive manner that minimised the requirement for in-person contact with potentially vulnerable people.

4.3 The Research Process

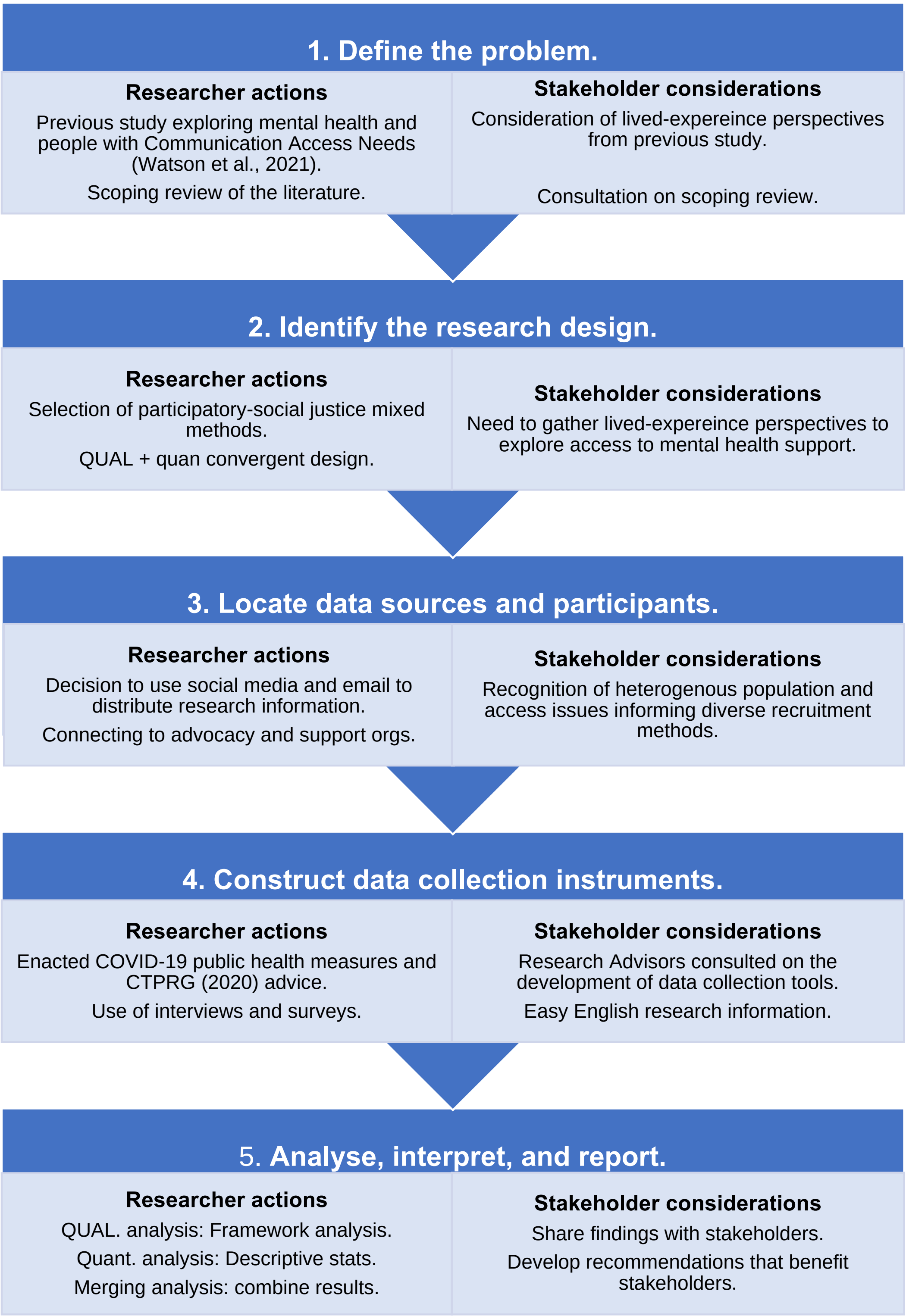
A five-stage research process for conducting mixed methods participatory-social justice research which integrates the perspectives of lived-experience groups at each stage has been suggested by Creswell & Plano-Clark (2018). The stages are: 1) defining the problem and searching the literature; 2) identifying the research design; 3) locating data sources and selecting participants; 4) identifying or constructing data-collection instruments and methods; and 5) analysing, interpreting, reporting, and using results. Before commencing research, ethical approval was gained from the Flinders University Human Research Ethics Committee (HREC, project no: 1885). Stage one of the research process has been addressed in Chapters 1 and 2 of this thesis. Stages two, three and four will be detailed in the following sections of this chapter. Stage five, analysis, will be introduced in this chapter through a procedural overview, with the analysis addressed in greater depth in the Findings chapters. Quality, rigour, and ethical conduct are further discussed at the end of this chapter. Figure 4.5 on the next page provides an overview of the research process outlining the key researcher actions and stakeholder considerations at each stage.

4.3.1 Ethics Approval and Management

Before recruiting participants, ethical approval was obtained from the Flinders University Human Research Ethics Committee (HREC, project 1885, see Appendix A). Throughout the project, six further modifications to the ethics application were requested and approved to reflect adjustments to data collection methods and recruitment methods. These modifications related to changes to recruitment materials (e.g., adding flyers), updating the survey questionnaire and interview schedule, and an adjustment to enable the researcher to assist participants with communication access to enter data into the online survey. Additionally, the ethics approval for the project was extended to the end of December 2022 to accommodate lengthy recruitment and data collection periods.

Figure 4.5

Researcher Actions and Stakeholder Considerations in the Research Process



1. Define the problem.

Researcher actions
Previous study exploring mental health and people with Communication Access Needs (Watson et al., 2021).
Scoping review of the literature.

Stakeholder considerations
Consideration of lived-expereince perspectives from previous study.
Consultation on scoping review.

2. Identify the research design.

Researcher actions
Selection of participatory-social justice mixed methods.
QUAL + quan convergent design.

Stakeholder considerations
Need to gather lived-expereince perspectives to explore access to mental health support.

3. Locate data sources and participants.

Researcher actions
Decision to use social media and email to distribute research information.
Connecting to advocacy and support orgs.

Stakeholder considerations
Recognition of heterogenous population and access issues informing diverse recruitment methods.

4. Construct data collection instruments.

Researcher actions
Enacted COVID-19 public health measures and CTPRG (2020) advice.
Use of interviews and surveys.

Stakeholder considerations
Research Advisors consulted on the development of data collection tools.
Easy English research information.

5. **Analyse, interpret, and report.**

Researcher actions
QUAL. analysis: Framework analysis.
Quant. analysis: Descriptive stats.
Merging analysis: combine results.

Stakeholder considerations
Share findings with stakeholders.
Develop recommendations that benefit stakeholders.

4.3.2 Locating Data Sources and Selecting and Recruiting Participants

As discussed in previous chapters, people with communication access needs make up a heterogeneous group. The population experiences a great deal of diversity between diagnosis and factors such as cultural identity, education, age, socio-economic status, and geographic location (Beukelman & Light, 2020; Blackstone et al., 2007). A range of recruitment strategies were required to connect with potential participants. This research project included contributions from three distinct groups: 1) People with communication access needs; 2) ECPs of people with communication access needs; and 3) MHWs. The study focussed on the adult population; all participants were aged 18 years or over. Table 4.1 outlines participation criteria and recruitment sources.

Table 4.1

Participant Criteria and Recruitment Sources

Group	Eligibility criteria	Recruitment sources
People with communication access needs	• Experiences communication access needs, and • willing to respond to questions about mental health and well-being, and • can provide yes/no responses independently, and • has access to AAC to enable interview participation, and • Is aged 18 years or over.	**Social media** • Facebook • Twitter (X) • LinkedIn **Email** • Professional networks • Disability support Services. • Mental health support services. • Advocacy organisations • Professional organisations
ECPs	• Has regular communication with an adult/s with communication access needs, and • has contact at least once per week over a six-month period (min.), and, • has a relationship of support with the person/s, and • is aged 18 years or over.	
MHWs	• Currently practicing in a community-based mental health service, and • willing to discuss professional practice and experience, • is aged 18 years or over.	

To facilitate participation, individuals were invited to self-identify regarding their experience of communication access needs. The information sheets, survey (Appendices B and C) and interview (Appendices D and E), specified that communication access needs are severe difficulties in the use of speech for communication; these difficulties do not result primarily from hearing impairment. Given the challenges experienced by people with communication access needs in obtaining a diagnosis of mental illness and accessing appropriate support services (Di Marco & Iacono, 2007; Holub et al., 2018; Pinals et al., 2022a), diagnosis was not a criterion for participation. Instead, in confirming eligibility, participants were asked whether they were comfortable sharing their views and experiences related to mental health and wellbeing.

ECPs are those individuals who have regular contact with people with communication access needs. As previously established, this group plays an important role in assisting people with communication access needs to connect with mental health care (Schlosser et al., 2007; E. Watson et al., 2021). This group includes family members, spouses, friends, peers, colleagues, and support workers. The recruitment criteria specified that ECPs should have an ongoing relationship of support with a person who experiences communication access needs. The duration of the relationship was required to be greater than six months with weekly contact between the ECP and the person.

MHWs were identified as being employed in roles such as community mental health workers, counsellors, mental health nurses, mental health social workers, occupational therapists, peer support workers, psychiatrists, or psychologists. Previous experiences of working with people with communication access needs were not a prerequisite for inclusion in the survey or interview. Rather potential participants were asked if they were willing to respond to questions regarding their practice and perceptions of working with people with communication access needs in mental health care.

Sampling and Recruitment. A purposive sampling approach was used to recruit participants for both the survey and interview, to intentionally gain perspectives related to the provision of mental health support to people who experience communication access needs (Liamputtong, 2013; Mertens et al., 2010). The recruitment strategies are presented under two separate headings; 1) Survey, and 2) Interview, to reflect the customised approach taken for each method of data collection.

Survey.

Following approval from the Flinders University Human Research Ethics Committee, survey recruitment commenced in October 2020 and concluded in January 2022, with the survey closing on the 3rd of February 2022. Due to the COVID-19 health directives and advice for researchers (CTPRG, 2020), online recruitment became the predominant method of sharing information about the survey. The projected number of respondents was 25 per group. Multiple methods were used to connect with potential participants from the three groups. Two main methods of distribution of information were used: social media and email. A social media profile was created for the research project on Facebook titled ‘PhD Project: Connecting to Wellbeing’. The flyer for the survey was posted on the Facebook page with a clickable link to the online survey. Developing the social media profile allowed recruitment information to be shared through social media networks, such as X (formerly Twitter) and LinkedIn. This extended the reach of the project, spreading information about the research to people with communication access needs and ECPs who were not engaged with support services, and MHWs in private practice.

Email invitations containing survey recruitment materials were sent to organisations and individuals. Recruitment materials included Information sheets (Appendices B, C, F and G) and flyers (Appendices H and I). People with communication access needs and ECPs were sought through support services, advocacy organisations and professional bodies known to provide support to the population. To recruit MHWs, assistance was sought via emails to organisations and peak bodies known to provide mental health care and advocacy. Additionally, the supervision team emailed recruitment information to their professional networks.

Interview. Recruitment for the interviews commenced following ethics approval. Recruitment occurred between March and December 2021. The first source of purposive sampling was through online survey participants who identified an interest in participating in an interview. Individuals who indicated their interest in an interview provided preferred contact details; an interview information pack containing a letter of introduction (e.g., see Appendix J), relevant information sheet (Appendices D, E, K, L) and flyer (Appendices M and N) was distributed to them via email or post. This method of recruitment yielded a small number of participants from each group: people with communication access needs ($n=3$); ECPs ($n=2$); and MHWs ($n=2$). Information about the interview was also posted to the PhD Project: Connecting to Wellbeing Facebook page in the form of a flyer with the researcher's contact details for potential participants to express their interest.

Due to the low yield of interview participants arising from the survey self-referral and Facebook posts, the research team sought an ethics amendment to enable snowball sampling and a direct approach to potential participants. Once approved, this modification allowed the research team to send out emails with the research information specifically addressed to known individuals among the research populations. Additionally, the snowball sampling modification allowed the researcher to offer hard copies of research information packs, or electronic copies via email, for participants to pass on to others after their interview. Munger & Mertens (2011) emphasise the importance of researcher connections when conducting research with the disability community; accessing community gatekeepers who can verify the researchers' credibility and establish trust among potential participants. Researcher connections proved essential in recruiting for this study, particularly interviews. When recruitment stalled with only a small number of participants from each group the snowball sampling and direct approach strategies bolstered participant numbers enabling the collection of sufficient data for analysis.

4.3.3 Participant groups

The study included three groups: people with communication access needs (survey *n=9*, interview *n=6*); ECPs (survey *n=9*, Interview *n=6*); and MHWs (survey *n=24*, interview *n=9*). In the following section, each participant group, along with the data collection methods used, is presented separately.

The study involved three groups: people with communication access needs (survey *n=9*, interview *n=6*); ECPs (survey *n=9*, interview *n=6*); and MHWs (survey *n=24*, interview *n=9*). In the following section, each participant group, along with the data collection methods used, is introduced separately.

People with Communication Access Needs. Data were generated through survey and interview methods.

Survey. Nine participants with lived experience of communication access needs completed the online survey. While the online survey and information sheet were accessed by 25 respondents, just 10 people met the eligibility criteria and continued to the survey questions. Of those 15 respondents who did not meet the eligibility criteria, nine people ceased their responses after viewing the information sheet, and one responded “no” to the question “Have you read and understood the information sheet?”. Five people responded “no” to experiencing communication access needs. One further data set was excluded from the analysis as it was insufficiently complete; the questions were answered related to demographics. Data from nine respondents was retained for analysis using a range of descriptive statistics in the SPSS software suite (IBM Corp., 2021). Four respondents completed the online survey with researcher support. The researcher helped read questions and input responses into the survey. This assistance was provided in-person (*n=3*) or via video call (*n=1*). An overview of demographic data of survey respondents with communication access needs is presented in Table 4.2.

The age of respondents with communication access needs ranged from 21 to 63 years, with a mean of 42.7 years (*SD* = 16.16). Most respondents were aged between 30 to 59 years (*n=6*). Almost all respondents had experienced lifelong communication access needs (*n=8*), while one respondent had acquired communication access needs fewer than five years earlier. Survey respondents identified cerebral palsy (*n=6*), Down syndrome (*n=1*), Leigh syndrome (*n=1*), and dystonia (*n=1*) as diagnoses impacting communication.

Table 4.2

Demographic Characteristics of Survey Respondents with Communication Access Needs

Characteristic	Variable	Count (*n*)
Age	18-29 years	2
	30-39 years	3
	50-59 years	3
	60-69 years	1
Gender identity	Female	5
	Male	4
Country of residence	Australia	7
	Other: Hong Kong (S.A.R.)	1
	Other: USA	1
State (if in Australia)	South Australia	4
	Victoria	2
	Queensland	1
Schooling	Specialist school	5
	Mainstream school	1
	Combination specialist and mainstream	3
Education	Year 10	1
	Year 12	4
	Bachelor’s degree	1
	Post-graduate certificate/diploma	1
	Doctorate	1
Living arrangements	Supported living w. housemates	4
	Living w. parents/ siblings	3
	Living w. spouse and/or children	1
	Living alone	1
Diagnosis	Cerebral Palsy	6
	Down syndrome	1
	Leigh’s syndrome	1
	Dystonia	1
Duration of communication access needs	All my life	8
	Less than five years	1

Recruitment materials for the online survey were distributed via social media. A consequence of social media distribution was that the survey was completed by participants both within Australia (*n=7*) and abroad (*n=2*). Australian residents were located across three states. Respondents lived in an array of settings with a variety of support arrangements. Four respondents lived with their family members: either parent/s and/or siblings (*n=3*) or a spouse and/or children (*n=1*). Four respondents lived in supported settings with housemates, and one respondent lived alone.

Education levels among the lived-experience respondent group ranged from year 10 high school certificate to doctoral qualification. One respondent did not answer the question regarding education. Respondents' occupations included paid employment (*n=4*), recreational programs (*n=2*), vocational program (*n=1*), and student (*n=1*), with one respondent identifying participation in a combination of part-time work and part-time recreation program (*n=1*). Demographic data provided by respondents indicates diverse characteristics related to age, living arrangements, education, and employment. The respondent group demonstrated a level of homogeneity, with more than 50% similarity among participants in diagnosis, duration of communication access needs, and country of residence.

Interview. After a lengthy recruitment period, six interview participants were recruited. Three of these participants had also participated in the survey. Five interview participants were female. Their ages ranged from 18-29 years to 60-69 years. To preserve the confidentiality of participants, the exact ages of the interview participants are not reported. All interviewees had lifelong experience of communication access needs which they attributed to developmental disabilities: cerebral palsy (*n=5*), and Leigh's syndrome (*n=1*). All interviewees with communication access needs lived in Australia, the majority in metropolitan areas of South Australia (*n=3*), New South Wales (*n=1*), and Victoria (*n=1*). One person, lived in regional South Australia. Four participants lived in supported independent living settings: Fleur, Chris, and Laura shared their homes with other housemates; and Hope lived in a two-bedroom unit in a complex that housed several other people with disability. Lisa lived with her parents and a sibling in her family home, and Amelia lived in her own apartment on a block of land shared with her parents.

Most interview participants (*n=4*) had attended high school with no further tertiary education. One of those participants, Chris, had completed high school and received his year 12 certificate. Fleur, Laura, and Hope had attended special schools; their education was age-based with no year levels. They completed school at 18 years of age. Two participants had participated in tertiary education. A summary of the demographic characteristics of interview participants with communication access needs is available in Table 4.3.

Table 4.3

Characteristics of Interview Participants with Communication Access Needs

Pseudonym	Age range	Gender	Education level	Education type	Diagnosis	Occupation	Living arrangements
Lisa	18 to 29 years	Female	Certificate IV	Mainstream education	Cerebral Palsy	Self-employed	Family home
Chris	30 to 39 years	Male	Secondary School Certificate	Combination	Leigh's syndrome	Combination: Paid employment/ Recreation program (individual/ group)	Shared household Supported Independent Living 24 hr support
Amelia	40 to 49 years	Female	Bachelor’s degree	Mainstream education	Cerebral Palsy	Paid employment	Own apartment
Hope	40 to 49 years	Female	No School Certificate	Specialist education	Cerebral Palsy	Retired	Own apartment Supported Independent Living 24 hr support
Fleur	50 to 59 years	Female	No School Certificate	Specialist education	Cerebral Palsy	Combination: Study/ Recreation program (individual)	Shared household Supported Independent Living 24 hr support
Laura	60 to 69 years	Female	No School Certificate	Specialist education	Cerebral Palsy	Combination: Recreation programs (individual/ group)	Shared household Supported Independent Living 24 hr support

Everyday Communication Partners (ECPs). An online survey and interviews were the two data collection methods for ECPs.

Survey. Nine everyday communication partners completed the online survey. Although 12 respondents consented to participate, the responses from three respondents were excluded due to being insufficiently complete (<58% of questions answered). Data from nine ECP respondents were retained for analysis. An overview of demographic data from ECP survey respondents is presented in Table 4.4.

Table 4.4

ECP Online Survey Respondent Characteristics

Characteristic	Variable	Count (*n*)
Age	18-29 years	2
	30-39 years	3
	40-49 years	2
	50-59 years	1
	60-69 years	1
Gender identity	Female	8
	Male	1
Relationship to person	Family member	4
	Friend	2
	Support worker	2
	Professional support	1
Education	Year 12	1
	Vocational qualification	3
	Bachelor's degree	2
	Post-graduate certificate/diploma	3
Country of residence	Australia	8
	Other: Hong Kong*	1
State (if in Australia)	South Australia	6
	Western Australia	2

ECP respondents were predominantly female (*n=8*) and were aged between 22 and 62 years with a mean of 39 years (*SD* = 13.22). The online survey was distributed via social media; however, most respondents were from Australia (*n=8*), with one participant located in Hong Kong (*Special Administrative Region of the People's Republic of China). Australian respondents resided in two states. The majority of ECP respondents were tertiary educated (*n=8*).

ECP respondents were predominantly informal supporters such as a family member (n=4) or friend (n=2). Paid supporters included support workers (*n=2*) and a professional (*n=1*). The duration of ECPs' relationships with the person/s varied from one year to 22 years with a mean of 10.11 years (*SD* = 8.35). Overall, the ECP group tended to be female, Australian, and tertiary educated. The age range and relationship to the person with communication access needs varied.

Interview. Six ECPs consented to interview participation, two of these participants had completed the online survey. All ECP participants identified as female and lived in South Australia.

Five ECPs lived in metropolitan Adelaide, with one ECP located in regional South Australia. ECPs' ages were in the range of 18-29 years to 70-79 years. Most ECP interviewees were tertiary educated and all ECPs in paid support roles possessed a tertiary qualification.

A criterion for participation in the interview was that ECPs have an ongoing relationship of support with person/s with communication access needs. The duration of these relationships ranged from 3 to 41 years with a mean of 19.7 years (*SD* = 15.33). ECPs described their relationship to the person/s with communication access needs as paid supporters (*n=4*), or parents (*n=2*). Both parent ECPs were retired but held voluntary roles as prominent advocates in the disability and mental health communities. One of the parents had previously been employed in the disability sector in managerial and advocacy roles, and the other had been employed in the mental health sector in education and advocacy roles. Of the paid supporters, two were employed as disability support workers, one was a service manager, and one was a practice leader. Table 4.5 provides additional detail regarding the ECP interviewee group.

Table 4.5

ECP Interview Participant Characteristics

Pseudonym	Age	Gender	Education	Occupation	Relationship	Duration
Ariel	18 to 29 years	Female	Bachelor's degree	Team Leader	Paid supporter	8 years
Demi	30 to 39 years	Female	Diploma	Support Worker	Paid supporter	3 years
Emmylou	30 to 39 years	Female	Diploma	Service Manger	Paid supporter	7 years
Aster	40 to 49 years	Female	Bachelor's degree	Practice Leader	Paid supporter	26 years
Karina	60 to 69 years	Female	Certificate IV	Retired/ Advocate	Parent	41 years
Paulette	70 to 79 years	Female	High school certificate	Retired/ Advocate	Parent	30 years

Mental Health Workers. As with the other two groups, both an online survey and interviews were used to gather data.

Survey. The online survey was completed by 24 MHWs. While 27 respondents consented to participate in the online survey, the responses from three respondents were excluded due to being incomplete (<70% complete). Most MHWs who accessed the survey completed all questions (*n=16*). A further portion of respondents (*n=8*) completed 71% of the survey, ceasing their responses late in the survey at the commencement to a cluster of short answer responses about skills and attitudes required by MHWs when working with people with communication access needs. The unanswered questions were treated as missing data. In total, data from 24 respondents were retained for analysis. An overview of demographic data for the MHW survey respondents is available in Table 4.6.

MHW respondents were predominantly female (n=20), with the remainder being male (n=3) and one respondent selected “prefer not to say” concerning gender identity. Respondents were aged between 29 and 59 years, with a mean age of 45.2 years (*SD* = 9.73). Most respondents were aged 50 to 59 years (41.7%). As with the lived experience and ECP groups, most respondents were located in Australia (n=23), with one respondent from the USA. Australian respondents were situated in four states.

All MHWs were tertiary educated, indicative of professional standards in the Australian mental health sector. Nine MHW respondents held qualifications ranging from vocational certificate level to doctorate. The MHWs were employed in diverse roles within the sector as Peer Support Workers (n=7), Community Mental Health Workers (n=6), Mental Health Support Workers (n=4), Occupational Therapists (n=2), Clinical Social Worker (n=1), Counsellor (n=1), Community Services Worker (n=1), and Mental Health Nurse (n=1). Respondents had been employed in the mental health sector for a period ranging between one and 25 years, with a mean employment period of nine years (*SD* = 6.14). It is of note that 20 MHW respondents (83.3%) had experience working with a person with communication access needs. This will be explored further in the next chapter examining the experiences and knowledge of the three groups regarding mental health and service provision.

Table 4.6

MHW Survey Respondents' Demographic Characteristics

Characteristic	Variable	Count (*n*)
Age	18-29 years	2
	30-39 years	6
	40-49 years	6
	50-59 years	10
Gender identity	Female	20
	Male	3
	Prefer not to say	1
Education	Vocational qualification	6
	Diploma	3
	Bachelor's degree	5
	Graduate diploma	3
	Master's degree	6
	PhD/ Doctoral degree	1
Country of residence	Australia	23
	Other: U.S.A.	1
State (if in Australia)	South Australia	15
	New South Wales	4
	Tasmania	2
	Western Australia	2
Employment	Peer Support Worker	7
	Community Mental Health Worker	6
	Mental Health Support Worker	4
	Occupational Therapist	2
	Clinical Social Worker	1
	Community Service Worker	1
	Counsellor	1
	Mental Health Nurse	1
	Psychiatrist	1

Interviews. Nine MHWs from a variety of roles within the mental health sector participated in interviews. Two of these MHWs also completed the online survey. Five participants identified as male and four female. The majority of MHW participants were working in metropolitan South

Australia (*n=7*) in the greater Adelaide region with one MHW working for a state-wide service. One interviewee worked in the greater Melbourne area of Victoria.

All MHW interview participants had attained tertiary education, the majority with university-level qualifications. Participants were employed in a range of roles in the mental health sector. The professions represented in this cohort were social work (*n=2*), developmental education (*n=2*), groups facilitator (*n=1*), mental health nurse (*n=1*), peer specialist (*n=1*), psychiatrist (*n=1*) and psychologist (*n=1*). All MHWs worked with adults as this was a criterion for participation. The populations served by the MHWs can be viewed in Table 4.7. The experiences of MHWs will be further explored in Chapter 5, Experiences: Informing Mental Health Knowledge and Practice.

Table 4.7

MHW Interview Participant Characteristics

Pseudonym	Age Range	Gender	Education Level	Occupation	Populations	MHW Specialisation
Aiden	40 to 49 years	Male	Certificate IV	Groups Facilitator, Business Owner	Youth Adults	Psychosocial support Group facilitation
John	40 to 49 years	Male	Certificate III	Peer Specialist	Youth Adults	Peer work Psychosocial support Mindfulness
Jordy	40 to 49 years	Female	Bachelor’s degree	Developmental Educator/ Counsellor	Children Adults	Counselling Emotional regulation skills Disability
Mike	40 to 49 years	Male	Master’s degree	Senior Social Worker	Older adults	Older people Dementia Crisis support
Hetty	50 to 59 years	Female	Master’s degree	Mental Health Nurse	Older adults	Older people Dementia Crisis support
Luis	50 to 59 years	Male	Master’s Degree	Psychologist	Adults	Counselling Psychoeducational intervention PBS Intellectual disability (communication)
Mari	50 to 59 years	Female	Bachelor’s degree	Senior Social Worker	Adults	Huntington's disease Counselling Psychosocial support
Miranda	50 to 59 years	Female	Master’s degree	Developmental Educator/ Counsellor	Adults	Counselling PBS Mental Health First Aid Disability
Siegfried	50 to 59 years	Male	Doctoral degree	Psychiatrist	Adults	Diagnosis Medication management Intellectual disability

4.3.4 Designing Data Collection Instruments

Pre-existing data collection tools to capture information about mental health seeking experiences of people with communication access needs could not be identified in the literature, hence there was a need to develop a survey. The survey and interview questions were initially drafted based on the literature review and research questions, and were designed to elucidate data regarding varied aspects of the same phenomena: mental health care seeking for people with communication access needs (Moseholm & Fetters, 2017). Using a deductive approach, this information was used to develop the research questions that underpinned the survey questions. By triangulating the inferences of survey data and the personal accounts provided in interviews, exploration of the phenomena was enriched (Mertens et al., 2010). Providing multiple data collection tools was a way of connecting with heterogenous participant populations (Mertens, 2007). Researchers who use the transformative ontology actively seek to adapt data collection methods to ensure that diverse participant groups can clarify their views on the research issue and capture the lived reality of this issue (Mertens, 2016). To facilitate the inclusion of participants who communicate in diverse ways, the initial survey and interview questions were refined and clarified via a collaborative process involving research advisors and the supervision team. This approach ensured that data collection methods and questions were relevant and appropriate to the lived-experience participants (Munger & Mertens, 2011).

Communication access was a key consideration in the delivery of this survey. Survey questions for all groups were written in a plain-language format. Multiple choice, scaled answers, and short typed responses were used to reduce participant fatigue when completing the survey. Drafts of the survey were provided to the two lived-experience research advisors and feedback was provided via consultation sessions. Furthermore, the final survey questions were reviewed and tested by the lived-experience research advisors and members of the supervision team. Using this process of testing and feedback from subject experts supported the establishment of face validity and content validity in the survey (Mertens, 2015). The consultation sessions were essential to further develop questions about communication access in mental health support. For example, in developing the online survey, one of the research advisors raised concerns about the accessibility of counselling phone lines and websites, which are commonly recommended in Australia, particularly during the COVID-19 pandemic. This led to the incorporation of survey questions about perceived accessibility of counselling helplines and websites.

The lived-experience research advisors also provided important feedback regarding the ECP surveys and interviews. They reiterated the importance that questions directed to ECP did not elicit answers that misappropriated the experiences of people with communication access needs. Research advisors emphasised the need for a caveat in the surveys and interviews regarding confidentiality and to emphasise that communication access needs were not a precursor to mental health problems (Appendix O). This feedback was essential in challenging a misassumption by the researcher that confidentiality would be implicit in ECP discussions due to commonly held values regarding privacy. The potential for power imbalances in relationships between people with communication access needs and ECPs needed to be explicit in the messaging conveyed within the data collection tools. Once finalised, the survey questions were entered into the Qualtrics[2] online software (Qualtrics, 2020) and shared among the supervision team and research advisors to test the navigation of the online survey prior to launch. At this stage, access problems and navigation problems were resolved by the PhD researcher.

Informed Consent Materials. The information sheets and consent questionnaires were developed for all groups involved in the research. Standard versions of the information sheets were written using plain language principles to support informed consent (Young, 2019). An additional Easy English version of the survey and interview information sheets was developed for participants with communication access needs (Appendices B and D). In recognition of varied literacy levels, participants were able to select which information sheet best suited their requirements (Beukelman & Light, 2020). Given the sensitive nature of the survey and interview content, the contact details of communication accessible mental health supports were included in all information sheets for the project.

Providing Consent. Information sheets were provided before the commencement of the online survey. Upon opening the survey, the respondents were presented with the option of selecting either the standard or Easy English information sheet. To progress to the survey questions, respondents must have checked a box stating that they had read the information sheet and consented to continue the survey. For the interview, information sheets and consent forms were provided at the request of potential participants before the interview. The information sheet recommended that participants carefully consider their participation and discuss this with a trusted person if required. Participants were given the option of signing or marking their consent form. Alternatively, individuals could state their consent verbally or using AAC upon being read each of the items on the consent form. Where consent was provided verbally or with speech generating AAC, this was audio recorded and transcribed.

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[2] Qualtrics and all other Qualtrics products or service names are registered trademarks or trademarks of Qualtrics, Provo, UT, USA. https://.qualtrics.com

4.3.5 Data Collection

Surveys. Online surveys were launched online in October 2020 after a process of design, testing, and HREC approval. The online survey was closed in February 2022 following a final round of emails and a Facebook posting in December 2021, no further surveys were completed. As stated previously, separate surveys were developed for each group to address differing research foci for each group. The online survey questions for each group are included in Appendices P, Q, and R. The survey consisted of eligibility and demographic questions followed by a series of experience questions with multiple choice, short answer, and scaled responses. A brief overview of the experience questions for people with communication access needs is included in Table 4.8.

Table 4.8

Overview of Survey Questions for People with Communication Access Needs

Survey Question	Question type
1. Have you ever learned about mental health? ○ What did you learn about? (multiple choice) ○ Who taught you about mental health? (multiple choice)	Multiple choice with text option
2. Where do you get your information about mental health?	Multiple choice with text option
3. What would you like to know more about in relation to mental health?	Multiple choice with text option
4. What issues impact most on your mental health?	Multiple choice with text option
5. Do you think that you have ever experienced a mental health problem? If yes, how do you describe the mental health problem?	Multiple choice with text option
6. When you are struggling with difficult feelings, moods, emotions, or a mental health problem, what helps you?	Multiple choice with text option
7. Who do you share your feelings, concerns, and emotions with?	Multiple choice with text option
8. When you share your feelings, concerns, and emotions, how useful are each of these communication partner behaviours?	Scaled responses
9. Have you ever sought help for a mental health problem?	Multiple choice with text option
10. What mental health supports have you used?	Multiple choice with text option
11. How accessible do you think mental health phonelines (e.g. Lifeline, Beyond Blue) are for people with communication access needs?	Multiple choice with text option
12. How likely are you use a mental health phone line?	Scaled response

13. How accessible do you think mental health chat rooms are (e.g. Lifeline, Beyond Blue) for people with communication access needs?	Multiple choice with text option
14. How likely are you to use a mental health chat room?	Scaled response
15. How do you think mental health support could be made more accessible for people with communication difficulties?	Short text response

Accommodations were made to the surveying process to allow participants with communication access needs to choose a support person to assist them. The information sheet stipulated that the support person could assist by setting up a device (such as an AAC system) to undertake the survey, reading the survey information and questions out to the person, and providing physical assistance for the person to input their answers into the Qualtrics interface. Once the online survey was released, feedback was received from people with communication access needs that this group found it difficult to identify appropriately skilled support workers to assist them with the online survey. An ethics modification was sought and approved. The information sheet for people with communication access needs was amended to include that, if required, assistance could be requested from the PhD researcher to complete the online survey. The researcher was able to assist by reading the written information and survey questions to the participant, and/or helping to input the participant's answers into the survey. Due to COVID-19 related government mandated restrictions, the researcher was only able to provide in-person support in the Adelaide metropolitan area, or online in other regions. Where assistance was provided in person, the researcher was required to abide by SA Health’s COVID-19 preventative measures. Participants were notified in the information sheet that their survey responses may no longer be anonymous if supported to complete the survey.

Interviews. The interviews took place from May to December of 2021. The purpose of the interview was to further develop understanding of communication access in mental health support. The interview questions differed for each of the three groups to reflect the different exploratory objectives for each group. Examples of interview questions for people with communication access needs are presented in Table 4.9. The full interview protocol for each group is included in Appendices S, T, and U. Interviews were offered online or in-person in the Adelaide metropolitan region. In conducting face-to-face interviews, the safety and wellbeing of participants was a priority (CTPRG, 2020). COVID-19 safety measures were outlined in the interview protocol documents. As an access measure participants with communication access needs were able to identify a person to assist them with communication during the interview. This person is referred to as a communication assistant throughout the thesis. The communication assistant could help the person prepare vocabulary and responses for the interview as well as co-constructing messages during the interview session. While many of the communication assistants were ECPs of the interview participants with communication access needs, no communication assistants participated in ECP interviews.

All participants were provided an overview of the interview questions prior to their meeting. The purpose of providing the interview overview in advance was primarily to enable participants using AAC to prepare their responses in advance, reducing the need to type messages into devices. Additionally, participants who used human communication assistants could make notes and clarify the experiences they would like to discuss. While this was originally a communication access measure, ECP and MHW participants also commented that having an overview of the interview questions enabled them to consider their experiences more deeply. Given the semi-structured nature of the interviews, participants were invited to expand upon and explore their responses in greater depth during the interview. Participants with lived experience were invited to use whichever modes of communication allowed them to convey their message with the greatest ease and accuracy. Modes of communication are discussed in greater detail in the following paragraphs.

Table 4.9

Overview of Interview Questions for People with Communication Access Needs

Interview question
1. What does mental health mean to you?
2. How did you learn about mental health?
3. How do you keep up to date with information about mental health?
4. What are the things that have a positive impact on your mental health?
5. What sorts of things have a negative impact on your mental health?
6. How does communication factor in your mental health?
7. Can you tell me about a time that you wanted to address an issue that was impacting on your mental health?
8. How did people respond when you expressed your feelings, concerns, or emotions?
9. What strategies have you noticed mental health professionals use to promote communication access?
10. Under what circumstances do you think ECPs should be included in the mental health intervention?
11. What would you like to know more about in relation to mental health?
12. Do you have any other comments or questions about communication access and mental health support?

4.3.6 Communication during Interviews

The amount of time and level of support required for communication varied between participants. Participants were invited to use whichever communication methods were most comfortable for them in the interview setting. All participants used a combination of aided and unaided communication methods to get their messages across. Aided methods included use of high-tech speech generating devices (SGDs), non-tech communication boards, as well as use of tangible objects and props such as photographs. Unaided communication methods included facial expressions, gestures, manual signs, and vocalisations. Lisa, Amelia, and Hope were able to independently type messages into their AAC devices, as well as using facial expressions, gestures, and vocalisations. The remaining participants (Fleur, Chris, and Laura) used a range of communication strategies but mostly used unaided methods and their AAC devices were symbol-based with limited vocabulary sets. These three participants opted to have the support of a communication assistant during their interview sessions. An overview of the characteristics of interview sessions is outlined in Table 4.10. The following paragraphs provide further detail about each participant's preferred methods of communication during the interviews. Particular attention is given to participants with greater communication support requirements to give context to the quotes provided in later results chapters.

Table 4.10

Summary of Communication during Interviews

Participant	Unaided communication methods	Aided communication methods	Duration of interviews
Fleur	Vocalisations Facial expressions Gestures	Communication assistant Communication book Communication board Objects Photographs	2 hours, 7 minutes.
Chris	Speech Gesture Facial expressions	Communication assistants Grid Pad®[3] Objects/ documents	3 hours.
Laura	Speech Gesture Facial expressions	Communication assistants iPad with Let Me Talk® [4]app. Choice board Photographs	2 hours, 8 minutes.

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[3] Grid Pad® is a registered product of Smartbox (www.thinksmartbox.com).

[4] Let Me Talk® is a registered application of AppNotize UG.

Amelia	Speech Gesture Facial expressions	Allora® SGD[5] Accent® SGD[6]	1 hour, 42 minutes.
Lisa	Speech Gesture Facial expressions	SGD (not specified)	45 minutes.
Hope	Speech Gesture Facial expressions	iPad with Notes app Objects/ documents Photographs	1 hour, 45 minutes.

Fleur. Fleur undertook her interview over two sessions, totalling 2 hrs 7 mins. The first session focussed on demographic questions and allowed the interviewer to review the information pack and consent questionnaire with her, respond to queries, and develop an understanding of Fleur's preferred communication strategies. The second session focused on interview questions related to experiences and perspectives. Fleur was eager to communicate her responses thoroughly. When asked questions, she listened carefully taking time to understand and decide how best to respond. She considered the best way to answer; with a facial expression, gesture, vocalisation, communication board/book, object, image, or calling on her communication assistant to help fill the gaps. Fleur used a range of facial expressions and gestures that are clear to those who know her well. In our first interview she informed me that she would say "yes" by squinting her eyes; I also noticed that she occasionally nodded her head and vocalised to emphasise a point. When the topic was positive, Fleur smiled or laughed in agreement. Fleur shook her head and pursed her lips to express disagreement; she also vocalised to stress a response. She was quick to respond when she did not agree with something. When I asked her how she would inform me that she did not want to answer a question, she opened her eyes wide, shook her head and vocalised loudly. When Fleur required more time to think about a question, she raised her right hand and pointed to her head, just behind her ear, indicating that she was thinking. She used facial expressions to contextualise; for example, she might point and shake her head indicating that she could not remember. Fleur also used a combination of eye pointing and partner-assisted scanning to select items in her communication book; she can directly select words on her iPad but chose not to use this in her interview. Throughout the interviews she pointed to objects in the room – a clock to indicate time, her bed to indicate sleeping, or a photograph of a person or event. She also pointed to her communication book, iPad, or her

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[5] Allora® is a registered product of Jabbla (www.jabbla.com)
[6] Accent® is a registered product of PRC-Saltillo (www.prentrom.com)

communication assistant when she needed them. Fleur’s preference during the interview was a combination of unaided communication and human assistance.

Fleur’s chosen communication assistant was a long-term support worker, they had known each other for over 20 years and there was clearly a relationship of trust between them. Fleur’s communication assistant waited for her to indicate when she needed her help and sought her consent consistently throughout the interview. At times Fleur asked her communication assistant to tell a story on her behalf, the communication assistant checked that the details of the story were correct as she was telling it, by asking “Is that right?”. Fleur and her communication assistant prepared notes prior to the interviews. They told me that Fleur had identified some experiences from her past that she would like to share. Nevertheless, this did not limit Fleur, as she made a significant effort to spontaneously share story about an event that her communication assistant was not expecting. This required a lot of props, objects, and questions from us both to ensure that we got her story right. Interviews with Fleur required deep engagement from us both; we watched each other closely and most importantly, communication took time. Many lengthy silences and communication breakdowns took minutes to repair. Fleur identified that she requires communication partners to be able to ask relevant questions as she finds giving yes/no responses easier.

Chris. Chris undertook three interview sessions totalling 3 hours. The first interview session focussed on demographic questions and reviewing the information pack and informed consent materials. This interview was conducted without a communication assistant. Chris uses speech as his primary mode of communication with familiar communication partners. As a new communication partner, it took me time to become attuned to his speech patterns. Chris also informed me of the gestures he uses; including manual signs for yes, no, stop, and okay. During the first interview, there were many communication breakdowns. A combination of strategies was used to repair communication breakdowns, repeating the response, asking yes/no questions, and using props (photographs, documents, and objects) to clarify the message. Toward the end of the first interview session, Chris stated that he also had a Grid Pad® SGDthat he would like to use in future interview sessions. Unfortunately, the Grid Pad® was not sufficiently charged for the duration of the interviews. Chris had not long had the Grid Pad® at the time of the interviews and had limited vocabulary programmed into the device. Though the device enabled Chris to independently express simple concepts, speech was easier and allowed him to access a more spontaneous and extensive vocabulary provided his communication partner could understand.

Chris chose to have a communication assistant present at his subsequent interviews to reduce the demands of communicating with an unfamiliar communication partner. He chose the Team Leader of the support workers at his home; a person he trusted to help with communication about sensitive experiences and perspectives. Despite careful scheduling to accommodate availability, Chris' preferred communication assistant was not available at the second interview session due to staffing issues. Chris decided to proceed with his interview with assistance from another staff member. There were interpersonal challenges to Chris presenting his perspectives independently during the second interview. Despite communication assistants being provided with instructions for interview support, Chris was interrupted by this communication assistant adding their perspectives. On two occasions the interview needed to be paused to remind the communication assistant only to support Chris' responses. After these reminders, the interview progressed. There were certain topics that Chris did not want to discuss with this communication assistant present, so later elected to reschedule an interview with the preferred communication assistant present. At the end of the interview, after the Grid Pad® had charged, Chris shared some perspectives on defining mental health.

The third interview session provided Chris with an opportunity to expand and clarify his experiences of mental health support seeking with the assistance of the preferred communication assistant. The tone of the third interview was notably different with the communication assistant seeking Chris' consent and actively working with Chris to co-construct responses. The communication assistant noted that some of the perspectives and worries expressed by Chris were new to him and thanked Chris for sharing these concerns.

Laura. Laura's interview was conducted over three sessions, totalling 2hrs 8 mins. The first session focussed on reviewing informed consent materials and, after consent was obtained, answering demographic questions. Laura had the Team Leader of her in-home support staff act as her communication assistant. The Team Leader was her preferred communication assistant. Laura informed the interviewer that her preferred methods of communication were facial expressions, gestures, and some speech, as well as the Let Me Talk® app on her iPad. The vocabulary on the Let Me Talk app was very limited and did not allow Laura to discuss a broad range of emotions and experiences, but simply to identify topics to prompt discussion and direct further clarifying yes/no questions. During the interview sessions, the iPad was placed on the table in front of Laura for her to pick-up and use when needed. Additionally, Laura used photos on her iPad to identify people and places, and hard copies of the choice boards around her home to specify activities. Laura used her hands to point to objects that assisted the interviewer's understanding. When Laura wanted to pause the audio recording, she was able to call out "stop" or use her iPad to say, "Stop please". Throughout the interview, Laura used vocalisations in tandem with gestures and facial expressions to emphasise certain points. When requiring help from her communication assistant she would pause and look toward them.

Laura’s preferred communication assistant was not available for the second interview due to an urgent staff shortage at another location. Laura elected to continue with the interview with the assistance of a casual support worker, whom she had known for several years. The communication assistant was provided with the information sheet and then interview proceeded. On one occasion the interview was stopped to remind the communication assistant only to support Laura in providing her perspective. During this second interview, Laura declined to answer some questions indicating that she would prefer to respond to these with her preferred communication assistant present. A third interview session was arranged accordingly. During the third interview Laura was supported by her preferred communication assistant. She worked with her assistant to respond to specific questions about her experiences of receiving mental health support. The communication assistant sought consent from Laura before sharing information. In one instance there was a story that Laura did not want to share, she stopped her communication assistant and stated which details were to be provided. The interviewer was able to check details with Laura by asking yes/no questions or seeking clarification using the Let Me Talk app on her iPad.

Amelia. Amelia undertook a single interview lasting 1hr 42 mins. This interview was conducted via video conference. Prior to commencing the interview informed consent materials were reviewed and consent provided. Amelia used a speech-generating device as her primary mode of communication. She prepared answers in advance using the interview questions guide to type long answer responses which were saved to her speech-generating device. The interviewer was able to clarify or expand responses by asking further questions and Amelia could type her reply into her speech-generating device allowing for an unlimited range of responses. Additionally, Amelia used some gestures and spoken words (e.g., yes, and no) to clarify or add detail. Communication took time and there were points in the interview where more clarifying yes/no response questions were needed in preference to longer typed responses, to reduce fatigue.

Lisa. Lisa conducted her interview in a single 45-minute session. The interview was conducted online via video conference. Before beginning the interview, informed consent materials were reviewed, and consent was confirmed. Lisa had prepared her responses in advance, typing them into her SGD. Lisa’s responses were clear and direct, and she was able to clarify responses by responding to considered yes/no response questions. Expanding on responses during the interview was challenging because typing long responses was fatiguing for Lisa; also yes/no responses may have been limiting in the online format as it was not possible to use props, and objects to support communication to the same extent as during in-person interviews. Lisa identified when a communication breakdown occurred and clarifying questions were used to correct the misunderstanding.

Hope. Hope conducted her interview over three sessions totalling 1 hr 45 mins. Hope used speech as her primary mode of communication along with gestures and facial expressions in the interviews. When required, Hope typed responses into the Notes application on her iPad to clarify her meaning. Additionally, Hope used photographs around her home and in her photo albums to raise topics related to family members and friends. She also used objects and documents, such as certificates and timetables to provide additional information.

Hope requested multiple shorter interview sessions to help manage fatigue and scheduling of activities. The first interview session focused on reviewing informed consent materials, responding to demographic questions, and developing rapport. The two subsequent interview sessions covered experiences and perspectives of mental health support. The first session provided an opportunity for the interviewer to attune to Hope's preferred modes of communication. Hope did not have a person that she trusted to act as a communication assistant or a comprehensive form of AAC, so it was essential to establish an understanding of her modes of communication and strategies to resolve communication breakdowns. Hope indicated "yes" by moving her gaze to the ceiling and "no" by shaking her head. If clarification was required, she would type words or sentences into the Notes app on her iPad and ask the researcher to read the words when she was done. Typing was fatiguing and time-consuming for Laura, so written messages tended to be short and included only the essential information to clarify the message.

Section conclusion. The information included in these paragraphs provides context for communication with interviewees with lived experience of communication access needs. The purpose of these detailed accounts of communication modes is to provide the reader with a deeper understanding of the interview process and the nature of the engagement between interviewer and interviewee. Such contextual information is not entirely evident in quotes that have been sourced from audio recordings of interactions.

4.3.7 Transcription

The researcher transcribed verbatim all the interviews with people with communication access needs, and included notes about communicative interactions throughout the process. Transcribing these interviews enabled the researcher to gain a deeper understanding of the participants' responses when contextualised with the interview notes. To adequately portray the diverse communication methods used by interviewees with communication access needs, Von Tetzchner & Basil's (2011) notational conventions for different forms of communication were used. In the transcripts one column was allocated to notes and observations of the use of non-audible forms of communication such as facial expressions, gestures, vocalisations, and descriptions of props/objects. Transcription of these interviews took significant time. This was for several reasons: firstly, interviews with participants with communication access needs were longer due to the additional time required for communication. Also, some participants had a preference to use speech that was difficult to understand in an audio recording. Deep and repeated listening to audio data was required to transcribe these passages of speech. This process of transcription yielded a deeper immersion in the data.

Another matter in the transcription of interviews was documenting communication breakdowns. Communication breakdowns are common with spoken language, however, when a person uses AAC or speech that is difficult to understand, multiple attempts may be required to clarify the breakdown (Beukelman & Light, 2020). Many interviews contained minor communication breakdowns due to the interviewer mishearing words or the person having insufficient vocabulary available in their AAC system. During the transcription process, the researcher corrected words that were misheard during the interview and noted the misunderstanding.

For the ECP and MHW interviews, most were transcribed by the researcher and a portion were transcribed by a paid transcription service. The transcripts that were not transcribed by the researcher were all read and checked by the researcher. This provided an opportunity to refamiliarize the researcher with the data and begin detecting themes before the formal analysis phase (Ritchie et al., 2014).

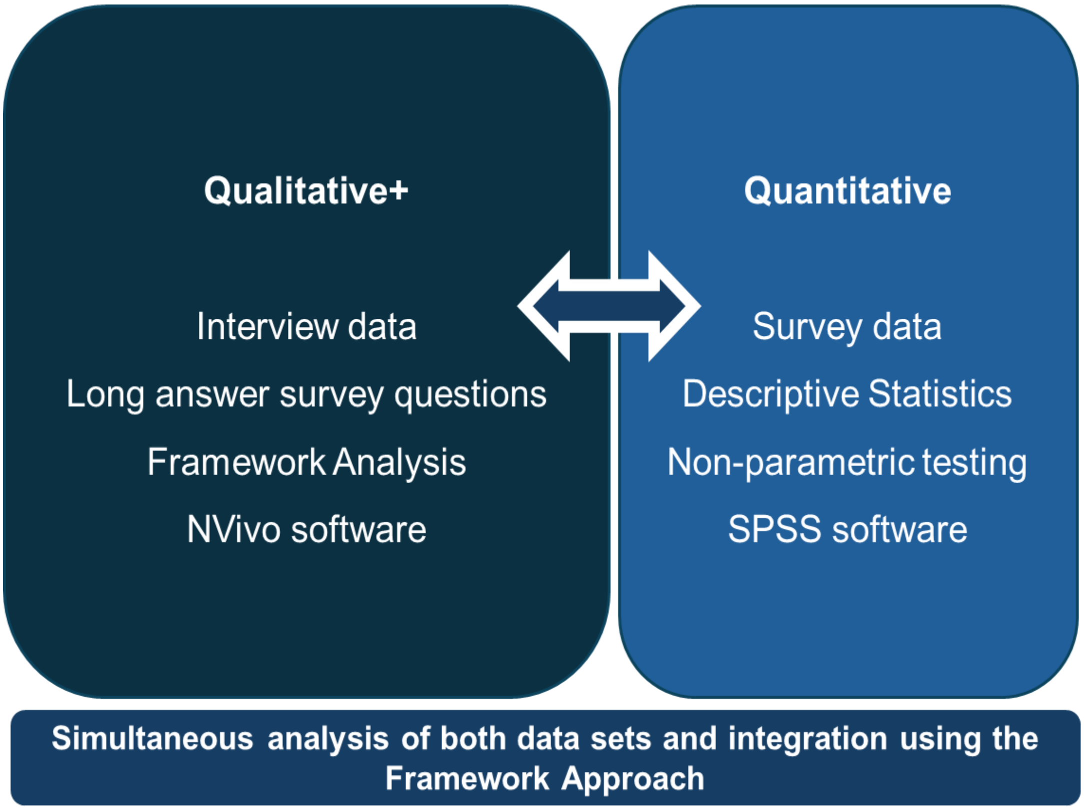
Participants were given the opportunity to member check their transcript following their interview to confirm that their views had been correctly represented. The typed transcripts were emailed or posted to participants with 10 days to respond and confirm the accuracy of the document. Two participants with communication access needs requested researcher assistance to read their transcripts. In these instances, both transcripts were very long, one 80 pages and the other 53 pages. For each of these transcripts the researcher created a summary document with the key points of the interview and communication breakdowns removed. These documents were read to the participant by the researcher to confirm the accuracy of key messages throughout the interview. During the member check process, participants provided clarifying information that was added to the transcript.

4.3.8 Data Analysis, Interpretation, and Reporting

In convergent mixed methods designs, qualitative and quantitative data are initially analysed separately before being integrated and compared, thus permitting a greater understanding of the phenomenon in question (Creswell & Plano-Clark, 2018). Analysing mixed methods data within a single stage of the research process is referred to as simultaneous data analysis. Quantitative data from each group were analysed using descriptive statistics tests in SPSS (IBM Corp., 2021). Qualitative data were analysed using the Framework Analysis approach (Ritchie et al., 2014). Quantitative and qualitative data were then integrated, comparing the findings of both forms of data (Moseholm & Fetters, 2017). As this is a predominantly qualitative research project, quantitative data were integrated into the thematic framework that was developed through the analysis of the qualitative data (Love & Corr, 2022). The survey and interview data conveyed complementary stories; however, the accounts received by interview participants extended upon the data from the survey. Figure 4.6 gives a visual summary of the interplay between qualitative and quantitative data in the data analysis phase of the project. The following section details the data analysis process for quantitative data, then qualitative data, then for integration of both data sets.

Figure 4.6

Simultaneous Data Analysis in a Predominantly Qualitative Mixed Methods Study



Analysing Survey Data. Collecting data via online survey enabled wide-spread distribution of the research to include the diverse perspectives of people with communication access needs, ECPs and MHWs (Sue & Ritter, 2012a). Quantitative data generated through the survey were analysed using IBM SPSS Statistics for Macintosh, Version 28.0 (IBM Corp., 2021). Data were analysed for descriptive statistics. In preparation for analysis, the researcher undertook additional SPSS training and met with the Flinders University Statistician who had expertise in the use of SPSS. A quantitative data analysis plan was developed to guide analysis and ensure that all research questions were addressed in a cohesive manner.

Once the survey was closed in February 2022, all survey data were imported into SPSS from Qualtrics. The data from each participant group was entered into a separate data file. All SPSS data files from Qualtrics required modifications, such as labelling variables and data cleaning before analysis could begin. Some data sets were excluded due to not meeting the eligibility requirements or being insufficiently complete. Survey attrition is discussed in greater depth under the participant groups heading. Before data analysis, missing data were identified and recoded, and some data were recoded for consistency across the data set (Sue & Ritter, 2012b).

Quantitative data were analysed primarily for descriptive purposes: providing summaries about each group's characteristics, knowledge, experience, and suggestions for improving practice relating to mental health care. Each question was analysed for response frequencies, and percentages were calculated. Due to small sample sizes and population heterogeneity, normative distribution of data was not assumed. As the data was sought for primarily exploratory purposes within a predominantly qualitative design, normative distributions of data were not expected (Love & Corr, 2022; Moseholm & Fetters, 2017). Once analysis of each group's data was complete, comparisons of corresponding data from lived experience and ECPs groups were undertaken. The purpose of this comparison was to identify differences in perceptions about useful communication strategies when addressing issues relating to mental health and emotional wellbeing. Frequency distributions for each question were displayed using tables and bar graphs for ease of viewing (Sue & Ritter, 2012b). The integrated findings from the survey are presented in the findings chapters of the thesis.

Analysing Qualitative Data: Framework Analysis. Qualitatively driven mixed methods data analysis maintains fidelity to the participants' accounts of phenomena under exploration (Hesse-Biber et al., 2015). The Framework Analysis approach has been utilised extensively by researchers in the fields of social policy and health to analyse and interpret qualitative data (Gale et al., 2013; Kiernan & Hill, 2018; Ritchie et al., 2014). Within the transformative paradigm, the Framework Analysis approach (Ritchie et al., 2014) enables researchers to remain close to participants' accounts whilst engaged in the analytic process. This approach was selected to incorporate a substantial amount of qualitative data and enable comparisons across groups (Kiernan & Hill, 2018).

The Framework Analysis process incorporates two phases of analysis that consist of multiple steps. The two phases are data management, and abstraction and interpretation. The data management phase involves organising the qualitative data and occurs in five steps: 1) familiarisation with the data; 2) developing the initial framework; 3) indexing and sorting the data; 4) reviewing data extracts; and 5) summarising the data. During the data abstraction and interpretation phase, three further steps are completed: 1) constructing categories; 2) identifying linkages; and 5) explaining, or accounting for patterns (Ritchie et al., 2014). These stages are not essentially linear and require the researcher to move back and forth between steps as lines of enquiry emerge (Gale et al., 2013). NVivo R1 (QSR International, 2020) software for Macintosh was used to assist the analytic process. The process of analysing the qualitative data is detailed in the following headings and summarised below in Table 4.11.

Table 4.11

Summary of the Framework Analysis Approach

Analysis phase	Step	Description
Data management	1. Familiarisation	Initial identification of topics discussed by interviewees. Data immersion via interviewing, journaling, transcription, transcript review.
	2. Constructing the thematic framework	Using the initial understanding of the data to create a thematic framework consisting of themes and subthemes.
	3. Indexing and sorting	Topic coding (Saldaña, 2013) and sorting data into the themes and subthemes (indices) within the thematic framework.
	4. Reviewing data extracts	Iterative amendments are made to the thematic framework as analysis progresses. The thematic framework is adjusted to maintain coherence with data.
	5. Data summary and display	The thematic framework is presented as matrices comprised of data extracts. Summary statements are written for each theme in the framework.
Abstraction and interpretation	1. Constructing categories.	The beginning of the interpretive process. Data extracts are and summaries are mapped to identify underlying categories of data.
	2. Identifying linkages.	The data are compared. Linkages are identified across the components of that are connected. Further typologies are identified.

	3. Explaining	The explaining stage involves accounting for patterns in the data. Researchers may or may not include the explanation as a component of analysis.

Adapted from Ritchie et al. (2014)

Familiarisation. The process of familiarisation with the data commenced long before the formal analysis began. During the data collection and transcription phase the researcher observed and noted concepts that emerged in interviewees’ accounts. By conducting interviews and transcribing data, the researcher gained an immersive understanding of participants’ stories and their relationship to the research questions. Once transcripts were approved by participants, de-identified hardcopies were printed and placed in a binder, and an electronic copy was moved to the NVivo database ready for formal analysis to begin.

Constructing the Thematic Framework. The initial thematic framework was developed based on the overview of the data gleaned from the familiarisation process. Because semi-structured interviews were used, the data collected broadly correlated to the research questions. Therefore, early themes related closely to the research questions, for example: learning about mental health; issues that impact mental health; barriers and facilitators to accessing mental health care; and the role of ECPs.

An inductive approach was used to code data, ensuring that the construction of the framework was led by the participants' accounts, rather than an a priori coding structure. The purpose of coding in this way was to deepen understanding of the participants’ perspectives (Saldaña, 2013). Developing the thematic framework was an iterative and collaborative endeavour that involved the entire supervision team. The process of reviewing and extending the thematic framework is discussed under the heading Reviewing Data Extracts.

Indexing and Sorting. Data from all three groups were indexed and sorted into the thematic framework. This involved topic coding (Saldaña, 2013) and sorting data into the indices within the thematic framework (Ritchie et al., 2014). As the indexing and sorting process progressed, iterative changes were made to the thematic framework. These changes enabled the exploration of three different perspectives on receiving, observing, and delivering mental health care to be incorporated within the one thematic framework. Because qualitative data were analysed group by group, creating three major iterations of the thematic framework, the indexing and sorting process occurred in three stages as the thematic framework developed. A combination of cross-sectional and non-cross-sectional data labels was used to allow for the exploration of data within each group and across all three groups. This meant that some labels referred only to one group, while some labels were relevant across all three groups.

Reviewing Data Extracts. Iterative amendments were made to the thematic framework as analysis progressed. The thematic framework was adjusted to maintain coherence with the perspectives presented by participants (Gale et al., 2013; Ritchie et al., 2014). Because the lived-experience perspectives were prioritised in this project, the first iteration of the framework was developed based on the analysis of data from people with communication access needs (Appendix V). Next, data from ECP interviewees were analysed and the framework was adjusted to generate new indices within the framework (Appendix W). The next iteration of the thematic framework incorporated data from MHW interviewees (Appendix X).

At the commencement of analysis of each group's data set, the researcher and supervision team met to collaboratively review two transcripts. The transcripts were distributed to the research team prior to the meeting for familiarisation and holistic coding, identifying basic themes (Saldaña, 2013). Further structural coding occurred at the meeting to identify further indices and categories within the thematic framework (Ritchie et al., 2014). The coding meetings were chaired by the PhD researcher and allowed the research team to provide feedback and build agreement about the structure and content of the thematic framework. These meetings were an opportunity to define each index and clarify the structure of the thematic framework. Before commencing formal indexing in NVivo, the PhD researcher provided the overview of the thematic framework to the supervision team with a brief description of each code. Feedback was received from the research team and the framework was amended as agreed among the team. The researcher then used the thematic framework to sort index interview data. Minor indices were added throughout the sorting process to reflect nuances within the data. The supervision team were kept informed as the thematic framework developed.

Data Summary and Display. In this phase of analysis, the thematic framework is presented as matrices comprised of data extracts then summary statements are written for each theme in the framework (Ritchie et al., 2014). Due to the extensive accounts provided by participants and large amounts of qualitative data, one framework was created for each thematic area in the framework. Framework matrices were constructed manually in Excel due to the limited functions available through NVivo for Macintosh. This enabled the researcher to view direct quotes in a grid view with participants in each row and subthemes in each column. Although the manual construction of thematic matrices was a laborious process, it allowed the researcher to view all the data about a particular theme and subtheme simultaneously. This was particularly beneficial given the substantial amount of information provided across the three groups. Having this broad overview of the data prepared the researcher to further refine categories, compare data, and map the connections among the participant accounts. Once the matrices were built and the researcher had familiarised themself with the extracts in each matrix, data summaries were written for each theme and subtheme. Developing these descriptive summaries required the synthesis of coded data and links between the codes and categories (Ritchie et al., 2014).

Devising Categories and Identifying Linkages. Devising categories represents the beginning of the interpretive process (Ritchie et al., 2014). The data extracts and summaries were charted to identify underlying categories of data. This was the point at which data integration began, and themes were mapped across the qualitative and quantitative data sets. This process resulted in the identification of two key themes: 1) Experiences: Informing mental health knowledge and practice; and 2) Factors that influence access to mental health care: Barriers and facilitators. The key themes are presented as findings in Chapters 5 and 6. Combining mixed methods data using the Framework Analysis is a novel approach to data integration (Mason et al., 2020) and is discussed in greater detail in the following section.

Explaining data. A substantive approach was taken to data analysis, whereby themes within the data were interpreted in a manner that would be meaningful to the objective of improving access to mental health care (Ritchie et al., 2014). The discussion in Chapter 7 further explains and situates the data among previous empirical research. The Conceptual Model of Access to Health Care (Levesque et al., 2013) was used to represent the trajectory of access to mental health care for people with communication access needs and provides a frame for the final recommendations in the thesis.

Integrating Qualitative and Quantitative Data. The synergistic integration of qualitative and quantitative methods leads to a fuller understanding of the mental health help-seeking experiences of people with communication access needs (Hesse-Biber et al., 2015). Integration is the process by which the researcher draws together qualitative and quantitative data for a coherent comparison (Creswell, 2015). Integration, in mixed methods research, occurs across the entirety of the research design commencing at the philosophical assumptions and culminating in the analysis and interpretations of data (Mertens, 2007, 2013). Creswell & Plano-Clark (2018) identify the objectives of data integration: to explore common concepts across the data; to compare qualitative and quantitative findings; to define the corroborating and conflicting results to expand understanding; and to interpret and resolve discordance between the qualitative and quantitative findings. To realise full integration of the findings, different procedures need to be used to represent the integrated results, such as joint displays or combined databases (Love & Corr, 2022). In this research project, data were combined in the process of devising categories and mapping data within the thematic framework.

The survey and interview data collection methods were matched, meaning that both explored similar variables, and this facilitated the integration of multiple data components

(Love & Corr, 2022). This enabled the data to be integrated under two key themes which were derived via Framework Analysis. Further integration of the qualitative and quantitative data components occurs in the discussion chapter. The Conceptual Model of Access to Health Care (Levesque et al., 2013) provides a structure to further examine factors that influence use of mental health services for people with communication access needs.

When assessing the quality and rigour of mixed methods research, integration refers to meaningful combination of qualitative and quantitative data to respond to the research question and aims (Hesse-Biber et al., 2015; O’Cathain, 2010). Integration of methods occurred at multiple stages across the research project, beginning with the selection of the transformative paradigm to ensure that the overarching axiology and theoretical perspectives were aligned with the mixed methods research design (Mertens, 2007, 2013). As described previously, qualitative, and quantitative data were integrated in the analysis phase of the project and this combined data is used to inform the discussion chapter of the thesis.

4.4 Quality, Rigour, and Ethical Conduct in the Research Design

Mixed methods research design brings together two vastly different research traditions with the objective of answering wicked questions (Mertens et al., 2016; Rittel & Webber, 1973). Debate endures regarding the best way to evaluate the quality and rigour of mixed methods research (Adu et al., 2022; Brown et al., 2015; Bryman et al., 2008; O’Cathain, 2010). While a portion of researchers believe that the rigour of qualitative and validity of quantitative components should be reported separately, the majority believe that distinctive criteria are required to describe the quality of mixed methods research (Bryman et al., 2008). A consensus has not been reached regarding criteria for assessing rigour in mixed methods (Brown et al., 2015; Mertens et al., 2016). Prominent authors in the field have suggested that where there is a dominant methodology, then the rigour criteria related to that approach may be adopted to integrate quality elements of the research design (Bryman, 2006; O’Cathain, 2010). Due to the dominant qualitative research design, the criteria for rigour from the qualitative tradition – credibility, transferability, dependability, and confirmability (Guba & Lincoln, 1982) – were of critical relevance to this project. An overview of the research strategies used to maintain rigour in the study is outlined below in Table 4.12.

Table 4.12

Research Strategies to Maintain Rigour in Qualitatively Driven Mixed Methods Research

Rigour criteria	Research strategy	Rigour procedures
Credibility	Audio recordings Transcripts Multiple data sources: interviews, surveys, and research journal	Collaborative design of data collection tools Purposeful sampling Member checking Triangulation Supervision Research Advisors
Transferability	Semi-structured interviews Online interviews Theoretical Framework	Stakeholder consultations Purposive sampling/ detailed descriptions of participants Interviews/ rich descriptions
Dependability	Research Journal Audio recordings Multiple data sources	Supervision Member checking Triangulation Use of data analysis software Group analysis of interview data Engagement of statistical consultant
Confirmability	Research journaling Supervision Team Collaborative analysis	Triangulation Research journaling Selection of analytic approaches Disclosure of researcher positionality

Adapted from Liamputtong (2020)

4.4.1 Credibility

Credibility refers to the trustworthiness of the findings (Liamputtong, 2020). Research gains credibility with strategies and procedures that ensure participants' expressed realities are represented with authenticity. The strategies used to enhance the credibility of this study included: Making audio recordings of all interviews, transcribing interviews verbatim, and collecting data from multiple data sources (interviews and surveys) and groups (people with communication access needs, ECPs, and MHWs). Additionally, procedures were implemented to support rigour as related to research credibility. Firstly, in the design of the survey and interview tools, credibility was understood as the conceptual parallel to validity, as in post-positivist research (Mertens, 2015). The strategies used to support validity in the development of the survey described earlier in the chapter included review and feedback from subject experts, as well as testing the survey to support construct and content validity. Additionally, participants were recruited intentionally so that they would be able to share accounts of mental health care for people with communication access needs. This required the researcher to develop accessible recruitment materials and connect with individuals and organisations with community knowledge to assist in recruitment, as well as ensuring that the inclusion criteria were clear so that potential participants could decide whether to participate. In the data management phase, it involved providing the opportunity for participants to member check their transcripts to ensure that their accounts were accurately represented by the researcher. In the analysis phase, triangulating qualitative and quantitative data and making comparisons among the participant groups assisted the researcher in gaining a deeper understanding of participants' perspectives. Supervision from three experienced researchers in the supervision team, and engagement with lived-experience research advisors ensured the accountability of the PhD researcher's practices.

4.4.2 Transferability

Transferability refers to the degree to which findings can be applied to other populations or contexts (Liamputtong, 2020). As a qualitatively driven mixed methods study, the findings of this study may not be broadly transferable, although there are aspects of the study that could be of relevance to other populations or geographic locations (Hesse-Biber et al., 2015). Using mixed methods may increase transferability: semi-structured interviews elicit rich descriptions of participants' experiences, while surveys enable the researcher to cast the net wide, gathering insights from a larger sample. However, in this study participant numbers remained few, reducing chances of transferability. As one counter to this, stakeholder consultations were central to the scoping review design (E. Watson et al., 2022) which sought to contextualise research evidence amid the experiences and perspectives of people with communication access needs, ECPs and MHWs. Additionally, the theories and models applied in this study improve the potential for theoretical transferability (O'Cathain, 2010). The Human Rights Model reflects the global movement towards attaining rights for people with disability (Degener & Castro, 2022), and the Conceptual Model of Access to Health Care (Levesque et al., 2013) provides a frame for pinpointing access issues relevant to people with communication access needs in mental health care settings. Using these models as a theoretical frame to explore access to health care, may reveal elements that are applicable to researchers in other CRPD signatory nations.

4.4.3 Dependability

Dependability refers to the reliability of the researcher’s process and the consistency Dependability refers to the reliability of the researcher’s process and the consistency of the findings over time and between researchers (Guba & Lincoln, 1982). In this study, one of the key strategies was to document the data collection and analysis process. The researcher maintained a journal that detailed insights and processes throughout the research project. During the analysis phase this was critically important, and software was used to assist in documenting. The use of the syntax function in SPSS (IBM Corp., 2021) enabled the researcher to analyse survey data and keep an account of any insights that arose during analysis. Additionally, using NVivo (QSR International, 2020) to analyse qualitative data meant that the researcher kept records of the data coding and indexing process that can be referred to at any time. Other procedures to support the dependability of these findings included member checking and triangulation of data via multiple data sources.

4.4.4 Confirmability

Confirmability refers to the fidelity between the research design, the participants’ accounts and the study’s findings, rather than the outcomes being determined by the researcher’s agenda (Liamputtong, 2020). In qualitative research it is accepted that the researcher is not without biases, therefore it is the confirmability of the data that is in question (Guba & Lincoln, 1982). In the present study the Thematic Analysis approach (Ritchie et al., 2014) was used. This was to ensure that the researcher remained in close contact with the perspectives of participants throughout the analysis process. Throughout the findings chapters, themes relate to quotes from participants and are linked to survey data where available. Providing detailed quotes from the participants illustrates the confirmability of the findings.

4.4.5 Section Summary

This section has drawn together elements of the research design to illustrate the use of strategies and procedures to promote research quality. Adopting the qualitative criteria of research quality was coherent with the predominantly qualitative design of this mixed methods study. Embedding these strategies and procedures in the research design enhanced the rigour of the study and the reliability of the findings.

4.5 Chapter Summary

The overarching aim of this research was to identify adaptations to improve access to mental health support for people with communication access needs. To propose relevant access solutions, it was essential to engage with people with communication access needs, ECPs and MHWs, enabling a deeper understanding of the barriers and facilitators that present when seeking mental health care. Utilising a transformative paradigm (Mertens, 2007) and Human Rights Model (Degener, 2016) to frame the research design, the participatory-social justice mixed methods approach (Creswell, 2015) enabled data collection via specifically designed tools, semi-structured interviews, and online surveys. The data collection methods were responsive to the requirements of research participants. Embedding the principles of the transformative paradigm culminated in an inclusive research design that was oriented towards social justice (Mertens et al., 2014). Prioritising accessibility guided the selection of research methods and the need to maintain fidelity to the participants' perspectives informed the analytic process. Adopting a mixed-methods approach enabled the researcher to remain responsive to participants' requirements and keep lived-experience perspectives at the forefront of decision-making while navigating turbulent research conditions. Quantitative data were analysed using descriptive statistics and qualitative data were analysed by applying the Framework Analysis approach (Ritchie et al., 2014). Qualitative and quantitative data were integrated to give a well-rounded understanding of the mental health help-seeking experiences of people with communication access needs (Hesse-Biber et al., 2015). The following chapters will present the research findings and discuss these in the context of existing empirical knowledge, practice, and policy.

CHAPTER 5. EXPERIENCES: INFORMING MENTAL HEALTH KNOWLEDGE AND PRACTICE

Chapter 5 explores the key theme of experience as it informs the mental health knowledge and practice among three groups: people with communication access needs; everyday communication partners (ECPs); and mental health workers (MHWs). The findings presented in this chapter relate predominantly to research questions two and four. These research questions are:

> 2) What do people with communication access needs and ECPs know or want to know about mental health and the related supports and services?
> 4) What are the experiences, perceptions, and skills of MHWs relating to providing mental health support for people with communication access needs?

Through the Framework Analysis process, five subthemes were identified within the key theme *Experience: Informing mental health knowledge and practice*. These subthemes are:

1. Factors that impact the mental health and wellbeing of people with communication access needs
2. The relationship between communication and mental health
3. Experiences of mental health help-seeking
4. Experiences informing knowledge of mental health and support systems
5. Experiences informing practitioner capacity and quality of mental health support.

All categories of data are explored within each subtheme, providing a fine-grained exploration of the perspectives presented by both survey respondents and interview participants.

The chapter opens with a definition of mental health based on the perspectives of all the study participants: people with communication access needs, ECPs and MHWs. Data relating to subthemes one to four are then explored, combining survey and interview data to present findings. To honour the unique knowledge of the participants with communication access needs concerning issues that influence their mental health and access to support, it is their perspectives that are prioritised above those of ECPs and MHWs. Last, under the fifth subtheme are explored the experiences of MHWs providing services to people with communication access needs.

5.1 Defining Mental Health

In defining mental health, the interview participants discussed concepts related to their own mental health and emotional wellbeing, or experiences of supporting the mental health of others. Their views are represented here group by group.

5.1.1 People with Communication Access Needs

Having lived experience, this group defined mental health based on their experiences and observations. All participants identified emotions as a defining factor, as demonstrated by Laura:

> *Laura:* *Yeh…* I'm happy.
>
> *Researcher:* *Oh right, so good mental health is when you're feeling happy.*
>
> *Laura:* *Yeh. (Very enthusiastic loud spoken "Yes").*

In addition, Lisa associated challenging emotions with mental health:

> *Lisa:* *"(To me) mental health means how I feel every now and then, which is down and sad."*

Alternatively, some participants related mental health with a full range of emotions:

> *Chris:* Happy. Angry. Sad. *(Chris deliberately selected these words on his Grid Pad)*
>
> *Researcher:* *So, can mental health be about all those different emotions?*
>
> *Chris:* *Yep.*

The concept of mental health was extended further to incorporate the relational aspect of mental health, sharing experiences and feelings with others, as expressed in this exchange with Hope:

> *Researcher:* *What does mental health mean to you?*
>
> *Hope:* *T-a-l-k-i-n-g a-b-o-u-t o-u-r f-e-e-l-i-n-g-s. (Typed into the Notes app on iPad)*
>
> *Researcher:* *So, for you, mental health means talking about feelings. All your feelings, or just certain feelings. All feelings?*
>
> *Hope:* *'Yes' (looks upward)*

Expanding this relational aspect of mental health, Fleur associated mental health with autonomy, or having others respect her decision-making capacity, whereas Amelia defined mental health as having a positive concept of herself.

> *Amelia:* *Feeling good about myself.*

In summary, participants with communication access needs defined mental health as being related to a wide range of feelings and being able to share these emotions with others. Their definitions of mental health were based on personal experiences of managing emotional wellbeing.

5.1.2 ECPs' Perspectives

ECPs viewed mental health as a holistic concept that impacts upon a person's functioning. A common idea was that mental health is related to all people. This quote from Demi encapsulates the holistic understanding of mental health:

> *Demi:* *I think just in general terms, it's like the wellness of your mind. Yeah, and I think that in turn kind of reflects everything else. Yeah, throughout your life and throughout your body, like if your mind isn't well, your body .. you know .. doesn't kind of follow on. It's like the beginning of everything is your mind.*

ECPs also viewed mental health as being relational; connected to the quality of relationships with other people and the community:

> *Karina:* *I think it's not only emotional wellbeing. That's what I wrote down, but you know, talking about someone's emotional wellbeing, it's also their ability to function and ability to relate to other people. And, you know, just to function in the community.*

Other ECPs linked the concept of mental health to the support available to people. Aster referred to this as a 'holistic circle of health'. Paulette associated mental health with support systems, drawing attention to the differential impacts experienced by people with mental health problems and the systemic challenges to addressing the needs of people who experience persistent mental health problems:

> *Paulette:* *I want to say that there's mental health services for people who have mental health problems, some of whom who have mental illness and who are disabled by their illness.*

In summary, ECPs considered mental health to be a facet of health which was important to all people. For ECPs, compromised mental health was indicated by a person's functioning. Maintenance of optimum mental health was reliant on social connectedness and the availability of mental health care.

5.1.3 MHWs' Perspectives

MHWs contributed a theoretical perspective to the concept of mental health. This group identified holistic perspectives that connected body and mind, as well as social aspects in the biopsychosocial model of mental health, as demonstrated by Luis:

> *Luis:* *I come back to the biopsychosocial, and it's about your emotional wellbeing, your social wellbeing, and physical wellbeing together. And I guess, how you cope with stress, is a big factor. Your ability to cope with stress. And ability to function and meet your needs and have a high quality of life. So, I think that's kind of in a nutshell.*

The MHW interviewees drew upon established definitions such as that of the WHO, illuminating the broad nature of mental health not in opposition to, but incorporating mental ill-health and wellbeing.

> *Carmen:* *I'd like to see it more.. like the World Health Organisation is using it on more the broad definition of mental health, not the narrow one of not having a mental illness.*

MHWs noted the fluidity of mental health as being changeable across the lifespan. Mike's definition included interrelated ideas such as coping and resilience as well as systems of support that exist within and beyond the mental health system.

> *Mike:* *I guess it's about – we all have our challenges in life. Life's not a straight line, there's bumps all along the way. I think when people generally manage their mental health well, it's – they've got strategies and things in place, they've got a sense of some resilience, they've got a great support system, of family and friends.*

Some MHWs connected definitions of mental health to their role in the system of support. Hetty provided an example that encompassed the relationship between helping professionals and people experiencing mental health problems:

> *Hetty:* *So, it's just helping somebody who's in such mental distress to find their way back to the world that they wish to be in, regardless of whether the symptoms are gone, or not.*

MHWs asserted the broad relevance of mental health initiatives across populations and communities, and at various stages of the lifespan. Some MHW interviewees adopted the definition of mental health given by the World Health Organisation (WHO) and integrated a holistic perspective.

5.1.4 Section Summary

In unifying the perspectives on mental health across all three groups, connections to experience are apparent; personal experience, observed experience, and professional experience. The definitions provided by all participant groups were grounded in their experiences of negotiating emotional wellbeing and supporting mental health. Mental health was conceived as an issue impacting the emotional and physical wellbeing of all people. It was perceived as being in a fluid state for which support should be available when the impacts of mental health problems impact upon a person's capacity to function or live a good life on their terms.

5.2 Factors that Impact the Mental Health of People with Communication Access Needs

This subtheme focuses on the information provided by participants with communication access needs in response to specific survey and interview questions about the factors that negatively or positively impact their mental health and emotional wellbeing. To further contextualise their information, included are ECP and MHW perspectives on factors impacting mental health that emerged from the analysis of their interview data.

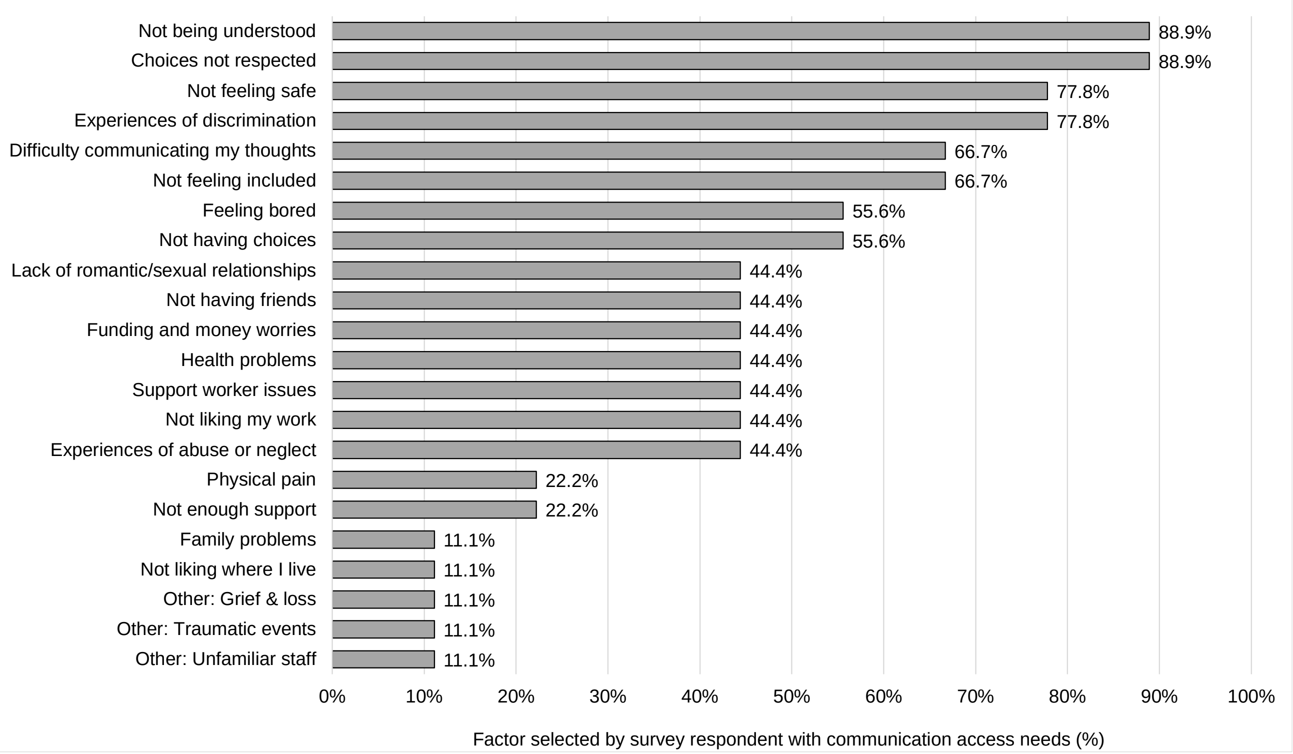
5.2.1 Negative Impacts

Participants with lived experience answered the question: "What issues most impact on your emotions or mental health?" Figure 5.1 below shows the factors identified by survey respondents with communication access needs.

Analysis of Table 5.1 indicates that the key factors influencing survey respondents' mental health and emotional wellbeing were: communication issues; lack of autonomy; safety and support concerns; exclusion and discrimination; and having limited social opportunities. Interviews with lived-experience participants provided further insight into these and additional factors. The two most frequently identified factors from the survey were lack of autonomy and communication issues. Lack of autonomy is discussed in the following paragraphs and impacts of communication on mental health are discussed in section 5.3: Relationship between Communication and Mental Health.

Figure 5.1

Factors that Negatively Impact Mental Health of People with Communication Access Needs



Lack of Autonomy. The only issue raised by all interview participants with communication access needs was *lack of autonomy*. A lack of autonomy was illustrated in accounts that represented choice being denied or not respected, as discussed by Laura, Hope, and in this example from Fleur:

> *CA:* *So, when you were living there, did you choose to leave or did the organisation change?*
>
> *Fleur:* *'Yes' (squints eyes)*
>
> *CA:* *The organization changed, because Fleur was getting 24-hr support and the other people weren't, so they decided that Fleur needed to go somewhere else, and they put someone else who didn't need the 24-hr support.*
>
> *Researcher:* *So, it wasn't your choice?*
>
> *Fleur:* *'No' (purses lips and shakes head)*

External restrictions also contributed to a lack of autonomy. For example, the COVID-19 suppression measures were noted by interviewees with communication access needs, Chris and Lisa. For Amelia a lack of autonomy related to having to compromise on her goal of living in her own home due to loneliness and deteriorating mental health. She felt she had to return to her family home to maintain her wellbeing.

Half of the ECP interviewees similarly identified lack of autonomy as an issue impacting the mental health of people with communication access needs. They related this to reduced decision-making powers, sometimes related to undermining personal choices in everyday matters, as related by Karina, an ECP:

> *Karina:* *But then there were people there who worked with him who, he doesn't like vegetables, but they put veggies on this plate every night and he won't even touch the plate if it's got veggies on it, you know. It'll just go up here (makes the motion of pushing the plate away), and they would say "He will learn to eat veggies" (commanding voice). I mean he's a 40-year-old man.*

ECPs also shared their observations of individuals with communication access needs lacking autonomy within the mental health system. Emmylou refers to the lasting impacts of involuntary detention and treatment for people who are on Guardianship Orders:

> *Emmylou:* *And it's sad that sometimes the impact from their mental health can affect their physical health. And that's where a Guardianship with Special Powers has to come into play. The impact of that is traumatic for not only them, but the people supporting them.*

It is of interest that the same two categories – lack of autonomy and communication frustrations – were the most frequently identified among MHW interviewees as impacting upon the mental health of people with communication access needs. MHWs noted that limited autonomy had implications for access to psychoeducational interventions. MHWs provided specific examples of the impact of losing autonomy in decision-making because of aging and progressive illness:

> *Mari:* *I think also when you're losing your ability to communicate, you can't advocate for yourself. You might have someone who's good at advocating for you, you might have somebody who advocates for things that you don't actually want. And you can't say that.*

Further, MHWs identified that people with communication access needs often experience reduced autonomy in support settings due to risk-averse policies and practices of disability organisations:

> *Miranda:* *I think all the disability organisations struggle because they have much more of those compliance tools in their systems that actually undermine, I think all the things that we want for clients regarding having a lot of opportunities in their life to improve their health and wellbeing, because it's all red taped and all – there is no risk-taking.*

And:

> *Jordy:* *(People with communication access needs) want something fresh because they, you know, often people have been supported in a certain way that doesn't necessarily meet their needs, or they've been judged. Or, you know they've been put in this situation where they've had to meet other people's expectations about their identity, or their goals, or whatever other people think. Many people are highly controlled.*

The practices of disability support providers can impact autonomy and lead people to seek mental health care. In some instances, the attitudes of support staff informed the type of assistance people believed was needed. Luis, an MHW, discussed an instance where interpretations of communicative behaviour failed to acknowledge reduced autonomy, which in turn, influences self-concept and limits thinking about the types of interventions that may be of use.

> *Luis:* *(I had) a referral for anger, but the person was just struggling to get their needs met (…) with a difficult provider. They just kept seeing him as angry. (…) somebody's told (the person with communication access needs) "It's anger management. You've got a problem with anger." But in fact, the goal is actually to learn how to assert (themselves) and get (their) needs met.*

The concept of *lack of autonomy* was also present in the survey data from participants with communication access needs. Several responses to the survey question "What issues most impact your emotions or mental health?" corresponded with the issue of *lack of autonomy*, including "not having choices respected" which was the most frequently selected multiple-choice option in the survey (*n=8*). Other survey responses that related to lost autonomy were "experiences of discrimination" (*n=7*) and "not having choices" (*n=5*). The ECP and MHW surveys did not include questions about the issues that impact the mental health of people with communication access needs. Comparative data from interviews with ECPs and MHWs has been included above to provide a triangulated view of the loss of autonomy and its impact on the mental health of people with communication access needs.

For participants considering the issues that negatively influence the mental health and emotional wellbeing of people with communication access needs, the power to make and act upon decisions regarding one's own life was significant, as was communication and connecting with others. The value of social connections is discussed under the next heading regarding positive influences on mental health and emotional wellbeing (section 5.2.2), while findings related to communication are detailed in the subsequent section (5.3): Relationship between Communication and Mental Health. While identifying the many risk factors for poor mental health, it is also important to recognise the capacity of people with communication access needs to respond to challenges to their wellbeing. Survey and interview participants also provided information about the strategies they used to manage mental health and emotional wellbeing when faced with risk factors. These findings are presented in the following section (5.2.2).

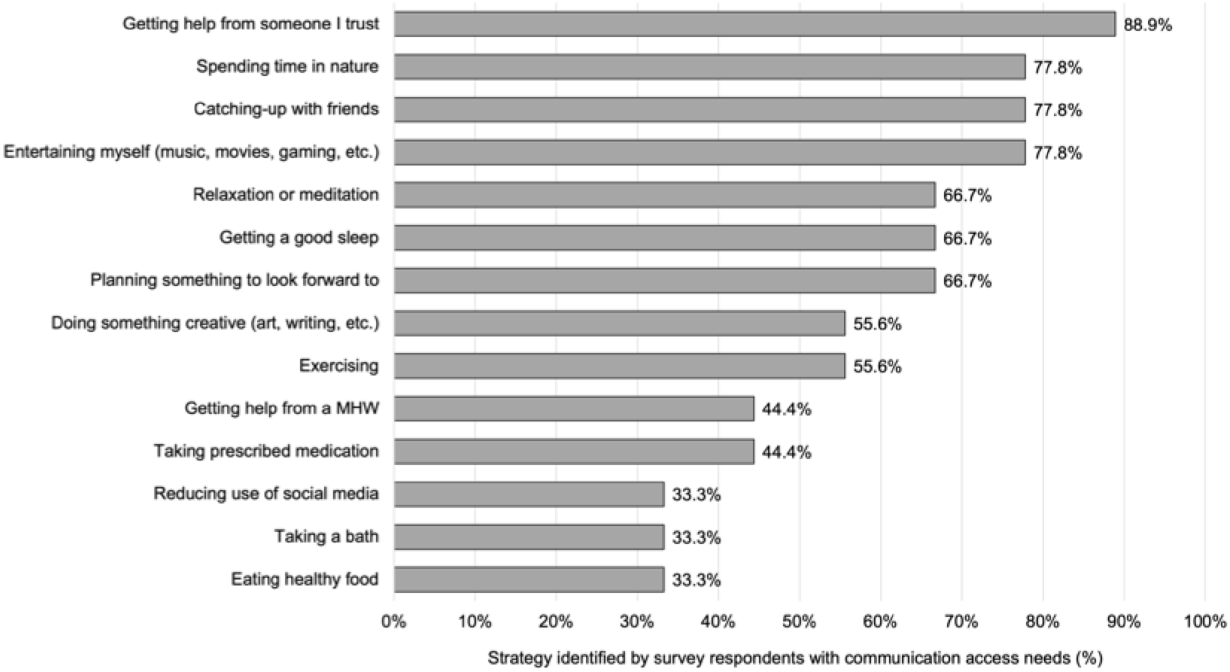
5.2.2 Positive Impacts

Interview participants discussed the things that provided benefits to mental health and wellbeing, either from a lived experience perspective or as observed by ECPs and MHWs. The content provided in this section focuses on the information provided by people with communication access needs. The major categories drawn from the interview data were social connection, and meaningful occupation. The survey data further highlighted the importance of social connection, as well as identifying the role of recreation and leisure, arts, and creativity, and maintaining physical wellbeing. The findings are discussed in greater depth in the following section.

Mental Health Self-help. Survey respondents with communication access needs identified a range of self-help strategies that they used to maintain their mental health and emotional wellbeing (see Figure 5.2). In responding to the question "What helps when you are struggling with a difficult emotion or mental health problem?", many participants drew upon social connections; selecting getting help from someone I trust (*n=8*) or catching up with friends or family (*n=7*). A range of physical strategies were selected such as getting quality sleep, eating healthy food, and exercising with swimming and hydrotherapy specified by two respondents. Relaxation and meditation were selected by over half of respondents with communication access needs (*n=6*). Engaging in activities was a prominent strategy with participants identifying that they spent time in nature (*n=7*), entertained themselves (*n=6*), or undertook creative pursuits (*n=5*). Planning future activities and events assisted respondents in remaining optimistic when experiencing difficult emotions (*n=6*). Fewer respondents identified that they got help from a mental health professional when struggling with emotional distress (*n=4*).

Figure 5.2

Mental Health Self-help Strategies Used by People with Communication Access Needs



Many of these strategies were echoed by the interview participants with communication access needs who discussed the importance of social connection, as well as the need to attend to physical wellbeing to support mental health, and the value of recreation and time in nature.

Social connection. All interview participants with communication access needs discussed the positive impact of social connections on mental health and wellbeing. Social connections were also identified as being a benefit to mental health by half of the ECP and MHW participants. Social connections were broad, most related to the importance of close family connections as well as friends, colleagues, neighbours, and support staff, but also connecting with acquaintances in the community.

An important quality of social connection was the reciprocity of emotional support in relationships. As demonstrated by Fleur, talking about her support worker:

> *C/A:* *I think what Fleur is wanting to say is that at the moment (D.'s) husband is very unwell, so she hasn't seen her [D] for a year, but we are catching up next week. But normally D. is in her life. It's just been that her husband is very sick (…). Are you saying that we telephone her to make sure that everyone is safe and happy?*
>
> *Researcher:* *Oh, so at the moment you're providing support to D.?*
>
> *Fleur:* *Yeh. (vocalises and nods)*

And Hope:

> *Researcher: So, if I were to summarise it. Your Mum is a big supporter?*
>
> *Hope: Yeh.*
>
> *Researcher: (…) you support your Mum at times too, so that goes two ways.*
>
> *Hope: 'Yes' (looks upward)*

The mutuality of these relationships serves as a reminder that people with communication access needs are providing emotional support to others in their lives.

Social connections with colleagues at work played an important part in supporting wellbeing, with both participants in regular paid employment (Amelia and Chris) identifying the social aspect of work as being important to them, as exemplified by Amelia:

> *Researcher: What is it about work that makes it so positive for you?*
>
> *Amelia: "Social connection"*

And Chris who identified enduring friendships developed at work:

> *CA1: And C (name)?*
>
> *Researcher: Oh, is that another friend?*
>
> *Chris: He is a good friend.*
>
> *CA1: You've worked with him for years, haven't you?*
>
> *Chris: Yeh.*

Social interactions with support workers also featured in interviews with people with communication access needs. Regular day-to-day interactions as well as ongoing friendships were discussed. Three interviewees had developed friendships with long-term support workers once they no longer worked with them. Hope discussed the progression of her friendships with ex-support workers:

> *Researcher: Do you think it's any different if the person is a worker?*
>
> *Hope: 'Yes' (looks upward)*
>
> *Researcher: It is different. When they stop being one of your workers, do you think that you can still have a friendship with them?*
>
> *Hope: Should be.*
>
> *Researcher: You think that you should be able to. Have you got people in your life where you started out working together and then became friends?*
>
> *Hope: Yeh, lots.*

Researcher: There are lots of people in your life that you met like that. So, there are people in your life who you used to work with you and then you stop working together and become just friends.

Hope: 'Yes' (looks upward)

Researcher: So, some people become friends and other people disappear.

Hope: Yeh.

Researcher: How does that make you feel when you keep the friendship going?

Hope: It's nice.

Researcher: Yeh, you've got a big smile on your face. Have you got some good friends that used to be workers?

Hope: 'Yes' (looks upward)

Researcher: Is it an important way that you meet people?

Hope: Yeh.

Researcher: What do you find out about people when you're working with them?

Hope: A lot.

Researcher: You find out a lot about them.

Hope: Yeh.

Researcher: Just from day-to-day chatting. Do you think that it's a good way to start a friendship?

Hope: Yeh.

Enduring social connections were valued by participants with communication access needs. All participants with living parents noted that they caught up with them regularly and that family were an important source of support for their wellbeing. Laura, who had no remaining biological family, enthusiastically discussed a lasting connection to her mother's best friend and her son who acted as her appointed Guardian. Laura's Guardian had been a family friend since her childhood, celebrating birthdays and special events together.

Some social connections also occurred in the community with businesses. Fleur raised the positive feeling she gets from interactions with staff at a hotel she frequents, being recognised as a valued customer:

CA: What about when you go to the hotel and the staff come and talk to you, and when you go and pay for the room, and you go out and people come up and say 'hello, welcome home!'

Fleur: Yeh. (vocalises "yeh", and smiles)

Social connections were also identified by half the participants from each of the ECP and MHW groups. The ECP interviewees who are parents of people with communication access needs discussed their role in providing social support and connection. Karina spoke about her relief at being able to remain connected to her son during the COVID-19 restrictions and the benefits to his mental health:

> *Karina:* *I'm so glad he was home during this lockdown because he would have been depressed if he hadn't seen us. Because he was so used to seeing us like at least once a week where he lived before. We always were there at least once a week.*

While Paulette discussed the role of social connection in mental health care need for mental health care providers to understand the value of social connection in promoting wellbeing:

> *Paulette:* *What they need three things; a home […]. A job: not necessarily employment, but something to keep them busy. And a friend. That's all they need. And they're the three things mental health (services) don't care about. You go to mental health services, and they talk about everything except what they really need.*

Many of the MHW participants discussed the role of close social connections in determining the success of mental health support, Mike provides the following example of the influence of a supportive social connection:

> *Mike:* *They've got a sense of some resilience, they've got a great support system, of family and friends. The people who've got big support systems are the people who don't stay with us very long. They only need us usually for a very short period of time and they get up and on with their lives.*

Whereas Aiden discussed the social aspects of psychosocial support groups as a benefit to developing supportive social connections:

> *Aiden:* *They're not coming into learn, they're coming here to socialise and they're coming here to be around people that like to do similar kind of stuff to what they do.*

Social connection was the most frequently discussed topic related to benefiting mental health and wellbeing. Social connection occurred in a range of settings, with family, friends, colleagues, paid supporters and in the community. Long-term, reciprocal relationships were valued by people with communication access needs and provided emotional benefits.

Occupation. Occupation is diverse for people with communication access needs; it includes paid employment and study, as well as community-based recreation programs (commonly referred to in Australia as day options). Of the interviewees with communication access needs, half were engaged in paid employment, and others participated in individual or group recreation programs and study. Most participants were involved in a combination of these activities. A key dimension identified from the occupation category was "keeping busy". Participants were involved in a range of activities during their week, and some stated directly that keeping busy was important for them in sustaining their mental health and wellbeing.

> *Researcher: Are you able to tell me about the things that impact positively upon your mental health and wellbeing?*
>
> *Amelia: "Work"*
>
> *Researcher: Yes.*
>
> *Amelia: "Being busy"*
>
> *Researcher: Is that about keeping your mind busy?*
>
> *Amelia: 'Yes' (gestures thumbs up)*

Participants who were engaged in paid employment noted social connections, personal meaning, and identity as being the most important factors in their work. None of the participants identified finances as the primary reason for the importance of their work. Participants noted the benefit of work that was personally meaningful to them. For Amelia, it was about working in fields that enabled her to make a societal contribution in her areas of expertise:

> *Researcher: You mentioned that you're employed in (a professional setting), is that important? If, you were employed in another type of job do you think work would have the same fulfilment?*
>
> *Amelia: "No, that is why my previous boss suggested the (present employer)"*
>
> *Researcher: Yes, so there is a lot of meaning that's derived through that particular job, rather than just work in general. Is that about the particular work that you do?*
>
> *Amelia: 'Yes' (Nods head)*

Similarly, Lisa's work as a self-employed visual artist kept her busy and was a source of wellbeing:

> *Lisa: Some things that have a positive impact on my mental health are the people who support me, my family, our puppy, keeping busy with my photography and seeing my photography on display.*

For Chris, work was connected to his identity as a “worker”. One of Chris’ interviews was scheduled after he had finished work. He was still wearing his uniform of high-vis shirt and trousers, which he references below when asked “What benefits your mental health?”

> *Chris:* *(inaudible)…. Working.*
>
> *Researcher:* *Ah, work, do you enjoy going to work?*
>
> *Chris:* *Yeh.*
>
> *CA1:* *Do you get enjoyment and fulfilment from your work?*
>
> *Chris:* *Yeh… (inaudible)*
>
> *Researcher:* *Who is at work that is important to you?*
>
> *Chris:* *(inaudible)…. You saw me.*
>
> *Researcher:* *I saw you?*
>
> *Chris:* *Yeh.*
>
> *Researcher:* *Ah yes, do you mean last time when I came, and you’d just knocked off work and you were wearing your uniform when I got here?*
>
> *Chris* *Yeh.*
>
> *Researcher:* *So work is an important thing for you, it helps you feel positive.*

Chris found pride in his identity as a worker in the recycling industry. His previously stated appreciation for nature may have amplified his pride, knowing that his efforts contributed to environmental conservation. Just as occupation was important to interviewees with communication access needs, so was recreation. Recreational activities identified by participants with communication access needs included gardening and time in nature, video games, art, music and dance, sport and exercise, and holidays. Recreation activities provided something to look forward to, a break from routine, relaxation, and opportunities for social connection.

5.2.3 Section Summary

This section has presented factors that influence mental health and wellbeing. Participants with communication access needs identified these influential factors in the context of their experiences. The negative influence of lacking autonomy was prevalent across survey and interview data. Similarly, the positive effects of social connection were highlighted throughout both data sets. Further to the factors presented above, communication was a factor that featured both positively and negatively in influencing the mental health of people with communication access needs. The role of communication in mental health is discussed in the following section.

5.3 The Relationship between Communication and Mental Health

Communication had both beneficial and adverse impacts on the emotions and mental health of people with communication access needs. Some participants viewed communication as generally positive, while some found that communication partner behaviours impacted negatively on their wellbeing. Survey respondents with lived experience identified multiple communication issues as impacting negatively on their mental health, the most frequently selected being “not being understood” (*n=8*), as well as “not being able to communicate my thoughts” (*n=6*). Interview participants identified “communication frustrations” and “communication partner behaviours” as harming mental health.

Exploring the data contained within this subtheme provided a deeper understanding of the interaction between communication and mental health. Most participants with communication access needs expressed that communicating about feelings and emotions was important to them. Fleur summarised the positive effects of communication below:

> *Researcher: How does communication factor in your mental health?*
>
> *Fleur: ‘It’s important’ (squints eyes with emphatic smile)*
>
> *Researcher: Okay, you’re giving me a smile… are you telling me that it has a big impact?*
>
> *Fleur: ‘Yes’ (squints eyes)*
>
> *Researcher: Okay with your facial expression you are telling me that communication is a big factor in your mental health. Can you tell me more – In which ways does it impact?*
>
> *Fleur: (Long pause indicating that smaller clarifying questions are required)*
>
> *Researcher: Can communication make you feel good?*
>
> *Fleur: ‘Yes’ (squints eyes)*
>
> *Researcher: Can communication make you feel bad?*
>
> *Fleur: ‘No’ (shakes head)*
>
> *Researcher: Communication usually makes you feel good, does it?*
>
> *Fleur: ‘Yes’ (squints eyes)*
>
> *Researcher: Okay, so does communication help your mental health?*
>
> *Fleur: ‘Yes’ (squints eyes)*

Participants had a range of ways to communicate about emotions and mental health. This included the use of aided and unaided AAC. The sufficiency of the person’s communication system played a role in the extent to which people could clarify their feelings or issues impacting upon their mental health. For Lisa, a comprehensive system that enabled her to independently generate messages meant that they could detail their feelings and concerns:

> *Lisa: "I use my communication device to say how I feel"*
>
> *Researcher: So (your communication system) is very important. Do you feel like you are able to say everything that you want to say using your communication device?*
>
> *Lisa: 'Yes' (nods head)*

Laura indicated that she was able to raise topics related to feelings using her AAC device, however, she lacked the vocabulary to provide specific details, relying on communication partners to help clarify the details.

> *Researcher: What sorts of things about communication help your mental health?*
>
> *Laura: "I feel frightened"*
>
> *Researcher: Is that sometimes you feel frightened?*
>
> *Laura: 'Yes' (nods head)*
>
> *Researcher: Yeh. And are you able to tell the people around you when you feel frightened?*
>
> *Laura: 'Yes' (nods head)*
>
> *Researcher: Do you have a way to tell people what you're feeling frightened about?*
>
> *Laura: 'No' (shakes head)*
>
> *Researcher: Do you think it would be helpful to have something on your iPad that helps you tell people what you're feeling frightened about?*
>
> *Laura: Yeh.*

Luis, an MHW, connected the confines of limited vocabulary and the capacity of the person with communication access needs to describe their emotions and experiences:

> *Luis: When you've got concrete messaging – We'll have to talk about (feelings and experiences) using concrete messaging. But if you can't communicate those more abstract concepts, particularly around emotions and mental health, and you're not given the time and space to do that, that can have an impact on your mental health.*

For Fleur, human assistance played an essential role in communicating about issues that impact mental health and wellbeing. Fleur had experienced situations where her decisions had been devalued and this had significantly impacted her emotional wellbeing.

These past experiences had led Fleur to think about addressing such issues as a group effort working with trusted supporters to address her concerns.

Researcher: Did you learn about advocating for your choices?

Fleur: 'Yes' (squints eyes).

Researcher: Do you think that it made you more confident or assertive in showing your choices?

Fleur: 'Not quite' (facial expression)

CA: Do you think it made you stronger?

Fleur: 'Not quite' (facial expression)

CA: More determined?

Fleur: 'Yes, that's it!' (Squints eyes and smiles)

Researcher: More determined, that's the word – more determined to get your message across. Sounds like it took a long time to get your message across, does it still take that long to get your message across?

Fleur: 'No' (shakes head)

Researcher: Do you feel like you're able to get your message across faster these days?

Fleur: 'Yes' (squints eyes)

Researcher: I wonder why that is – what's changed? Oh, you're looking to C.A.

CA: Do you think it's because we go and talk about these things with you… Like if you want to make a complaint about something you know that I'll support you to go and speak to someone.

Fleur: 'Yes' (squints eyes)

Hope also identified that she communicated her emotions through behavioural changes:

Researcher: Do you think other people can tell if you're going through a time when you're stressed out or worried?

Hope: Yeh.

Researcher: What would change about the way you're acting if you're going through a stressful time?

Hope: (Smiles)

Researcher: Oh, you're smiling at me, what would happen?

Hope: I would (inaudible)… I can't talk.

Researcher: Oh, you can't talk. Is that when you're very stressed you can't talk?

Hope: ‘Yes’ (looks upward)

Researcher: Oh really, do you become quiet?

Hope: ‘Yes’ (looks upward)

Researcher: Is that how people can tell that something is wrong because you become quiet?

Hope: ‘Yes’ (looks upward)

MHWs frequently discussed communication about emotional distress in terms of behavioural changes. Mari linked progressive loss of speech and alternative modes of expression, such as behaviour, as an indicator of distress:

> *Mari: (when someone is) having a limited ability to express emotion then often we see behaviours that people have as a result of not being able to express it and not being understood. And then these behaviours are misunderstood.*

Mari identified a paradox whereby people with reduced means of expression use behavioural communication, which in turn is misunderstood by the people they seek help from. Luis identified how these misunderstandings can have flow-on implications for a person seeking mental health care:

> *Luis: I guess particularly if the person appears to be angry, some people don’t interpret that well, they don’t understand, the person’s angry because they’re communicating, and you can’t understand what they’re trying to say. Some services will go, “They’re angry, I don’t want to see that person anymore. They’ve got anger issues.” I mean, you don’t understand they’re not trying to hit you, that’s quite a whole different level of violence, they’re just angry at the fact – they’re doing the best that they can to try and get a message across, but you can’t understand what they’re saying. Sometimes people can have services set up who then withdraw, because of their misinterpretation of why the person is angry and frustrated.*

Effective communication about issues that impact mental health, no matter the method of communication, requires receptive communication partners. Interviewees with communication access needs identified that some people were better than others in discussions about emotions and mental health. Time and opportunity for conversations were important factors, as discussed with Hope:

Researcher: Do people take the time to communicate (about your feelings)?

Hope: Some do … Some don’t.

Researcher: Some do, and some don't. How does it make you feel when people don't take the time?

Hope: Fucked.

Researcher: How about when people do take the time?

Hope: Happy.

Poor communication partner behaviours impacted the mental health and wellbeing of participants with communication access needs. Behaviour such as rushing communication, disregarding the person's preferences and choices, lack of respect, and exploitation of reduced communication opportunities, impacted emotions and wellbeing.

Finally, communication could affect participants' concept of self-worth, as noted by Amelia:

Amelia: "Self-degrading thoughts"

Researcher: So, is that self-image stuff?

Amelia: 'Yes' (Nods head)

Researcher: Is that about certain things?

Amelia: "Speech"

Amelia stated that her use of speech had become less reliable following brain surgery and, to address this issue related to communication and mental health, she had sought support from a Speech Pathologist. This indicates the diverse mental health support systems that might be needed by people with communication access needs.

Lived-experience participants described the fundamental role that communication plays in their mental health. They described the benefits and risks to mental health, the strategies that they used to convey messages about wellbeing, as well as the impacts of communication partner behaviours. Because communication is a two-way interaction it is important to explore the role of ECPs in communication about mental health and emotional wellbeing. Thus in the next section findings regarding the role of ECPs are introduced.

5.3.1 ECPs and Communication about Mental Health and Emotional Wellbeing

The participant ECPs provided an important perspective on how people with communication access needs express the need for emotional or mental health support, pointing out that their psychological distress could be indicated through multiple modes of communication. ECP survey respondents identified that the person/s they supported were most likely to demonstrate the need for mental health support through their behaviour (*n=7*), followed by using AAC (*n=5*) or voice (*n=4*). When asked "How do you think the people around you can tell that you need help?" Fleur looked to her communication assistant to ask how they could tell. The communication assistant responded that she could tell because Fleur cried more frequently and her facial expression changed:

> *CA:* *Fleur, you go like this, you make like a drawn face… And sometimes you hold your head, like… I think it's with both hands. But you just look sad, you just look different.*
>
> *Fleur:* *(makes a facial expression like she is sad)*
>
> *CA:* *Like that!*

Fleur's CA's reflections indicate the importance of having familiar communication partners who notice, acknowledge, and respond to expressions of distress and assist the person in acting to remedy issues impacting emotional wellbeing. The relational nature of mental health care seeking is further demonstrated in section 5.4 about experiences of help-seeking.

5.3.2 ECPs Providing Opportunities to Communicate Emotions

The opportunities provided by ECPs to discuss issues related to mental health and emotional wellbeing were a key facilitator for access to mental health support. Participants with communication access needs discussed a range of communication strategies employed by ECPs to communicate about wellbeing. Fleur had a trusted ECP with whom she preferred to share her feelings. Together Fleur and her CA explained the system that they used to raise and address concerns.

> *Researcher:* *Okay, so if you have a worry these days do you find that it's easier to tell someone about it and get it sorted out?*
>
> *Fleur* *'Yes' (squints eyes and looks to CA indicating she wants to add more information)*
>
> *Researcher:* *You're looking specifically at (your CA). Is it also about knowing that (CA name) is around?*
>
> *CA:* *If you want to do something different or change something that you're not happy with, we usually just go around and around. It's mainly when I read the diary from the last time that I've seen Fleur until the next time, and I'll read it to her, and she'll sort of tell me if she had a good day and if it had to do with that day. And then I'll sort of ask questions…*

Interviewees with communication access needs indicated that ECPs who provided opportunities to discuss mental health were responsive to the ways they communicated emotions. Chris stated that his parents acknowledged his emotions when he cried and responded by providing physical comfort and emotional support. Laura and Hope identified that some people provided opportunities to communicate about mental health by enquiring how they were feeling. They identified that there were some ECPs they trusted and preferred to discuss emotions and feelings with. Laura used her AAC app to specify which staff members she liked to share her feelings with. Hope preferred to share her emotions with family members and close friends.

ECPs indicated that they often responded to emotional support needs that were expressed via behaviour rather than AAC or speech, as discussed by Aster:

> *Aster:* *And then if they tell you that they're not okay, or if they show behaviour or you observe something that's a little bit concerning, then that's how I would recognise that they might need a referral to a professional. Or a further conversation about what they might need to help them feel better or well supported, yeah.*

One ECP described how they provide opportunities to the people they work with by noticing changes in people's behaviour and demeanour:

> *Demi:* *One of the houses that I work at they all kind of hang out in one area together. If certain people aren't hanging out there, and I know that they're having time to themselves, which is like not always an indicator, but that kind of sometimes is. Then I'll go in and I'll chat, ask some questions. Sometimes they'll tell me something wrong. Sometimes I went, sometimes just sitting with them is good, sometimes they want to be alone. It's just from situations that happened. But yeah, generally, you can kind of tell when you come on (shift), the way they're acting or not wanting to talk or be a part of the house or the group or whatever setting we're in.*

One ECP noted that sometimes their role was to enable the person to express their feelings in the moment, and they may not require further professional support.

> *Emmylou:* *Sometimes people may not need help with their mental health, but they just want to get it out, "I'm feeling like this today." And just to be heard – just to actively listen. They don't want a solution, they just want someone to know, someone to acknowledge them. And that's not just the people we support, but the people supporting them.*

ECPs discussed varied levels of confidence among disability support workers and that support workers with less confidence would be less likely to broach conversations about emotional wellbeing. Lack of confidence could be compensated for by having trusted team members with whom the person could address issues related to their mental health and wellbeing.

> *Aster:* *(The support workers) still felt confident to work with him and communicate with him on everyday matters. But it was when it related to him feeling*

> *distressed. But the good thing was that they then identified me as the person who he felt comfortable with. So, he would indicate to them if he needed to talk to me.*

Some MHWs identified that the person was receiving mental health services due to a lack of opportunity to communicate about their mental health and wellbeing with ECPs. Seeing a counsellor could provide opportunities for communication where there was a lack of skilled or trusted ECPs in the person's life.

ECP survey respondents provided advice for conversations about mental health and emotional wellbeing. The ECPs reiterated that people with communication access needs express themselves in diverse ways and there was a need for ECPs to be attuned to physical and vocal communication cues of emotional distress. Some of the specific advice provided by the ECPs included:

- Avoid asking multiple questions at once
- Avoid finishing the person's sentence, talking over, or making assumptions about what they are trying to communicate
- Avoid redirecting the person from their emotions, or saying "it's okay"; even in a comforting way that may be perceived as being dismissive
- Acknowledge the person's feelings
- Consider the person's mental health and emotional wellbeing as part of regular support routines
- Consider confidentiality and discuss mental health in privacy
- Do not rush communication; give the person time to get their message across
- Give the person your full attention.

5.3.3 Section Summary

Findings about the impact of communication on mental health and wellbeing have been detailed in this section. Communication had positive and negative influences, self-image related to communication difficulties and devaluing communication partner behaviours were detrimental to emotional wellbeing. Conversely, acceptance of diverse communication methods and opportunities to share feelings and ideas were protective elements. Additionally, the important role of ECPs in communication about mental health and emotional wellbeing was introduced. Findings regarding barriers and facilitators related to ECPs and communication partner behaviours are further explored in the following chapter.

5.4 Experiences of Mental Health Help-seeking

In this thesis mental health help-seeking refers to the attempts of people with communication access needs to secure assistance to alleviate emotional distress or the symptoms of a mental health problem. Lived experience interviewees sought help for issues that impacted their mental health, such as: neglect in support, grief and loss, traumatic events, sexuality, funding stress, and managing the impact of COVID-19 restrictions. The help-seeking experiences of the six interviewees with communication access needs are described in the following paragraphs.

5.4.1 Lived-Experience Perspectives of Mental Health Help-seeking

Fleur shared two stories about issues that had impacted her mental health. Both related to situations where her autonomy had been diminished by the actions of support workers. In the first story, Fleur described experiencing severe oral ulcers caused by her tongue thrusting over her bottom teeth. While she had the ulcers she was in a great deal of pain and had lost weight. She sought advice from a dentist who advised that she could have the front bottom teeth removed to reduce the rubbing of her teeth on the tongue.

CA: *Can you point to it?*

Fleur: *'My teeth' (points to mouth to indicate to the CA that she wants to recount a story)*

Researcher: *Okay, so Fleur you're pointing to your tongue and you're moving your tongue in and out… so it's something about your mouth?*

Fleur: *'Yes' (facial expression)*

Researcher: *Tongue?*

Fleur: *'No' (shakes head)*

CA: *Teeth?*

Fleur: *'Yes, my teeth' (nods head in agreement)*

Researcher: *Okay, and you're looking to (your CA) to ask her to help tell the story?*

Fleur: *'Yes' (squints eyes)*

CA: *Okay, so maybe about 10 years ago Fleur used to get a lot of ulcers, she has a very strong tongue thrust and she used to get lots of ulcers under her tongue, and one time it started to split part a bit. So, Fleur said to the staff that she wanted to have the two bottom teeth taken out. And, I can't remember, Fleur did the dentist suggest that?*

Fleur: *'Yes' (Fleur nods)*

CA: Yes, that's right the dentist suggested that; I couldn't remember (…) So, the staff didn't want her to have teeth out. They said she was talked into it and she shouldn't have them taken out to stop the tongue thrust.

Fleur: 'That's right.' (As the CA speaks, Fleur can be heard in the background softly vocalising in agreement. As she speaks, the CA is looking to Fleur to check that what she is saying is correct.)

Fleur was pleased to accept this advice and proceed with the removal of the teeth, thus alleviating her pain and allowing her to eat comfortably. However, members of her staff team disagreed and protested the operation demanding that Fleur get a second opinion. Fleur's mother assisted her in making a complaint and arranged a meeting with her support agency to discuss the decision to have treatment. Eventually, the support agency agreed to support Fleur's decision to have the teeth removed, however, she did not feel that her decision had been respected:

CA: So, because of the ulcers you were losing weight, it was really hard to eat. You lost a lot of weight, didn't you Fleur?

Researcher: That sounds like a really hard time…

Fleur: 'Yes' (Fleur vocalises – long and soft in agreement)

Researcher: So, it was a big choice. So, in the end, your choice was respected?

Fleur: 'No' (Fleur shakes her head emphatically)

Researcher: Oh! You feel that your choice wasn't respected?

Fleur: 'No' (shakes head).

The process of advocacy to undergo the surgery took approximately six months and caused Fleur significant emotional distress and pain.

When asked whether Fleur wanted to share another story, she was eager and persistent. She went to great lengths to get her CA and myself to understand the situation that she wanted to discuss. It took five minutes of scanning vocabulary, with Fleur directing us towards relevant objects in her home for us to establish which story she wanted to tell. She was determined to get her message across and tell her story. The account is summarised in the following paragraph as it incorporates several pages of the interview transcript.

Fleur was living in her own apartment when one of her support workers used to leave her in bed all day. The support worker would then get Fleur out of bed at the end of their shift and lie about the things that she had been doing all day. This behaviour went on for about a year and Fleur tried to tell people what was happening, but no one understood. Eventually, Fleur was able to tell her mother that the worker had been leaving her in bed all day. Fleur identified that she was angry and hungry as she did not get anything to eat or drink on those days. The issue was never truly resolved as Fleur was moved to another house, resulting in a further loss of autonomy.

Chris identified the death of his pet as a time when he wanted support for his emotional wellbeing. Chris' pet dog was very important to him, and he was very distressed by the passing of his childhood pet. Chris says that his parents noticed that he was upset and comforted him:

> *Researcher: Do you find Mum and Dad can tell when something is wrong?*
>
> *Chris: What do you mean?*
>
> *Researcher: Do you have to speak to them to tell them, or can they pick it up?*
>
> *Chris: They pick it up.*

Chris indicated that his parents can generally pick up his emotions, though there may be behavioural indicators that they respond to, as demonstrated below:

> *Researcher: Oh, they could tell your emotions… Did you cry?*
>
> *Chris: Yeh*
>
> *Researcher: Is that how Mum and Dad could tell you were upset?*
>
> *Chris: I was very, very sad.*
>
> *Researcher: It sounds like a very sad time. So, could you tell them (you were upset) by the way your emotions were showing, because you were crying?*
>
> *Chris: Yeh.*

Chris' CA noted that he and his parents communicate openly about emotions. While Chris felt that his parents could "read his emotions" they were likely acknowledging, interpreting, and responding to his behaviour by providing emotional support. Such accounts of mental health-help-seeking reinforced the need for responsive communication partners.

Laura has sought mental health support for a few reasons. Her first experience of receiving mental health services followed a traumatic event. She did not want to discuss the details of the event during the interview and interrupted her CA to ensure that the details were not divulged. Laura was offered counselling services by the police as aftercare following a crime. Laura accepted the counselling support, undertaking several sessions until she felt she no longer needed the counselling. The next time Laura sought support from an MHW it was to address issues related to expressing her sexuality. Laura struggled with her support workers' negative attitudes towards her sexuality and was finally able to gain affirming support from a psychologist to provide skills and knowledge to assert her right to explore her sexuality.

CA 1: *Laura, do you want me to explain about the (psychologist) you saw?*

Laura: *'Yes' (nods head)*

CA 1: *So, Laura saw a psychologist for sexual health. And that helped your mindset because you were able to openly explore your own needs. That really impacted on (your) mental health in that (you) felt accepted. Because, for a long time Laura's wants and needs were not being accepted and supported.*

Amelia experienced significant emotional distress and sought mental health support around the time of the implementation of the NDIS, the system that delivers individualised funding and supports to eligible Australians with disability:

Amelia: *"I felt pretty awful around the time that the NDIS was being introduced".*

Researcher: So, when NDIS was being introduced, what were you feeling?

Amelia: *"I would have to prove my disability all over again".*

During this time, Amelia had threatened to leave her home in a state of severe emotional distress, which she said was very out-of-character behaviour for her. Her parents assisted her in attending a hospital emergency department as they were concerned for her safety and wellbeing. Amelia stated that her mood had been deteriorating for about a month at the time she sought emergency mental health support. Amelia identified her father as an important support in her accessing mental health support. When she attended the emergency department at the hospital, he assisted by helping her to provide context for her distress. At the emergency department, Amelia was assessed and received a referral to community mental health and was able to see an MHW promptly.

Lisa stated that the only issue that had impacted negatively on her mental health help-seeking had been the COVID-19 restrictions; otherwise, she was able to gain support through her natural connections and did not require professional mental health support.

Lisa: *"Some things that can negatively impact my mental health are COVID lockdowns restricting what I do, such as going to art class, going for coffee, seeing my friends and family. Before COVID-19 there wasn't anything that would negatively impact my mental health."*

Hope discussed how the actions of disability support workers can impact her mental health, stating that she has at times wanted professional mental health support. Hope also discussed being "forgotten" by support staff when they failed to show up for a morning shift. She had been left in bed and was unable to get up or contact anyone to get help.

Researcher: So, (…) you were left in bed. How did you feel about that?

Hope: *Fucked… it's awful.*

> *Researcher: Did that happen a long time ago?*
>
> *Hope: 'No' (shakes head)*
>
> *Researcher: Did it happen recently?*
>
> *Hope: 'Yes' (looks upward)*
>
> *Researcher: Has it happened more than once?*
>
> *Hope: 'Yes' (looks upward)*
>
> *Researcher: It has happened more than once.*
>
> *Hope: Yeh. All day.*
>
> *Researcher: Did you say all day?*
>
> *Hope: Yeh.*
>
> *Researcher: Did you get left in your bed all day one day?*
>
> *Hope: Yeh.*
>
> *Researcher: What happened?*
>
> *Hope: 'I don't know' (shrugs).*
>
> *Researcher: How did you feel about that, like were you angry, sad…*
>
> *Hope: More.*
>
> *Researcher: More than angry and more than sad?*
>
> *Hope: 'Yes' (looks upwards)*
>
> *Researcher: If you could rate that feeling on a level of one to 10, where was it?*
>
> *Hope: Ten.*
>
> *Researcher: Ten. So, you were at your top level of those emotions.*

She complained to the manager on these occasions but believes that the issue was not investigated, and she was not given a response. She felt invalidated and vulnerable, and this led to ongoing worry and reduced trust in her in-home support team.

> *Researcher: So, on that day that it happened, you got left in bed you were stressed and worried. Did that feeling of worry hang around after that day?*
>
> *Hope: 'Yes' (looks upward)*
>
> *Researcher: Did you worry whether your staff would come and get you out of bed on the days after?*
>
> *Hope: A lot, yeh.*
>
> *Researcher: Okay.*

Hope: It was so bad.

Throughout our interviews, Hope informed me that dissatisfaction with her support is a significant source of distress and that she wanted to engage an MHW but has not been able to. She has recently sought assistance from her NDIS Support Coordinator to explore other support agencies and is optimistic about this process.

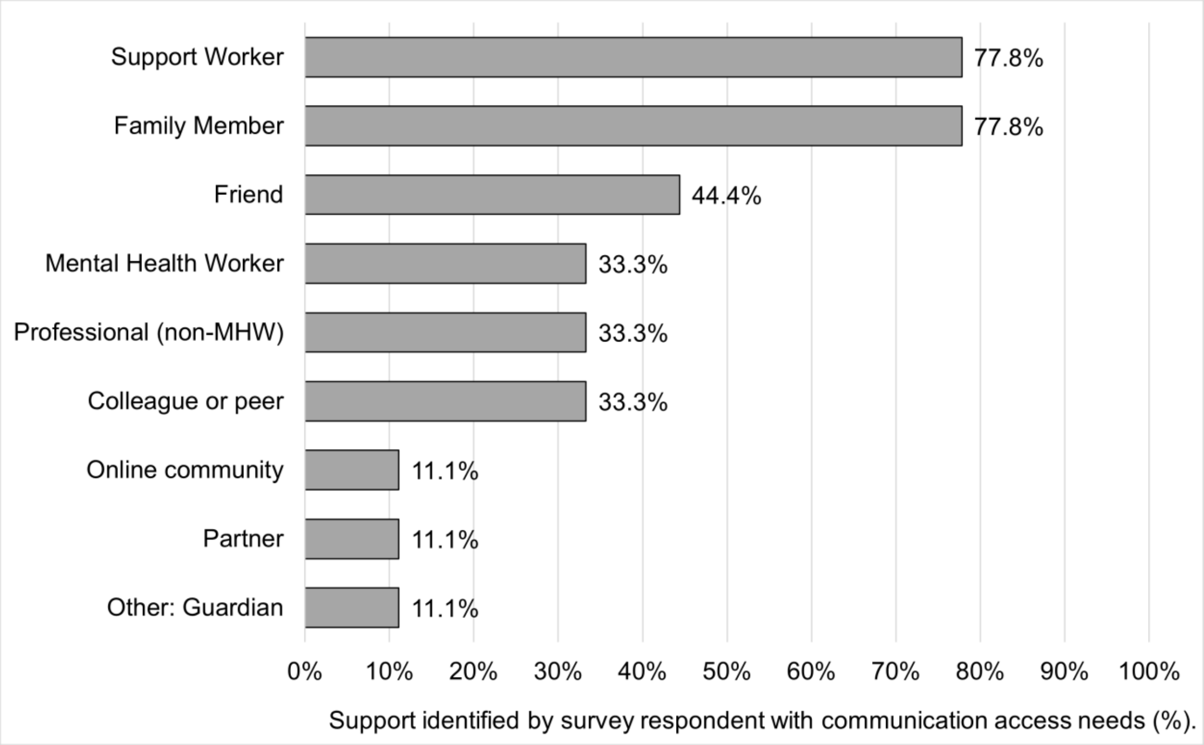
In exploring the mental health help-seeking experiences of people with communication access needs it is possible to envision the interplay of communication with ECPs and MHWs. Additionally, the different levels of mental health literacy and awareness of mental health services as well as the trajectories by which mental health care is realised. The key theme of experience informing mental health knowledge and related support service systems is outlined in the following section.

5.4.2 ECPs in the Mental Health Help-seeking Process

ECPs play an important role in the help-seeking experiences of people with communication access needs. They are often the first point of contact when emotional distress presents. ECP responses can determine the course of mental health support and access to specialist mental health care. Survey respondents with communication access needs indicated that they were most likely to share their feelings, concerns, and emotions with a family member (*n=7*) or support worker (*n=7*), followed by friends (*n=4*), colleagues or peers (*n=3*). A third of survey respondents indicated that they shared their emotions, concerns, or feelings with a professional (non-mental health) (*n=3*) or MHW (*n=3*). Figure 5.3 provides an overview of the sources of emotional support identified by lived experience survey respondents (*n=9*).

Figure 5.3

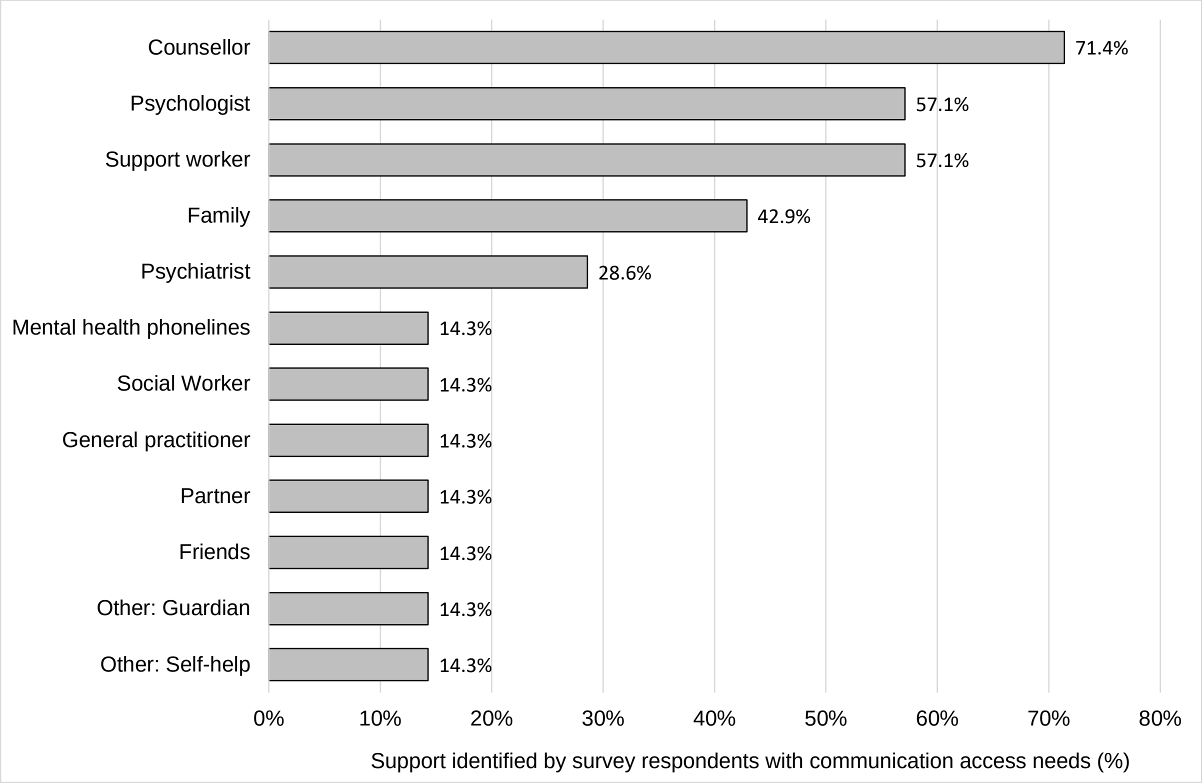
Sources of Emotional Support for People with Communication Access Needs



Of the survey respondents with communication access needs, 78% (*n=7*) had tried to get help for a mental health problem . The survey data presented in Figure 5.4 indicates that of the seven respondents with communication access who had sought formal mental health assistance the majority were able to access professional mental health care from a Counsellor (*n=5*) or Psychologist (*n=4*). Informal supporters, such as support workers and family members also featured as a source of mental health support. However, ECP survey respondents indicated greater use of informal and non-mental health professional support with 75% of people with communication access needs seeking help from GPs and support workers (*n=3 each*), followed by 50% consulting counsellors, psychologists, or family members (*n=2 each*). The two respondents who had not sought mental health help identified the reasons as “I did not ask for help”, “people did not understand”, and “I did not have access to the vocabulary I needed to express the problem”. When professional mental health care was required, some people with communication access needs were able to access professional MHW support.

Figure 5.4

Sources of Formal Mental Health Support for People with Communication Access Needs who Sought Mental Health Support (n=7)



The indication that informal supports (ECPs) played a significant role in mental health support was consistent with accounts from interviewees with communication access needs. This is demonstrated in the accounts of mental health help-seeking provided previously in this chapter. ECPs were often the first people approached when an issue arose that impacted mental health and emotional wellbeing. Consequently, the responses of ECPs could determine the types of support that were offered to the person with communication access needs.

Some ECPs tried to be guided by the person with communication access needs, supporting them to explore emotions in their own way.

> *Ariel:* *With the grief and loss, we've seen one customer doing prayers. So, she'll ask you to, well sometimes she'll do it by herself or sometimes she'll ask (staff) to come in and because she is of a different nationality, she will do things in line with the culture that she's seen at funerals. So, she'll get fresh fruit, or some sort of food and cups of water and she wants to light a candle and then she would say a prayer and she would ask you to kneel and say a prayer up. But like, you know, this is all like a little bit of foreign territory. We don't know what to do, how to support and not say the wrong thing or anything…*

Ariel grappled with her capacity to support people through experiences such as grief and loss and expressed a desire for more training and professional MHW support to assist her in this role. Ariel's account exemplifies the varied confidence among ECPs and the desire for MHW guidance in assisting people with communication access needs to address issues that impact mental health and emotional wellbeing. Similar sentiment was expressed by support workers, Demi, Aster, and Emmylou.

Throughout interviews, people with communication access needs identified important qualities of ECPs as mental health supporters. These characteristics were corroborated by ECPs who had assisted in accessing mental health care. The identified characteristics of a good ECP who supported mental health were:

- The "right" person: The "right" person had a personal compatibility and trusting relationship with the person with communication access needs. Lived experience interviewees identified that there were some people with whom it was easier to share their feelings. This ECP knew them well, or "got" them. Often, the right person had an enduring relationship with the person and was a friend, family member, or long-term support worker. For Chris, Laura, and Hope, a sense of humour was an important quality in the right person.
- The ECP's attitudes: The desirable attitude for mental health supporters was non-judgement of mental health issues. A non-judgmental attitude was demonstrated by an openness to conversations about feelings and mental health issues. Also, person-centred attitudes indicated by an authentic interest in the person with communication access needs and respect for dignity were considered valuable.
- Offering opportunities for mental health conversations: Some ECPs were able to create opportunities for communication about mental health and emotional wellbeing. These may have been offered proactively, or in response to a particular issue, event, or change in behaviour. These conversations gave chances to address issues or seek further support if needed.
- Providing safety and comfort: As Chris and Laura identified, some ECPs noticed their emotions and were aware of how to provide comfort to them when they were distressed. Comfort was often conveyed in non-verbal ways; a look, or touch, or sitting with the person. Providing comfort and safety was a key part of developing trust and opening a space for communication about mental health and emotional wellbeing.
- Promoting autonomy: Promoting decision-making in addressing issues that impact mental health and wellbeing. Additionally, including the person with communication access needs in making choices about mental health care. This included seeking

consent before sharing information about the person with MHWs or other support people.

- Mental health awareness: This quality is related to knowledge of helpful approaches to use when a person is experiencing emotional distress or symptoms of mental ill-health. Additionally, an awareness of mental health services and supports, or a willingness to help the person access mental health care was considered useful. For many ECPs mental health awareness was developed through training.

Mental health help-seeking happened at various stages and came from varied sources: mental health self-care, ECPs, health care professionals, MHWs, and mental health crisis services. What was evident through the accounts of participants with communication access needs, ECPs and MHWs was a requirement for ECPs to be responsive to communication that indicated changes in mental health and wellbeing, and to assist the person to act. Responses include providing comfort, problem-solving assistance, advocacy, or connecting to specialist mental health care. The role of ECPs is further explored in Chapter 6 which details the barriers and facilitators encountered by people with communication access needs seeking mental health care.

5.5 Experience Informing Knowledge of Mental Health and Support Systems

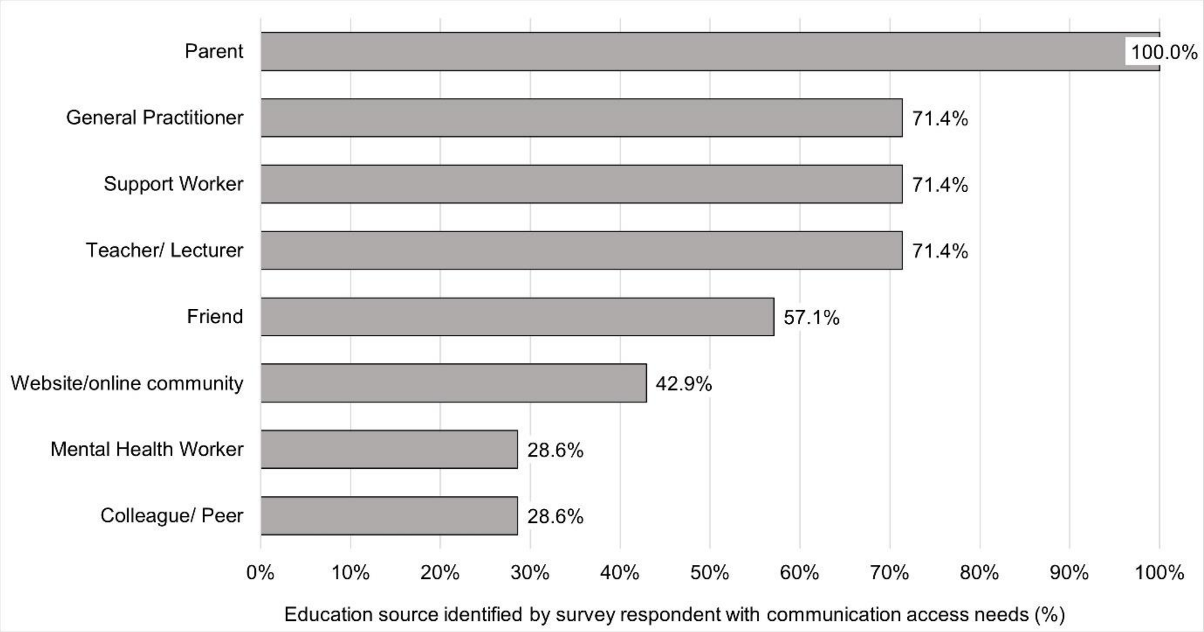
This section explores how participants with communication access needs and ECPs learned about mental health and related support systems. The survey data collected from people with communication access needs and ECPs provided a cross-sectional picture of their existing and desired mental health knowledge. Analysis of the interview data provided a deeper understanding of how mental health knowledge was gained and how mental health literacy impacted help-seeking behaviour.

5.5.1 Mental Health Knowledge of People with Communication Access Needs

Of the nine survey respondents with communication access needs, the majority answered that they had learned about mental health from a combination of formal and informal sources (*n=7*). Two respondents identified that they had not been taught about mental health. All respondents who had learned about mental health identified that they had been taught about it by a parent (*n=7*), with two respondents learning about mental health from an MHW (see Figure 5.5). Respondents with communication needs identified that they had learned about a range of mental health related topics including stress reduction and relaxation (*n=7*), identifying emotions (*n=7*), ways to improve mental health (*n=5*), support pathways (*n=6*), and different mental health problems (*n=4*). Data were not collected about how this content was taught and by whom.

Figure 5.5

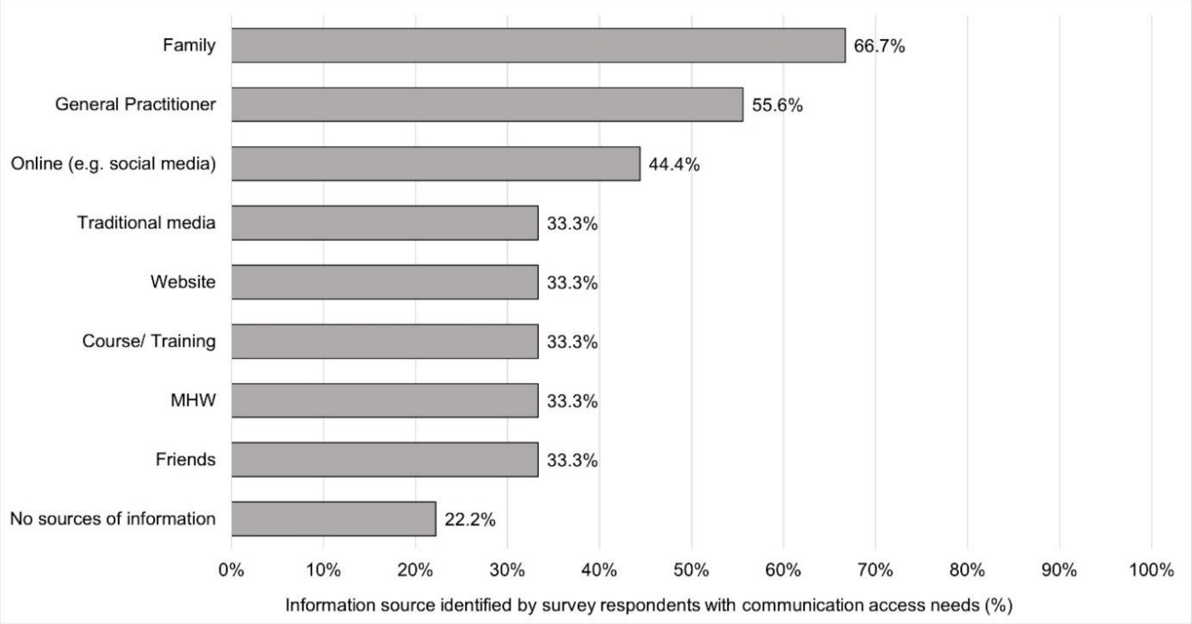
Sources of Mental Health Education for People with Communication Access Needs



The mental health landscape is shifting, and public information is required to remain up to date with current support services (Newman et al., 2022). Survey respondents with communication access needs identified their sources of information about mental health (refer to Figure 5.6), as predominantly ECPs, such as family members (*n*=*6*), followed by General Practitioners (*n*=*5*). Two lived experience survey respondents identified that they had no sources of current mental health information.

Figure 5.6

Sources of Current Mental Health Information for People with Communication Access Needs



Interview participants with communication access needs presented two distinct experiences of learning about mental health: school and experience. Participants who had attended mainstream schools had learned about mental health at school and stated that they had received assistance from a school counsellor:

Amelia: "I did have a great school counsellor"

Researcher: And were they open to conversations about mental health and wellbeing?

Amelia: 'Yes' (nods head)

The four participants who had attended special schools had not received education about mental health at school. All participants with communication access needs emphasised the role of experience in their learning about mental health and related supports including those who had learned about mental health at school:

Researcher: You mentioned that sometimes you feel down and sad, did you ever get help from a mental health professional for that?

Lisa: "Back in high school"

Those interviewees who had learned about mental health through experience noted that this included their own experiences as well as the experiences of others. Amelia identified learning from her own experiences:

Researcher: So how did you learn about mental health?

Amelia: "I have struggled with it on and off for years"

Researcher: So, your experiences brought you to your understanding of mental health?

Amelia: 'Yes' (nods)

Interviewees described learning about mental health by observing the experiences of family members, peers, neighbours, colleagues, and housemates, as noted by Chris:

Chris: (inaudible) Mental health… (housemate name). Living here.

Researcher: Oh (your housemate)?

Chris: Yeh.

CA1: And you've seen (your housemate) when he's been going through a hard time, when he's been upset. You've observed him, haven't you?

Chris: Yeh.

Participants with communication access needs identified a range of formal and informal sources of mental health education. Fleur described attending a community event at which people with disability had shared their experiences of navigating mental health problems. People discussed their experiences and how they coped with challenges. It was about ten years ago, but it had had a strong impact on Fleur. She did not feel that it was particularly helpful for her to share her story, but she felt that it was helpful to hear other people's stories.

> *CA:* *We spoke about how there were people in the community that had problems and they all talked about how they got through it, remember we talked about that afterwards with your Mum. We got introduced to some people, and some of the people were doing paintings and some would listen to music, and they got to the other side of their mental health problems…*
>
> *Fleur:* *Yes, yes. (Yes expression. Low, solemn vocalisation.)*
>
> *Researcher:* *Was that helpful to hear about what other people had done to help them get through their mental health difficulties?*
>
> *Fleur:* *Yes. (Emphatic vocalisation and facial expression)*
>
> *Researcher:* *It was useful to hear about what they had done…*
>
> *Fleur:* *Yes. (long, rising pitch and volume.)*

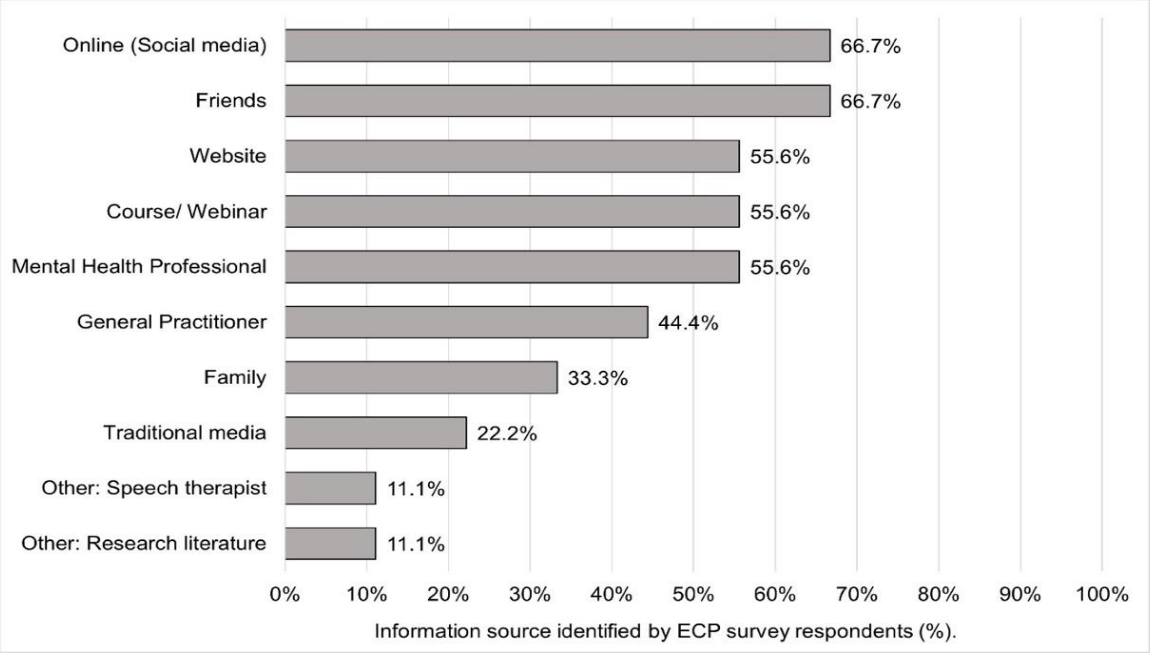
Other formal opportunities for learning included courses. One participant, Fleur had attended a formal course on the topic of “positive thinking” at her local adult education centre. Though this course was not specific to recovery from mental health problems, Fleur identified this as a source of mental health learning.

5.5.2 Mental Health Knowledge of ECPs

The mental health knowledge of ECPs requires exploration because people with communication access needs frequently receive information about mental health from them. Of the ECP survey respondents, 66.7% had participated in formal mental health education (*n=6*). ECPs mental health education included topics such as relaxation and stress reduction (*n=5*), information about different mental health problems (*n=4*), identifying emotion (*n=4*), strategies to improve mental health (*n=3*), support pathways (*n=3*), and supporting people with mental health problems (*n=1*). ECPs identified that they sought current mental health information from a range of sources as illustrated in Figure 5.7.

Figure 5.7

Sources of Current Mental Health Information for ECPs



All the ECP interviewees, including parents of people with communication access needs, had learned about mental health through their work. This included formal training such as preparatory vocational education, in-house training, as well as informal learning through experiences of supporting individuals to address mental health problems. Additionally, all ECPs identified that they had learned about mental health either via their own experience of mental health help-seeking or by observing the help-seeking experiences of family members or friends. Two ECP interviewees had participated in Mental Health First Aid courses, and one had completed a Certificate IV in Mental Health. Demi and Karina had learned about mental health via other vocational courses:

> *Demi:* *I mean in (Diploma of Youth Work) we did mental health, so we learned different types of therapies, and you know support lines and all those kinds of things.*

And Karina stated of her vocational course:

> *Karina:* *Well, I learned about it when I did my Cert IV. There was obviously a component of mental health in that.*

Additionally, some interviewees identified the benefit of targeted in-house workplace training to equip disability support workers to better assist the people they work with.

> *Emmylou:* *I was working in a house, so with children under the Guardianship (of the Minister). And it kind of went along with all the trauma training that we'd done.*

Ariel spoke about the diverse mental health learning opportunities available through her employment:

> *Ariel:* *I had very different managers over the years who all sort of taught their experience to me, and also through my Certificate IVs, each of them. There's been a few (short courses) that I've done.*

Two ECPs, Karina and Paulette, were parents of adults with communication access needs who had also held paid employment in the mental health and disability sectors. Paulette found that she had to educate herself following her son's diagnosis of schizophrenia. She connected with a peer support group which was an invaluable source of education and support:

> *Paulette:* *They handed me a brochure from the Schizophrenia Fellowship. That's what did it. That was my first bit of information, and that was the best thing she could have given me. Nothing about mental illness. Nothing about anything, just the Schizophrenia Fellowship. So, I made an appointment straight away with the wonderful (name of educator). She was just fantastic. She had a daughter with schizophrenia, and I spent an hour with her, and she was terrific.*

In time, Paulette began contributing to the knowledge of parents and MHWs as an educator and advocate.

Karina had participated in Mental Health First Aid and vocational courses as part of her role as a manager at a disability service, though she found that her life experiences had a greater contribution to her understanding of mental health.

> *Researcher:* *If you think about the courses and you think about the life experiences that you've had, which has been more impactful, courses or experiences?*
>
> *Karina:* *Oh, the life experiences! (…)*
>
> *Researcher:* *What did you get out of the life experiences that you didn't get from the courses?*
>
> *Karina:* *Oh, a real understanding of how it impacts a person's life. You know you're not going to get that understanding out of the book.*

Karina's work experiences had yielded valuable knowledge of mental health support systems and practitioners skilled in working with people with communication access needs. When her son needed MHW support, she was able to connect with a former colleague.

> *Karina:* *Oh, we got a psychologist straight in. We knew (the psychologist) and because I've known him before .. I worked at the (Autism Association) for a while (…). So, we actually, you know, pulled in a favour because I've worked in the sector for so long, I know a lot of people. So, I was determined that I wanted him in straight away and he came. I mean, within a week and you know. And he worked with us on the best ways of dealing with that. And he worked with the day options at the time because (my son) was having some trauma.*

ECPs, Emmylou and Demi identified that their own experiences of mental health help-seeking had influenced their knowledge of the support services available to people experiencing mental health problems.

> *Emmylou:* *I'm quite open about my own mental health journey. I suffered with anxiety for a really long time, before I decided to go to the GP, and I was medicated for it. I have been on and off medication for the last two years, and it's helped me immensely. And I think, again, it's breaking down that stigma, normalising mental health, and creating bridges for people to seek their own solutions, should they choose to, or giving them the option to come to me to ask for help to get those solutions.*

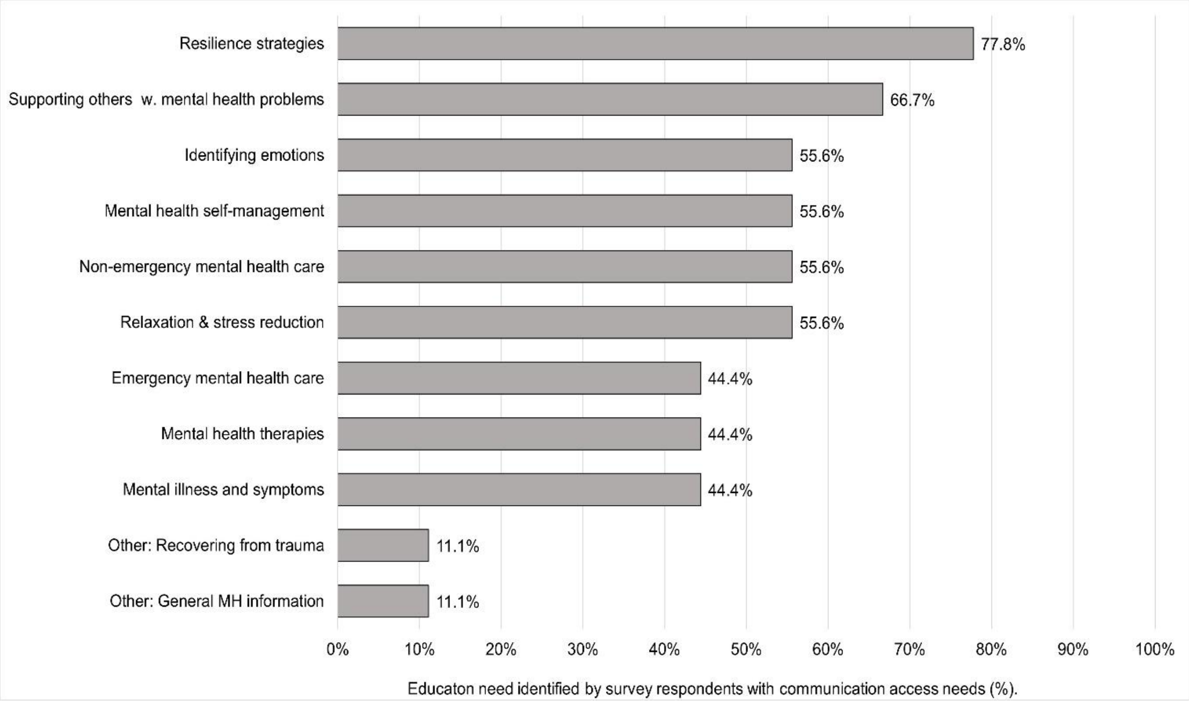
Demi similarly stated that she'd learned about MH through her own experiences of mental health help-seeking. She identified that her experience of seeing an MHW had helped her to notice potential MH problems in people and offer opportunities to communicate about mental health.

5.5.3 Desired Mental Health Knowledge of People with Communication Access Needs and ECPs

Survey respondents were able to identify the specific mental health topics that they desired more information about. Survey respondents with communication access needs most frequently cited a desire for information about resilience-building strategies (*n*=*7*). The next most frequently selected topic was "how to help other people with mental health problems" (n=6) indicating that participants with communication access needs were playing a role in providing mental health support to others. The information from lived experience interviewees was consistent with survey data; information to help them assist other people experiencing mental health issues was the most frequently discussed area of need for education. Figure 5.8 gives an overview of the topics that people with communication access needs wanted to know more about.

Figure 5.8

Desired Mental Health Knowledge of People with Communication Access Needs



Interviewees with communication access needs also wanted general information about mental health and support pathways. Lived experience interviewees expressed that there was a need for mental health information for ECPs to assist them in managing mental health issues and connecting with professional support services. Hope discussed the need for mental health education for support workers in the context of the limitations of her current support services:

Researcher: Do you think it would be beneficial for your support staff to learn about mental health?

Hope: Yeh. (emphatic response)

Researcher: Would it be useful for staff to learn about how to help people to get mental health help?

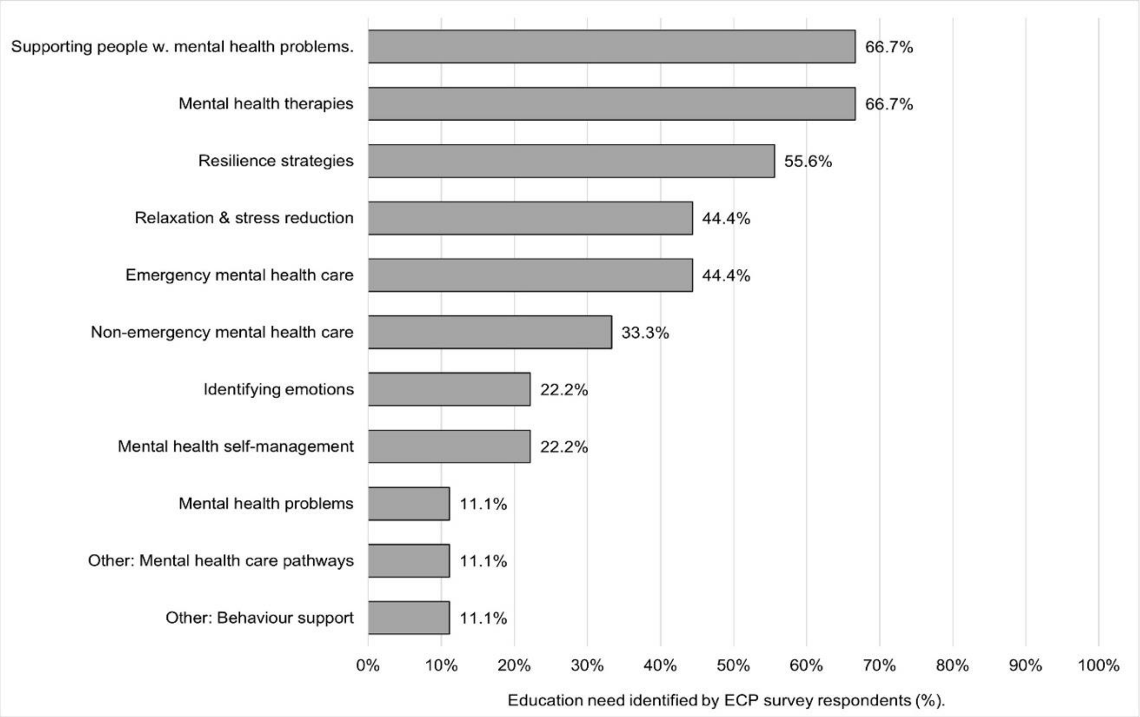
Hope: 'Yes' (gazes upward)

The need for mental health information for ECPs was echoed by ECP interviewees as the most discussed area of desired knowledge, as stated by Demi: “It's like, you know, as far as my job and what I could do – I think we could be doing so much more. I think we could use up-to-date information”.

Findings from ECP survey respondents corresponded with the interviewees and reflected a desire for more information to support the mental health of people with communication access needs. They most frequently identified that they wanted to know more about supporting the mental health of others (*n*=6), and different mental health therapies. (*n*=6) Respondents added that they wanted to know more about mental health support pathways and behaviour support. Figure 5.9 provides the details of ECP responses to the question "What would you like to know more about regarding mental health?"

Figure 5.9

The Desired Mental Health Knowledge of ECPs



ECP interview participants identified that they wanted more information on specific topics such as grief and loss to better support the people they work with. Ariel described the challenges related to gaining training on this topic to better support individuals with communication access needs:

> *Ariel:* *We've been trying really hard to get grief and loss training to support one of the customers, but there's a lot of barriers with who pays for that and trying to get it out of NDIS funding in that these days, so yeah, we haven't. We haven't been able to do it, but it's been in the works for like a year and a half or something now.*

ECPs in paid support roles also wanted clearer information about support pathways and mental health practitioners who were experienced in working with people with communication access needs:

> *Aster:* *I always want to know more generally. I would really like to know more (…) people who we can refer people to. Because really, I'm only familiar with (name of psychologist). There are some good psychologists and psychiatrists but that's where people have already got that diagnosis and they're referred through the system. Not necessarily referred through (support organisation name). And it's not people who use communication devices, or who don't have AAC at all, but are non-verbal. I'm not aware of professional supports were available for those people.*

One disability support worker noted that she wanted to know more about advocating for mental health support for the people that she worked with:

> *Demi:* *I guess; what I can do to help them get support. Do I need to wait for the team leader to do something about it or (…) how I can push that more or make it understood more that I think this is very important, but then is that my agenda?*

She felt that there was a general need among the disability workforce to improve awareness of the mental health support requirements of people with disability:

> *Demi:* *You know you have all the yearly medication administration training; you have CPR you have all of these physical type things to help people but nothing that focuses in on the mental health requirements. Unless it is the behaviour support stuff we had, people come and talk about that. But it's only about behaviour, not about mental health.*

Participants' lived experiences and engagement with mental health services informed their understanding of the supports available to enhance mental health and wellbeing. Formal learning experiences, observations of other people's experiences, and personal experiences of help-seeking contributed to an awareness of mental health support systems that was accumulated over time. For example, Fleur's early experiences of help-seeking led to her creating a group of advocates around her; she can now call on her friendship circle to assist her to address issues that impact upon her mental health and wellbeing as they arise. The following story was recounted by Fleur's communication assistant with her consent:

> *CA:* *So, what Fleur did is she called up a few friends, I think there was five of us friends. and we all sat around, and Fleur was indicating 'this is what I want to do', (…) and we spoke about our point of view and what we thought, and we were saying that if that's what Fleur thinks, that doing this would heal her tongue she should have the teeth out. So… you wanted it… But it was still a lot of people against it, so we all supported Fleur. Her friends, and (her mother) got together, and she ended up getting (the teeth) out.*

Other participants had identified supports that they had come to rely upon when experiencing emotional distress. For Chris and Lisa, it was their families, Laura identified her support worker, and Amelia noted her father and psychologist.

5.5.4 Section Summary

Participants with communication access needs and ECPs had existing knowledge of mental health, though the path to attaining their knowledge was varied and largely developed through experience rather than educational approaches. Those with communication access needs and ECPs had a desire to develop their knowledge of mental health and the mental health care system. The following section details findings relating to the knowledge and experiences of MHWs regarding their work with people with communication access needs.

5.6 Experience Informing MHW Capacity and Quality of Mental Health Care.

In examining the data relating to MHWs' experience, skills, and perceptions of providing mental health care to people with communication access needs it was apparent that experience was a major factor informing practice. The key dimensions underpinning MHW knowledge were: training for the role; experience informing practice; learning from experiences of communication diversity; and sharing knowledge to improve practice.

5.6.1 Training for the MHW Role

Although 83.3% of the 24 MHW survey respondents had experience of working with people with communication access needs, 58% had undertaken training regarding working with people with disability (*n=14*). When asked “Do you feel equipped to work with someone with communication access needs?” 45% responded that they felt somewhat under equipped (*n=11*), while 50% felt somewhat equipped (*n=12*), and 4.2% felt well equipped (*n=1*). MHWs were provided the opportunity to give additional information about what would enable them to feel better equipped for working with people with communication access needs. 23 respondents provided suggestions, including training (*n=19*), resources (*n=9*), and mentoring (*n=4*). MHWs wanted specific training regarding communication access strategies, AAC, Auslan and Key Word Sign. Desired resources included information about the population, access to interpreters, guidance from other professionals (e.g. speech pathologists) with specialised skills, and suitable diagnostic assessment tools to use with people with communication access needs.

MHW interviewees identified a lack of specific training for working with people with communication access needs. Siegfried, a psychiatrist, identified that he had received some basic pre-service training at university, but began educating himself further once he began working with people with intellectual disability.

> *Siegfried:* *My training was fairly limited and largely theoretical, I suppose. I guess, since I've started working with this group, I've done some of the (3DN) training, which has got a series of online modules. So, I've basically worked my way through those, and I've also made some contact with a specialist in Adelaide and had a few sessions of clinical supervision, I suppose would be the best way of putting it, around that. So, that's probably the limit of it, other than some personal reading (…).*

Siegfried's experience of sourcing supportive training and resources was echoed by other tertiary educated MHWs who had trained in Psychology, Social Work, and Nursing.

John, a peer-worker, described how, although he had not received training, he was able to use his personal experience to inform his approach to working with a person with communication access needs.

> *John:* *I wasn't really qualified to – or I didn't have a lot of experience working with someone like that. Based on my personal experience, I managed to use body language and eye contact and they could say things, but they were very short and then the words – you had to listen (…) I just tailored it as best I could to put my knowledge and skills to that person's (ability) – and we had some rapport, but it was difficult to work with the person, but that was based on some different things, because I could get one-word answers and I could understand the word. But that was a barrier that I had with them. And so, if we had more staff, people trained a bit more.*

John notes the requirement for more training to assist MHWs working with people with communication access needs to provide effective services.

5.6.2 Experience Informing Practitioner Capacity and Quality of Mental Health Support

The majority of the MHW survey respondents (*n=20*, 83.3%) had experience of working with persons with communication access needs. All the MHW interviewees had worked with individuals with communication access needs; most had extensive experience spanning over many years. The subtheme regarding experience and practice encompassed predominantly qualitative data and expanded upon the quantitative survey questions about MHWs' experience of working with people with communication access needs. In this subtheme MHWs describe the role that experience played in informing their knowledge and practice relating to communication access in mental health care provision.

> *Luis:* *(There wasn't) much in my undergraduate, not much in my master's degree. So, formal qualification, no. So, really on the job experience is the*

> *main way. It sounds strange, but that was the main way. And then over time, I did work – I've worked closely with speech pathologists, and they've taught me a lot. And I've worked with some quite leading speech pathologists in this area, who have kind of developed a space. So, that's probably – and who've crossed into mental health, so I've probably learnt a lot off them. So, it's been more informally and working with them. I haven't actually – I mean, there isn't any actually particular training I've done around complex communication and disability, no (…). So, learning on the ground, yeah.*

Two MHW interviewees, Miranda, and Jordy, began their careers working primarily with people with disability as Developmental Educators and undertook further training to become Counsellors.

> *Miranda:* *I worked for about ten years in disability in the Netherlands before we came here, and then I started working here in mental health through the peer work project, and then I – I think I chose counselling based on doing that sort of work after my Certificate IV, but then through work I came back to disability and I think that's when I started to combine probably the two.*

Jordy elaborated to discuss the influence that her previous work with people with communication access needs had on her present practice as a counsellor and her ability to adjust communication to meet people's requirements.

> *Jordy:* *I think that that's where being a (Developmental Educator) is good, and also having been a support worker. I've worked with people with lots of different needs so therefore I can support people to use their (communication) board, their device, whatever means they have. I can modify something so they can communicate, understand their speech patterns, takes a while.*

Mike, a social worker, summarised the development of his practice when working with people with communication access needs: "That's a bit of lifelong learning through work really. I've learned a lot on the job, I guess, in the last 20-odd years."

5.6.3 Learning from Experiences of Communication Diversity

Many MHW interviewees commented on their learnings from working with other communication diverse populations to inform their values and practices. MHW interviewees working for publicly funded mental health services made connection with their work with culturally and linguistically diverse (CALD) populations.

> *Hetty:* *Do we need something in their own language? (…) Or we need an interpreter? We use interpreters, mental health uses them quite often*

> *because we have to know what they're saying. We have to know, absolutely.*

While John noted that the value of his experiences in CALD service provision had informed his approach to communication access, he identified discrepancies in the training and support available regarding working with people with communication access needs.

> *John:* *There is interpreting services and sometimes access to cultural – Aboriginal liaison officers – with culture and can help with language barriers. And some of the other cultures, so there's usually someone who you can contact to help with interpreting if you're having a family meeting or something. But in terms of speech impediments, someone who can understand you fairly clearly, but you can't understand them very well, to me, that's where there's a problem lying there as far as I'm concerned…*

Another MHW, Aiden, further identified how symptoms of psychosis can impact a person's capacity to communicate and highlighted communication adjustments required for this population.

> *Aiden:* *I don't have a huge amount of experience working with people that need communication boards or anything like that. But I have worked a lot with people that need information reframed or simplified, or have a processing delay. I've worked quite a bit with people who hear voices and I've noticed that they can find it really hard to pay attention and they miss a lot of communication.*

Experiences with communication diverse populations, particularly CALD communities, provided MHWs with knowledge, skills, and attitudes to promote the inclusion of people with communication access needs in mental health care.

5.6.4 Sharing Knowledge to Improve Practice

MHW interviewees identified that other practitioners were an important source of information in supporting their practice with people with communication access needs. The previous quotes from Luis described the value of collaborations between psychology and speech pathology disciplines. Over years of collaborating, Luis had developed expertise in providing mental health care to people with communication access needs. Additionally, Siegfried discussed seeking advice and mentoring from another psychiatrist who was experienced in working with people with intellectual disability when commencing work with this population. These experiences illustrate the importance of MHWs incubating communication access skills by sharing knowledge with other professionals.

MHWs with extensive experience in working with people with communication access needs were able to share their knowledge with other less experienced practitioners through training and professional mentoring. Mari expressed a willingness to share her knowledge with other MHWs to ensure that the people she works with could access good quality mental health care:

> *Mari:* *I'm quite happy to speak to anyone who is a psychologist who's working with anybody who's got Huntington's. And that's where I start with people. I say, "Go find someone who you can actually relate to, who you can connect with. And then we can fill in the gaps about Huntington's." So, get the relationship bit right and then we'll deal with the extras stuff that they might need to know.*

Luis discussed his role in sharing his knowledge through teaching pre-service psychology students at university and other MHWs at conferences:

> *Luis:* *I lecture at (a university) on mental health, and I bring complex communication in as a large part of that, and that's to Clinical Psychology Master's students. So, that's their introduction to it there. So, […] various seminars I'm asked to do, presenting at conferences regularly.*

Jordy emphasised the value of ongoing practice supervision and mentoring, even for experienced MHWs: "one of my supervisors, she's a psychologist, but she uses heaps of this stuff in her practice. I'm really lucky to have her because she sort of suggests things."

5.6.5 Section Summary

This section has introduced the basis of MHWs' knowledge relating to their practice with people with communication access needs. MHWs' practices, knowledge, and attitudes are explored further in chapter 6 where the barriers and facilitators related to access to mental health care are detailed.

5.7 Chapter summary

Chapter 5 has presented the critical role of experience as a foundation for mental health knowledge and practice. The findings detailed in this chapter responded to research questions that sought to develop an understanding of the mental health knowledge of people with communication access needs and their ECPs. The findings revealed the role of experience in learning about mental health for these groups. Furthermore, experience has been a key informant in the practices of MHWs who identified the insufficiency of pre-service training to equip them to work with people with communication access needs.

People with communication access needs possess a deep understanding of what benefits or compromises their mental health and emotional wellbeing. In exploring the mental health help-seeking experiences of this group with information provided by ECPs and MHWs, it has been possible to glean insight into the barriers and facilitating factors that are present across the help-seeking trajectory. These barriers and facilitators to accessing mental health care are further described in-depth in Chapter 6.

CHAPTER 6. FACTORS THAT INFLUENCE ACCESS TO MENTAL HEALTH CARE: BARRIERS AND FACILITATORS

> *Everything about how and where they provide counselling should be accessible, inclusive, and welcoming. People using AAC often are made to feel like we are 'less than' and 'the other'. Such trauma can be sparked or negated by how such issues are handled. (*Anonymous survey respondent with communication access needs)

Above is a quote from a survey respondent with communication access needs. The quote highlights the critical need for accessibility, inclusivity, and welcoming environments in the provision of mental health services for members of that population. The survey respondent's comment highlights the traumatising experience of feeling marginalized or "othered" while receiving mental health care, which was common among participants in this study. It emphasises the importance of not perpetuating such experiences of exclusion when providing mental health support for people with communication access needs. In this chapter, the barriers and facilitators to mental health service access are explored. Interview participants and survey respondents across three groups – people with communication access needs, ECPs, and MHWs – provided important perspectives regarding what helps and what hinders access to mental health support. This chapter responds to research questions three and five:

> 3) What are the barriers and facilitators to mental health help-seeking for people with communication access needs?
>
> 5) How can mental health care be adapted to improve access to systemic resources that promote the mental health of people with communication access needs?

Survey respondents across all three groups provided concise advice to promote communication access in mental health support via short answers and multiple-choice questions, whereas interview participants discussed in-depth the barriers and facilitators that they had encountered or observed in mental health support for people with communication access needs. Given the richness of information provided by interviewees, the factors described in this chapter draw largely from those data. Framework Analysis of interview and descriptive analysis of survey data guided the categorisation and explanations of barriers and facilitators across five subthemes:

1. Communication Access Factors

2. System Factors
3. ECP Supporter Factors
4. MHW Practitioner Factors
5. Environmental Access Factors

A description of each subtheme, a summary of barriers, and a detailed overview of facilitating factors is provided at the commencement of each section throughout this chapter.

6.1 Communication Access Factors

Factors relating to communication access featured in interview and survey data across all groups and was the one subtheme where many more facilitators were proposed than barriers (see Table 6.1). Communication access facilitators were defined for this study as those factors that enable the person to get their message across, be understood, and understand the information provided to them. Some communication access factors intersected with the knowledge and skills of the MHW or ECP. In those instances, the communication partner's knowledge and skills are discussed under the corresponding headings of ECP Supporter Factors and MHW Practitioner Factors to group the findings most cohesively. Some communication access facilitators were also discussed in the previous scoping review chapter, as stakeholders also provided feedback on the efficacy of communication access strategies presented in the literature on psychoeducational interventions (E. Watson et al., 2022). In this section an overview of communication access barriers is provided, followed by a detailed account of the communication access facilitators.

Table 6.1

Overview of Communication Access Factors: Barriers and Facilitators

Communication Access Barriers	Communication Access Facilitators
Time constraints	Adequate time
Lack of reliable AAC and vocabulary	Access to reliable AAC and vocabulary
Lack of accessible mental health information	Relevant/customised mental health resources
Lost histories	Use of communication access strategies • Human assistance for communication • Incorporating AAC into intervention and resources • Use of plain language • Accessible written information • Use of visual aids • Recapping information

	Persistence in getting the message across

6.1.1 Communication Access Factors as Barriers to Mental Health Care

Communication access barriers related to time constraints, lack of access to AAC and relevant vocabulary, lack of accessible information, and lost histories, as summarised in Table 6.2. Time constraints were identified as both a communication barrier and a systems barrier. The systems factors, which related primarily to funding will be addressed in greater detail under Systems Access Factors (6.2). Regarding communication access, interviewees with communication access needs identified that they did not want to be rushed when expressing their emotions and discussing mental health. Amelia stated that she frequently ran out of time during her sessions with MHWs. Limited appointment time meant that she had little time to get her message across.

Time constraints. Time constraints were more frequently identified as a barrier to mental health support by ECPs and MHWs than by the interviewees with communication access needs. ECPs discussed the apprehension of MHWs to spend the additional time required to communicate. MHW interviewees indicated that time pressures led to people who used AAC having insufficient time to express themselves. Additionally, people with cognitive processing difficulties required more time to understand and respond to new information and make informed decisions. Time pressures led MHWs to a greater reliance on third-party reports about the person with communication access needs. The necessity for mental health services to allow additional time for intervention was emphasised by MHWs with extensive experience in working with people with communication access needs.

Limited access to AAC and relevant vocabulary. The modes of communication available to people with communication access needs and topics they could discuss were restricted by limited access to AAC and relevant vocabulary. This left some participants unable to broach issues that impacted their mental health and emotional wellbeing. Fleur, Chris, and Laura all had limited vocabulary for describing emotions and relied on communication partners to co-construct messages to gain a more complete understanding of experiences and feelings. People with AAC systems with limited vocabulary sets, or where words and symbols were selected by others, meant people were unable to raise certain issues. Fleur provided an example of a counselling session in which she wanted to discuss an issue that impacted her mental health but could not specify the circumstances due to a lack of relevant vocabulary. ECPs who supported multiple people compared the acquisition of mental health support between those with reliable AAC systems and those without. MHWs identified the challenge of seeking mental health support when one does not have access to AAC or relevant vocabulary to make such requests. In this instance MHWs specified that not having vocabulary can also affect the awareness that support is available and knowing what to ask for.

Lack of accessible mental health information. Lived experience interviewees who were unable to read were provided with inaccessible written information from MHWs. Emails or information sheets were not accessible to two of the lived-experience participants; however, both had been able to gain assistance from trusted ECPs to read information. Additionally, multiple interviewees with communication access needs indicated that mental health information campaigns designed for the general Australian population, such as R U Ok Day were not reaching them. A number of interviewees identified that they needed targeted approaches to information provision, such as having brochures sent directly to them via post or email or having an ECP tell them about it. Lack of accessible written information was identified as a barrier by an ECP who discussed her experiences of supporting her son who does not read, noting the inaccessibility of online information about mental health services.

Lost histories. A further negative factor was the loss of historical information and vocabulary that would enable the person to address matters from their past. Lost histories limited MHWs' and ECPs' ability to understand the person in the context of the entirety of their life experience and is further discussed as a barrier under the subtheme of ECP Supporter Factors (6.3.1).

Table 6.2

Summary of Communication Access Factors as Barriers to Mental Health Care

Coding	**References**			**Example quote**
Participant groups	L.E.*	ECP	MHW	
Time constraints	2	9	12	Researcher: *So, did you have any challenges communicating with (MHWs)?* Amelia: "I would often run out of time" Paulette (ECP): *A lot of time is required for people with chronic communication problems, and no one is prepared to take that on.* Mari (MHW): *So, there's limitations of time offered by carers or services to address the issues. So, everybody is on a different timeframe. They ask a question, expect an answer, then they've moved on to the next thing, when this person might still be back at point A, and not point D or F or whatever. So, that timeframe stuff is really important and challenging for people.*
Lack of reliable AAC and vocabulary	7	8	16	CA: *Fleur, was it that they didn't believe you? (pause) Or they didn't understand what you were saying? (CA uses their fists to represent each of the two options.)* Fleur: 'They didn't understand.' (Fleur uses her eyes to point to the fist) Researcher: *Oh, they didn't understand. So, you tried to tell them, but they didn't understand.* Fleur: *Yes (Fleur is vocalising short sharp bursts)* Researcher: *Did you eventually find someone who understood?* Fleur: 'No' (shakes head) Researcher: *No. Did you try to tell more than one person?* Fleur: 'Yes' (facial expression) Researcher: *So, were you trying to tell people using your communication board?* Fleur: 'Yes' (facial expression)

Coding	References			Example quote
				Researcher: *Did you have the right words on the communication board to tell them?* Fleur: ‘No’ (shakes head) Aster (ECP): *I reflected about when I was working alongside people. And the communication aids and there just wasn’t a focus on communication (…) when I started working. So, a lot of our older customers have missed out on those opportunities. (…) If older people experience emotional distress, it’s not really recognised in the same way that younger people who might have a (AAC) device.* Luis (MHW): P*eople might have indicated in the first session they’ve got a device and then by your third session in and they’ll come and there’s (…) nothing in the bag. And you go “Where is it– what’s happened?” Somebody hasn’t packed (the device).*
Lack of accessible information	3	1	0	Researcher: *Did the psychologist give you any written information, anything that was written down?* CA1: *She sent emails.* Researcher: *She sent emails… do you read?* Laura: ‘No’ (Shakes head) Researcher: *Okay, so how do you keep up to date with information about mental health?* Laura: (Long pause) Researcher: *Do you keep up to date?* Laura: ‘No’ (Shakes head) Researcher: *So while we’ve had all of this Covid-19 stuff going on there has been lots of money going towards mental health and helping people’s mental health while they’re in lockdown. Did you hear anything about that?* Laura: ‘No’ (Shakes head) Researcher: *No. Okay let’s think of another example, another thing that happens each year is a day called R U Ok Day, have you heard of that one?*

Coding	References			Example quote
				Laura: ‘No’ (Shakes head) Researcher: *Okay, let me think of another one. What about your doctor, does your doctor ever talk to you about mental health?* Laura: *Yeh*
Lost Histories	0	1	5	Luis (MHW): *You’re relying on other people to complete that communication book, grief, and loss - names disappear from people’s books. So, you’ll have Joe, and they die, and they disappear. And so, I see somebody a year later, they’re out of their (communication) book (…). So, that person can’t talk about the person who’s died, because they’re out of the book because they died.*

*L.E. = Lived experience. This acronym has been used to identify participants with lived experience of communication access needs.

6.1.2 Communication Access Factors as Facilitators in Mental Health Care

Survey data produced information about communication partner behaviours that promote dialogue about mental health and emotional wellbeing, while interview data provided further insight into communication access strategies and their implications when used by ECPs and MHWs. The facilitators identified were: providing adequate time, access to reliable AAC and vocabulary, using relevant and customised mental health resources, and incorporating communication access strategies into mental health care. Where communication access facilitators were specific to the ECP or MHW groups, these are explored in detail under the ECP Supporter and MHW Practitioner Factor headings (6.3 and 6.4). This section details the major communication access facilitators in mental health support.

Figure 6.1 provides and compares findings related to the most useful communication partner behaviours when addressing issues related to mental health and emotional wellbeing with people with communication access needs. Lived experience (*n=9*) and ECP (*n=9*) survey respondents identified useful communication partner behaviours when addressing matters of mental health and wellbeing. People with communication access needs and ECPs were largely in agreement about *time* being the most important facilitative factor in this type of communication. Lived-experience respondents indicated that ECPs allowing time to listen was the most important (*n=9*) followed by ECPs allowing time for expression (*n=8*). ECPs also prioritised time, with time for expression being the most important (*n=9*) and time for listening and understanding being a lower priority (*n=6*). Further, booking longer appointments was viewed as being a very useful strategy by over half the participants from each group (*n=6,* ECP *n=5*).

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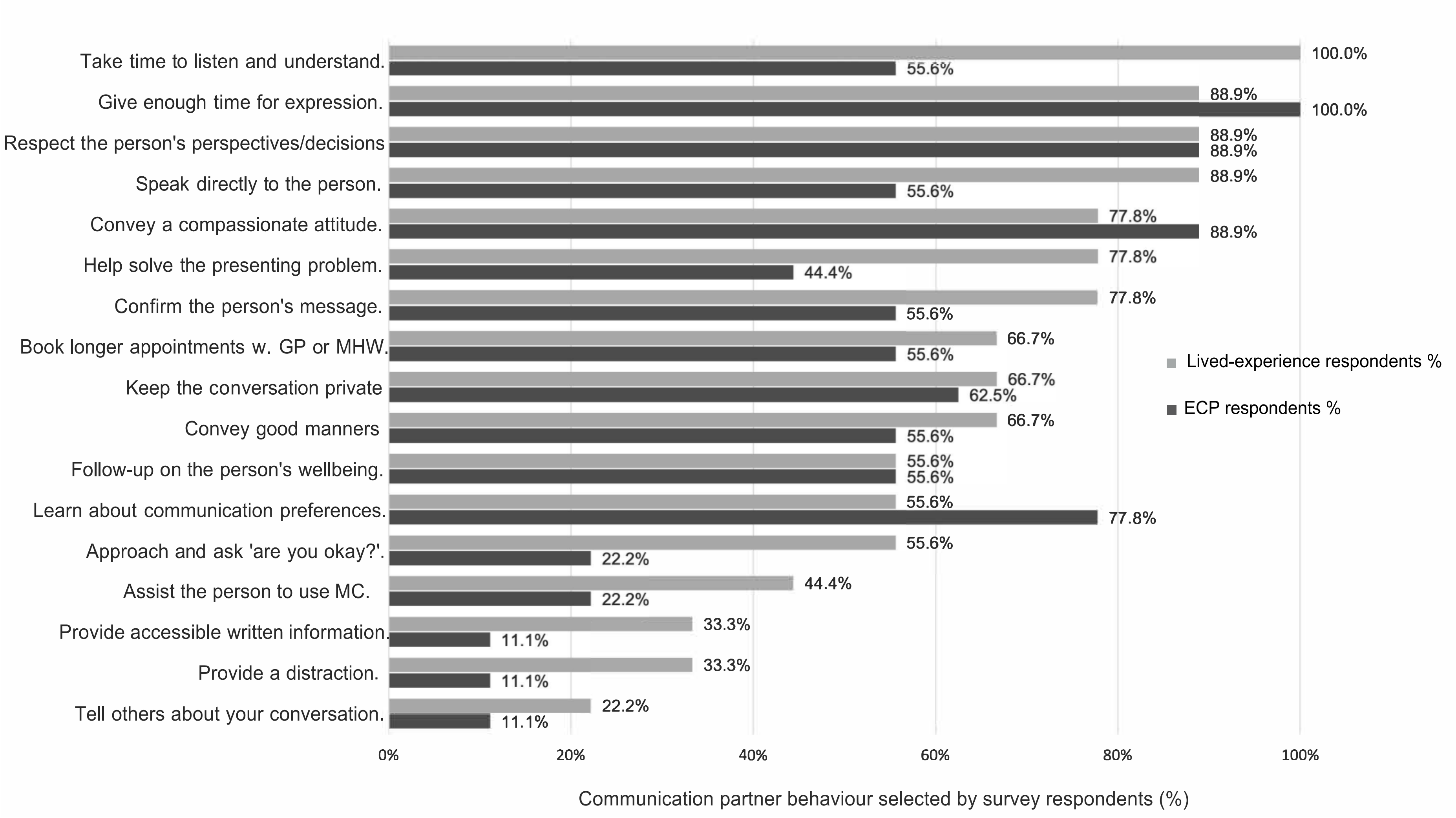
(*n*=*9*) followed by ECPs allowing time for expression (*n*=*8*). ECPs also prioritised time, with time for expression being the most important (*n*=*9*) and time for listening and understanding being a lower priority (*n*=*6*). Further, booking longer appointments was viewed as being a very useful strategy by over half the participants from each group (*n*=*6,* ECP *n*=*5*).

Respondents with communication access needs indicated that it was important that people speak directly to them (*n*=*8*) when addressing mental health. Other communication partner behaviours such as confirming what was said and using AAC were in the mid-range of helpfulness. Attitudes such as compassion and respect for autonomy and decision-making were identified as important by both groups (*n*=*8* each). As described in the previous chapter, autonomy was also considered influential in the mental health and wellbeing of people with communication access needs.

Figure 6.1

Most Helpful Communication Partner Behaviours: Comparison of Survey Data from People with Communication Access Needs and ECP Respondents



Discrepancies between participants with communication access needs and ECP respondents related to communication partners initiating discussions about mental health and assistance to resolve problems that impacted wellbeing. Half the lived-experience respondents (*n=5*) identified that it was very helpful for ECPs to initiate discussions about mental health and emotional wellbeing, while fewer ECPs identified this as a priority (*n=2*). Additionally, participants with communication access needs identified the importance of ECPs in assisting to resolve the presenting problem regarding issues affecting mental health and emotional wellbeing (*n=7*). Fewer ECP (*n=4*) respondents identified problem-solving as being important in communication about mental health. In what follows, survey findings will be linked with interview findings, to further explore communication access as a facilitator in mental health care.

Adequate Time for Communication. Time was indicated as being very important by lived experience and ECP survey respondents alike. Similarly, providing adequate time was discussed by more than half of all interviewees, with higher prevalence in the lived experience and MHW groups. For interviewees with communication access needs, having enough time to get one's message across without feeling pressured or rushed was important in the context of mental health support. A level of personalisation regarding time was identified as being helpful. For example, for some people shorter or standard sessions were more suitable:

> *Researcher: Did they make sure that they gave you enough time to communicate in your appointment?*
>
> *CA1: How long did your appointment go for, was it about 50 minutes?*
>
> *Laura: Yes. (Nods head).*
>
> *Researcher: That's pretty standard. Was that enough time for you?*
>
> *Laura: Yes. (Nods head)*
>
> *CA1: You were pretty done, and you had decided that you were ready to go at that stage.*

In contrast, others identified the benefit of longer appointment times:

> *Researcher: Is it helpful if the counsellor gives you extra time for communication?*
>
> *Hope: Yes! (Emphatic voice).*
>
> *Researcher: Oh wow. That's a yes – definitely. So, you definitely want to make sure that you have extra time.*
>
> *Hope: Yes (looks upward)*

Additionally, for some interviewees having adequate time required MHWs to be patient, slowing the pace of communication, as discussed with Chris:

> *Researcher: You've already said that you'd like (MHWs) to make sure that they're listening to you when you use your Grid Pad, what else do you like them to do?*
>
> *CA2: You like them to be patient, don't you?*
>
> *Chris: Yeh*
>
> *CA2: You don't like them to rush you along.*
>
> *Chris: No.*

Two survey respondents with communication access needs identified that mental health services could be made more accessible by providing longer appointment times and one respondent suggested that MHWs need to "'take time to listen to AAC".

Half of ECP interviewees discussed the value of providing adequate time; one stated that ECPs can be proactive in securing additional time by requesting longer appointments with MHWs.

> *Emmylou: As support workers, we tend to try to book double appointments anyway.*

Another ECP discussed the benefit of having support workers trained to deliver ad-hoc mental health support as part of her son's daily support routine.

> *Paulette: It's too hard, takes up too much time. They (MHWs) haven't got time. These workers now are having success because they spend 7 or 8 hours a day with him.*

MHWs working with NDIS or Medicare funding had more constraints on the time they spent providing intervention. Miranda discussed the benefit of having adequate funding to build foundational rapport for further intervention.

> *Miranda: I'm very lucky at the moment that I've got for a couple of clients with a huge amount of hours for behaviour support, and it's so nice (…). You have a chat; you can build rapport.*

MHW interviewees who worked for community mental health services noted that they were able to manage the length of time they spent with consumers.

> *Mike: We assume it's going to take a lot longer to get through (…) what we need to discuss. Here, we're in charge of our own diaries, so we can spend as much or as little time with people as we wish, and you can balance your day depending on who you're seeing and knowing roughly how much time you might need for each of them.*

MHWs with extensive experience in working with people with communication access needs discussed the need for adequate time for processing information and expressing messages. Mari and Luis emphasized the importance of silence providing time and space for communication to allow for unexpected breakthroughs in counselling:

> *Mari:* *So, whilst I'm allowed double the time with the person than I would with somebody else to convey the same information, that that they can process it, I also need to be conscious of "OK, I'm there for longer, but I don't need to fill every space with my words." Because they need that time, without that interruption and continued language, to actually process it and take on board what my question is. And then think about the answer. Then, try and get the words out. So, it's a real process (…) the cognitive impact of communication that's really important to be aware of.*

Further, MHWs noted the need to work with the person to determine what was adequate time for intervention, incorporating factors such as attention and processing to adjust session length outside of the standard 60-minute appointment.

> *Jordy:* *Sometimes people's processing is such that you have to have quite long sessions, and then for other people you have to have really short sessions because they can't keep on track.*

Luis discussed the options available to MHWs working within the confines of Medicare funding to personalise intervention times:

> *Luis:* *Yeah, (time is) a crucial part of it. Crucial! (…) it's doubly as long to get messages across, so you've got to have more time. The model of Medicare mental health is 10 sessions. We need 20 sessions! (…) So, rather than the traditional one hour a week, probably you're looking at, might be better at three half-hour sessions a week, over more weeks.*

Luis explained that Medicare billing could allow for shorter appointments where that was required. He stated that not many people seemed to be aware of the flexibility in billing. Time-related barriers and facilitators that are linked with funding are further discussed under the systems factors subtheme in section 6.2.

Access to AAC and Relevant Vocabulary. All groups discussed the importance of access to AAC and relevant vocabulary as being beneficial to accessing mental health care. In the previous chapter, participants with lived experience identified risk factors associated with a lack of reliable AAC. In this chapter, the focus is on the relationship between access to AAC and vocabulary, and obtaining mental health care. Aster, an ECP, provided a summary of her experiences of supporting people both with and without reliable AAC to access mental health support.

Aster: I also think he got (mental health support) because he had a communication device, but some people don't. And I don't think they receive that support. So, something will happen, and people will observe that they're physically okay, but (…) they're not receiving the same emotional support (…). I think it plays a very, very important role. It really gives people that voice and the tool to recognise happy, sad, need help.

Once mental health support had been acquired, a shared understanding of emotional vocabulary for therapy to be effective was considered particularly important by MHWs.

Jordy: When I first meet someone, I need to sort of find out (…) what emotions they understand a concept of. What emotions they understand in themselves, and what emotions do they understand in others? And I mean some people (…) might only recognize the four basics: happy and sad, angry, and excited. And so, then kind of building on that.

MHWs who were skilled in integrating the person's multimodal communication strategies into their therapeutic approach assisted people in developing an understanding of their own emotions and the emotions of others. Access to AAC and relevant vocabulary also enabled people with communication access needs to convey issues that impacted their wellbeing and seek support.

Relevant Mental Health Resources. Interview participants discussed the value of relevant mental health resources that promoted mental health awareness and/or allowed the person with communication access needs to express mental health care requirements. Participants described both custom-made and off-the-shelf resources. However, most examples were customised tools that incorporated elements of AAC and visual aids.

Luis: They're usually tailor-made. I can't think of much visual that's not tailor-made. I mean, the visuals like the counselling information sheets we have, they're (…) visual aids as well.

The relevant mental health resources identified by lived experience interviewees included tangible objects, websites, videos, and visual aids. When explaining her right to express her sexuality, Laura's psychologist provided a range of educational resources including multi-media information and tangible objects:

Researcher: So, you found a psychologist that could help you with that?

Laura: 'Yes' (Nods head)

CA1: And she had a heap of resources, didn't she?

Laura: 'Yes' (Nods head)

> *CA1: Some different videos and there was a touch therapist (…) that we didn't know about, and you weren't so keen to explore that, but it was still good to know about it.*
>
> *Laura: Yeh. (Laura vocalises her response adding emphasis)*

To improve the relevance of the mental health related information and to ensure the person's acquisition of skills and knowledge, MHWs adjusted the way they presented content. ECPs and MHWs also discussed the use of objects and games to convey information.

ECPs discussed working with professionals to customise resources such as visual aids and social stories to create opportunities for people with communication access needs to express themselves.

> *Emmylou: I think probably the (Developmental Educator) support helps a lot, whether it's not even necessarily in a positive behaviour support plan, but in things like social stories, just creating opportunities for expression.*

Karina discussed working with a developmental educator and psychologist to develop a social story for her son who was very anxious following a traumatic event.

> *Karina: He was having trauma on the bus every night, so we wrote a social story. You know, that the workers there were supposed to read with him every day, but they didn't. You know, with the photo of this house, with a photo of (my husband) and I saying, "When the bus gets to (service name), Dad will be there waiting for you".*

In one instance, an ECP had worked with a person with communication access needs to develop an AAC tool to enable a person to initiate conversations about mental health and solicit assistance.

> *Aster: That prompted me to work alongside the person (with communication access needs) and (we) developed a tool to help him communicate when he felt distressed. To help staff understand what different levels of distress he had and what situations made him feel most distressed. He felt it was a wonderful tool, but the other thing that went alongside that was again having that rapport. (…) The things I thought that would make him distressed were different to what he actually said made him distressed.*

Aster's experience yields important insight into the need to provide relevant resources to empower ECPs to act to support mental health and wellbeing.

Two ECPs discussed the importance of having information interpreted to help them support the mental health of people with communication access needs who use behaviour to communicate emotional distress.

Ariel: *Most of (the people I work with) have got different (behaviour) scales (that tell us) what approach to use in each part of the scale or for each behaviour. In my opinion, behaviours are far more linked to mental health than disability, so it's basically a "supporting mental health plan".*

Behaviour scales, a component of PBS plans, helped ECPs understand and respond to behavioural indicators of anxiety and emotional distress in people with communication access needs. Karina discussed the role of her son's psychologist in interpreting technical information about behaviour into clear and concise instructions to equip ECPs to respond when her son is experiencing heightened anxiety.

Karina: *(The psychologist) is responsive to us here. He tells us what we need to do. We probably (tell) him those reactions, those responses to the behaviours, but (the psychologist) puts them in a way that they can be understood.*

Karina presented a brightly coloured infographic which had been printed and laminated and provided to the staff who work with her son. The infographic is a quick reference guide for support workers, guiding them on how to respond to her son by observing changes in his behaviour.

MHWs also discussed the types of resources they had developed for people with communication support needs. MHWs had developed visual schedules, prompts for medication and wellbeing strategies, as well as pictorial mood diaries, customised to meet the requirements of the individual. MHWs discussed the use of visual aids to prompt general self-care and strategies specific to maintaining mental health:

Mike: *Yeah, visual reminders (…), It might be as simple as, "Have you taken your medication today?" For our people who don't take it or don't remember to take it. Or, what keeps me happy? Ring mum, do this, do that, just try, and do this. – For those people who maybe have a combination of both cognitive and communication issues, just to remind them of the things that keep themselves happy and keep themselves well.*

Hetty had developed pictorial prompts to remind a person with bipolar disorder to observe fluctuations in mood, while Luis had created mood diaries to assist people with communication access needs to record emotions.

Luis: *So, it's the diary, but that's where this modification, so I'll use some sheets, and I'll use some pictographs. (…) they could circle a mood for each day or different times of the day.*

Two MHWs provided examples of creating customised resources through art therapy intervention. Both MHWs identified that artefacts developed during sessions can serve as a reminder of the work they had done, whether to support their self-image:

> *Miranda:* *I did with a few clients who are doing the identity building, they make a portrait of themselves and then I've got fabrics and other stuff and they often like those sorts of things, so yeah.*
>
> *Researcher:* *And then I guess whatever artefact they create; they can also use that as a tool of expression.*
>
> *Miranda:* *Or as a reminder for themselves regarding their positive self-image when they feel down or when they're very critical of themselves or feel sad.*

Or to help them cope:

> *Jordy:* *I get tangible items too (…) because people sometimes need a reminder. I did this whole stage of doing those origami choice-maker things. I was doing those with affirmations. So, every number got to an affirmation.*

Some MHWs discussed the value of off-the-shelf resources that had been designed with a focus on communication accessibility.

> *Miranda:* *The two books from Scope. One is Building Self Esteem, and the other one is called Anger Management (…) It's all Easy Read, all the stuff. So, it's very easy to follow but also, I think it's done in a nice way that it isn't too childish or anything, so I use it with a range of people because I think, even if you don't have that much of an intellectual disability, often those visuals are really helpful.*

The off-the-shelf resources enabled the MHW to select from a range of accessible tools to complement their practice. Additionally, one of the MHWs had been involved in developing a practice guide, inclusive of video demonstrations and written information for counsellors working with people with communication access needs. Relevant mental health resources were often personalised by MHWs to meet the requirements of the individual. These resources were designed through collaborative processes with the MHW, the person with communication access needs and their ECPs.

Specific Communication Access Strategies. Participants from all groups identified communication access strategies that were beneficial in promoting access to mental health services. The strategies identified were: human assistance, incorporating AAC, provision of accessible written information, use of visual aids, and recapping information. A summary of the communication access strategies described by participants is presented in Table 6.3 with an overview of strategies in the following paragraphs.

Human Assistance. Human assistance refers to the inclusion of an additional person to assist communication by translating speech that is difficult to understand, co-constructing messages, providing additional contextual information where requested, reading written information, note-taking, or rephrasing messages so that they are easier for the person with communication access needs to understand. Human assistance was identified as being beneficial by most interviewees with communication access needs and half of the ECPs. The majority of MHW survey respondents (*n=13*) identified that the inclusion of a person to assist with communication was a strategy that they had used in practice. MHW interviewees indicated that communication assistance was provided by family members and support workers, rather than a professional Communication Assistant with specific training for the role. The role of ECPs in providing human assistance in mental health care is discussed under the heading ECPs as Conduits to Mental Health Care in section 6.3.2.

Incorporating AAC. For interviewees with communication access needs, incorporating AAC in mental health intervention was the most discussed communication access strategy. Including the person's preferred modes of communication was viewed as being important by interviewees from all groups. Amelia and Laura shared positive stories of MHWs adjusting their approaches to incorporate their use of AAC. Chris, Lisa, and Hope noted their desire for MHWs to include all their modes of communication when delivering mental health care. More than half of the MHW interviewees discussed including AAC in mental health interventions, while a quarter of MHW survey respondents (*n=4*) had used AAC in their practice.

Use of Plain Language. The majority of MHW interviewees stated that they used plain language to support the accessibility of interventions. For example, by simplifying spoken communication to ensure the clarity of content, rather than omitting information. Additionally, MHWs discussed allowing pauses in spoken communication to enable people to process information. MHW survey respondents did not explicitly identify that they used plain language; however, they noted other approaches to support the clarity of communication. These strategies were: simplifying the objectives of the intervention (*n=13*), reducing distractions in the environment (*n=12*), and limiting information to one new piece of information at a time (*n=10*). The use of plain language was not discussed by interviewees and survey respondents with communication access needs nor ECPs.

Accessible Written Information. In the interviews, the provision of accessible written information was discussed by participants from each of the groups. Half of the interviewees with communication access needs viewed accessible forms of information, such as Easy English, as being beneficial in increasing their comprehension of textual information. The provision of accessible written information was not identified as a strategy in use by MHW survey respondents.

Visual Aids. The use of visual aids to support mental health interventions was the most discussed communication access adaptation for MHW interviewees. Visual aids were used by many of the MHW survey respondents (*n=10*). Most ECP interviewees viewed visual aids as improving access to mental health care. However, this was not the case among participants with communication access needs.

Recapping Information. Recapping information refers to the repetition of key information to confirm the person's understanding of those messages. Most interviewees with communication access needs stated that recapping information was a useful strategy to promote the accessibility of mental health interventions. MHW survey respondents also identified repetition as a beneficial communication access strategy. The strategies used by MHWs included: repeating information as required (*n=13*), increasing the rate of "checking-in" with the person (*n=12*), and checking for recall of information between sessions (*n=8*).

Persistence of the Person Seeking Support. In many instances, participants with communication access needs demonstrated the need for persistence to get their message across and to source the support required to address matters related to mental health and wellbeing. Fleur, Chris, and Laura, three interviewees who used AAC with limited symbol sets, provided examples of the perseverance required to make themselves understood when attempting to communicate complicated matters. Fleur's communication assistant reflected on her persistence to address matters that had caused her distress:

> *CA:* *Fleur, when you're upset, I'm thinking about when you're trying to tell us something that's important to you, you don't give up. You'll keep on trying (…) you keep on going and going until we eventually, hopefully, we figure it out.*

Table 6.3

Summary of Communication Access Strategies

Coding	References			Example quote	Survey data
Participant group:	LE	ECP	MHW		
Human assistance	11	3	1	CA1: *I said to you that you could ask me to leave at any time, but you wanted me to stay to help you get your message across in case it wasn't on your iPad.* Researcher: *Did you find that helpful having someone that you trust to help you communicate?* Laura: 'Yes' (Nods head)	81.3% of MHWs used human assistance provided by a nominated person. 37.5% of MHWs had used formal communication assistants.
Incorporating AAC	16	6	15	Researcher: *So, were you able to introduce how you use AAC to the mental health professionals?* Amelia: 'Yes' (nods head) Researcher: *Did you have any challenges in doing that?* Amelia: 'No' (shakes head). Researcher: *Were the mental health workers open to using (AAC)?* Amelia: 'Yes' (nods) Emmylou (ECP): *One (MHW) was really lovely, asked if (the person) had a device, if there was certain things she would need to know, if she could word things differently to help the person.*	25% of MHWs identified that they incorporated AAC in their practice.

Coding	References			Example quote	Survey data
				Hetty (MHW): *Within the (mental health) service itself is pretty good because we have standardised tools, communication tools.*	
Use of plain language	0	0	14	Jordy (MHW): *Yeah, and there's this sort of perception about simplifying information. You know it's not about. It's simplifying information is actually for everybody. It's not about kind of like dumbing down information, it's actually about providing clear and meaningful information to everybody.*	MHWs did not identify using 'plain language'. 81.3% of MHWs did simplify the objectives of the intervention. 75% of MHWs limited environmental distractions. 62.5% of MHWs did limit information to one new item at a time.
Accessible written information	4	4	11	Researcher: *Do you like therapists to use symbols or pictures like this when they give you information?* Chris: 'Yes' (nods head) Researcher: *Okay, so do you like writing and pictures as well?* CA2: *You do like a mix, don't you mate?* Chris: *Yeh.*	No MHW survey respondents identified that they had provided accessible written information.

Coding	References			Example quote	Survey data
				Luis (MHW): *I should say I did develop some (Easy English) fact sheets. I do send that out as well. So, there’s an Introduction to Counselling, this is what’s involved, and this is the communication.*	
Visual aids	0	6	6	*Hetty (MHW): I sometimes use mood diaries, but they’re pictorial. So, for one lady I made up a little laminated thing with the different faces on it, saying I feel really good, etc. For the fridge just to check. Have an emotional check every day. Check where you're at.*	62.5% of MHWs used visual aids in practice.
Recapping information	5	3	6	Mari (MHW): *But, at the end of an appointment with somebody, if there's things for me to do and there’s things for them to do, recapping is important, writing it down is important.*	81.3% of MHWs repeated information as necessary. 75% of MHWs increased their rate of ‘checking-in’ with the person. 50% of MHWs checked the person’s recall of information between sessions.

Similarly, Chris' preferred communication assistant discussed Chris's persistence in getting his message across when his ECPs do not understand.

> *CA:* *So, if you're telling them something and one person just can't understand. Chris, you usually keep on saying it until someone comes up and says, "Oh yeh! That's it!"*

As described in the previous chapter, it took some people years to get their message across to a receptive communication partner. Emmylou discussed having worked with a person for over six years before establishing that the person wanted to visit her mother's grave.

> *Emmylou:* *The staff were trying to figure out what was going on. (…) it was actually another person we support who said something about her mum, and we're like "Oh, mum! Mum is in heaven." It was coming up to Mother's Day, she missed her mum, and in the 6.5 years I'd known her, I'd never known her to go and visit her (mum's grave).*

One MHW stated, "(people with communication access needs) will have to be extremely motivated to get support", highlighting the perseverance required to get mental health care.

Communication access factors present both barriers and facilitators for people with communication access needs attempting to access mental health care. Communication access factors are further contextualised in later subthemes; ECP Supporter Factors (6.3) and MHW Practitioner Factors (6.4).

6.2 Systems Factors

Within the category of factors that influence access to mental health care, the second subtheme related to the system of formal, funded mental health services that are available to the general population. Key findings under this Systems Factors subtheme relate to the adequacy, availability, and affordability of mental health care. Thus, the major Australian health and disability funding schemes – Medicare and NDIS –were implicated in findings regarding funding. Other pertinent systems factors included referral processes and the integration of disability and mental health systems. The barriers and facilitators related to support systems are summarised in Table 6.4 and discussed in the following paragraphs.

Table 6.4

Summary of Mental Health System Barriers and Facilitators

System barriers	System facilitators
Funding barriers. Time constraints. Lack of appropriately skilled MHWs. Lack of clear referral pathways. The complexity of the mental health system. Delayed access to mental health care. Exclusion of people with disability by mental health services. Physical health support prioritisation.	Adequate funding and adequate time. Referrals process. Mental health and disability service collaboration. NDIS system factors: • Co-location services. • Staff working across both systems. • MHWs participating in NDIS training. • MHWs providing PBS. Consent for service provision.

6.2.1 System Factor Access Barriers

The system factor access barriers mentioned in the above table are further expanded in Table 6.5 and described in the following paragraphs.

Funding barriers. Funding barriers such as the insufficiency of Medicare subsidies for people with communication access needs were noted by many interviewees, and interviewees from all groups connected time constraints in mental health care provision with funding barriers. ECPs who were disability support workers had a unique overview of this situation, as observers of funding decisions that were not controlled by the person with communication access needs. Ariel commented on the inadequacy of the Medicare Better Access rebate resulting in prohibitive out-of-pocket expenses for individuals who received the Disability Support Pension. Further, Demi pointed out the tension between competing funding priorities and the opinions of supporters.

Lack of appropriately skilled MHWs. ECP and MHW interviewees identified insufficiency of appropriately skilled MHWs as an issue. However, this barrier was not discussed by interviewees with communication access needs, which implies that ECPs played a substantive role in identifying appropriate mental health practitioners. ECPs considered that providing mental health care to people with communication access needs required a specialised skill set. In the previous chapter reference is made to MHWs discussing the limitations of their pre-service training in preparing them to work with people with communication access needs, and this chapter expands upon that subtheme, exploring more broadly the challenge of sourcing suitably skilled MHWs.

Lack of clear referral pathways. The problem of locating clear referral pathways was linked to other categories of barriers including delayed access to mental health care, lack of appropriately skilled MHWs, and perceived complexity of the mental health system. Referral pathways were limited by geographical location, demand for specialist mental health care, and discriminatory service eligibility criteria. MHWs noted that certain diagnostic populations with a high likelihood of coexisting communication access needs were listed in the service's exclusion criteria. Hetty explained that the mental health service she worked for frequently received referrals from people with co-existing disability and unmet support needs. Although the service was not meant to accept referrals from these populations, MHWs used their discretion to provide interim services and assist people in locating the other supports they needed.

Delays in access to mental health support. According to participating ECPs, people with communication access needs frequently experienced delays in access to mental health support. Such delays were exacerbated by limited awareness of mental health supports, lack of reliable AAC and vocabulary, ECPs not understanding communication about distress, unclear referral pathways, the lack of appropriately skilled MHWs, and prioritisation of physical support over emotional support. Interview data revealed that delays to mental health support compounded over time. Once the person perceived a need for mental health and wellbeing support, they then needed to identify a communication partner who would understand and respond. The next steps involved entering the mental health system; identifying a GP to complete a mental health care plan, locating a suitable MHW to refer to, and then waiting for services either as planned, or because a crisis point has been reached, necessitating emergency mental health services. For some people with communication access needs, the process of securing mental health services took many years.

Complexity of the mental health system. ECPs and MHWs perceived the mental health system as complex for people with communication access needs to navigate. Demi, an ECP, noted that not only was the system difficult to access, but there were further challenges in knowing what services to access. The perception of complexity and prioritisation of physical support needs may further exclude people with communication access needs from mental health services.

Siloed disability and mental health service systems. A major issue discussed by ECP and MHW interviewees as the siloing of disability and mental health service systems which led to the exclusion of people with co-occurring disability and mental ill-health. ECPs identified that people with communication access needs were excluded from receiving mental health services due to lacking a diagnosis of mental illness. Almost all MHW interviewees described instances of people with disability being excluded when attempting to access mental health services. MHWs explained misconceptions in the public mental health system that specialised mental health services were available for people with co-occurring disability. One MHW inferred that the exclusion of people with disability from public mental health services was possibly a means to manage an already overwhelming demand for services.

Prioritisation of physical health support over mental health care. Physical support requirements at times inhibited access to mental health support services, because some psychiatric wards in hospitals were not equipped to support people with health support needs related to disability. One ECP spoke about the challenges of getting psychiatric support as well as support for her son to manage diabetes. MHWs noted discrepancies in the standard of mental health support when people were admitted to general wards versus specialist psychiatric wards. ECPs also discussed the prioritisation of physical health requirements over giving psychological support in disability services.

Table 6.5

Summary of System Factors as Barriers to Mental Health Care Access

Coding	**References**			**Example quote**
Participant group:	L.E.	ECP	MHW	
Funding Barriers	1	20	8	Researcher: *What do you think the limitations were around the amount of time (for MHW appointments).* Amelia: ‘Money’ (rubs fingers together gesturing ‘money’). Aster (ECP): *We associate most supports that we provide to people with NDIS funding. So, if they don’t have the funding, they don’t receive the support. And we have to apply for the funding and then that takes time, but they need the support right now.* Miranda (MHW): *There’s of course the (Medicare funded) mental health plan, but that is not really suitable, because (…) often the clients are in between; they’re a bit too complex for the ten sessions of a mental health plan.*
Time constraints	2	9	12	Researcher: *I was just thinking about how you said that you would have your dad there at the beginning and end of the session, and I thought by the time you have your Dad there for 10 minutes at the beginning and 10 minutes at the end, psychologists tend to work on a 50-minute schedule, that’s only half an hour for you to explore the things that you want to explore in the session.* Amelia: ‘Yes’ (Nods head) Researcher: *Is that enough time?* Amelia: ‘No’ (Shakes head)

Coding	**References**			**Example quote**
				Demi (ECP): *It's not always easy to walk into a situation with someone when they can't talk that well and then understand what they're saying. You need to spend time. And mental health care plans are only 5 to 10 sessions, so it might take longer to understand how that person is communicating.* John (MHW): *And the real world is we have time limits and that's how people sometimes get paid.*
Limited awareness of MH services	1	2	4	Mike (MHW): *I guess the general population doesn't have great literacy around both health and community services and what's out there for people.*
Lack of referral pathways	0	6	21	Emmylou (ECP): *Being regional or rural, we don't get quite as many opportunities or options available. So, if we found out that they were available, that would be amazing.* Siegfried (MHW): *I'm just doing one day a week working with this population, and I'm very much aware that I've certainly been swamped with referrals, and I really had to stop accepting any new ones for the time being because then there's no time to deal with the ones I'm already seeing.*
Lack of skilled MHWs	0	15	17	Ariel (ECP): *I tried to research to find psychologists that are culturally aware and disability aware... Yeah, and that don't have a year-long wait list. Hard to come by, not that readily available from my experience.* Mari (MHW): *So, accessibility is incredibly difficult for people in rural areas. And counselling not in person is almost impossible with people with Huntington's. So, for some people who are articulate, it's all right, but a lot of the people are struggling with a lot of levels of communication needs (...).*

Coding	References			Example quote
Delayed access to MH support	0	13	8	Aster (ECP): *And wait lists, wait lists! Even for behaviour support at the moment there’s a significant shortage of behaviour support practitioners. So even when people have funding, they’re often on a waitlist.* Demi (ECP): *You know, it just seems everything is always exhausted and that's always, like I said, the systemic thing of mental health not being important because it's easy to put on the back burner and hope it goes away.* Siegfried (MHW): *By the time somebody with an intellectual disability ends up in the ED (…) people have been really struggling for some time before it gets to that stage. So, the system is really not fit for purpose in this particular area.*
Complexity of the MH system	0	3	11	Demi (ECP): *I do think it's confusing. Or knowing what is actually needed, like, whatever the emotional or mental health issue they're experiencing is a counsellor appropriate, or do you need some sort of actual therapy, or psychologist, or medication, or a combination of all of them. Yeah, because no one really knows what it is until you've talked to the appropriate person. But how do you get to that person?* Jordy (ECP): *So, that's just one thing about going to the GP and then when you actually, if you do get a mental health plan. Then you need to be able to understand how you can use that plan and where you can use that.*

Coding	References			Example quote
Siloed services: Exclusion of people with disability in the mental health system	0	7	14	Emmylou (ECP): *We have been told at the local hospital that they do not have the capacity to assist someone with mental health needs who needs medical care. So, someone I support who had mental health issues had to go to the (hospital in the city), because of his mental health issues (…).* Siegfried (MHW): *I know my working career has been within public mental health, and I know from that perspective that there is absolutely a view that intellectual disability doesn't belong here, that they need to sort of sort that out (in disability services).* *Mari (MHW): For a lot of our people, it is very difficult to access mental health services. Because as soon as they hear, "Oh, you've got Huntington's. That's neurological. It's not us."*
Prioritisation of physical support needs.	0	8	4	Demi (MHW): *But then you know, people with disabilities are spending X amount of money on physical wellness (…) and there's so many things that they're spending their money on that already cost so much because they need the extra support, and then you've got either the family saying that they can't afford that, or I don't want to pay for that.*

6.2.2 Support System Access Facilitators

Interviewees discussed very few facilitators in the mental health system. Those identified were: adequate funding, consent, clear referral processes, collaborations between the mental health and disability services, and NDIS factors. These facilitating factors are described in detail in the following paragraphs.

Adequate Funding and Adequate Time. Access to funding was more frequently identified as a barrier, however, there were a few instances where people with communication access needs had been able to gain MHW services through their NDIS funding. Just one lived experience interviewee, Amelia, was able to access adequate mental health services using Medicare Better Access funding. Fleur and Laura had accessed mental health supports using NDIS funding to meet their wellbeing related goals.

> *Researcher: So is that how you ended up seeing the psychologist, was that part of the positive behaviour support plan?*
>
> *Laura: No (Shakes head)*
>
> *CA1: No. that was separate that was through the NDIS. Because Laura put it as one of her goals. That she wanted to learn more about her sexual health and wellbeing*

ECPs who were parents spoke of securing mental health services with NDIS funding for their family member who had communication access needs.

> *Karina: Well, it's the only private psychologist we've ever seen. And … Well, it's NDIS funded so they had to follow the goals.*

This was an example of being able to access NDIS funding for MHW services because of alignment with NDIS goals, rather than diagnosis of mental illness. Another parent, Paulette, discussed the impact of NDIS-funded daily support on her son's mental health and wellbeing.

> *Paulette: Yes, the last two years have changed things so much. And my only interest in (my son's) mental health now is the medication. Because (he) doesn't go to hospital anymore since he's had proper support.*

MHWs noted that gaining access to adequate funding can be dependent on advocacy.

> *Siegfried: (Engaging mental health services) sort of varies depending on NDIS funding, and who they've got advocating for them, and all the rest of it.*

While identifying many barriers to mental health support, Luis, an MHW, noted that Medicare Better Access and NDIS had made mental health support more accessible to people with communication access needs: “It’s definitely got better. Medicare and NDIS has actually made access to funding better.”

Clear Referrals Processes. Having a clear referral process made it easier for people with communication access needs to obtain mental health services. Referrals for mental health care occurred at multiple levels, via self-referral, disability services, general health services, and mental health services.

One lived experience interviewee discussed a referral process that resulted in timely access to mental health care. Amelia was referred to a community mental health service after attending the emergency department of a hospital in a mental health crisis.

> *Researcher: Did you get any referrals to other mental health professionals?*
>
> *Amelia: “Community Mental Health.”*
>
> *Researcher: Did the referral happen quickly?*
>
> *Amelia:* ‘Yes’ *(nods head)*
>
> *Researcher: So, it was treated as an emergency, and you got in to see (the MHW) at Community Mental Health. How long did it take for you to get an appointment with the psychiatrist at community mental health?*
>
> *Amelia: “Not long.”*

One ECP, a parent, discussed how making a referral based on professional connections resulted in timely mental health service provision.

> *Karina: Oh, we got a psychologist straight in. We knew (the psychologist) and because I've known him before (…) we actually pulled in a favour. Because I've worked in the sector for so long, I know a lot of people. So, I was determined that I wanted him in straight away and he came (…) within a week.*

As explored in the previous chapter, ECPs play a significant role in connecting people with communication access needs with mental health services.

MHWs also discussed their role in referring people to mental health support services. MHWs who understood the system played a crucial role in connecting people to support.

> *John: And with our service, we also on-refer people to other services that can help with that person, whether that’s a social group or a psychologist.*

One MHW further explained the imperative for mental health services to connect people with suitable services, to ensure that they did not go without mental health care.

> *Mike: About 15 years ago, there was a report that came out called “There’s no Wrong Door” and we’re supposed to live by that philosophy, that if a client*

> *is referred to us and we're not the right fit, we don't say, "Sorry, not an appropriate referral" we need to point them in the right direction of who would be the appropriate one.*

MHWs identified that referrals generally originated from GPs, family members, disability or aged care service providers, or hospitals. The catalyst for referral to MHWs tended to be behavioural issues or accessing crisis services. Only one MHW mentioned self-referral and stated that this was extremely rare.

Mental Health and Disability Service Collaborations. MHWs identified the benefits of collaborations between the disability and mental health service systems. Collaborations between the two service systems were viewed as having a de-siloing effect on mental health support provision while enriching disability services. One MHW spoke of the need for improved collaboration between disability and mental health service systems.

> *Luis:* *I've always thought mental health needs to be more embedded in disability services. There needs to be a specialisation within disciplines. The fragmenting hasn't worked. I know the UK; they embed it within Disability Services. They've got a good system there, where the mental health expertise sits within Disability Services.*

Two of the MHW interviewees were employed part-time by disability organisations and were able to use their positions within these organisations to promote access to mental health care. MHWs who were employed by community mental health services provided examples of collaborating with other allied health services such as occupational therapy, and physiotherapy. This is discussed further under the heading Multi-disciplinary Mental Health Teams in section 6.4.2. Additionally, the recent consolidation of some mental health and disability service providers under the NDIS is discussed under the following subtheme heading.

NDIS System Factors. Interviewees provided perspectives on the system changes that had occurred since the advent of the NDIS. One of the prevalent categories of this subtheme was closing the gap between disability and mental health support systems. An MHW working predominantly with people with disability in the NDIS system noted the de-siloing of the systems:

> *Miranda:* *I think the consequence of the NDIS is that it brings mental health and disability together, I think previously it was even more siloed. I see more collaboration now with mental health teams.(…) Often both have the same support workers providing the support, so there's a lot more understanding and acceptance, and it's not as rigid anymore, which I think is brilliant.*

ECPs and MHWs both identified the benefit of having support staff working across both the disability and mental health systems. MHWs working with NDIS participants were required to undertake training. One MHW discussed learning about communication strategies through his NDIS training.

> *John: When I did my NDIS training, I saw a sample video, of someone who had cerebral palsy and there was the carer or support worker who had spent a long time with that person. They really understood that person and (how) that person would communicate (…). They had a really good rapport and understood the person's situation and communication style.*

Organisations providing NDIS funded supports were noted as having begun co-locating mental health and disability services which further dissolved barriers between the systems.

> *Miranda: I think, where they often share the same office and have a little bit more to do with each other, but I think that's good progress, so I think in our perspective NDIS is helping.*

Additionally, NDIS funding has resulted in more MHWs providing PBS:

> *Luis: There are some (referrals) through NDIS that come through there. So, this is where the NDIS and some of their behaviour support work. If you talk PBS, one of the key things is around mental health. So, there'll be funding through that as well.*

And

> *Miranda: I think the other facilitator is that there are more psychologists doing behaviour support now as well, (…) I think that's brilliant because that will bring different skill sets and if they feel more confident and competent in working with people with disabilities, they can provide the therapeutic supports as well.*

An ECP survey respondent noted that NDIS Support Coordinators could play a greater role in connecting people with communication access needs to mental health supports:

> *Anonymous ECP: If a mental health professional does have experience in AAC etc. this should be advertised within the wider community. NDIS support coordinators should have access to this information – and potentially have a greater responsibility for advocating for individuals (with communication access needs) to consider receiving this support.*

NDIS has brought together disability and mental health service providers under the same system of funding. The consequences of this unified funding system have been collaborations between the systems, through sharing physical spaces, training, and employees working across both sectors.

Consent. Interviewees with communication access needs discussed the importance of MHWs gaining their consent before sharing information or selecting who supported mental health interventions.

> *Researcher: Do you have any recommendations for mental health workers in engaging support people in mental health interventions, what do you think the terms and conditions should be?*
>
> *Amelia: Ask the person.*

For ECPs, consent meant seeking approval from a person with communication access needs before discussing mental health care. Gaining consent was a means to uphold the confidentiality and autonomy of the person they supported.

> *Researcher: So, you go into a psychologist, they're not sure what to do, do they include other professionals to help them understand how they might work with the person?*
>
> *Emmylou: Yes. If the right privacies and consents are in place, and (the person) says yes, absolutely.*

Emmylou here referred to the formal processes of consent required by her employer, a disability support organisation. Another ECP spoke of the role of consent in treatment, alleviating her son's stress when receiving in-patient mental health services.

> *Paulette: And because he didn't have to be detained there, he could come away. He could get on his bike, come home, you know, stay two minutes, and go back again. Yeah, that was enough for him to stay there.*

MHWs also spoke about the role of consent in their work with people with communication access needs. Most MHWs spoke about the process of seeking informed consent and consent to share information with ECPs or other professionals and services.

> *Mike: We've got a little pack of information when we come out to meet you the first time and there's a consent form in there. Which gives me permission to look at your medical health records, but also to talk to family. There's also a little section of who don't you want us to talk to because there might be a member of the family who's very nosy.*

According to MHWs, gaining consent facilitated trust and ensured that the right people were involved to achieve mental health outcomes. MHWs also discussed variable levels of consent between different interventions and the need for transparency.

> *Miranda:* *With behaviour support, I'm always very clear from the start that it is about everyone working together. So, confidentiality for that is secondary to me because I need to work with the whole (support system).(…) If I do counselling with the clients, that's a safe space and the people around don't need to know unless we discuss that it might be appropriate or helpful to talk to others about certain things.*

Consent was described as an ongoing process, beginning with formal provision of consent, and continuing to ask permission to involve other people throughout the duration of mental health care provision.

> *Luis:* *So, I see … consent as a continual process. Not a signing a form at the start … You start with that, but it's ongoing – every time you introduce somebody new or every conversation, you have to check in regularly. And it's probably more imperative that you do this overtly with the person.*

From a systemic perspective, consent was important in developing trust and upholding the rights of people with communication access needs in mental health care.

6.3 ECP Supporter Factors

The third subtheme relating to factors that influence mental health care concerned the influence of ECP supporter factors and the roles of such supporters in aiding the mental health and wellbeing of people with communication access needs, whether as sources of information, sources of emotional support, or as conduits to mental health care. Table 6.6 gives an overview of the ECP supporter factor barriers and facilitators reported as being encountered by people with communication access needs seeking mental health care.

Table 6.6

Summary of ECP Supporter Related Barriers and Facilitators

ECP supporter barriers	ECP supporter facilitators
ECP skills and knowledge: • ECPs not understanding the person's communication • Limited awareness of mental health services • Delayed mental health support ECP attitudes: • Stigma • Unsupportive of mental health care ECP support issues: • Lack of trusted ECPs • Prioritisation of physical health requirements • Limited opportunities to discuss mental health and wellbeing • Lost histories	ECP skills and knowledge: • Knowing the person well • Providing opportunities to discuss mental health • Awareness of mental health and related services Positive attitude to mental health support: • Mental health support is for everyone • Behaviour is communication ECPs as conduits to mental health care: • Responsive to communication about mental health • Support to engage in mental health care • Maintaining mental health vocabulary

6.3.1 ECP Supporter Barriers

Certain barriers affecting access to mental health care were sometimes evident in reference to ECPs and supporters. These occurred across three key areas: knowledge, attitudes, and support issues. ECPs knowledge related to their mental health literacy, as well as their knowledge of the person with communication access needs. A notable attitude that acted as a barrier to mental health care was stigmatisation of people with mental illness because ECPs with such an attitude could conclude mental health care to be redundant or ineffective for people with communication access needs. Support issues included a lack of trusted ECPs, prioritisation of physical health care over mental health care, limited opportunities to discuss mental health and wellbeing, lost histories, and substitute decision maker issues. A summary of these barriers is presented in Table 6.7.

ECP knowledge barriers. There were two dimensions of knowledge that affected access to mental health care: 1) *insufficient awareness of mental health*, and 2) *insufficient knowledge of the person* and their communication methods. ECPs mental health literacy and knowledge of the mental health care system have been detailed in Chapter 5. Most ECPs who participated in the interviews and surveys had received training in mental health training, but they identified limitations in their knowledge. Interview findings indicated that ECPs found it difficult to remain abreast of the changing mental health care landscape. They were challenged to identify MHWs with the appropriate skills to work with people with communication access needs. The second dimension of knowledge was related to knowing the person with communication access needs and being familiar with their communication methods. ECPs who did not know the person well found it difficult to recognise communication about emotional distress and misunderstood behavioural indicators of mental ill health. High rates of staff turnover in disability services resulted in some ECPs having a limited understanding of the personal and their communication about emotions.

Stigmatising attitudes. Where ECPs held stigmatising attitudes towards people with communication access needs, this had the potential to curtail access to mental health care. Stigmatising attitudes had multiple dimensions: generational, cultural, and ableist (e.g. expectations that people with disability would be depressed about their lives). Some ECPs also possessed attitudes that were *unsupportive of seeking mental health care*. The examples provided in Table 6.7 demonstrate that attitudes can be insidious and embedded in daily interactions. A survey respondent with communication access needs commented on how their efforts to engage an MHW had been disrupted by the conflicting views of ECPs: "Even though I have wanted to use a counsellor, I haven't successfully engage(d) one. Lots of people in my life have different ideas about the type of support I have. Some think I don't need mental health help". Attitudinal barriers had flow-on effects such as limited opportunities to discuss to mental health and wellbeing, and delayed access to mental health care.

Support issues. For interviewees with communication access needs, a *lack of trusted ECPs* with whom they could share their feelings was a fundamental barrier to help-seeking. Hope and Fleur described times in their lives when they could not rely upon the ECPs to help them address wellbeing issues, exacerbating their levels of distress. Additionally, ECPs and MHWs discussed the conflicting demands on paid ECPs' time, which sometimes led to the *de-prioritisation of mental health care requirements*. The lack of trusted ECPs as well as the prioritisation of physical health support by time-pressured disability support workers led to *limited opportunities to discuss mental health and wellbeing.*

Lost histories refers to another support issue, when ECPs fail in the stewardship role that they assume for the safekeeping of historical information and the need to ensure the person with communication access retains custody of their historical information. Interviewees indicated that people were at risk of losing important historical information when their life circumstances changed, such as when moving to a new home, changing disability support providers, or deteriorating in health. The loss of historical information limited ECPs' understanding of the person with communication access needs: their preferences, social connections, and their experiences.

Table 6.7

ECP Supporter Factors as Barriers to Mental Health Care Access

Coding	References			Example quote	Survey data
Participant group:	L.E.	ECP	MHW		
ECP attitudes					
Mental health stigma	3	2	9	Aster (ECP): *I think since COVID it's actually changed. And I think the stigma has lessened. But then when I think about it in work terms and for people with disability, I don't think it has changed very much … In the general community, I don't think people recognise the needs of people with a disability.* Hetty (MHW): *Some cultures don't want anything to do with mental health, so, you know, it's really hard unless they got a raging schizophrenia. But they were told to, you know, you've got a job, you've got roof over head, you've got food in your mouth. Why are you depressed?*	
ECP unsupportive.				Researcher: *Would you have had your Mum attend the (MHW) appointments?* Amelia: *"<u>She has a belief that mental health is not really a thing</u>"*	
ECP knowledge					
Limited awareness of mental health services				Aster (ECP): *But also, our awareness of who those (mental health) professionals isn't very high.* Mari (MHW): *Access to counselling services. I think often people don't actually even consider that someone might benefit from counselling services. And if you*	

Coding	References			Example quote	Survey data
				can't ask for it yourself or you don't know how to, then that's pretty hard to achieve.	
ECPs don't understand communication.				Demi (ECP): *And then you try to, in my mind, eliminate all the things that it could be and then nothing is happening. Maybe it is psychological distress, or he's depressed, or he doesn't want to be there, or, you know, there's other things going on.* Hetty (MHW): *They may not even pick it up. Their frustration, their distress, and things like that.*	55% of ECP respondents found it difficult to understand the person's communication about the emotions and mental health (n=5).
Support Issues					
Lack of trusted ECPs				Researcher: *Would you want the MHW to include your support people in your sessions (…)?* Hope: 'No' (Shakes head emphatically) Researcher: *You're looking at me like 'no way!'… Would you want (the MHW) to include any support workers?* Hope: 'No' (shakes head) (…) Researcher: *Can I just ask, based on what we discussed before, is that because you don't really have people that you trust to help with mental health at the moment?*	

Coding	References			Example quote	Survey data
				Hope: ‘Yes’ (looks upwards) Aster (ECP): *Alongside the issues with funding, we also are experiencing staff shortages and so people are burning out and exhausted and leaving. So, it’s difficult to build that rapport because we’re not having staff who are staying for a long time.*	
Prioritisation of physical health care				Demi (ECP): *Sometimes we barely have time to get people up and dressed and up to their whatever they're supposed to be doing during the day. Like where do you have time to fit in mental health support?* Mike (MHW): *(Person with bipolar disorder and complex communication needs) would probably get left to a degree. He’s got quite a few physical health needs, so the staff are addressing those with him.*	
Limited opportunities to discuss mental health				Researcher: *If we were to go back in time, would you want someone like (service manager name) to notice that you were down and approach you and ask ‘I’ve noticed that your struggling would you like help to contact a (mental health worker)?* Hope: ‘Yes’ (looks upwards) Researcher: *So, you think it would be good if support people approached you and asked if you wanted help, offered it to you?* Hope: ‘Yes’ (looks upwards) Researcher: *But people haven’t offered it to you?*	

Coding	References			Example quote	Survey data
				Hope: ‘No’ (shakes head).	
Lost Histories				CA: *Fleur was saying that something happened when she was very young, and it was before I knew (her). So, it was really hard for me to help her say what happened. Was it back when you lived in (Name of Institution)?* Fleur: ‘That’s right’ (squints eyes) CA*: Something happened that you weren’t happy with, and you were scared… but that is all that I knew. So, it was hard to figure out what it was.* Siegfried (MHW): *I guess that another challenge, is that if you’re doing a good clinical assessment, you really want to have a lot of background information. You want to know developmental history, and you want to know have there been any sort of traumas, and for the people I’m seeing, often a lot of that’s lost in the mists of time, it’s never really been written down. So, they came to the facility 30 years ago when they were 10, it’s often that you just don’t have much of an idea about what their background is, what their past experiences were (…). I think a lot of people in this population, there are high risks, that there’ve been various traumas, whether at home or even within institutions.*	

6.3.2 ECP Supporter Facilitators

ECP supporter facilitators concern skills and knowledge of communication and mental health, affirming attitudes towards mental health, and providing conduits to mental health care. In this section, the focus is on the roles of ECPs in offering effective support for emotional wellbeing and developing connections with mental health services.

ECP Skills and Knowledge. Interviewees indicated that ECPs required knowledge of the person, their communication methods, and mental health literacy to facilitate connections to mental health care. In this section, the categories “knowing the person well”, “providing opportunities to discuss mental health” and “awareness of mental health” are described.

Knowing the Person Well. The presence of ECPs who knew the person with communication access needs well was facilitative of obtaining mental health support. Familiar ECPs were able to notice changes in behaviour that indicated a need for mental health support or more formalised care. In the previous chapter, the experiences recounted by people with communication access needs demonstrated that ECPs with an enduring relationship with the person were able to recognise signs of emotional distress. For example, Chris’ parents could tell he was sad and grieving after the death of his pet, and Amelia's parents assisted her in going to the emergency department when she experienced heightened psychological distress. ECPs who knew the person well were able to support access to mental health care:

> *Researcher: Is there anything else you want to add about including communication partners?*
>
> *Amelia: He knows me well. (Smiles and nods).*
>
> *Researcher: It sounds like that’s valuable, having a person (…) who knows you well.*
>
> *Amelia: ‘Yes.’ (nods head)*

Some interviewees with communication access needs identified long-term support workers who knew them well as being able to help them resolve issues related to mental health. This was the case for Fleur who assembled a group of trusted supporters and friends to help her advocate.

Another dimension of knowing the person well was understanding the person, knowing their communication preferences, and helping them to get their message across.

> *Emmylou: So, we have a good relationship, and she quite often knows that I’m able to figure out what she’s trying to say. We go through a bit of a process of elimination, so we’ll use yes/no answers, and we’ll just keep going until we get a little bit more of the sentence, and we narrow it down until we get*

what we need. And she knows that I can do that quite quickly normally, so she'll press the button on her iPad, "Can I call Emmylou?"

Parent ECPs felt a unique responsibility in supporting communication and mental health, as discussed by Paulette: "I know that he is closer to me than anyone else. And even then, the communication is still very, very difficult." One MHW shared a story of the role a spouse played in helping staff to better understand his wife when she entered a nursing home because of experiencing worsening effects of Huntington's disease:

Mari: *I went in with the husband and he talked about what she was like when he met her, about what life was like together and about the things that she loved and what they used to get up to and her cheeky side and all that kind of stuff. So, that community was prepared for her when she came and that's how they saw her.*

Family, friends, support workers, as well as health professionals with an enduring relationship of support, played an important role in helping others to better understand people with communication access needs in the context of mental health care.

Providing Opportunities to Discuss Mental Health. As identified in Chapter 5, ECPs providing opportunities to discuss wellbeing was an important facilitator for access to mental health support. ECPs who provided opportunities to discuss mental health were responsive to communication about emotions and proactively broached conversations about wellbeing. As identified in Chapter 5, ECPs used their good rapport with the person to broach conversations about emotions as the need arose. An interaction between Laura and her CA, who was also one of her support workers, illustrated this point:

Researcher: *That leads me to an important question, are your support workers important to your mental health?*

Laura: *Yeh (looks to CA and smiles)*

CA1: *That's lovely thank you. We're pretty big on putting words to feelings, and it's okay to have big feelings, it's what happens next. Whether you want to have some time alone in your room or whether you want to listen to some music really loud and dance, or if you want to go out and have a coffee or want to organise to go and see mum. It's okay to have big feelings, whatever those feelings might be, isn't it?*

Laura: *'Yes' (Laura nods and looks deeply at CA1).*

CA: *It's about where we go from there.*

One MHW identified that some people with communication access needs may be seeking mental health services due to a lack of opportunity to communicate about their mental health and wellbeing in their everyday lives. The MHW discussed equipping ECPs with the skills to have conversations about emotional wellbeing regularly.

> *Miranda:* *I feel that with the counselling it could be done, because often it’s low-level sort of counselling where I think when you’ve got a good support worker who just takes the time to have a chat, can do that as well. So, then I feel I could do for this client. I could also develop tools or supports or do other things that would actually make a bigger impact on their lives.*

While ECPs mentioned varied levels of confidence in discussing matters related to mental health, Miranda held the view that ECPs could learn skills to promote their ability to have conversations about emotional wellbeing.

Awareness of Mental Health. Lived experience and ECP interviewees noted the value of support people having an awareness of mental health and related services. People with communication access needs viewed ECPs with mental health literacy as being valuable members of their support teams:

> *Researcher:* *It sounds like (support worker) knows a bit about what is going on in the local area for mental health supports. Is that right?*
>
> *Laura:* *Yeh.*
>
> *CA1:* *We check out lots of different advertisements. Like sometimes you might get newsletters, and it may have an advertisement in the little local newsletter about different services. We have been down to the community centre before, and they quite often run different groups and things as well.*
>
> *Researcher:* *Fantastic. So, like mental health courses, or what?*
>
> *CA1:* *Yep. Support groups, that sort of thing. Sometimes Carers SA will send out information and I will bring that in as well.*
>
> *Laura:* *(words inaudible, vocalising enthusiastically).*

ECPs with knowledge about mental health support strategies were able to apply their skills to assist the person in managing emotional distress and other symptoms of mental ill health:

> *Paulette:* *You have to work out how to help with whatever is happening that needs to be addressed (…) So how to deal with the hallucination. Like, you know, that's one of the first things I learned at the schizophrenia fellowship. You don't challenge.*

Additionally, ECPs with knowledge of mental health services could assist the person to connect with formal mental health care:

> *Karina:* *Nothing has been offered to us, no. So, any (mental health support) that we have found, we found because of my networks.*

ECPs with mental health knowledge were a source of information, support, and referral, enabling people with communication access needs to connect with mental health care.

Affirming Attitudes towards Mental Health. ECPs with affirming attitudes towards mental health viewed emotional wellbeing as a concern for all people. As described in the previous chapter, a defining characteristic of mental health was its general relevance and everyday nature.

> *Aster:* *I think to a point everyone needs some level of emotional support all the time. So, just treating everybody with unconditional positive regard and asking them how they are when you see them is providing emotional support.*

ECPs with positive attitudes towards mental health problems adopted a person-centred approach and sought to understand the person's perspectives and experiences:

> *Emmylou:* *I think just having a positive outlook, looking for opportunities, seeing past the initial paperwork. Everybody comes with a book, this folder says everything about them, but it's not really who they are.*

Additionally, ECPs with affirming attitudes to mental health saw behaviour as a form of communication, their role being to understand the message being conveyed.

Behaviour is Communication. ECP survey respondents indicated that behaviour was the mode of expression most frequently used by people with communication access needs to indicate emotional distress. Similarly, interviewees with lived experience noted that their behaviour changed when they were emotionally distressed. Almost all ECP interviewees held the attitude that behaviour was a form of communication and that symptoms of mental ill-health could be indicated through changes in behaviour.

> *Aster:* *Understanding that behaviour is communication and if someone's experiencing ill mental health, they might display behaviour of concern. And that we need to have a positive approach to address their communication needs and their mental health needs so that we can meet their needs.*

Beyond being symptomatic of mental ill-health, ECPs also discussed behaviour as indicating a need for connection, to seek reassurance or comfort. As discussed by Emmylou:

> *Emmylou:* *She was seeking a connection. She was trying to communicate, and that's all that it was. It was not a behaviour concern, it was that she was trying to communicate with us, and we just weren't listening in the right way.*

ECPs also identified that in responding to behavioural communication they played a role in assisting the person to managing their distress:

> *Karina:* *If we do see that a situation is causing him stress, we remove him from it straight away; it doesn't matter where we are, 'cause we don't always know what's caused him stress.*

The need to investigate the communicative intent of behaviour was summarised by Emmylou: "There is a reason behind every behaviour, you just have to figure out what it is".

ECPs as Conduits to Mental Health Care. The findings yielded from the qualitative data demonstrated that ECPs have a multifaceted role facilitating mental health care at every stage of the help-seeking journey. The functions of ECPs in connecting people with communication access needs with MHWs were: initial responses to communication about emotional distress, documenting mental health and wellbeing, taking action to seek mental health care, advocating for access to services, assistance at the service interface, collaborating in mental health care, maintaining and developing mental health vocabulary, supporting preparation for MHW appointments, and implementing strategies with the guidance of MHWs. These roles are addressed in the following section under the headings: ECPs responding to communication about emotions, providing support to engage in mental health care, and supporting recovery and maintaining mental health.

ECPs Responding to Communication about Emotional Wellbeing. Responsive ECPs facilitated access to mental health support by noticing and acknowledging changes in behaviour, then responding by offering support, which might be a one-off or lead to more intensive professional support.

Laura, an interviewee with communication access needs, demonstrated the physical response she likes to receive when she is expressing emotional distress.

> *Researcher:* *How do you think they should respond (when you're distressed)? Oh, you've got a smile on your face… and you're looking to (CA.2) and you're reaching out and you're holding her hand. Is that what people would usually do if you were expressing your emotions?*
>
> *Laura:* *Yeh. (emphatic voice)*
>
> *Researcher:* *Yeh, and by holding hands and looking at you in the eyes, does that give you comfort?*
>
> *Laura:* *Yes. (nods head)*

Interactions like the one described by Laura provided comfort and eased distress, while being responsive to emotions required ECPs to notice mood changes indicated through behaviour and other non-verbal communication methods.

Responsive ECPs also used documentation to help them understand the context for changes in the person's behaviour and seek solutions.

> *Emmylou:* *I think just documentation is really important. We progress-note on every shift that we work, and I can use that as an investigation tool to go back through. It might be a certain staff member that is triggering something, we can work together to do something differently (…) So, looking through the documentation is really important, because it gives us a good head start on how long it's been happening, what we've already tried, and then it'll lead us to what we can do next.*

ECPs discussed getting to know about difficult dates, occasions, and occasions that may cause the person worry or distress, and being proactive in providing emotional assistance around these times. ECPs also discussed the need for resources and training to enable them to respond to the distress of the people that they supported in appropriate ways, initiating formal mental health support when required. One ECP, a practice leader for a disability service, described the process that she used to check in with the emotional wellbeing of people she worked with and connect them to support:

> *Aster:* *I visit (…) people's homes probably at least a few times a week. And so, when I visit I ask each customer about how they are and often the customer can't speak. But they might smile, or they might look withdrawn and unhappy and then I'll go and ask the staff people what might have happened for the person that day or that week. And how their health is going. And I might refer to documentation to see what's been happening for the person and then I'll follow up. If it's a physical health issue, I'll follow up with our health practice leader. Make sure that a GP appointment might have occurred. And if it's an emotional issue, just make sure that the person feels well supported.*

All ECP interviewees discussed the role that they played in responding to the mental health support needs of the people that they worked with. They indicated that they regularly communicated with the person/s with communication access needs about emotions, from daily to every few weeks.

Support to Engage in Mental Health Care. ECPs may have many roles in supporting people with communication access needs to engage with mental health care. According to the information provided by interviewees, ECP supporter roles included: locating mental health services, arranging referrals, booking appointments with GPs and MHWs, arranging transport to and from appointments, preparing for appointments, advocacy, providing collateral and contextual information, assisting with communication in appointments, reading written information, note-taking, supporting implementing of strategies, and documenting issues related to mental health and emotional wellbeing. In this section, the focal point is ECPs' support for people with communication access needs to engage at the mental health care interface.

When Amelia sought emergency mental health care, her father acted as a communication assistant, helping her by providing contextual information to MHWs in the hospital:

> *Amelia:* *And dad helped.*
>
> *Researcher: Your dad helped. What did your dad do to help?*
>
> *Amelia:* <u>*Communicate*</u>*.*
>
> *Researcher: He had a conversation with you?*
>
> *Amelia:* 'Yes' (nods head) *"<u>And to the doctor</u>" (…)*
>
> *Researcher: So, he helped you communicate with the doctor at the hospital?*
>
> *Amelia:* 'Yes' (nods head)
>
> *Researcher: Okay, so once you got into the emergency department at the hospital, your dad acted as a communication assistant for you.*
>
> *Amelia:* 'Yes' (nods head)

An ECP described the process of introducing the MHW and the person to enable them to gain an understanding of the person's communication methods, before phasing out her presence:

> *Emmylou: I've been able to do appointments, initial appointments where the person I support has asked me to come in. I've been a part of that first consult, and then I've left, and they've been able to continue on.*

As previously reported in this chapter, Laura and Amelia identified that they appreciated this type of intermittent communication assistance in their mental health care. Additionally, participants with lived experience indicated that it was important that they selected who assisted with mental health care appointments. MHWs also viewed ECP assistance as being valuable in helping them to get to know the person's communication methods and develop rapport:

> *Jordy: (There was) somebody who had a new referral, he decided that he wanted to come in with his dad. His dad is a good support person, he wanted dad to be able to tell me some things about him before we started.*

ECPs also acted as advocates in mental health care settings, with ECPs and MHWs noting that access to and quality of mental health care can be influenced by the presence of advocates in the person's life. An ECP stated:

Karina: *I think we've been quite successful in getting (our son) the help that he needs. But I think about if there was another (person like our son) out there (…), say in the house that (our son) lived in. (…) If something happens to one of them - they don't have family members, they're up the creek. No one's going to help them. They're not going to be able to access the things that (my son) has.*

Maintaining Mental Health Vocabulary. Some people with communication access needs required assistance to update and maintain their AAC devices, to ensure that relevant vocabulary is available to request emotional support.

Researcher: *As a result of seeing the psychologist, did you end up with any new vocabulary on the iPad?... Any new words on Let Me Talk about (your mental health)?*

Laura: *No (shakes head)*

Researcher: *Any new words about feelings?*

Laura: *No (shakes head)*

CA1: *If you'd like to, we can put some of those words on there.*

Laura: *Yes please (nods head)*

Those maintaining a person's vocabulary may overlook the importance of incorporating narratives and vocabulary related to past events, as well as the need to engage in mental health care discussions.

MHWs identified that where people have had different support people throughout their lives, those supporters are responsible for the safekeeping of the person's stories. Contextual information regarding experiences such as trauma, illness, and loss which may impact upon an individual's psychological wellbeing was often absent. Consequently ECPs are often relied upon to share stories that enable the person with communication access needs to maintain their identity:

Mari: *So, if that groundwork isn't done around what a person likes, doesn't like, what they value, who their connections are with, all that stuff, if that's not made known to the community around them that is caring for them, then they lose all of that value themself. And they become someone that they don't even relate to themselves necessarily.*

Preserving documentation of these stories and maintaining relevant vocabularies to discuss the issues of mental health and wellbeing was an important responsibility of ECPs and could facilitate opportunities to address past events.

6.4 MHW Practitioner Factors

The fourth subtheme in the data regarding factors influencing access to mental health care was *MHW practitioner factors*. This subtheme is related to the work practices of MHWs and their capacity to enhance or limit the participation of people with communication access needs in mental health care. This section summarises MHW behaviours that act as barriers and MHW practices that support access to mental health care (see Table 6.8).

Table 6.8

Summary of MHW Practitioner Related Barriers and Facilitators

MHW practitioner barriers	MHW practitioner facilitators
MHW lack of skill and knowledge: • MHW reliance on speech. • Lack of rapport. MHW attitude: • Misconceptions about capacity to engage in mental health care. MHW approach: • Disagreement re: intervention objectives. • Lack of feedback on intervention. • Exclusion of ECPs. Barriers to diagnosis: • Diagnostic overshadowing • Over-reliance on medications to manage symptoms and behaviour.	MHW skills and knowledge: • MHW communication skills. • Use of communication access strategies. • Adjusting teaching strategies. • Examines communicative intent of behaviour. • Developing trust and rapport. MHW attitude: • Open to communication diversity. • Person-centred approach. MHW approach: • Holistic approach. • Multi-disciplinary teams. • Use of appropriate diagnostic tools. • Collaboration with ECPs.

6.4.1 MHW Practitioner Barriers

Many practitioner barriers identified in the data related to the skills and knowledge of MHWs in providing services to people with communication access needs. These barriers led to further challenges such as lack of access to diagnostic assessment, misdiagnosis, and overuse of medications. Barriers are summarised in Table 6.9 and expanded upon in the paragraphs before and following the table.

MHW Skill and Knowledge. Almost all MHW interviewees identified that a lack of skills and knowledge impeded access to mental health services for people with communication access needs. Some MHWs held a perception that they were not well enough equipped or trained to work with people with communication access needs. Even

MHWs with extensive experience working with people with disability felt that they could do more to equip themselves to communicate in diverse ways, for example, by learning sign language. Knowledge and skill barriers were not strictly related to communication skills, with one MHW demonstrating a lack of knowledge about policy and legislation related to equal opportunity in mental health care. MHWs with experience working with people with communication access needs felt that communication breakdowns in mental health care came from a lack of MHW confidence and education regarding working with this population.

Both interviewees with communication access needs and ECP interviewees identified that some counsellors did not understand the person's methods of expression and consequently dismissed their communication. For example, Fleur preferred not to use her communication board in counselling sessions. It was important to her that MHWs used a range of communication strategies to support her independence, asking well-crafted questions and drawing on information from her CA to provide context where needed. ECPs also identified that some MHWs were challenged by needing to adjust their counselling style to use more closed questions. In counselling and psychotherapy, there may be an assumption that speech is essential, as one ECP said: “With psychologists, it's all about communicating, so what happens when they can’t talk?” Further, one MHW stated that people who do not use speech may not benefit from the mental health service the MHW worked for: “If the person’s (…) unable to verbalise what it is that they want, they may not find us particularly helpful.” MHWs' use of traditional “talk therapies” can limit participation in therapy for people with communication access needs. One MHW called upon practitioners to be more innovative about how they involved people with communication difficulties in mental health support.

Interviewees from all groups discussed a lack of skills and knowledge among MHWs to adequately promote communication access. This had flow-on impacts on diagnosis and intervention including providing opportunities for feedback, establishing goals for intervention, and developing rapport.

MHW Attitude. The key attitudinal barrier related to MHWs’ misconceptions about capacity of people with communication access needs to engage in mental health care. Misconceptions about the capacity led MHWs to refer to ECPs instead of the person seeking mental health care. Additionally, MHWs who did not understand the person tended to limit the therapeutic options offered to the person. Some MHW attitudes appeared to stem from the systemic exclusion of people with communication access needs described previously under the systems factors subtheme.

MHW Approach. The data highlighted the importance of the approach used by MHWs, which had the potential to act as a barrier to access mental health care. Lived experience and ECP interviewees identified three MHW approaches that reduced access in mental health care: disagreement on intervention objectives, lack of opportunities for feedback, and exclusion of ECPs in mental health care delivery. MHWs failed to establish agreed objectives for mental health interventions. In some instances, MHWs relied upon information from ECPs, rather than the expressed goals of the person with communication access needs.

Additionally, some MHWs may not grasp the power imbalances that occur in intervention. Interviews with MHWs provided a picture of the power imbalances that may arise in mental health care. Power imbalances were evident in the prescribing of psychoactive medications without proper diagnostic investigations and in the presentation of treatment options. Some MHWs suggested that people with communication access needs were not given opportunities to give feedback about treatment, and they may have accepted sub-standard services, including being prescribed medications that do not benefit them or that are detrimental to their health.

Barriers to Diagnosis. MHWs discussed challenges in diagnosing mental illness in people with communication access needs, particularly with diagnostic tools predominantly reliant on spoken self-reports of symptoms. MHWs mentioned that clients struggled to describe their experiences and symptoms if they did not have access to the vocabulary they required. MHWs also spoke about the risk of acquiescence due to cognitive fatigue when using unsuitable diagnostic tools with lengthy self-report questionnaires. They highlighted a need for validated assessment tools with options to modify communication where needed. MHWs identified one of the risks for people with communication access needs attempting to access mental health care as *diagnostic overshadowing*. Some MHWs also referred to this as “behavioural overshadowing”. Diagnostic overshadowing occurs when symptoms, or behaviour, indicative of a mental health problem or psychological distress are misattributed to the person’s disability diagnosis. Diagnostic overshadowing was discussed by ECP and MHW interviewees with extensive experience working with people with disability. One of the consequences of diagnostic overshadowing mentioned was the exclusion of people with disability from mental health services, as discussed under the systems factors subtheme. ECPs spoke about the challenges of diagnostic overshadowing for people with communication access needs, as expressed by Aster: “I think it can be hard for people to get a diagnosis when they have other disabilities that can mask their psychosocial needs”. The consequences of diagnostic overshadowing were seen as denial of access to proper diagnostic processes, exclusion from mental health services, limited treatment options, and mis-prescribed medications.

Overreliance on Medication. ECP and MHW interviewees also spoke of an overreliance on medications to treat symptoms of mental ill health. ECPs spoke of medication as the only strategy in place to manage symptoms of severe distress in some people with communication access needs. Additionally, MHWs discussed the legacy of people being prescribed dangerous levels of medication without proper oversight of their treatment. One MHW connected the risk of over-prescribing with the experience of communication access needs, particularly for people who use behaviour to express distress. Other MHWs discussed discrepancies in the management of psychoactive medicines prescribed to people with communication access needs compared to the general population, highlighting a lack of medication reviews. Miranda described her experience of supporting a woman and her family to advocate for a medication review. She cited the NDIS restrictive practices policy as a source of support for MHWs advocating for greater transparency in the prescription of psychoactive medications. Overmedication and medication mismanagement were a key issue identified by MHWs and ECPs, an issue that links to diagnostic barriers and the exclusion of people with disability from mental health services.

Table 6.9

MHW Practitioner Factors as Barriers to Mental Health Care Access

Coding	**References**			**Example quote**
Participant group	L.E.	ECP	MHW	
MHW Skills & Knowledge				
MHW communication skills	6	13	26	Fleur: (Looks to C.A. They have obviously spoken about this prior to the interview.) CA: *Yes. I supported you at counselling many, many, many years ago. And it was really hard because the counsellor didn't know Fleur. I felt like he thought I was putting words in her mouth… We did it 3 times and then I think because we talked about the issue a couple of times, Fleur said 'that's it, I don't want to do it anymore' (...). And then more recently she saw (another counsellor).* Researcher: *Okay, so that's a good example the first one, so you just went the three times, did you find it useful?* Fleur: 'No' (Shakes head) Researcher: *Are you saying that you didn't really find it useful?* Fleur: 'Yes' (Nods head) Researcher: *Did the counsellor understand your communication?* Fleur: 'No' (Shakes head) Aster (ECP): *I think it's a lot more difficult because the additional communication tools that might be needed aren't necessarily in the area of expertise of every mental health professional.*
Reliance on speech	0	2	6	Miranda (MHW): *I think there's still too much focus on the talking therapies, and I think there's a lot more to do it and actually talking – especially when you've got communication difficulties or you*

Coding	References			Example quote
				can't express yourself, it might not be the most effective way to address mental health and wellbeing, so I think we can get a bit more creative. *Luis (MHW): The other thing is most of the approaches to mental health are speech, so they do rely on speech. That's generally how they're designed. We don't have a lot that don't rely on speech.*
Lack of rapport	0	9	4	Demi (ECP): *These people that we support, they will never get that choice. They will get one (MHW) assigned to them, if they get there, and that would be it. And if they don't like that person or they don't connect, or they don't understand because people don't always understand each other. You need to find the right person, like, you're not friends with everyone.* Mari (MHW): *Developing a rapport with new people is incredibly difficult for people with communication issues. And yet it's what's at the basis of our work. So, for a support worker coming in who knows nothing about this person, they can't ask the person the question. Or they can, but the response is going to be limited.*
MHW attitudes				
Misconceptions about capacity.	1	2	1	Emmylou (ECP): *I've seen people that will automatically assume that we will talk for them, and other times they will be really wonderful, and they will wait, and look and wait for the answer. So, I get quite frustrated when someone will automatically turn to me when they are talking to a person I support. And I will make it very clear that the person I support is going to answer that question, and if they need assistance, they will ask me to help themselves.* Aiden (MHW): *I've had to advocate for people so many times to encourage people to actually talk to them instead of to talk to me. And then expect me to answer for someone and that happens even more if someone hard to get through to or if they've got a cognitive delay.*

Coding	**References**			**Example quote**
MHW approach				
Lack of agreement re: intervention objectives	4	1	2	Researcher: *With the (MHW), did they focus on your goals? The things that you wanted to do.* Laura: ‘No!’ (Shakes head) Hetty (MHW): *But also, like some of them, remember, some of ours are on (involuntary) Treatment Orders and so they hate us, and they just don't like us.*
Lack of opportunities for feedback on intervention.	1	0	4	Researcher: *Was there anything you found helpful from doing CBT?* Amelia: ‘No’ (Shakes head) Researcher: *You’re shaking your head, that’s a definite no. Who delivered the CBT?* Amelia: “*Psychologist*” Researcher: *Did you go to the psychologist specifically for CBT?* Amelia: ‘No’ (Shakes head) Researcher: *Okay, so you were seeing them for counselling more generally and they used CBT as an approach.* Amelia: ‘Yes’ (Nods head) Researcher: *Okay. Did they persist with CBT for long?* Amelia: “*Years*” Researcher: *Years! But you don’t feel that you got any benefit from it?* Amelia: *No.* Researcher: *How did you feel about it at the time? You kept going with it even though you felt you weren't getting the outcomes…* Amelia: “*Frustrated*”

Coding	References			Example quote
Exclusion of ECPs	0	6	2	Paulette (ECP): *(My son) kept saying he didn't want any help. He was fine, it was just his mother was worrying. They believed him and he deteriorated and was another year until… Exactly two years after his assault that they eventually detained him because he basically he's almost starved himself to death.* Karina: *You know, you might go to (an MHW), and they might come out with all these strategies. Let's do this. Let's do that. But they don't listen to us. When I say, you know, we've actually tried that, and this was the result of that.*
Barriers to diagnosis	0	1	13	Aster (ECP): *There are some good psychologists and psychiatrists but that's where people have already got that diagnosis and they're referred through the system.* Siegfried (MHW): A *lot of your assessment tools are based on communication, it's based on people telling you what's going on for them, what their subjective experience is, what's going on inside their head, and if you don't have that, it can be very difficult from a clinical point of view.*
Diagnostic overshadowing	0	9	7	Paulette (ECP): *They took him off (the medication) once. That was when he ended up with two years in (a psychiatric facility) (…) the psychiatrist said, "look, I honestly think most of (his) symptomatology is due to his acquired brain injury and I want to see what it's like without any medication at all".* *Miranda (MHW): (Symptoms) are often classified as behaviours and they're immediately handballed back. People don't even get reviews. So, they're hospitalised for behaviours which could very well likely be caused by mental health issues but are not even doing a psych assessment.*

Coding	References			Example quote
				Luis (MHW): *So, mental health is not picked up, because it’s what we’d say diagnostic overshadowing (…) and sometimes, we have this behavioural overshadowing.*
Overuse of medication.	0	1	9	Demi (ECP): *I don't believe that there is any, that I've ever seen really, mental health support. And like this one person that has mental health issues, he's just on medication and I think that's the ultimate of his support.* Siegfried (MHW): *I guess the absence of, or poor communication, or difficulties with communication shall we say, I think also leads to maybe overtreatment, and sometimes inappropriate treatment being administered in order to try and manage the challenging behaviour or the maladaptive communication, or whatever you want to call it.*

6.4.2 MHW Practitioner Facilitators

While the barriers related to MHW practices were far-reaching, survey respondents and interviewees from all groups were able to identify a range of important facilitators that enabled people with communication access needs to gain mental health care. These practitioner factors were related to MHWs’ communication skills and knowledge, facilitative attitudes, and beneficial practitioner approaches. They are described in-depth in the following sections.

MHW Communication Skill and Knowledge. MHW survey respondents were asked to identify the top five skills required by practitioners providing mental health services to people with communication access needs. Of the 29 MHW survey respondents, 14 responded to this question (see Table 6.10). MHW responses to this question related predominantly to counselling micro-skills; attending to non-verbal cues, listening actively, checking back with the person to ensure the message had been correctly received, and using clear speech. Additionally, providing enough time was among the frequently identified MHW skills. This was consistent with the most useful communication partner skills identified by survey respondents and ECPs under the subtheme communication access factors (section 6.1). Data from interviews yielded further detail regarding the communication skills and knowledge required by MHWs. MHW interviewees discussed using adapted teaching strategies to assist people in developing skills to manage their emotional wellbeing and the importance of examining the communicative intent of underlying behaviour. Additionally, MHWs identified the value of communication skills in developing trust and rapport with clients with communication access needs. Many of the specific communication skills employed by MHWs have also been discussed in the scoping review (E. Watson et al., 2022) and findings in Chapter 5.

Table 6.10

MHW Skills Required to Work with People with Communication Access Needs

Skills category	Skills	MHW responses (Total *n=14*)
Micro-skills	Attend to non-verbal cues	6
	Listening	6
	Clear speech	6
	Check, confirm, or summarise message	6
	Use closed questions	1
	Use open questions	1
	Use eye-contact	1
	Focus on client	1
Adaptations	Time/ patience	6
	Provide written information to summarise session	3
	Offer breaks	1
	Use intervention less reliant on speech (mindfulness)	1
	Provide literacy supports	1
	Match communication to the person's abilities	1
	Use a cultural advisor	1
	Provide accessible written information	1
	Use plain language	1
Planning	Simplify or clarify intervention objectives	3
	Establish communication strategies before intervention	1
	Plan intervention	1
	Review intervention on ongoing basis	1
	Consultation	1
AAC skills	Human assistance: ECP.	3
	Human assistance: Professional	2
	Incorporate AAC	2
	Use visual aids	1
Knowledge	Knowledge of condition impacting communication	1
	Experience of working with people w. CCN	1
	MHWs train to work with people w. CCN	1

Teaching Strategies. Like the personalised mental health resources discussed previously, teaching strategies were adjusted to meet individuals' requirements. ECP and lived experience interviewees noted that teaching strategies needed to be personalised in terms of timing, motivation, and acceptability to the person. ECPs discussed the use of roleplay, tactile objects, and equine therapy to teach interpersonal skills, problem-solving, affective awareness, and coping skills.

MHWs discussed their use of different teaching strategies with people with communication access needs including roleplay, video modelling, board games, drama, drawing, art, and crafts. Most MHWs used a range of resources and strategies to improve communication access in their practice. MHWs used adapted teaching strategies to assist people to learn about emotions and behaviour.

> *Luis:* *I use CBT. I use whiteboards, graphics, you block it up into four, and people draw. So, it's a lot of drawing. (…). I carry a portable whiteboard with me, and people draw and write.*

MHWs discussed the need for a nuanced approach whereby MHWs seek out naturally occurring moments for learning.

> *Aiden:* *I don't set out with an agenda; so okay, today I'm gonna focus on this or this or this. I've got a few things that when the opportunity arises organically, I want to work into the group (…) But I need to wait for the moment where it's going to be most impactful.*

In group psychoeducational support, MHWs discussed the value of participants learning from one another.

> *Luis:* *Because of the learnings cross by different people sharing experiences. And people start to teach each other (…) Yeah, the cross learning is really powerful.*

MHWs described personalised approaches to teaching skills and concepts as being most valuable when working with people with communication access needs.

Examining the Communicative Intent of Behaviour. The majority of MHW interviewees identified the importance of exploring the communicative potential of behaviour changes as an indicator of emotional distress or a mental health problem. For MHW interviewees investigating behaviour was important and worthy of investigation as it related to communication about distress.

> *Mike:* *Are there other things going on as to why they're clearly distressed and agitated, but why? Why are they not able to tell us what's going on for that, that requires quite a bit of investigation.*

MHWs discussed how observing changes in a person's behaviour and functioning could improve understanding of the person, assist in measuring the efficacy of intervention, and lead to improvements in quality of life. Recording behaviour was a way to gain an understanding of the person's response to intervention.

> *Jordy:* *Observations, observation is really key. But I also do some recording at times around mood, participation, engagement. You know that's really important for how you feel and whether you're coping.*

One MHW spoke about using the CAUSE-HD model, an adapted model that focused on exploring behavioural indicators of distress in people with Huntington's disease.

> *Mari:* *So, what it's about is really looking at the person and their environment and whatever the behaviour is that's going on. Trying to establish an understanding of why something might be happening, why a person might be behaving in the way that they are, so that you can look at those issues of how we get them to a stage where they feel comfortable, and those behaviours are not necessary anymore.*

Observing behaviour and changes in functioning was part of a holistic approach to supporting mental health and wellbeing. Additionally, behaviour was identified as an indicator of distress in particular scenarios requiring observation to informing changes that support quality of life.

Building Trust and Rapport. All MHW interviewees spoke about the importance of rapport in establishing a successful therapeutic relationship. MHWs acknowledged that a fundamental part of developing rapport was gaining an understanding of the person's preferred communication methods.

> *Jordy:* *I like to learn someone's speech patterns. At the moment I'm working with someone, and I haven't learned their speech patterns yet, and in order to learn their speech patterns, they have to actually speak, so they have to be comfortable enough with me to speak, which is difficult for them. (…) I can then understand their speech pattern. So, there's all this stuff that's happening before you even get to the actual therapy point.*

MHWs also discussed the importance of understanding the person's strengths, interests, and concerns in developing rapport.

> *Mari:* *And particularly with communication with people too. At the end of the day, understanding the person who I'm with and having some knowledge about their background and how they've done things in the past will influence our communication and what we might be able to use in terms of connecting. And, for me, that personal connection is the key. If you make some connection with somebody, then you've got something to work with. So, that therapeutic relationship is essential.*

MHWs accepted responsibility for creating a comfortable space in which people could communicate openly to support their personal growth.

> *Luis:* *If they don't feel comfortable in their communication with you, they won't want to come back and tell you, and they won't learn to grow. So, it has to be a rich communication environment (…) I have to create that world for the person.*

MWHs discussed trust and rapport as the foundation of mental health care. Gaining an understanding of a person's communication preferences, strengths and interests was viewed by MHWs as essential to developing an effective therapeutic relationship.

MHW Attitudinal Facilitators. MHW attitudinal factors were identified in both the surveys and interviews. MHW survey respondents (*n=15*) answered an open question asking: "What are the most important attitudes of MHWs working with people with communication access needs?" Because this question yielded answers that were outside of the existing framework, the responses were coded separately, and key dimensions were explored for frequency. The word cloud in Figure 6.2 illustrates the most important attitudes as identified by MHWs. Patience (*n=7*), an attitude associated with the behaviour of waiting, was the most frequently identified disposition for effective practice with people with communication access needs. This was followed by compassion (*n=4*), openness to communication diversity, assuming capacity, persistence, and openness to learning (*n=3*). Elements related to personalisation such as adaptability, flexibility, and person-centredness (*n=2*) were less common. All other attitudes in the word cloud were identified by one MHW. Findings from the interviews yielded the following attitudinal categories: openness to communication diversity, and person-centredness, which are explored below.

Figure 6.2

Important Attitudes for MHWs Working with People with Communication Access Needs

MHWs Openness to Communication Diversity. A key facilitating factor in promoting communication access was MHW attitudes toward communication diversity. *Openness to communication diversity* among MHW interviewees was not predicated on extensive experience of working with people with communication access needs. Lived experience interviewees highlighted the importance of MHWs being open to learning about the ways that they communicate.

> *Researcher: You've got a lot of ways of communicating, do you want (MHWs) to pay attention to all of them?*
>
> *Chris: Yes*
>
> *Researcher: So, watching for your hand signals, your facial expressions, your voice, and Grid Pad as well.*
>
> *Chris:* 'Yes' (Chris is smiling and using his hand signal to indicate 'Yes')
>
> *CA2: You've got a variety of ways of (communicating), haven't you buddy?*
>
> *Chris: Yeh.*

MHWs with little experience of working with people with communication access needs, discussed being guided by their values to learn about the person's communication preferences.

> *John:* *So, it’s mainly just my own common sense and compassion and all those things and just learning about the person, and that’s how I really learn to communicate with (people with communication access needs).*

John also mentioned drawing on experiences of working with translators to support the inclusion of people from culturally and linguistically diverse backgrounds in mental health support.

MHWs with more experience spoke about being willing to try a variety of communication strategies to assist the person to benefit mental health services.

> *Jordy:* *If somebody doesn't have verbal communication, you can do this in so many different ways because you can do it with scrapbooking, with artwork, with (play). (…) It doesn't have to be telling the story verbally. There's a lot of scope and I think it's a lot easier for people to understand.*

Luis, a MHW with vast experience working with people with communication access needs, demonstrated how valuing communication diversity permeated his approach to counselling, reflected in a responsive and personalised approach:

> *Luis:* *This is the other thing too, that comes in really strong in individual counselling, is the way people like to communicate (…) So, I actually start to slip away from some of the devices, because people would prefer to use speech – if there’s a bit of speech, (…) and they prefer to stick with yes or no, (…) and we only go to (the AAC device) if we need to. So, (…) we try to keep communicating by looking and watching at how we react to each other, and we only go to those devices when we really need to.*

MHWs’ *openness to communication diversity* was important to people with communication access needs. Openness meant that preferred methods of communication were utilised and respected in mental health support. MHWs who discussed having an open attitude to communication diversity were amenable to trying a variety of modes of communication to ensure that people with communication access needs benefited from mental health support.

Person-centredness. Lived experience interviewees discussed the benefit of *person-centred attitudes among MHWs.* Person-centred attitudes in mental health support manifested as respect for communication, supporting active participation in intervention goal setting, and the personalisation of mental health support. Lived experience and ECP interviewees spoke about the importance of MHWs working towards the person’s self-defined goals, communicating in ways that conveyed respect and developing rapport. These therapeutic qualities have been discussed in previous sections. In this section, the focus is the MHW concept of person-centredness and its impact on the provision of mental health services.

MHW interviewees discussed the importance of the person with communication access needs defining the direction and mode of the intervention. Multiple MHWs discussed how a person-centred approach underpinned the personalisation of counselling practice.

> *Jordy:* *I'm so passionate about counselling. You find a way, right? Somebody has come to you because they want to sort some stuff out. Sometimes people come because they actually want to understand themselves better. That's really cool. And my job is to find a way where they can do that.*

Another MHW spoke about layering techniques and strategies over the person-centred approach to counselling.

> *Luis:* *So, when I do cognitive behaviour therapy, it sits on top of the person-centred. When I do anger management, sits on the person-centred. (…) So, everything is trying to get the person to lead, to be in control of that conversation, where they're going.*

Multiple MHWs discussed the role of person-centred attitudes in recovery oriented mental support. John a peer-specialist MHW noted that person-centredness was part of the culture of the service that he worked for as well as personal value deeply connected to his lived experience.

> *John:* *Well, not only is it ingrained in the services that I work for, but it's ingrained as a personal value because I have lived experience and I've been a person who has used services, and when I'm having the input into my own recovery – I feel like people are listening to me and have an understanding of what I'm going through.*

MHWs who discussed person-centredness were committed to inclusion in mental health support. They ensured that people with communication access needs were driving goal setting in mental health interventions and were adaptable in their approach. Person-centredness was a value that was connected to strengths-based, recovery-oriented mental health support.

MHW Approach. MHWs employed a range of approaches that were viewed as facilitating access to mental health care. Beneficial MHW approaches were holistic in nature, meaning that the MHWs adopted an approach that considered all domains of the person's life: social, psychological, physical, and cognitive. The holistic approach was integrated with other approaches such as multi-disciplinary mental health care, use of appropriate diagnostic processes, and collaboration with ECPs.

Multi-disciplinary Mental Health Teams. The benefits of working in a multidisciplinary team were discussed by MHWs and ECPs. The disciplines mentioned included occupational therapists, speech and language pathologists, developmental educators, psychiatrists, psychologists, PBS practitioners, physiotherapists, and social workers. Others included in the multi-disciplinary team were family members, friends, advocates and in some instances an appointed guardian. All interviewees who discussed multi-disciplinary teams spoke about the advantage of having multiple perspectives on the person's mental health support. These diverse perspectives resulted in a more holistic model of mental health support which was considered important in meeting the intersecting impacts on the mental health of many people with communication access needs.

> *Demi:* *I think that making sure you have lots of different eyes on the situation, not just someone who is focused on behaviour, or someone who's focused on health. You need the holistic approach with everything.*

And

> *Hetty:* *Because again it's that specialty and getting that holistic approach to that person is vital, especially in our cohort.*

Another ECP relayed a story where having a team with varied expertise work together to support the person's mental health had resulted in funding for a communication device.

> *Emmylou:* *By everyone being on the same page it created more opportunities and being able to then communicate themselves. A communication device was put into play after years of it being knocked back, and the difference that it made was amazing. And the impact of that is his mental health has just been so much better. The anxiety has lessened, and the support workers now are looking for things they never thought they'd be able to do with him.*

MHWs also discussed the benefit of learning from other professionals in a multi-disciplinary team, developing their capacity to support the person with communication access needs.

> *Mike:* *And what's nice is – if you work in a good workplace with a multi-disciplinary team, everyone shares their knowledge and their information. You do learn a lot quite quickly from others. We might all have a little bit of a different perspective and a different lens, but you will learn from the others really fast. In the social work area, it's very much – you learn from the others and then you find the service that will meet that person's needs.*

MHWs valued and respected the role of other professionals. Multi-disciplinary approaches to mental health care enabled MHWs to develop their knowledge and skills regarding communication access. Multi-disciplinary teams provided a holistic perspective on the issues that impact on the mental health and wellbeing of people with communication access needs.

Appropriate Diagnostic Assessments. Barriers to diagnosis were identified as an impediment to mental health care access. Reliance on speech for diagnosis and diagnostic overshadowing prevented people with communication access needs from receiving appropriate investigation and treatment for potential mental health problems. Conversely, MHWs discussed the use of diagnostic processes that comprehensively examined the physical, psychological, and behavioural symptoms alongside behavioural changes and life circumstances.

MHWs who worked for an older persons' mental health service provided examples of using assessments as a process of elimination with people with communication access needs. Mike discussed using the Montreal Cognitive Assessment (MoCA) to determine the origins of symptoms of mental ill-health related to cognitive changes.

> *Mike:* *We do a MoCA, it's a cognitive test with them, and we have a neuropsychologist on the team who will do more comprehensive testing if that mocker puts them in a bit of a grey area if it is something maybe neurodegenerative going on here, and then obviously off for MRIs and CT scans.*

The same MHW discussed a comprehensive diagnostic assessment process inclusive of pathology tests of blood and urine, as well as depression and anxiety scales to better understand the presentation of symptoms in people with communication access needs and ensure the person received the correct treatment.

The only psychiatrist to participate in an interview discussed the challenges using adapted diagnostic criteria.

> *Siegfried:* *The checklists that I'm using aren't actually targeted towards this population. I do have a copy of the DM-ID2, which is essentially the translation if you like of the DSM, for people with intellectual disabilities of various levels. That can be quite helpful I guess, to try and translate some of those diagnostic criteria, although often it loses something in the translation, I think.*

MHWs indicated that diagnostic processes for mental health problems in people with communication access needs require attention to the suitability of the assessment tools. Diagnostic tools are needed that accommodate for difficulties with the use of speech, as well as other social determinants, like access to education.

> *Hetty:* *Sometimes you just.. like it depends on the way a person knows how to learn. And don't forget quite a lot of our cohort never went past grade*

> *seven. So, one thing we do is – which I'm trying to instil in everybody – is that we do a cognitive test first and see what the baseline is. So that we're not giving them tasks that they can't do because they haven't got the concept or the context, or the education to do so.*

According to the MHWs, the use of appropriate and comprehensive diagnostic processes to determine the origins of symptoms of potential mental health problems could enable better access to suitable treatments and services.

Collaborative Approach with ECPs. Interviewees from all groups discussed the need for a collaborative approach to mental health support that included ECPs. As previously discussed, collaboration between MHWs and ECPs is ideally undertaken with the consent of the person with communication access needs and builds upon a person-centred model of support. ECPs discussed various modes of contribution to mental health support, from meeting with MHWs to help frame their understanding of mental health concerns to implementing support strategies. One parent discussed how she, her son, and his MHW negotiated appointments to ensure transparency.

> *Paulette: I think that very first psychiatrist we had, she set it up. She talked to (my son). Then she talked to me, and then she brought him back in, and the three of us talked.*

Paulette and her son continue to work together with psychiatrists in this way to manage his medications. Other MHWs negotiated communication with ECPs and the person with communication access needs, to ensure that the person retained the central focus in mental health care.

> *Mari: It takes time, and it takes care, but it's possible. And I think that that's a really important element, that having those supports around when you're doing that communication and demonstrating how to do it respectfully. And acknowledging that (the ECP) might know stuff, but it's good to ask (the person) if there's anything else as well.*

MHW interviewees felt that ECPs made important contributions to mental health support and provided valuable perspectives on the person's experience, particularly those who knew the person well.

> *Siegfried: I think some of the more complex people are actually very fortunate that there are some very good carers there. A lot of them have got people working with them who have got a lot of experience (…), so that I think that has been really helpful for some.*

MHWs also spoke about providing psychoeducation to ECPs to enable them to better support the person with communication access needs in managing mental ill-health.

> Hetty: *But also understanding things like depression. (…) a lot of that is educating the person regarding the mental health issues and the family members. (…) And so, there was a lot of education around family and things like that.*

Equally, ECPs wanted their training and education needs to be considered in the funding of mental health support so that staff were better equipped to help the person.

> Ariel: *I would like to see it more recognized by NDIS. And I understand that the customer is a very important person, but they also need to think of the staff and include staff training because in the end (we're) there for the customer.*

MHWs highlighted the need to balance the rights of the person receiving mental health services and the knowledge of their supporters. ECP and MHW interviewees highlighted the need to respect the perspectives of ECPs while maintaining a person-centred approach.

6.5 Environmental Access Factors

The fifth subtheme within the factors affecting access to mental health care for people with communication access needs concerned *environmental access factors* – those factors related to the environments that mental health care was provided in. In considering the environmental factors, participants discussed physical aspects of the services location as well as the comfort and safety of the space. Environmental access related to the ease with which people with communication access needs could use the mental health care space. The barriers and facilitators related to environmental access factors are presented in Table 6.11 and discussed in the two following sub-sections.

Table 6.11

Summary of Environmental Access Barriers and Facilitators

Environmental barriers	Environmental facilitators
Poor physical access to mental health services' premises.	Home visits from MHWs. Telehealth.

6.5.1 Environmental Access Barriers

Environmental access barriers in this study were synonymous with physical access to the spaces where mental health services were provided. Interviewees identified few environmental access barriers in mental health service access, and none were identified by survey participants. Interviewees from all groups discussed access to buildings where mental health services were provided to people with communication access needs who used mobility aids. In each instance where barriers were noted, the entire building was either completely inaccessible, requiring services to be delivered in an alternative location, or parts of the building were unavailable to people using mobility aids. One participant identified that accessible service delivery spaces where people could move freely made people feel welcome. Table 6.12 summarises the environmental access barriers.

Table 6.12

Environmental Access Factors as Barriers to Mental Health Care

Coding	**References**			**Example quote**
Participant group:	L.E.	ECP	MHW	
Poor physical access to mental health services.	1	1	1	Amelia: "*I remember having to see one guy in the hospital because his rooms were not accessible*" Emmylou (ECP): *There are a lot of facilities that are not accessible. Just because a place has a ramp, it doesn't mean that an electric wheelchair is going to fit through it or have the room to turn around in. (…) They've been able to get in the door, but they've taken chunks out of hallways. You can't turn around, there's no space, so it's not really accessible at all.* Aiden (MHW): *I mean when we first rented this place, we're really concerned about the positioning of the hand basin in the bathroom because you can get a manual wheelchair through there. But an electric one would potentially not work. So yeah, we thought about it a lot, and at the end of the day we were constrained by the properties that were on the market where we needed them.*

6.5.2 Environmental Access Facilitators

Environmental access facilitators related to the ease of access in the environments where mental health care was provided. Interviewees emphasised the need for mental health care to be delivered in safe, comfortable environments that were easy to reach. In this section findings are presented regarding home-visits and telehealth to improve accessibility of mental health services for people with communication access needs.

Home Visits. Interviewees from all groups identified the benefits of home visits and telehealth in circumventing barriers related to environmental access. From the environmental access perspective, the provision of mental health services via telehealth and home visits supported access where a person could not tolerate being in a clinical office setting. Paulette provided an example of an exceptional GP who was able to address access barriers related to medical trauma and communication access needs by providing home visits.

> *Paulette:* *There's such a lack in the services and because (our son) is seen by services as being "difficult to engage" (...). But you can engage, you know. We got a GP once. GPs are so hard to get with people like (our son) because he won't go to doctor's offices, he just won't. Anyway, we got this amazing doctor (…). When she heard about (our son), she agreed to come out to see him (…). She came and she knew the situation and (our son) came and went, (…) And she had pieces of paper and stuff because she knew, he writes. And eventually he came and sat down.*

This example illustrates the time and flexibility required to build enough trust to support engagement and communication. This was facilitated by providing a safe and familiar environment (the home) for appointments. For Paulette's son, physical and mental health are intrinsically linked as his chronic health condition is increasingly difficult for him to manage when mentally unwell.

ECPs and MHWs discussed how home visits allowed people who were often excluded in office settings to receive mental health services by providing space for the person to self-regulate input, engaging and disengaging as required.

> *Siegfried:* *It is helpful seeing people in their context, absolutely, yes. It depends on the individual but (…) because where I'm at is an unfamiliar environment, and they'd rather be elsewhere, and I'm unfamiliar, that can lead to distress, or "I want out", or whatever. That might not necessarily be something that you see in their home environment, where they're feeling a bit more comfortable.*

MHWs described the benefits of providing mental health services in alternative locations, making mental health services accessible to people who find unfamiliar environments difficult to tolerate.

Telehealth. Laura, who lived in a regional area noted that she liked telehealth because it reduced travel to mental health services in the city, a 90-minute drive from her home.

CA1:	*How would you make (your mental health services) different?*
Laura:	'Use the phone' (Shapes hand like a phone receiver)
CA1:	*So, you want to have more support to call (the MHW)? (pauses) Or do you want to be able to have the appointment over the phone?*
Laura:	'That's it!' (Nods head)
CA1:	*Yes, to over-the-phone support?*
Laura:	'Yes' (Nods head)
CA1:	*Or do you mean (video call on the phone)?*
Laura:	'Yes, video call' (Nods head for video call)

One MHW cautioned that the success of telehealth appointments is dependent upon having access to appropriate technologies and human support to use those technologies.

Mari:	*OK, so we've got telehealth available, but not everyone's got a computer at home. Not everyone's got a laptop, not everyone's got an iPad. Even if they had an iPad, they may not be able to use it. So, we have a whole raft of things to think about (…) like will there be someone there who can assist them to join the link? Do they need somebody there who can help us understand what they're saying?*

Survey data echoed a need to consider the accessibility of telehealth services. One MHW survey respondent stated that there was a need for "More face-to-face appointments and not telehealth". In their survey responses 89% of people with communication access needs (*n=8*) identified that they were unlikely to use mental health phonelines. When asked about ease of access of mental health phonelines 44% of respondents with communication access needs (*n=4*) identified that they felt this type of service was not at all accessible. A further 22% of respondents identified that access to mental health phonelines required some support (*n=2*), while 33% were not sure how easy it would be to use phone supports (*n=3*).

Survey respondents with communication access needs were more likely to use mental health care delivered via instant messaging or chat rooms. Half of the respondents were likely to use this type of support: 44% were somewhat likely (*n=4*), and 11% were very likely (*n=1*), while 44% were not at all likely to use live chat supports. Regarding accessibility of chat supports 11% of respondents (*n=1*) believed these services were easy to use, 33% stated that they would require some support (*n=3*), and 22% found these services in accessible. The three remaining respondents were unsure about how accessible mental health chat rooms were.

Environmental access related to ease of use of the spaces where mental health services are provided. Physical access was an important consideration in spaces where mental health care was provided. However, the accessibility of online service spaces must also be evaluated.

6.6 Chapter Summary

To summarise, the findings presented in this chapter exposed the barriers and facilitators encountered by people with communication access needs when seeking mental health care. Several key insights have emerged across the subthemes of Communication Access Factors, Systems Factors, ECP Supporter Factors, MHW Practitioner Factors, and Environmental Factors. Communication access factors, including the availability of AAC and the presence of skilled communication partners, were identified as pivotal facilitators for effective communication between individuals and MHWs. Systems Factors, such as funding, fragmented service delivery, and siloed support systems emerged as significant barriers, highlighting the need for integrated mental health care pathways. ECP supporter factors, including the role of family members, friends, and support workers, demonstrated that ECPs were essential in aiding access to mental health care. Mental Health Practitioner Factors, encompassing knowledge, attitudes, and practices, were highlighted as influential in determining the quality of care and therapeutic experience. Lastly, Environmental Factors, such as physical accessibility, played a critical role in fostering a safe and inclusive environment. These findings demonstrate the interplay between a range of factors in shaping the mental health care experiences of people with communication access needs. By addressing barriers and leveraging facilitators, mental health systems can work towards creating more accessible, inclusive, and person-centred care settings.

In Chapter Seven the findings in this chapter and Chapter 5 will be discussed, using Levesque et al.’s (2013) Conceptual Model of Access to Health Care as a framework. Chapter 7 will conclude with a range of recommendations for improving access to mental health care for people with communication access needs informed by these findings, and by existing literature and policy.

CHAPTER 7. DISCUSSION

This chapter provides a discussion of the views and perspectives of the three groups of participants in this research: people with communication access needs, everyday communication partners (ECPs), and mental health workers (MHWs), on the topic of communication access in mental health support. The researcher explored the mental health knowledge and help-seeking experiences of people with communication access needs and ECPs, and the attitudes, knowledge, and skills of MHWs to gain a deeper understanding of the factors impacting mental health and access to support. The findings increase understanding regarding the accessibility pinch-points encountered by people with communication access needs across the mental health system. In addition, the findings shed light on how mental health supports can be adapted to promote access for people with communication access needs. Prioritising lived-experience perspectives in the research design and analysis elucidated access solutions relevant to the community.

The chapter relates the findings to current research and policy, first exploring the role of human rights as social determinants of mental health and establishing the mental health care requirements of people with communication access needs by applying the Conceptual Model of Access to Health Care (Levesque et al., 2013). This synthesis of findings informs the implications for policy and practice to support people with communication access needs to navigate their mental health care-seeking journey.

7.1 Establishing Mental Health Care Requirements of People with Communication Access Needs

Although specific data regarding the prevalence of mental health problems among people with communication access needs is limited (AIHW, 2019; 2022)), researchers have begun to explore large data sets to understand prevalence among other populations that experience communication difficulties, such as adults with intellectual disability (Cooper et al., 2015; Howlett et al., 2015), with autism (Foley & Trollor, 2015; Rydzewska et al., 2018), or with multiple disability (Dunn et al., 2020). The current findings lend support to the existing research that indicates a heightened level of need for mental health care among people who experience impacts upon communication due to disability.

Most participants with communication access needs in this study reported that they had experienced challenges to their mental health and emotional wellbeing and had attempted to access mental health care. Of the six participants interviewed, five expressed a desire to access formal mental health care services, informing us of unmet mental health care needs and a desire to access services that were out of reach to them. This supports the established and broadly accepted view that there is a need for mental health care among people with communication access needs (Pinals et al., 2022a; Weise et al., 2020). Our findings also corroborate research that identifies people with communication access needs as being under-supported by mental health services despite a higher prevalence of distress than non-disabled populations (Di Marco & Iacono, 2007; Noyes & Wilkinson, 2022; E. Watson et al., 2021). As such, where this population experiences decreased mental health, they have the right to access support to restore mental health and improve wellbeing (CRPD, 2006; WHO & CGF, 2014).

7.2 Human Rights and the Realisation of Optimum Mental Health and Wellbeing

The unique set of issues impacting the emotional wellbeing and mental health of people with communication access needs is highlighted in the current study. Participants from all groups indicated an inextricable connection between human rights and mental health. The WHO & CGF (2014) specify that where populations experience undue impact upon mental health and wellbeing, mediating supports should be put in place to ameliorate risks. In regard to determining their sense of emotional wellbeing participants in this study discussed the role of education, suitable housing, meaningful occupation, secure funding for supports, and most emphatically, social connections. As such, mental health promotion among people with communication access needs must consider access to human rights in the attainment of optimum mental health and wellbeing (WHO, 2021a, 2021b).

In this thesis, the exploration of access to mental health care is underpinned by the principles of the CRPD (2006): respect; non-discrimination; full participation and inclusion in society; respect for diversity; equal opportunity; and accessibility. Some specific CRPD articles hold pertinence in interpreting the findings of this study, these are: Article 9: Accessibility; Article 21: Freedom of expression and access to information; Article 25: Right to health; and Article 26: Right to habilitation and rehabilitation. Article 9 deals with accessibility, so the application of the Conceptual Model of Access to Health Care (Levesque et al., 2013) fosters a stepped journey through the process of seeking and realising effective mental health care. The focus of Article 21 is on communication, the right to self-expression and access to information. For participants in this study, respect for diverse modes of communication and the provision of written information in accessible formats was invaluable in both research and mental health care. Articles 25 and 26 deal with access to health care, habilitation, and rehabilitation; the concept that persons with disability have the right to access the highest attainable standards of health without discrimination based on disability (CRPD, 2006). The CRPD comprises the underpinnings for Australian disability legislation and is increasingly influential in policy and practice directives. This study indicated that people with communication access needs faced systemic barriers to obtaining mental health care, suggesting a need for greater human rights protections to promote equitable service use.

During the six months of finalising this thesis, prominent governmental reports were released examining the efficiency of the services available to people with disability in Australia. The final report and recommendations of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Commonwealth of Australia, 2023a) were released in September 2023 and the findings of the Independent Review into the NDIS (Commonwealth of Australia, 2023e) were released in October 2023. These two systemic inquiries and their recommendations are designed to substantially influence the future direction of mental health care services for people with communication access needs. While neither report focuses on access to mental health care specifically, the findings of both reports are presented within a human rights paradigm and therefore are in keeping with the approach taken in this research study. The findings of this study support the recommendations from the Disability Royal Commission that there is a need for better recognition of the rights of people with communication access needs (Commonwealth of Australia, 2023c). Similar to the findings of the Disability Royal Commission, the accounts provided by participants in this study highlighted human rights as intertwined with wellbeing – access to education and employment, secure housing, connection to community and culture, and safe social support systems that enable flourishing, not simply survival, across the lifespan.

In this study lived-experience, ECP, and MHW groups all identified experiences of abuse and neglect as having ongoing impacts on the mental health and emotional wellbeing of people with communication access needs. This information clarified the types of psychological harms sustained by people with communication access needs within the disability support system and the insufficiency of current compliance measures to eradicate abuse and neglect. As suggested by the Disability Royal Commission, a legislative focus on the Human Rights of people with disability will heighten awareness and develop a structured system of compliance reducing the prevalence of rights abuses in the daily lives of people with disability (Commonwealth of Australia, 2023b). In this study the accounts provided by people with communication access needs and ECPs told us that mental health care does not begin and end with the provision of mental health services – structural and social changes are required to prevent psychological harm in daily life, particularly in segregated settings. To inform these changes there is a need for deep engagement with lived-experience perspectives in mental health care design and development (Katterl et al., 2023; NMHC, 2023). Katterl et al.'s (2023) response to the Royal Commission into the Victorian

Mental Health System stipulates that collaboration is essential to repair the harm done to people in the mental health system and establish inclusive and safe support services. Similarly, the NMHC emphasises that collaboration between mental health care consumers, supporters, and service providers via structured co-production processes is vital to designing, delivering, and understanding the impacts of mental health care for marginalised populations (NMHC, 2023). Such findings indicate an acknowledgement within the mental health care system that strategic action is necessary to reduce stigma and exclusion, and better integrate services that sustain emotional wellbeing and mental health.

7.3 A Conceptual Framework to Explore Access to Mental Health Care

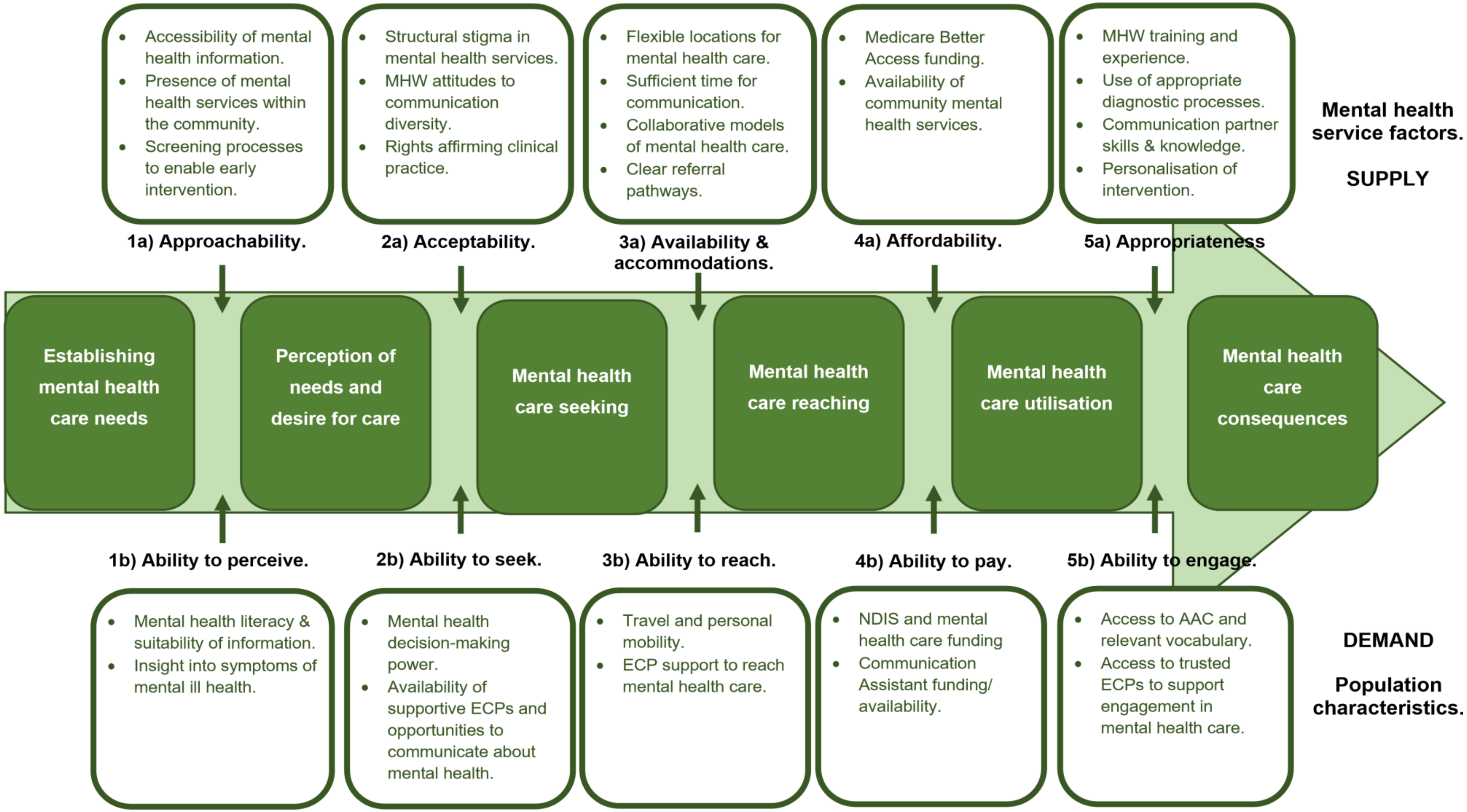
The study contributed compelling evidence to support the need for accessible mental health care among people with communication access needs, which was predicted through the literature and scoping reviews. Acquiring mental health services presents significant challenges to people with communication access needs, from developing knowledge of mental health and conveying a requirement for support to establishing connections with MHWs for effective therapeutic support. Analysis of the survey and interview data revealed that challenges to securing mental health care occurred along a trajectory, with opportunities for support at multiple stages. This trajectory of mental health care seeking was well represented by the Conceptual Model of Access to Health Care (Levesque et al., 2013) which was introduced in the methodology chapter of the thesis (refer to Figure 4.2). The findings from the current study were further synthesised using the Conceptual Model as a framework to track access issues along the mental health care seeking journey. An adapted version of Levesque et al.'s (2013) Conceptual Model of Access to Health Care with integrated findings from this study is presented in Figure 7.1.

Levesque et al. (2013) propose six stages in the mental health help-seeking process: 1) establishing mental health care needs; 2) perception of support needs and desire for care; 3) mental health care seeking; 4) mental health care reaching; 5) mental health care utilisation; and 6) consequences of mental health care (Levesque et al., 2013). The model presents five intersecting dimensions of accessibility with a supply aspect related to service provision (at the top of Figure 7.1) and a demand aspect related to consumers' capacity to access services (at the bottom of Figure 7.1). The intersecting dimensions are: 1a) approachability of mental health services with the corresponding 1b) ability of people with communication access needs to perceive the requirement for mental health care; 2a) acceptability of mental health services and the corresponding 2b) ability of people with communication access needs to seek services; 3a) availability and accommodation of mental health services and the corresponding 3b) ability to reach services; 4a) affordability of mental health services and the corresponding 4b) ability of people with communication access needs to pay for services; and 5a) appropriateness of mental health services and 5b) the ability of people with communication access needs to engage with mental health services. Figure 7.1 illustrates how these five dimensions intersect with the six stages of care seeking outlined in the Conceptual Model of Access to Health Care (Levesque et al., 2013).

Levesque et al. (2013) define access as “opportunity to reach and obtain appropriate health care services in situations of perceived need for care”. Opportunities to access mental health care are influenced by the characteristics of two parties: mental health care providers (represented by the factors at the top of the diagram) and consumers (represented by the factors at bottom of the diagram). For this discussion, the characteristics of providers refers to the overarching public system of health care, as well as mental health organisations, and MHWs who provide services within the mental health support system. The term “consumers” refers to people with communication access needs. While acknowledging the heterogeneity of people with communication access needs, the purpose of this research has been to draw upon commonalities in the experiences among this group. Through the exploration of common experiences, recommendations will be generated to improve access to mental health support for this population. Throughout this section, factors that influence access at each stage of the mental health care seeking process are discussed, incorporating the barriers and facilitators identified in the findings. Using the Conceptual Model of Access to Health Care as a framework to further synthesise data and literature has fostered the development of the implications for policy, service provision, and practice detailed at the end of this chapter.

Figure 7.1

Conceptual Model of Access to Mental Health Care with Integrated Findings, Adapted from Levesque et al. (2013).



7.3.1 Establishing Mental Health Care Needs (1)

The first step in gaining access to mental health care is identifying that there is a requirement for support among the population and conveying the message that there are services available to provide the necessary assistance (Levesque et al., 2013). The two aspects involved in establishing mental health care needs are: 1a) the approachability of mental health services and 1b) the ability of the population with communication access needs to perceive a need for mental health care. Perception of a need for mental health relies on relationships of trust between mental health services and target populations, as well as the health beliefs and attitudes of those seeking mental health care (Schwarz et al., 2022). In this section, we will explore the role of mental health services in informing mental health knowledge and establishing relationships with people with communication access needs.

1a) Approachability of Mental Health Services. The approachability of mental health services is indicated by awareness among the community that mental health services exist, are available, and may benefit the health and wellbeing of an individual (Levesque et al., 2013). Characteristics such as availability of information about services, community presence, and screening processes are generally associated with the approachability of mental health services. These characteristics are applied to the present study in the following paragraphs.

Accessibility of Information about Mental Health, Services, and Resources. Underlying the capacity to establish the need for mental health care is the need for mental health literacy among people with communication access needs as well as ECPs and other supporters. Developing effective health literacy requires health promotion activities designed to enable people with communication disability to access, understand, appraise, and apply health information (Turnbull et al., 2022). However, participants with communication access needs indicated that they had little exposure to mainstream mental health awareness information. While many participants received messages about mental health via traditional media and social media, this mass-media information did not serve to improve their understanding of mental health care. Interviewees were unaware of high-profile mental health awareness promotions such as R U OK Day? (Ross & Bassilios, 2019), indicating that important messages designed for the public might be missed by other people with communication access needs. Participants in this study indicated that mainstream mental health information was not reaching them or was not perceived as being relevant, presenting a significant barrier to access.

People with communication access needs may gain greater benefit from explicit teaching about mental health with tailored and contextualised information (Douds et al., 2014; Hagiliassis, Gulbenkoglu, et al., 2005). Access to information is a right cited throughout Australian legislation and health care policy and the CRPD (Australian Government, 2010; CRPD, 2006; Disability Discrimination Act, 1992). However, mental health care agencies and government bodies frequently fall short of providing information in ways that can be understood by people with communication difficulties (Dew et al., 2018; Newman et al., 2022). With a greater reliance on social media to transmit health information, the accessibility of such modes is an important consideration.

Previous research identifies the importance of mental health literacy among ECPs in encouraging referrals for mental health care (Costello et al., 2010; Holub et al., 2018; Man & Kangas, 2019b). In the present study, all ECPs employed revealed that they engaged in mental health training related to their work and caring responsibilities. However, an important point that emerged from interviews was that people with communication access needs also wanted mental health training. Interviewees with communication access needs expressed a desire for education and information about mental health, including how to help themselves and other people. They identified that they provided emotional support to friends and family members, but at times felt out of their depth in directing them towards more formal assistance. Although the value of the reciprocity of emotional support in relationships for people with intellectual disability is well documented (Callus, 2017), the role of people with communication access needs in supporting the mental health and emotional wellbeing of others has not to my knowledge yet been investigated by research. The findings of this study suggest that further investigation is needed to better understand the mental health education requirements of people with communication access needs. Such research can inform the content of primary and preventative mental health messaging for the population.

Presence of Mental Health Services Within the Disability Community. Our data revealed that people with communication access needs have limited awareness of mental health care services, and ECPs perceive that the mental health system is complex and difficult to navigate. These findings indicate that mental health services have a limited presence in the disability community. Previous evaluations of the Australian mental health system have identified the need to de-silo the mental health care system from other social support structures, inclusive of disability services (NMHC, 2017b; 2023). This study suggests that some integration of disability and mental health care has commenced with the arrival of NDIS-funded services for people with psychosocial disability. MHWs and ECPs noted the benefit of support workers and Support Coordinators working across both sectors to benefit people with coexisting communication access needs and mental health problems. Additionally, MHWs noted that the colocation of NDIS-registered mental health and disability services led to resource and information sharing among staff and consumers. Employment of specialist MHWs by disability organisations was identified as a benefit to staff and service users of those organisations. The NMHC reported that historically the mental health and disability sectors had not been well integrated before the NDIS rollout. However, the inclusion of psychosocial disability in the overarching model of NDIS funding, governance and delivery of services has brought the sectors into closer alignment (NMHC, 2017b).

Under the NDIS funding model, the process of de-siloing disability and mental health services appears to have commenced in Australia. However, the legacy of inaccessible mental health services has persisted. Accounts of people with communication access needs being refused access to mental health care services, particularly crisis services, indicate that there is a lingering perception that mainstream mental health services are not inclusive of people with co-existing disability. These perceptions of mental health systems being inadequate to support people with communication access needs are largely formed by negative or at times traumatic experiences (Bennett, 2014; Weise, Fisher et al., 2020) which may have a lasting impact on trust between people with communication access needs, their ECPs, and mental health services. This study revealed that specialised mental health services for people with disability were perceived as being more reliable in providing quality mental health services, based on practitioners' possessing specialised knowledge and skills. Recent mental health system reviews demonstrate a recognition of the challenges faced by people with disability navigating the mental health system and the need to work collaboratively with lived-experience populations and their support networks to improve mental health care (Katterl et al., 2023; NMHC, 2021, 2022). Intersectoral collaborations are required to defragment service provision and develop trust among a community that has previously experienced exclusion from mental health services.

Primary Screening for Mental Health Care Needs. People with communication access needs frequently have co-occurring health care needs that are managed with the assistance of a GP (Foley & Trollor, 2015; Morris et al., 2014; Perera et al., 2020). As such, GPs are often the first port of call, requiring practitioners to possess a depth of awareness to ensure proper referral and diagnosis, and appropriate prescription of psychotropic medications (Sheehan et al., 2015). This relationship places GPs in a strong position to provide screening for potential mental health problems as a component of regular check-ups, triggering access to mental health care earlier in the help-seeking trajectory. Participants in our study discussed the important role that GPs play in connecting people with communication access needs to MHWs. Two interviewees with communication access needs highlighted the benefit of their GP's proactive approach to mental health care in keeping their psychological wellbeing on the health agenda.

Early detection of health conditions is a policy priority area for Australians with disability (Commonwealth of Australia, 2021). Screening refers to the use of tests to identify early indicators of illness to improve health outcomes for the target population (Australian

Government, 2023). Screening is not diagnostic testing; rather, it enables early detection of health conditions so that further treatment can be sought. Given the high rates of psychological distress (AIHW, 2022), elevated exposure to risk factors (E. Watson et al., 2021), and prevalence of mental health care access barriers (NMHC, 2021, 2022), screening for mental health problems at a primary health care level would reduce further distress among people with communication access needs. The predominant mental health screening tool used by GPs is the K-10 (Kessler et al., 2003), while additional checklists for depression have been developed for GPs to use when working with people with intellectual disability (Torr et al., 2008). However, guidance for GPs regarding communication accessible mental health screening tools for other populations has not been foundevident. This places an expectation on GPs to adapt their approach to meet the requirements of the individual with limited guidance.

The need to invest in capacity building for mainstream health practitioners was recognised in the Disability Royal Commission, with the recommendation of the development of Cognitive Disability Health Capabilities Framework (Commonwealth of Australia, 2023c). In the Australian Medicare model of health care, GPs often act as gatekeepers for specialist mental health support (Foley & Trollor, 2015), developing mental health care plans and providing referrals. They also play an essential part in planning and coordinating complex health care, so their involvement in facilitating timely mental health care is essential. However, GPs often report feeling underequipped to work with populations with communication access needs (Foley & Trollor, 2015; Pinals et al., 2022b; Wilkinson et al., 2012). Improved access to mental health care requires GPs to be equipped with the skills and resources to screen for potential mental health problems in patients with communication access needs. The rapidly changing landscape of Australian health care policy will necessitate further exploration to map changes in GPs' skill, knowledge, and attainment of resources to assist mental health screening for people with communication access needs.

1b) Ability to Perceive Mental Health Care Needs. Paired with the approachability of mental health services is the ability of the population to perceive the requirement for mental health care. The capacity of the population to perceive the need for mental health care is determined by general factors such as health literacy and expectations about services (Levesque et al., 2013). Additionally, there are factors specific to people with communication access needs such as suitability of mental health information, insight into symptoms, previous experiences of mental health help-seeking, ECP attitudes toward mental help-seeking, and opportunities to communicate about emotional wellbeing and mental health across the lifespan. Participants in the present study identified mental health care needs across the entire trajectory of the help-seeking process, commencing at primary and preventative health care phases. Mental health care in the earlier stages may impact upon the person’s ability to perceive a need for mental health support, as discussed in the following paragraphs.

Mental Health Literacy and Suitability of Mental Health Information. In this study, people with communication access needs identified a lack of mental health education as a barrier to identifying a need for mental health support. Due to a lack of mental health education, participants with communication access needs were largely reliant on learning about mental health through experience. They expressed a desire for greater mental health education, granting them awareness of symptoms and pathways to support. People with communication access needs are likely to have lower levels of health literacy than the broader population due to a lack of access to health-related information (Turnbull et al., 2022). Additionally, people with communication access needs are afforded few opportunities to learn explicitly about mental health and managing emotions (Hagiliassis, Gulbenkoglu, et al., 2005). The findings revealed a lack of availability of suitable mental health information. Without access to suitable information about mental health, the expectation that people will be able to perceive a need for mental health care is unreasonable. Low levels of mental health literacy among people with communication access needs impacts upon the ability of this population to seek mental health care (E. Watson et al., 2021). Reduced access to mental health information due to a scarcity of accessible formats and limited educational opportunities is a concern across the lifespan for people with communication access needs. These issues must be considered as influential in the ability of people with communication access needs to request and access mental health care.

Turnbull et al (2022) found that health literacy levels of people with communication disability are more closely related to their level of education than to their communicative capacity. In Australia, the education system is responsible for developing and delivering social and emotional learning for students in the Personal and Social capability curriculum (Australian Curriculum Assessment and Reporting Authority, 2023). This formal social and emotional learning provides students with knowledge about wellbeing, affective awareness, and emotional regulation skills. However, students with disabilities may be excluded from such social and emotional learning, or gain fewer benefits if information is not presented in ways that enable them to understand (Daley & McCarthy, 2021). Within the cohort of participants in this study, very few had learned about mental health and emotional wellbeing at school. Older participants with communication access needs had attended special schools before the advent of the Disability Discrimination Act (1992) and were not afforded equitable access to the curriculum. These participants had learned about mental health and emotions through life experiences, often experiencing protracted periods of distress before securing mental health support, if they were able to at all.

Improved accessibility to mainstream mental health awareness campaigns was identified as a concern for people with communication access needs. Participants with communication access needs identified that they were missing out on key mental health information aimed at the public. Australia’s Disability Strategy 2021-2031 specifies that primary and preventative health campaigns must address people with disability (Commonwealth of Australia, 2021). Information in accessible formats and using targeted strategies to convey this critical health information upholds the rights of persons with communication access needs as per Article 21 of the CRPD (2006).

Insight into Symptoms of Mental Health Problems. Some people with communication access needs struggle to identify a need for mental health care due to a lack of insight into the presentation of symptoms or an inability to describe mental health problems (Hwang et al., 2020). In such instances, ECPs play a critical role in perceiving mental health care needs and soliciting mental health care (Costello et al., 2007; Foley & Trollor, 2015; Pinals et al., 2022b). ECPs in the present study demonstrated an awareness of signs of emotional distress and symptoms of mental health problems, and some had an excellent awareness of mental health services. ECPs who were parents had developed their connections to treating MHWs over time and were a critical link to mental health services when their adult children required mental health support. This was consistent with other recent research that demonstrated good levels of mental health literacy among parents of adults with co-existing disability and mental health problems (Man & Kangas, 2019a). Where people with communication access needs currently possess limited insight into the signs of mental health problems, ECPs’ mental health literacy and responsiveness to symptoms is essential. ECPs with an awareness of mental health are more likely to refer the person with communication access needs for further mental health support (Costello et al., 2007) and advocate for the person's access requirements to be met (Man & Kangas, 2019a). The present study indicates that while ECPs have developed an understanding of the indicators of emotional distress and mental ill-health through training and education, people with communication access needs have not been included in these educational approaches. Previous studies indicate that people with communication access needs can learn about indicators of mental health problems and develop appropriate help-seeking strategies (Douds et al., 2014; Douglass et al., 2007; Hagiliassis, Gulbenkoglu, et al., 2005; Hsieh et al., 2012).

Approachability requires the mental health system to be aware that a proportion of the community has communication access needs and that there is a requirement for mental health services to tailor approaches to promote knowledge among the population (Newman et al., 2022; Turnbull et al., 2022). The ability to perceive a need for mental health care necessitates an awareness among people with communication access needs that mental health services are available and that there is a right to access these services. For some people with communication access needs, ECPs increase the person's ability to perceive a need for mental health care. This represents the very first stage in accessing mental health care.

7.3.2 Perception of Needs and Desire for Care (2)

Gaining access to mental health care requires awareness that help is needed, that mental health care services exist and may be beneficial, and that people with communication access needs have a right to access these services (Levesque et al., 2013). The two aspects associated with this stage are the acceptability of mental health services, and the ability of people with communication access needs to seek mental health services. These aspects relate to socio-cultural aspects of mental health care seeking; including the culture of mental health services, values and attitudes of MHWs, and the autonomy of people with communication access needs in sourcing support services (Haggerty et al., 2020). The acceptability of mental health services and the ability of people with communication access needs to seek support will also be discussed in this section.

2a) Acceptability of Mental Health Services. Examining the acceptability of mental health services requires exploration of the congruence between the culture of mental health services, and values of MHWs (Levesque et al., 2013). The key factors associated with the acceptability of mental health care in this study were structural stigma in mental health services, MHWs' attitudes towards communication diversity and inclusion, and the use of rights-affirming clinical practice.

Systemic Stigma and Ableism in Mental Health Services. The extent of acceptability of mental health care may be limited by the presence of systemic stigma among mental health and disability service providers. Stigma is increasingly being acknowledged as a determining factor in access to health care (Hatzenbuehler et al., 2013; Mladenov & Dimitrova, 2023; Nicolaidis et al., 2015). People with communication access needs face multiple structural stigmas that impact upon seeking mental health care such as exclusionary policies, absence of MHW training, under-allocation of mental health resources, omission of people with communication access needs in mental health research, diagnostic overshadowing and reduced decision-making power in health care (Holub et al., 2018; Lundberg & Chen, 2024; Nicolaidis et al., 2015). The systemic stigmatisation of people with disability in mental health care leads to mistrust among the population and reduces the acceptability of mental health services. This is an aspect of structural ableism, which refers both to discriminatory treatment and inaccessibility of health care systems (Lundberg & Chen, 2024).

Legislative and health care policy solutions are required to address access inequalities associated with stigma within systems of care (Blake & Hatzenbuehler, 2019). In Australia, the ratification of the CRPD reflects an aspiration to override structural stigma and ableism in health care through systemic change. Such aspirations are reflected in local legislation such as the Disability Discrimination Act (Disability Discrimination Act, 1992) and the NDIS Act (2013), and policies such as Australia's Disability Strategy (Commonwealth of Australia, 2021). While these documents demonstrate a governmental commitment to addressing discrimination in health care, evidence of structural stigma persists with pertinent examples provided to the Disability Royal Commission (Commonwealth of Australia, 2023b, 2023c).

Information from participants in this study illustrates incremental changes in accessibility with the advent of NDIS funding positioning people with disability as economic participants in mental health services. However, there is limited indication of a reduction of stigma associated with people with communication access needs seeking mental health care. Interviews revealed multiple accounts of people encountering exclusion from mental health care services based upon disability and diagnostic overshadowing, which can be linked to ableist policies and biased practices (Holub et al., 2018; Jamieson & Mason, 2019). Additionally, people with communication access needs face stigmatising attitudes from disability support providers that devalue mental health care (Costello et al., 2007; Holub et al., 2018). In the present study, structural stigma was reflected in MHWs indicating an openness to communication diversity but lacking training and awareness about communication access or exclusionary service eligibility criteria. Systemic stigma may be a driving factor in the under-resourcing of mental health support for people with communication access needs (Lundberg & Chen, 2024). Structural ableism was reflected in the insufficiency of services and lack of suitably skilled MHWs to support effective access to mental health care despite participants' elevated exposure to risk factors. These findings indicate that there is more to be done to address structural stigma and ableism in mental health care. One useful approach is to protect the human rights of people with communication access needs in attaining equitable access to mental health care in legislation. Further, policies that address the social factors underpinning stigma such as equitable access to housing, education, and economic participation will also benefit the mental health of this population.

MHW Attitudes to Communication Diversity and Inclusion. MHW attitudes to communication diversity and inclusion underpin the quality of the mental health services provided to people with communication access needs. Beneficial MHW attitudes and professional values identified by participants included person-centredness, a holistic view of mental health, collaboration with ECPs, and commitment to upholding the right to access equitable mental health care. Negative attitudes towards people with intellectual disability and co-existing mental ill-health have been linked to exclusion and unethical MHW practices (Weise, Fisher et al., 2020). Additionally, organisational culture encompasses the values espoused by the organisation and their influence on the attitudes of employees and ultimately the quality of service delivery (Looi, Maguire, et al., 2022). Policy can influence the attitudes of MHWs, for example, policies stipulating eligibility criteria for services being used to justify exclusionary attitudes toward individuals with co-existing disability seeking mental health care (Evans et al., 2012; Weise et al., 2021). Similarly, pre-existing beliefs are related to mental health care access for marginalised populations (Glisson & Williams, 2015; Looi, Allison, et al., 2022). This study found that attitudes of individual MHWs were significant in combating organisational cultures of exclusion. MHWs who expressed a personal commitment to social justice and attitudes of inclusion in mental health care were likely to adjust their practice to ensure that individual communication access needs were met. Positive attitudes toward communication diversity were demonstrated by MHWs with varied knowledge of working with people with communication access needs, from those most limited to those with extensive practice experience.

Rights Affirming Mental Health Care. Acceptable mental healthcare for people with communication access needs requires respect for the rights of the person seeking health care, and support to enable the person to exercise rights that enhance emotional wellbeing. Findings presented in this study indicate the need for mental health care that affirms rights through clinical practices such as person-centred practice, strengths focus, and a holistic approach. Person-centred practices based on respect for capability in decision-making, adapting practice to meet the person’s requirements, collaboration, and consent were perceived by all groups as acceptable. These characteristics are consistent with previous investigations into desirable characteristics in generalist MHWs (Weise et al., 2018).

Person-centred approaches were identified by the Disability Royal Commission as being critical to achieving equitable access to mental health care for people with disabilities (Commonwealth of Australia, 2023c). Person-centredness in healthcare is described as a flexible approach to service provision and a willingness to adjust standard procedures to meet the needs of the individual (Commonwealth of Australia, 2023c). This is pertinent to creating inclusive mental health care settings that actively seek to meet communication access requirements. Having mental health care options communicated effectively and being able to select between interventions is essential in person-centred mental health care for people with communication access needs (Watchman et al., 2021). As per previous studies (Watchman et al., 2021; Whitehead et al., 2021), this study indicates that where the person was not actively involved in setting the goals and objectives, nor provided with information regarding intervention options, mental health services were not perceived as beneficial. Further to considering access requirements, rights-affirming mental health care must recognise the diverse and intersectional identities among people with communication access needs (Brinkman et al., 2022). People with communication access needs are heterogeneous and possess unique experiences and strengths that inform the acceptability of mental health care.

In this study, consent for services was essential in building trust in mental health care. Universally, participants believed that consent should be sought from the person with communication access needs regarding treatment, inclusion of ECPs, and information sharing. A further issue of consent related to the use of restrictive practices, predominantly overuse of medications, to manage distress in people with communication access needs. Under the NDIS Act, reduction of restrictive practices is a key objective. Restrictive practices refer to “any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability” (NDIS Act, 2013, p. 21). However, there are instances when decision-making rights are not upheld in mental healthcare, for example under involuntary psychiatric treatment orders (Dawson, 2015). This was the case described by ECPs and MHWs, that experiences of being detained left people with communication access needs and ECPs feeling traumatised. And that MHWs found it difficult to engage people once they had been detained. There is a need for greater investment in early interventions for mental health care with alternatives for crisis support that uphold the dignity and rights of people with communication access needs. The need to balance capacity and decision-making rights is a developing space in mental health legislation and policy (Dawson, 2015; Duffy & Kelly, 2017). This is illustrated in the South Australian Mental Health Act (2009) by the predominant focus on outlining the terms of involuntary detainment, rather than the right to access quality care and uphold decision-making rights throughout an episode of mental illness. Despite the existence of the NDIS Act and guidance for practitioners regarding restrictive practices (NDIS Quality & Safeguards Commission, 2020; 2024), our data indicates that over-medication – a form of chemical restraint –persists for many people with communication access needs. A rights-affirming approach to mental health care is required to improve the acceptability of services. People with communication access needs and ECPs must feel confident that the mental healthcare system will maintain the dignity of the person and not result in further trauma. Creating a welcoming mental healthcare environment care relies upon mental health services being perceived as safe and supportive spaces, particularly when people have previously experienced trauma or exclusion.

2b) Ability to Seek Mental Health Services. Knowledge of mental health care options and the right to access mental health care is foundational in perceiving and seeking support services (Haggerty et al., 2020). As previously discussed, the accessibility of mental health information is a critical factor in equipping people with communication access needs with an understanding of their entitlement to mental health services. Additionally, seeking mental health care is determined by the person's ability to convey their health care requirements, as well as having mental health care choices respected and supported by ECPs and other primary care providers. Mental health care is deemed acceptable when people with communication access needs perceive that it is safe, inclusive, and affirming of the rights of people with disability. The key factors that influence the person's ability to seek mental health care are autonomy in health decision-making and the availability of supportive ECPs who offer opportunities to communicate mental health care needs.

Mental Health Decision-making Power. As the acceptability of mental health care is influenced by rights-affirming practices within the sector and the availability of suitable mental health care options. Similarly, the ability to seek mental health care is underpinned by the power of the person to make informed choices about the care they receive. People with communication access needs are frequently excluded from the healthcare decision-making process, with decision-making power afforded to family members, support people, or other legally appointed guardians (Doherty et al., 2020; O′Donnell et al., 2023; Watson et al., 2017). CRPD (2006) Article 12 states "that people with disability enjoy legal capacity on an equal basis with others in all aspects of life" and that where required appropriate provisions will be made to support informed decision making, including safeguarding. This article has formed the basis of the movement towards increasing the decision-making power of Australians with disability (J. Watson, Anderson et al., 2022). In this study, people with communication access needs described scenarios in which their choices had been disrespected or overridden by ECPs and disability service providers. This disregard for personal autonomy was identified as the key contributor to psychological distress. ECPs indicated that they had made decisions on behalf of the person about whether to pursue mental health care or not, without seeking the person's expressed wishes. Additionally, they identified that some disability organisations prioritising some aspects of health support over others inadvertently reduced people's right to make decisions. Resources have been made freely available to support the uptake of supported decision-making processes among ECPs (Inclusion Australia, 2022; National Disability Services, 2019). However, the findings of this study indicate a need for further action to ensure that decision-making rights of people with communication access needs are upheld. Contested power in healthcare decision-making leads to further health and social inequity (O′Donnell et al., 2023), which makes addressing decision-making power a key action for mental health services to reduce further harm to service users. This study indicates that MHWs can foster autonomy by recognising the person with communication access needs as the primary decision maker by seeking consent for treatment, and the involvement of ECPs and others. Additionally, a person-centred, rights-affirming model of mental health care, which incorporates supported decision-making is required.

Supportive ECPs and Opportunities to Communicate Mental Health. Participants with communication access needs consistently explained that they required trusted ECPs to provide opportunities to discuss mental health – to notice and enquire about changes in behaviour, offer support and comfort when the person appeared distressed, and help seek out support. Of the participants who had secured access to MHWs, all had been assisted by an ECP to locate mental health care services, playing an essential role in providing emotional support. However, people with communication access needs may have a lack of trusted ECPs with whom they can discuss issues that impact emotional wellbeing (Dark et al., 2011; Petroutsou et al., 2018; E. Watson et al., 2021). The data demonstrate that people with communication access needs appreciated ECPs who took a proactive approach, offering opportunities to discuss issues that impact mental health. Additionally, participants with communication access needs identified that they wanted ECPs to be responsive to changes in their behaviour that indicated emotional distress or a decline in wellbeing. Responsive ECPs provided comfort and support to remedy the immediate impacts of emotional distress, as well as identifying and referring to professional support. This is consistent with previous research recognising the need for responsive communication partners who assist the person to act in connecting to mental health care when required (E. Watson et al., 2021). Additionally, the present study indicates that ECPs use strategies to identify opportunities for conversations about mental health and wellbeing. ECPs discussed the use of documentation, predominantly daily journals, to pinpoint changes in mood and behaviour, as well as potentially distressing events. These sources of documentation were utilised by ECPs to promote discussions about wellbeing and to work with the person to resolve issues.

7.3.3 Mental Health Care Seeking (3)

Seeking mental health services requires presence of services in the community in physically accessible and safe locations, with suitably skilled providers (Levesque et al., 2013). The two aspects associated with reaching mental health care are the availability and accommodation of mental health services and the ability of people with communication access needs to reach mental health care. In this study, the ability of the participants with communication access needs to reach mental health care was dependent upon personal mobility, accessibility of transportation, personal scheduling, and availability of ECPs and other paid supporters, if required.

There is much to learn from the attempts of participants with communication access needs to reach mental health care. As detailed in the findings chapters, reaching mental health care was often a protracted process, taking years. In some cases, attempts to reach mental health care culminated in crisis support, triggering access to mental health services. Considering the steps to realising mental health care informs us of the gaps in the system of support to reach care.

3a) Availability and Accommodations. To enable people to reach mental health care, services must be present and geographically available in communities (Levesque et al., 2013). Shady et al. (2022) describe this dimension as the "physical, environmental, and time accommodations" made by the system or providers to meet the requirements of the focus population. For people with communication access needs important accommodations include flexibility in service delivery modes and locations, sufficient time for intervention, collaborative models of support, and clear referral pathways to mental health care.

Flexible Locations for Mental Health Care Delivery: Telehealth, Clinic, and Home Visits. Since the advent of the COVID-19 pandemic, telehealth has rapidly expanded as a mode of Medicare-funded mental health service delivery (Chatterton et al., 2022; Yeatman et al., 2023). However, questions remain as to the capacity of telehealth to offer inclusive care to marginalised populations (Lepkowsky, 2023; Yeatman et al., 2023). In their study of telehealth services for people with developmental disability and mental ill health, Kramer et al. (2023) propose four factors that determine the effectiveness of telehealth. These factors are: 1) accessibility of telephone and video conferencing for the person with communication access needs, 2) competing demands on ECP time and capacity to use technology, 3) the availability and reliability of telecommunications infrastructure, and 4) the ability for services to respond to the requirements of the person and their ECPs (Kramer et al., 2023). In the present study, a number of interviewees with communication access needs felt that telehealth was inaccessible and preferred video conferencing over services delivered via telephone. Additionally, most participants required help to set up and use computers, phones or tablets required for telehealth participation, creating a reliance on ECPs to support access to this type of service delivery. This study did not explore the availability of telehealth infrastructure; however, access to devices and stable internet connection must be considered a potential barrier among marginalised populations (Yeatman et al., 2023). Although telehealth offers benefits in terms of service access for people residing in regional areas (Chatterton et al., 2022), this study supports the view that accessibility factors must be examined before delivering telehealth services to people with communication access needs (Kramer et al., 2023). The findings indicate that telehealth may ameliorate some access barriers related to travel and discomfort in clinical environments. However, people with communication access needs and ECPs expressed a preference for mental health care to be provided via home visits by the MHW. Attention must also be afforded to the locations where mental health care is provided, prioritising emotionally safe and physically accessible spaces.

Sufficiency of Time for Communication in Mental Health Care. MHWs identified patience as the most important attitude when working with people with communication access needs. Patience is the attitude associated with waiting (Comer & Sekerka, 2014); it requires MHWs to slow their usual pace of communication, thus affording sufficient time for the person to understand and convey responses. Resoundingly, participants with communication access needs identified that “allowing sufficient time” for communication was the most important access strategy when discussing mental health and emotional wellbeing. The Affordability dimension of the Conceptual Model (Levesque et al., 2013) examined the tension between allowing sufficient time and the time-bound funding sources for MHW services. However, giving sufficient time is an essential MHW communication partner skill and must be considered a means to achieving equitable access and improving mental health outcomes (Noyes & Wilkinson, 2023). In the scoping review, few researchers acknowledged the requirement for additional time for intervention delivery as an access factor (Aoun et al., 2015; Crawford, 1987; Hsieh et al., 2012). This may indicate a lack of recognition that time is an access factor that impacts upon engagement and satisfaction with mental health care. In the presently time-bound model of mental health funding, it is principally up to the MHW or their employer to determine what is adequate time for intervention. This is the antithesis of person-centred practice. However, MHWs who were self-employed or employed by block-funded services, were able to customise appointment length, responding to clients who required additional time, or shorter more frequent appointments, as an access measure.

Collaborative Models of Mental Health Care: Responding to Holistic Support Requirements. The need for holistic models of mental health care that recognise the social, biological, and psychological aspects of the person’s life was evident throughout the accounts of all participant groups. The need for holistic mental health care is reflected in Australian research examining services’ approach to people with intellectual disability (Evans et al., 2012; Howlett & Trollor, 2013; Weise et al., 2018, 2021; Whitehead et al., 2021; Whittle et al., 2018). However, it is less explored in other populations that experience communication barriers in accessing mental health care. Recent reviews of disability services have revealed that mainstream health services, including mental health services, are falling short in their responsibility to provide equitable care to Australians with disability (Commonwealth of Australia, 2023b, 2023d). The NDIS independent review identified poor integration between mental health care and other disability support systems (Commonwealth of Australia, 2023e), and our findings would indicate this summation to be accurate. Additionally, Australia’s Disability Strategy (Commonwealth of Australia, 2021b) aims to enhance the capacity of mainstream health services to better meet the requirements of people with coexisting disability. Many people with communication access needs experience coexisting health support needs (Pinals et al., 2022b; Shady et al., 2022). However, the siloing of disability and mental health services makes some forms of mental health care, particularly in-patient services, inaccessible to people with communication access needs and physical disability (E. Watson et al., 2021).

There are lessons to be learned from the implementation of the NDIS system. The NDIS funding model has inadvertently encouraged co-location, shared staffing and resources, and unified organisational policy, as dominant service providers extend their reach across disability and mental health service provision (NMHC, 2023). However, this has not resulted in a more coordinated system of supports for people with communication access needs and mental health concerns. The recent review into NDIS has recommended the development of complex care coordination processes that work across the public mental health system and NDIS-funded supports (Commonwealth of Australia, 2023e). Such a process would enable people with communication access needs to access mental health supports outside the disability system, giving access to a greater choice of practitioners and selection of services. Additionally, such a strategy might debunk persistent misunderstandings that have arisen in the historically separated systems regarding the existence of specialist mental health care for people with disability. A further strategy that enhanced access to mental health care for participants in the present study was the employment of MHWs by disability organisations. This allowed MHWs to develop expertise in working with people with communication access needs and provided those ECPs employed by disability services with guidance in their practice. Thus the employment of MHWs in disability services had an incidental de-siloing effect on service delivery. However, more intentional, systemic approaches to the integration of disability and mental health support are required to improve the capacity of private and state-operated mental health services (Commonwealth of Australia, 2023e).

As identified in previous research (Baker et al., 2021; Whittle et al., 2018), there is a need to explore innovative models of mental health care for people with communication access needs, models that address barriers and receive the person in the context of their life. International models, such as the emerging START program for people with a developmental disability in the USA, offer a promising model of mental health care (Pinals et al., 2022b; Weise, Cvejic, et al., 2020). START refers to a network of services for people with developmental disability and co-existing mental ill health which applies a biopsychosocial model of support, offering multi-disciplinary assessment and treatment options (Beasley et al., 2018). START's model of mental health care is underpinned by strengths-based and person-centred values that are compatible with Australian policy (Commonwealth of Australia, 2021).

Clear Referral Pathways to Appropriately Skilled MHWs. Access to effective mental health care is facilitated by clear and timely referral processes that enable the person with communication access needs to connect with appropriately skilled MHWs. Reflecting the unique nature of their role in negotiating access to mental health services (Barratt et al., 2023; Brolan et al., 2012; Man & Kangas, 2019a), ECPs identified the need for clear referral pathways as a critical aspect of access. ECPs and MHWs described confusing referral processes, lengthy service waitlists, and a lack of appropriately skilled MHWs as critical barriers to gaining mental health care for people with communication access needs. The scarcity of MHWs who are equipped to work with people with communication access needs has been noted in previous research (Evans et al., 2012; Man & Kangas, 2019a; Weise et al., 2021) and was apparent to ECPs who had sought referrals. Lengthy wait times for mental health services are broadly acknowledged as a concern in the Australian mental health care system (NMHC, 2023). This study indicated that delays to service access were exacerbated where the person had co-existing support requirements. People with communication access needs and their ECPs encountered flow-on effects such as increased use of emergency mental health services, and reliance on ECPs to manage mental health care needs. As discussed previously, fragmentation between the disability and mental health sectors may exacerbate ambiguity in referral pathways. At present, according to this study, experiences of gaining entry to the mental health care system are characterised by dead ends and false trails. For people with communications access needs, a no-wrong-door approach to mental health care access is necessary. This study indicates a need for collaboration across multiple service streams to enable access to mental health services via general healthcare, disability, aged care, and positive behaviour support (PBS) services. Additionally, mental health services must establish means of self-referral for people with communication access needs. Early access to mental health care via clear referral pathways will reduce reliance on emergency mental health services.

3b) Ability to Reach. Common considerations in terms of ability to reach relate to personal mobility, access to transport, and access to social support to enable attendance of appointments (Levesque et al., 2013). However, among participants with communication access needs the ability to reach mental health services relied heavily on the capacities and attitudes of ECPs and other supporters in facilitating the process. For the wider population with communication access needs, consideration needs to be given to the role of ECPs as conduits to care.

Travel and Personal Mobility. The capacity to negotiate mobility and transportation to access mental health care is an essential access consideration (Haggerty et al., 2020). Our data revealed a lack of services for people with communication access needs and co-existing mental health care requirements in regional areas of South Australia. As is the case in most parts of Australia, specialist MHW services are centralised in the capital city, Adelaide. This is a common theme in mental health service provision throughout Australia (Chatterton et al., 2022; NMHC, 2023), and has amplified impacts for individuals with more complex mental health care requirements.

Additionally, the capacity of the person to travel independently must be considered. Most participants with communication access needs required assistance from ECPs to travel to appointments, with some requiring assistance to manoeuvre their wheelchairs. Reliance on ECPs for transportation and mobility impacts the person's ability to reach mental health care premises and move about premises with independence. A further consideration in personal mobility and mental health care provision is the person's ability to leave their home, tolerate travel and feel safe. We received multiple accounts of people with communication access needs becoming distressed at attending clinical offices, with heightened anxiety due to extended travel times for people in regional areas. Location of services and personal mobility are very important considerations for this group, with many participants preferring in-home appointments with MHWs.

ECP Support to Reach Mental Health Care. A range of ECP factors impacted a person's ability to reach mental health care, notably mental health literacy, attitudes to mental health, and responsiveness to communication about emotional distress. As previously discussed, there is a substantial role for ECPs in gaining access to mental health care. There is a need for responsive ECPs with good mental health literacy to assist people to recognise a need for mental health care (Costello et al., 2007; Lawn et al., 2017; Man & Kangas, 2019b). Where the person with communication access needs has limited autonomy in making decisions about health care, ECPs may act as gatekeepers or facilitators of access to mental health care. Additionally, there is potential for discord between the person's perception of the need for mental health care and the ECP's perception. In this study, there were examples of people with communication access needs wanting mental health care and ECPs disagreeing, and vice versa. While levels of independence vary among people with communication access needs, for many ECP support will be a critical factor in reaching mental health care (Noyes & Wilkinson, 2022).

This study also identified the very practical roles that ECPs play in enabling people with communication access needs to connect with mental health services. Depending on the requirements of the individual, ECPs assisted in identifying MHWs for referral, booked appointments, planned and prepared for appointments, arranged transport to and from appointments, provided communication assistance, relayed contextual information, advocated for service equity, and offered emotional assistance related to mental health appointments. Where mental health services are delivered via telehealth, ECPs may be required to provide additional technological support (Kramer et al., 2023). Participants with communication access needs stipulated that they must have autonomy in deciding which ECPs assist them in managing mental health care. They indicated that mental health support was a nuanced role, requiring a trusted ECP who knew them well and had good communication skills. The qualities of good mental health supporters as perceived by people with communication access needs have not previously been detailed in research.

7.3.4 Mental Health Care Reaching (4)

Cost of services is a critical factor in considering access to mental health care. In this section, the affordability of mental health care and the ability of people with communication access needs to pay for services are discussed (Levesque et al., 2013). These domains must be considered within the context of primary health care, such as access to referring GPs, as well as secondary mental health care services, such as psychotherapy and counselling.

4a) Affordability. The affordability of mental health care is related to systemic factors including the direct costs and funding mechanisms available to people to enable access to affordable health care (Levesque et al., 2013). Key systemic affordability factors identified in the research project were the suitability of the Medicare Better Access to Mental Health scheme, access to NDIS funding to address issues relating to mental health and wellbeing, and the availability of low-cost public mental health services. Barriers were identified concerning all three affordability factors, increasing the risk of people with communication access needs forgoing mental health care.

Medicare Better Access Funding. The Medicare Better Access to Mental Health scheme, whereby Australians eligible to access Medicare may receive subsidised psychological services, is broadly acknowledged to have improved access to mental health care for the general Australian population (Meadows et al., 2015; Pirkis et al., 2022). Through the Better Access scheme, individuals can develop a Mental Health Treatment Plan with their GP, which functions as a referral for MHW services (Australian Government, 2024). In most cases, Better Access funding requires a co-payment for MHW services from the service recipient (Pirkis et al., 2022). ECPs reported that the capacity to pay for mental health services was out of reach for people on the Disability Support Pension. Recent evaluation of the Better Access scheme has revealed insufficiencies in the program to meet the cost and intervention duration requirements for individuals with complex mental health support needs (Pirkis et al., 2022; Yeatman et al., 2023). One interviewee with communication access needs identified that the funding provided by the scheme did not allow for enough sessions to benefit from mental health supports, given the time required to communicate comprehensive messages about emotions and wellbeing. As people with communication access needs are likely to require additional time for communication, access to mental health services must consider funding that accommodates flexibility in the length of sessions and duration of intervention to achieve equitable outcomes.

Recommendations yielded from the evaluation of Better Access state that mental health care should be holistic, and that Medicare funding should enable collaborative practice when a person has complex support requirements (Pirkis et al., 2022). This recommendation is consistent with data from MHWs in this study who viewed working with other practitioners across disciplines as beneficial to effective mental health care delivery. MHW interviewees identified funding constraints as preventing collaboration with other practitioners to develop personalised mental health care strategies. On similar grounds, Pirkis et al. (2022) suggest that strategies to fund complex mental health care would benefit mental health service users with communication access needs. The NDIS Independent Review has further recommended that systemic coordination is required when mental health care is resourced by both mainstream and disability services (Commonwealth of Australia, 2023e). Further review of the Australian state and federal mental health care systems is necessary to determine the adequacy of funding streams, referral processes, and mental health care coordination to achieve equity in service access for people with communication access needs.

Availability of Community Mental Health Services. In Australia, public mental health care is provided via a network of community-based outpatient services which are operated by the state and territory governments, and referred to as community mental health care services (Australian Government, 2022). Despite the identified need for greater collaboration between mental health and disability services (NMHC, 2021), some community mental health care services maintain policies that exclude people with disability. For example, Adelaide’s principal state-funded community mental health providers’ policy document states that the service “does not accept referrals for people with a primary diagnosis of intellectual disability, autism, acquired brain injury, or dementia” (Central Adelaide Local Health Network, 2022, p.14). These are all conditions that are frequently associated with communication access requirements. This model of candidacy for mental health care indicates significant potential for systematic exclusion from mental health care of people with communication access needs. Also, the reasoning for such models of candidacy for mental health care contravenes Article 25 of the CRPD (2006). Only one participant with communication access needs had accessed community mental health services and they resided in NSW. None of the South Australian participants had accessed community mental health services. One MHW participant employed by a community mental health service mentioned employees going outside of policy guidelines to ensure that people with communication access needs who did not meet the eligibility criteria were able to gain the mental health care required.

Additionally, MHW interviewees indicated that there is a misconception among mental health service providers that there was an alternate specialist service for people with disability and that these services would better meet their mental health care needs. This misconception appears to arise from fragmentation between disability and mental health services. The lack of engagement between the two systems has ultimately led to a failure to provide safe, holistic, and effective mental health support to people with dual disabilities (Perera et al., 2020; Pinals et al., 2022b; Weise et al., 2021).

4b) Ability to Pay. The ability to pay for mental health care considers the person's income, assists, social capital, and availability of health insurance (Levesque et al., 2013). The person's capacity to pay for mental health care should not have a detrimental impact on their quality of life and ability to meet other basic needs (Haggerty et al., 2020). However, participants with communication access needs faced a unique set of concerns in paying for mental health care. Specific considerations were the availability of mental health support through NDIS funding, managing co-payments while on the Disability Support Pension (DSP), paying for multiple therapists, paying for longer or more sessions, and the availability of suitable communication assistants to support mental health appointments.

NDIS Funding and Mental Health Support. The advent of NDIS funding seemed to promise an end to funding challenges for Australians with disability. Conversely, in reforming the mental health system, psychosocial support has retracted due to funding uncertainty, resulting in reduced diversity and availability of publicly funded mental health care programs (Salvador-Carulla et al., 2022). Public sources of NDIS information state that funding is not available for clinical mental health care and directs NDIS participants to use mainstream mental health services via the Medicare Better Access Scheme (NDIS, 2022). As previously established, the Better Access funding is likely to be insufficient for individuals whose mental health support requirements are complex (Pirkis et al., 2022). This effectively creates a service gap for individuals who access NDIS funding, but also require mental health care for common mental health issues such as anxiety or depression. This gap in publicly funded mental health care has recently been acknowledged in the NDIS review (Commonwealth of Australia, 2023e), and reveals a need for Australian state governments to act to meet their contractual obligations under the National Mental Health and Suicide Prevention Agreement (Australian Government, 2022). Understandably, confusion for ECPs about how to pay for mental health care acts as a deterrent to accessing mental health care.

MHW interviewees discussed variability in access to NDIS funding for MHW services for people with communication access needs. ECP and MHW interviewees pointed out that people with communication access needs could access MHWs with NDIS funds when it coincided with NDIS plan goals. Examples included addressing issues related to disability and sexuality, developing skills for social participation, and reducing restrictive practices through PBS. However, NDIS funding was not responsive to mental health support needs related to the person's experience of disability. People who wanted to address experiences of abuse or neglect that had occurred within the context of disability service provision could not do this using NDIS funds (CRE-DH, 2021; Commonwealth of Australia, 2023d). Additionally, high out-of-pocket mental healthcare costs and limited incomes of people with communication access needs led ECPs in this study to perceive disability support expenses as competing with mental healthcare needs. Some ECPs identified physical supports such as physiotherapy, speech pathology, and occupational therapy as a priority rather than an equal component in a picture of holistic wellbeing that included mental healthcare requirements.

Communication Assistant Funding and Availability. The term communication assistant refers to those who provide human assistance to support communication. The use of formal communication assistants was initially proposed to enable state parties to meet their obligations under the CRPD enabling access (Article 9) and freedom of expression (Article 21) to people who use AAC in all facets of public life (Collier et al., 2010; CRPD, 2006). In Collier et al.'s (2010) study, communication assistants undertook training and assisted AAC users to interact with service providers with limited skill and knowledge who were engaging with people with communication access needs. The state-funded service functioned similarly to interpreter services for linguistically diverse and Deaf communities. However, none of the participants in this study had used communication assistant services in mental health care settings, all relied on informal communication support from ECPs. This may be because people with communication access needs prefer to be supported by someone they know well. Alternatively, people with communication access needs may already be paying support workers to attend appointments, and formal communication assistants are perceived as too great an expense. An additional and likely possibility is that communication assistant services are not widely available in Australia. However, sole reliance upon informal communication assistance comes with a slew of issues that impact the autonomy and confidentiality of the person seeking mental health care (Dee-Price, 2023; Noyes & Wilkinson, 2022). To uphold the rights of people with communication access needs in mental health care, a range of affordable access solutions, including the availability of human assistance must be considered.

7.3.5 Mental Health Care Utilisation (5)

Once mental health care services have been sourced, these services must be assessed as useful to people with communication access needs. The appropriateness of mental health care and the ability of the person seeking mental health care to engage with services (Levesque et al., 2013) applies to the technical capabilities of MHWs and the adequacy of mental health services. Equally, mental health care utilisation requires the person with communication access needs to engage in mental health care activities.

5a) Appropriateness of Mental Health Care. The appropriateness of mental health care services considers the technical knowledge and skills of practitioners, as well as interpersonal qualities that influence the adequacy of care provided (Levesque et al., 2013). For participants with communication access needs the factors influencing the appropriateness of mental health care included: MHW training and experience in working with people with communication access needs, use of appropriate diagnostic processes, MHW capacity as a communication partner, and the ability to personalise mental health care to meet the requirements of the individual.

MHW Training and Experience in Working with People with Communication Access Needs. Lack of training means that MHWs may feel unprepared to work with people with communication access needs related to aphasia (Baker et al., 2021), intellectual disability (Man et al., 2017; Weise et al., 2021), and autism (Pinals et al., 2022b). The present study suggests that MHWs develop knowledge of communication access strategies through experiences of working with people with communication access needs. With experience, MHWs gain sensitivity, skills, and confidence. However, education and guidance are required to enable MHWs to work more effectively with this population and attain equitable quality in mental health care. The findings of the Disability Royal Commission (Commonwealth of Australia, 2023a) and Australia’s Disability Strategy (Commonwealth of Australia, 2021) echo the need for targeted education for mainstream healthcare professionals. Although practice guides are available to MHWs working with people with communication access needs (3DN, 2017; Hagiliassis et al., 2006; Man et al., 2017), further structured training opportunities and practice frameworks are required to enable effective inclusion of people with communication access needs.

Knowledge and skill of MHWs impact the appropriateness of diagnostic processes used, the types of mental health interventions offered, and more specific communication skills utilised by MHWs. Based on a recent body of research literature, a range of adaptations to support communication access was proposed in the scoping review (E. Watson et al., 2022). With a different focus, the Intellectual Disability Mental Health Core Competency Framework (3DN, 2016, 2017), developed by the Department of Developmental Disability Neuropsychiatry at the University of NSW in collaboration with NSW Health, describes the skills and attributes that are necessary for MHWs to deliver quality mental health care to people with intellectual disability in Australia. Its overarching principles, relevant to many populations who experience disability, are to act in ways that are person-centred, pro-active, strengths-based, flexible, multi-disciplinary and cross-agency, empowering, and inclusive (3DN, 2016). Communication is one of the key domains of the competency framework and specifies the following six communication capabilities for MHWs working with people with intellectual disability:

1. The MHW demonstrates the ability to learn about the person's preferred communication methods and adapt communication to effectively meet the requirements of the person.
2. The MHW is reflexive in their communication and confirms the accuracy of communication.
3. The MHW uses assistive technologies for communication (AAC) as required.
4. The MHW adjusts the environment to enable autonomous and free communication.
5. The MHW uses respectful language when describing people with co-existing intellectual disability and mental ill health.
6. The MHW seeks support from and makes referrals to a communication specialist when required.

If adopted in the pre-service curriculum of future MHWs, these competencies are broadly applicable to the aim of improving the quality of mental health care for people with communication access needs. However, MHWs will require practical information and guidance to enable the attainment of these competencies.

Without appropriate training and guidance, MHWs risk impinging upon the human rights of the person. Two human rights issues emerged in the present study concerning MHWs' lack of knowledge in working with people with communication access needs: 1) restriction of liberty via the overuse or misuse of psychoactive medications to manage mental health, and 2) denial of access to equitable mental health care due to diagnostic overshadowing. Overuse of medications to manage symptoms among people with communication access needs who use behaviour to convey distress is a known issue (Bowring et al., 2019; Painter et al., 2018; Sheehan et al., 2015). The NDIS Quality and Safeguarding Commission classes the use of medication to influence a person's behaviour as a form of chemical restraint (NDIS Quality and Safeguards Commission, 2020). Our findings indicate a legacy of psychotropic medication use that constitutes chemical restraint being used to manage behaviour without proper investigation of underlying causes, including the presence of mental ill health. A thorough and appropriate diagnostic process, assessing underlying causes of behaviour, is required before prescribing psychoactive medications to people with communication access needs (McClean et al., 2007; Pinals et al., 2022b; Wilson et al., 2023).

Use of Appropriate Diagnostic Processes. Diagnostic overshadowing presented a persistent barrier to the effective identification and treatment of mental health problems in participants with communication access needs. Diagnostic overshadowing refers to the biased misattribution of symptoms of mental illness as factors associated with co-existing intellectual, developmental, or communication disability (Holub et al., 2018; Jamieson & Mason, 2019). The presence of diagnostic overshadowing in the mental health system is now acknowledged as a systemic challenge for people with disability seeking to access mental health support (Whittle et al., 2018). Interviewees confirmed the challenges of diagnostic overshadowing highlighting the differential treatment of people with co-occurring diagnoses of Autism, traumatic brain injury, and intellectual disability when seeking mental health care.

Over the past decade, a body of literature has been growing in acknowledgement of concern about diagnostic overshadowing in the treatment of mental health problems in people with disability. Some of this literature refers directly to people with communication access needs (Di Marco & Iacono, 2007), but a larger component relates to people with intellectual disability (Bennett, 2014; Hagiliassis & Di Marco, 2017; Jamieson & Mason, 2019) who often experience communication access needs. MHWs frequently attribute behaviours that may be indicators of psychological distress to disability factors (Bowring et al., 2019; Hemmings et al., 2013). A range of reasons are proposed for diagnostic overshadowing by MHWs. Many MHWs are challenged to distinguish symptoms of mental health problems, particularly when the person struggles to articulate their experience using conventional speech (Bowring et al., 2019; Jamieson & Mason, 2019). However, there is a lack of agreement among researchers as to behavioural indicators of mental health problems in people with communication access needs, with two distinct lines of thought. The first is that behavioural equivalents of symptoms of mental ill health can inform diagnosis (Painter et al., 2018), and the second is that behavioural equivalents cannot be determined due to the idiosyncratic nature of symptom presentation (Westlake et al., 2021). In the present study, one MHW discussed the presence of behavioural overshadowing as an issue, seeing it as related to diagnostic overshadowing, and stating that, rather than examining the causes of behaviour change as an indicator of a mental health problem, service was denied due to behaviour being a facet of their existing diagnosis. This is contradictory to dominant messages in mental health messaging for the general population regarding the connections between behavioural change and mental health problems (Ross & Bassilios, 2019).

A further challenge to diagnosis is the underutilisation of targeted mental health assessment tools for people with communication difficulties (Weise et al., 2021). MHWs in this study have identified shortcomings in the tools used to diagnose mental health problems in the general population, due to atypical presentations and challenges in self-describing emotional experience and symptoms. The Diagnostic Statistical Manual (American Psychiatric Association, 2022), the primary resource for the diagnosis of mental health problems, requires patients to report upon complex emotions, which the person may not have the vocabulary, affective awareness, or experience to describe (Foley & Trollor, 2015;

Jamieson & Mason, 2019; Pinals et al., 2022). MHW interviewees agreed that reliance upon self-report assessment tools represented a significant challenge to accurately diagnosing mental health problems in people with communication access needs. There are alternative diagnostic assessments that may be used in the diagnosis of individuals with intellectual and developmental disability, such as the Psychological Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) (Rojahn et al., 2011; Torr et al., 2008). However, the only psychiatrist included in our study indicated that in their experience, the assessments did not adequately meet their needs and were time-consuming to learn to use, particularly when people with intellectual disabilities are a minority patient group. Other MHWs identified the insufficiency of diagnostic tools that rely upon self-reporting of emotion.

Brinkman et al. (2022) point to the lack of collaborative design in diagnostic assessment as a barrier to the development of appropriate assessment. The existing specialist diagnostic assessments have focused predominantly on the population with intellectual disability, with a lack of attention to the heterogeneous and intersecting characteristics of people with disability (Brinkman et al., 2022). The persistence of diagnostic overshadowing as a barrier to accessing appropriate mental health care may be based on ableist notions of how psychological distress should be conveyed (Holub et al., 2018). Standardised assessments for mental health problems rely upon self-reported descriptions of symptoms, and typical behavioural presentations (Di Marco & Iacono, 2007; Holub et al., 2018). There is an ongoing need for research regarding atypical presentations of mental health problems that support the diagnostic process, particularly if behavioural symptoms are a determinant of access to mental health services.

MHWs as Communication Partners: Skill & Knowledge. In this study, participants with communication access needs noted many more facilitators than barriers when describing MHW communication skills and strategies. Through the accounts of interviewees, the pervasive influence of MHW communication partner skills on mental health care was evident. Communication partner skills impacted MHW’s capacity to build rapport, apply a person-centred approach, respond to holistic care requirements, offer options for intervention, and provide opportunities for feedback. Some of the most valuable communication partner skills discussed were planning communication, AAC-specific skills, adapting communication, and using counselling micro-skills. Many of the micro-skills are common in counselling interventions (Geldard et al., 2021). Thus the appropriateness of mental health care was largely dependent upon the practitioner’s knowledge of communication access strategies and their capacity to integrate these skills into practice.

Practice guides for MHWs working with people with disability offer varied levels of guidance related to communication partner skills. The Guide (3DN, 2014) offers brief and general advice for MHWs working with people with intellectual disability, such as finding out how the person communicates and incorporating strategies into mental health interventions. Additionally, 3DN has developed a toolkit for making information accessible to people with intellectual disability (Newman et al., 2020). The toolkit focuses primarily on adapting written information into easy-to-read formats, with some environmental communication considerations. However, most participants in the present study did not view easy read as being a useful format due to limited literacy. Beyond Speech Alone (Hagiliassis et al., 2006) offers more specific information for MHWs providing counselling services to people with communication access needs with a detailed description of various modes of AAC as well as communication access strategies. While Beyond Speech Alone exemplifies a commitment to upholding communication rights, it does not necessarily reflect current contexts for mental health care provision, nor technological advances in AAC due to the age of the document. Updates are required to offer a practice guide for MHWs that offers a range of communication access strategies regardless of diagnosis. The findings of this study offer a range of strategies that can be incorporated into future practice guides and implemented by MHWs to enhance the appropriateness of mental health services for people with communication access needs.

Personalisation of Intervention and Mental Health Resources. Personalisation of intervention and mental health care resources was one of the key facilitating factors identified through the scoping review. Members of all participant groups in the present study were in agreement that the most benefit was gained from personalised mental health care approaches – a person-centred model of mental health support that was integrated within the person's everyday life. Personalisation was necessary for two main reasons, first, combinations of mental health concerns, communication preferences, and cognitive processes varied considerably among people with communication access needs. Second, there are very few existing resources to inform practice, leading MHWs to draw upon a range of approaches and tools to support their method of intervention. The necessity for personalisation required a level of awareness of different counselling approaches, as well as knowledge of communication access strategies, and a capacity to collaborate with ECPs who assist in the implementation of wellbeing strategies.

The scoping review revealed a range of psychoeducational interventions that were readily personalised to meet the communicative and therapeutic requirements of the person. MHWs using a cognitive-behavioural approach employ strategies such as drawing and art to support understanding of thoughts, feelings, and behaviour (Douds et al., 2014; Douglass et al., 2007; Fernando & Medlicott, 2009). Developing personalised visual aids was a prevalent strategy discussed by MHW interviewees, this was reflected in the scoping review literature as well (Chapman et al., 2006; Crowley et al., 2008; Hagiliassis, Gulbenkoglu, et al., 2005). Visual aids were most frequently used to convey information about self-care routines related to mental health and wellbeing. Visual aids discussed in the literature stepped out strategies for dealing with distressing emotions most commonly in CBT interventions. PBS was another example of an intervention that may be readily personalised to meet specific goals and enable communication strategies among people with communication access needs. PBS has been used to support people in managing behavioural difficulties related to mental health for people with intellectual disability (McClean et al., 2007), with some urging the broader use of PBS among other populations using mental health care services (Clark et al., 2020). Good examples of PBS include mental health support, which is holistic, person-centred and engages with mental health professionals to improve quality of life through goal attainment and promotion of human rights (Leif et al., 2023; McClean et al., 2007). This study suggests that PBS services frequently link people with communication access needs to MHWs. Further research examination of PBS' potential as a personalised intervention that supports mental health and wellbeing is required to help guide PBS professionals from diverse disciplines.

5b) Ability to Engage. The ability to engage in mental health services is indicated by the person's decision-making regarding treatment and active participation in health care (Haggerty et al., 2020). The ability to engage is generally impacted by empowerment, provision of information, agreement with the program of intervention, and levels of support from other stakeholders (Levesque et al., 2013). For people with communication access needs two factors influence the ability to engage: access to AAC and vocabulary that enables participation in mental health care, and the presence of trusted and supportive ECPs.

Access to AAC and Relevant Vocabulary. The means to communicate is essential to engaging with mental health care. From communicating emotional distress and desire for help to sharing experiences with MHWs at the mental health care interface. Communication is a two-way process, whereby messages are sent by one party and received, intact, by another and vice versa. Underpinning successful communication in the mental health care context is the goal of achieving shared understanding and moving towards improved wellbeing (Geldard et al., 2021). AAC refers to a range of aided and unaided strategies to enhance communication and promote understanding among communication partners and people with communication access needs (Beukelman & Light, 2020). To engage in mental health support participants in this study used aided AAC such as printed communication boards, and electronic speech-generating devices, as well as mainstream technologies such as smartphones with apps, and human assistance from an ECP who knew their communication preferences and personal history well. Unaided AAC methods were also used – communication strategies such as facial expressions, gestures, manual signs, as well as vocalisations and some speech. Of course, communication is a multi-modal process, therefore people with communication access needs will often use multiple modes to get their message across (Beukelman & Light, 2020; Blackstone et al., 2007). All interviewees with communication access needs wanted to be able to use their AAC strategies to participate in mental health care. In this section we have already explored the capacities of MHWs to support the engagement of people who use AAC, here we will discuss the impact of AAC access on engagement in mental health care access for people with communication access needs.

Access to a means to express one's distress and identify the issues that impinge upon emotional wellbeing is fundamental in seeking mental health care (Johnson & Yee, 2020; Noyes & Wilkinson, 2023; E. Watson et al., 2021). In AAC, vocabulary refers to the words available to the person and may not reflect the person's entire known lexicon (Beukelman & Light, 2020). In the context of seeking and accessing mental health care, relevant vocabulary includes lexicon related to expressing emotional distress, asking for mental health help, and disclosing communication preferences. MHWs stipulated the value of vocabulary about the person's past, including influential people, grief and loss, and experiences of institutionalisation, or abuse. Some people who use AAC to type out messages, like Amelia and Lisa, giving them access to a shared vocabulary that is broadly understood among those who speak or read the same language. Others had access to a limited range of words and used more idiosyncratic methods of communication. Fleur, Laura, Chris, and Hope used communication aids with limited word/symbol sets in tandem with a range of facial expressions, gestures, signs, and human assistance to get their message across. This had implications for engaging with mental health care. For example, Laura's ECPs had dominated goal setting with one MHW and Laura had been unable to object. For Fleur, who had wanted to discuss her experiences in an institution for people with disability but had been unable to share her story, the issue was lack of vocabulary to describe her experience, and limited documented history of her time living there.

Establishing AAC strategies and shared vocabulary to enable access to mental health care may require a collaborative approach, requiring the person to work with the MHW and other stakeholders, such as ECPs and Speech Pathologists (Bell & Cameron, 2003; Hagiliassis, Gulbenkoglu, et al., 2005; Noyes & Wilkinson, 2022). This study indicates that previous experiences of mental health help-seeking can equip the person with AAC strategies to enable more efficient communication of mental health care needs, accelerating access to support. For a number of participants with communication access needs, initial experiences of mental health help-seeking tended to be protracted experiences, complicated by misunderstandings about communication of distress and fraught with service access barriers. However, data demonstrates that participants with communication access needs were not deterred by experiences of inaccessibility and expressed that they would attempt to access professional mental health care if required in the future.

Availability of Trusted ECPs and Engagement in Mental Health Care. This study reveals the extent of ECPs influence on the effective inclusion of people with communication access needs in mental health care. Trusted ECPs provided initial responses to emotional distress, identified mental health information, assisted with referrals, advocated for access to mental health care, helped with preparation and transport for MHW appointments, and provided information about communication methods. It is known that ECPs are frequently the first source of support for emotional distress and their responses can determine access to more specialised mental health care (Dark et al., 2011; E. Watson et al., 2021). Additionally, ECPs can provide MHWs with critical contextual information about the person's usual functioning, historical matters such as traumatic experiences, changes in health, wellbeing, occupation, and living arrangements. These factors influence mental health status and are essential in gaining an effective diagnosis and obtaining mental health care (Di Marco & Iacono, 2007; Holub et al., 2018; Pinals et al., 2022a). Further, ECPs offer continuity of support. Parents in this study expressed a deep responsibility for the ongoing wellbeing of their offspring.

The scoping review revealed a different aspect of ECPs' involvement in mental health care, and their role in implementing mental health interventions. In the research literature, the roles of ECPs varied from inclusion as participants in the intervention (Magai et al., 2002; Walker et al., 2010), to observing and documenting between sessions (Cambridge, 2013; Crowley et al., 2008; Douds et al., 2014; Fernando & Medlicott, 2009). In some interventions, ECPs supported the attendance of psychoeducational groups, helping with information uptake and promoting the use of strategies in naturalistic settings (Crowley et al., 2008; Douds et al., 2014; Douglass et al., 2007; Hagiliassis, Gulbenkoglu, et al., 2005; Walker et al., 2010). Douglass et al. (2007) indicated that ECP support was influential on some people's ability to engage in the intervention. The level of ECP support to prepare for and attend mental health appointments can impact the outcomes for the person with communication access needs (Douglass et al., 2007). However, guidance for ECPs about how to effectively fulfil the role of mental health supporters is absent from the literature. Noyes & Wilkinson (2022) raise important considerations regarding confidentiality and the potential for ECPs acting as informal communication assistants in mental health care settings to influence the therapeutic relationship. While research suggests the benefits of formal communication assistance in a range of settings (Collier et al., 2010; Dee-Price, 2023), this option is not widely available in Australian healthcare settings. The findings of this study offer information for ECPs that can help in mental health care seeking and provide effective assistance at the mental health care interface.

7.3.6 Consequences of Mental Health Care Access (6)

The consequences of access to mental health care impact the individual's economic participation, life satisfaction, and overall health and wellbeing (WHO, 2021a). Despite elevated levels of psychological distress (AIHW, 2022), Australians with communication access needs experience persistently low levels of access to mental health care (Baker et al., 2021; Di Marco & Iacono, 2007; Howlett & Trollor, 2013; E. Watson et al., 2021). Despite the drive toward equitable access to mental health care which is underpinned by Australia's position as a signatory to the CRPD (2006), systemic challenges to inclusion are underscored in governmental reporting (Commonwealth of Australia, 2023a; McCallum, 2020; NMHC, 2023). Pervasive barriers across the trajectory of seeking mental health care present an obstacle to exploring the consequences of realised access. As this study reveals, very few people with communication access needs can reach the mental health services that they want.

The consequences of inaccessible mental healthcare include persistent psychological distress (AIHW, 2022; E. Watson et al., 2021), reliance on ECPs and hospitals to provide mental healthcare (Bennett, 2014; Howlett & Trollor, 2013), and the use of restrictive practices to manage behavioural symptoms (Bowring et al., 2019; Painter et al., 2018; Sheehan et al., 2015). Howlett & Trollor (2013) reported that informal carers absorb a significant portion of the costs of inaccessible mental health care, providing unpaid labour and shouldering the burden of care. When opportunities for care are unrealised, missed, or unsatisfactory leading the person to crisis, Levesque et al. (2013) consider this is a failing of the health care system.

Levesque et al. (2013) identify that the consequences of access relate to health and fiscal factors, as well as satisfaction with services, while the findings of the scoping review offer insight into the consequences of realised access to mental health care (E. Watson et al., 2022). The review revealed manifold benefits of access to psychoeducational interventions delivered with communication access strategies (refer to Figure 3.3). Psychoeducational interventions aim to improve mental health literacy, teach self-management skills, foster recovery, and identify help-seeking pathways (Sarkhel et al., 2020; Zhao et al., 2015). As summarised in the scoping review, the outcomes of psychoeducational interventions included community participation (McClean et al., 2007; Wark, 2012; Webber & Harkness, 2016; Willner, 2004), strengthened relationships (Aoun et al., 2015; Couchman et al., 2014; Fernando & Medlicott, 2009), greater influence over support systems (Cambridge, 2013), treating physical pain (Cravero et al., 2016), and managing distress (Averill et al., 2013; Chapman et al., 2006; Crowley et al., 2008; Douds et al., 2014; Douglass et al., 2007; Hagiliassis, Gulbenkoglu, et al., 2005). The outcomes described demonstrate that people with communication access needs can experience positive consequences from access to mental health care. It is of value to note the holistic approaches adopted by these studies in addressing mental health challenges.

Advocating for better access to mental health services requires a concept of what good mental health support should look like. Realising the objective of accessible mental health care demands the examination of alternative models of mental health care that improve efficiency and reduce exposure to trauma, reliance on ECPs, and hospitalisations arising from psychological distress (Howlett & Trollor, 2013). The following implications for policy, service provision and practice provide access solutions across the help-seeking trajectory, from prevention and primary mental health care through to specialist mental health support. The overarching aim is to achieve equity in mental health care for people with communication access needs.

7.4 Implications for Policy, Service Provision and Practice

The predominant objective of this research project was to identify improvements that could promote access to mental health care for people with communication access needs. This section offers a range of strategies that can be implemented in policy, service provision, and practice contexts. The strategies are grouped under the following seven recommendations:

1. Empower people with communication access needs as active participants in mental health care
2. Recognise the human rights of people with communication access needs
3. Improve communication access in preventative and primary mental health care
4. Enhance integration between the disability and mental health support systems
5. Develop inclusive mental health care environments
6. Improve training and guidance for MHWs to improve service delivery to people with communication access needs
7. Develop ECPs' capacity to promote communication access and mental health support.

The relevance of these recommendations is enhanced using a research design that maintains a close connection to the knowledge of lived-experience groups and practice-based information gleaned from ECPs and MHWs.

7.4.1 People with Communication Access Needs as Active Participants in Mental Health Care

It is recommended that mental health peer-worker roles for people with communication access needs are further explored to determine potential benefits, community interest, and feasibility. Further, as communication is a fundamental component of expressing one’s mental health status and conveying issues impacting wellbeing, AAC and vocabulary to maximise autonomy in mental health care must be made available.

Explore Mental Health Peer Work Roles for People with Communication Access Needs. This study placed the researchers in contact with people with communication access needs who had developed significant knowledge in advocating for access to the mental health system. This unique lived expertise placed them in a position to assist others in similar situations. Considering the findings from this study, the exploration of peer-work roles for people with communication access needs in mental health care is recommended. Peer work refers to the paid employment of individuals with experience of mental ill health, with recognition of the valuable capabilities they contribute to mental health service provision (Schweizer et al., 2018). Peer work is a developing area of research in mental health (Cabral et al., 2013; Schweizer et al., 2018) and AAC (Grace & Raghavendra, 2019), with evidence for the inclusion of peers with lived-experience expertise in intervention delivery.

Ensure Access to AAC that Enables Self-management of Mental Health and Wellbeing. People with communication access needs and ECPs identified how people can use AAC to expedite access to mental health care and address issues impacting emotional wellbeing. Access to AAC and vocabulary accompanies mental health education in ensuring people with communication access needs are aware of supports and can request assistance when needed. AAC for mental health and emotional wellbeing may take various forms, unaided and aided, from communication dictionaries explaining the communicative intent of gestures and behaviours, to high-tech devices. Vocabulary must reflect the life stage, common concerns, and preferences of the person.

Many people with communication access needs require assistance from ECPs to ensure that the AAC vocabulary set on their AAC systems remains relevant. Where required, ECPS must be equipped with skills and support from other professionals to help identify and add vocabulary to AAC devices about emotions and other themes related to well-being, such as known causes of distress and preferences. Access to AAC is significant in empowering people to self-manage mental health, as such, it is recommended that access to AAC and relevant vocabulary is considered in efforts to enhance access to mental health care.

7.4.2 Recognise the Human Rights of People with Communication Access Needs

To give enduring protection to the human rights of people with communication access needs, adoption of human rights legislation at federal and state levels of government is recommended. This study indicates that such protections would benefit the mental health and emotional wellbeing of people with communication access needs across the lifespan.

Furthermore, commitment to legislation would uphold the right to equitable health care and support the case for improved communication access in mental health care.

Adopt Legislation to Protect the Human Rights of People with Communication Access Needs. In Australia, it is recognised that current discrimination legislation is insufficient to fully protect the human rights of people with disability (AHRC, 2022; Commonwealth of Australia, 2023b; Katterl et al., 2023). The movement for a federal Human Rights Act is establishing traction, with some states moving to implement human rights legislation in their jurisdictions (AHRC, 2022). South Australia, where this research was undertaken, is not included among the states and territories to introduce a Human Rights Act. However, the present research lends support to the need for improved protections for the human rights of people with communication access needs. Legislative measures that uphold communication rights (Brady et al., 2016) and the right to equitable access to health care are of critical importance (CRPD, 2006).

7.4.3 Improve Communication Access in Preventative and Primary Mental Health Care

Considering the findings of this study, action is required to improve communication access to primary mental health care, including population-based mental health literacy strategies and public awareness campaigns. Further, people with communication access needs must be afforded education that improves mental health literacy and enables self-management of mental health, support of others, and seeking support when required. These recommendations align with the Australian Disability Strategy’s health and wellbeing policy priorities to enhance access to primary and preventative support (Commonwealth of Australia, 2021).

Improve Targeted, Communication-Accessible Mental Health Care Information. Having knowledge of mental health care is foundational in getting support when it is required. This study indicates that information about mental health is inaccessible to many people with communication access needs. Article 21 of the CRPD (2006) relates to the right to accessible information, which is under-recognised in mental health policy in Australia (Newman et al., 2022). One Australian jurisdiction, NSW has developed communication access guidelines for mental health services (Newman et al., 2020), to better include people with intellectual disability. It is recommended that communication access guidelines be developed in other jurisdictions, and that these guidelines include all populations with communication access needs.

Another important consideration in public mental health campaigns relates to the modes used to transmit information. There is an established need for targeted information that is delivered in an easily comprehendible way (Newman et al., 2022; Turnbull et al., 2022). Where necessary, public health campaigners will need to form connections with

ECPs and disability services to facilitate personalised delivery of mental health information. Our study found that parents and family members were a primary source of mental health information. The use of ECP linkages to mediate mental health information is an essential consideration in improving the reach of mental health information for people with communication access needs. While people have varied levels of independence in obtaining health care information, most participants in this study indicated a reliance on ECPs to help locate information about services. Public health campaigners must observe the limitations of online information, social media, and telehealth in reaching people who experience barriers to online inclusion (Given et al., 2022).

Mental Health Education for People with Communication Access Needs. In this study, people with communication access needs expressed a desire for greater mental health education. A finding that was particular to this study was the recognition of the role that people with communication access needs play in supporting the mental health of others. Unanimously, interviewees with communication access needs wanted information and training to assist them to better support family members and friends experiencing emotional distress and mental ill health. Improved access to primary mental health care will require better integration between mental health services and other support systems and efforts towards the realisation of human rights for people with communication access needs (WHO & WONCA, 2008). Mainstream education about mental health and emotional wellbeing is delivered across the lifespan, in early education, schools, workplaces, and throughout adulthood. Similarly, people with communication access needs must be afforded opportunities to engage with the educational opportunities. It is recommended that guidelines be developed to assist educators in enhancing communication access to mental health-related curricula in schools. Additionally, the development of guidelines for the inclusion of people with communication access needs in mental health literacy programs that are available to the broader population. For example, programs like Mental Health First Aid view people with intellectual disability as a population of concern (Bond et al., 2021), but have not yet developed a program that would be accessible to participants with communication access needs and intellectual disability and that would enable them to give mental health support to others. These gaps in the availability of suitable mental health educational materials could be remedied by a better understanding among educators and service providers of communication access strategies.

7.4.4 Enhance Disability and Mental Health Systems Integration

Clear referral pathways are required to ensure that people with communication access needs can gain timely mental health care. People with communication access needs and ECPs wanted direction for disability services and mental health care providers about how to access appropriate mental health care. Additionally, MHW lamented the persistent myth among mainstream mental health services that NDIS funding covered specialised mental health care for people with communication access needs. Resolving this misunderstanding requires inter-sectorial collaborations between mental health and disability service providers.

Clarification of Referral Pathways to Enable Timely Access to Mental Health Care. This study revealed a need for clarification of referral pathways and funding options available to people with communication access needs seeking mental health care. This issue was primarily a concern for ECPs seeking support for a person with communication access needs. Misunderstandings arose from unclear directions about mental health service eligibility, availability of skilled MHWs, and funding sources. The historical siloing of mental health and disability services in Australia has led to persistent access barriers and confusion regarding entry into the mental health system (Evans et al., 2012; Weise et al., 2021). We recommend the development of clear referral directives for people with communication access needs seeking mental health care. Referral directives must include information regarding funding options and information to ensure that people can select suitable services. Service information must include funding and any service-user costs, to ensure that people can make informed decisions about the services they select.

An additional recommendation is a “no wrong door” approach to mental health care access for people with communication access needs seeking service. In this study, MHWs noted that ECPs and GPs were a major source of referrals, indicating a need for collaboration to enable access to mental health services via general health, disability, aged care, and positive behaviour support (PBS) services. Additionally, mental health services must establish means of self-referral for people with communication access needs. Early access to mental health care via clear referral pathways will reduce reliance on emergency mental health services.

As raised by ECPs in this study, a further aspect of developing clear referral pathways is having a suitably skilled mental health workforce to refer to. This is of critical importance as ECPs with low trust in mental health services are less likely to make referrals (Man & Kangas, 2019b). Recommendation 4 addresses the need to develop the skills and knowledge of MHWs to equip them to enable communication access in mental health care.

Expand Collaboration of Mental Health and Disability Sectors. While this research indicated that fruitful collaborations are emerging between mental health and disability providers under the NDIS model, challenges remain in the integration of disability services and mainstream mental health care. Important lessons can be learned through the NDIS system which has encouraged co-location, shared staffing, and organisational policy that spans across sectors. The recent review into NDIS has recommended the development of complex care coordination processes that work across the public mental health system and NDIS-funded supports (Commonwealth of Australia, 2023e). Based on the findings of this study, these further recommendations are presented to improve intersectoral collaborations:

- Review of community mental health eligibility processes which may exclude people with communication access needs
- Review of Medicare and NDIS funding to ensure adequate time and duration of mental health care for people with communication access needs
- Expansion of low-user-cost psychosocial supports available to people with communication access needs outside of the NDIS system
- Improvement of access and funding for multidisciplinary community mental health care
- Delivery of positive behaviour support that bridges mental health and disability support systems.

Structural change is required to ensure people with communication access needs have access to mental health care that is holistic, inclusive, and affordable. Further review of mental health policy and funding mechanisms, which is beyond the scope of this project, will illuminate facilitative actions to enhance access to mental health care.

7.4.5 Develop Inclusive Models of Mental Health Care

Inclusive mental health care must respond to both the requirements of the community and individuals with communication access needs. To address community expectations of communication inclusion, there is a need to involve people with communication access needs and ECPs in the design of mental health care services. Similarly, to ensure access to the means to maintain mental health and emotional wellbeing, there is a need to design and plan holistic disability support. This requires a holistic approach to mental health care.

Co-design of Mental Health Services that Promote Communication Access. Reports on mental health service efficacy call for lived experience input in development phases to ensure relevance for a range of populations and reduce exposure to harm in the mental health system (Katterl et al., 2023; WHO, 2021a). Participants with communication access needs informed that all aspects of mental health care must be accessible to prevent further exposure to trauma. Previous findings indicate a need to engage with the perspectives of people with communication access needs when designing large-scale healthcare initiatives (Given et al., 2022). Services that provide equitable access, address ableist practices and limit exposure to further psychological harms are fit for purpose to be used by people with communication access needs (Holub et al., 2018). This is especially pertinent to in-patient mental health care. If mainstream mental healthcare is to adequately include all members of the population, inclusive design processes are essential. This study offers guidance to support the inclusive design of mental health services; however, it is apparent that active engagement with people with communication access needs, as well as including communication access advisors in co-design and co-production, can ensure the relevance of mental health service offerings.

Plan for Holistic Mental Health Care Using Person-Centred Approaches. In this study, all groups discussed the importance of mental health care that responds to the whole person including interpersonal relationships, housing, health, occupation, culture, social support, and spirituality. ECPs discussed the lack of knowledge and resources to support the mental health of people living in supported accommodation settings. The need for holistic approaches to mental health support for Australians with disability has been identified in previous research (Evans et al., 2012; Weise et al., 2018, 2021). Accordingly, in the present study, disability support worker ECPs identified that disability support agencies had existing processes and plans to support physical health which are auditable and require review on an annual basis. Based on the findings presented it is recommended that people with communication access needs are assisted in planning to maintain mental health and emotional wellbeing in conjunction with health reviews.

Given the heterogeneous nature of the population with communication access needs (Beukelman & Light, 2020), there will be great diversity among individuals in what is required to realise and maintain psychological wellbeing and be well supported to do so. Person-centred approaches must underpin holistic mental health care planning to uphold the human rights of the person. This approach to planning is also conducive to implementation of the Disability Royal Commission’s recommendations for disability services (Commonwealth of Australia, 2023a, 2023d). The essential elements of holistic mental health planning identified in this study include: social connection, access to meaningful occupation, decision-making power, physical wellbeing and bodily autonomy, safe housing, cultural and spiritual fulfilment, and access to reliable support. It is recommended that these domains be key considerations in goal setting and planning for comprehensive service provision and support funding. Adopting a planning approach of this nature will incorporate mental health support as a component of ordinary disability support provision.

7.4.6 Improve Training and Guidance for MHWs to Improve Service Delivery to People with Communication Access Needs

Given these findings, it is recommended that MHWs be equipped with the necessary knowledge and skills to work with people with communication access needs. This will require the integration of content regarding communication access strategies into pre-service education programs for MHWs. For this purpose, it is recommended that the Intellectual Disability Mental Health Core Competence Framework (3DN, 2016, 2017), currently in use in NSW, be adopted more broadly in developing pre-service training for MHWs in Australia. MHWs also require on-the-job guidance to support communication access in practice. To this aim, ongoing development of practice guides to promote communication access across all diagnostic populations is required.

Pre-service Training and Professional Development for MHWs to Support Communication Access. In this study, MHWs stated that they lacked pre-service training to support communication access and had learned how to include people with communication access needs only via on-the-job experience. We recommend training that enables MHWs to provide communication access in mental health care. The Department of Developmental Disability Neuropsychiatry (3DN, 2016, 2017) at the University of NSW has proposed a Core Competency Framework for MHWs working with people with intellectual disability. The framework consists of a manual and practical toolkit outlining adjustments to clinical practice, diagnostic assessment methods, and resources many of which apply to communication access. It is recommended that the Core Competency Framework be used to design curricula for future MHWs with expansion on competencies related to communication access. Further consideration of the multiple diagnostic populations who experience significant communication access barriers in seeking mental health care is required, and there is a need to develop MHW training that acknowledges the diversity of the population with communication access needs, but is more specific than general disability awareness resources. This study and scoping review (E. Watson et al., 2022) can provide insight into the communication access strategies used in research and practice with supporting information from stakeholder groups. Additionally, the importance of inclusive attitudes toward people with communication access needs seeking mental health care was highlighted in the accounts of those with lived experience and the MHWs. It is recommended that pre-service-MHWs undertake training modules to assist in identifying implicit and explicit biases to address ableist attitudes and foster inclusive attitudes in mental health care.

The need to equip MHWs with competencies to engage with the broad cross-section of people with disability is supported in Australian health and social policy. Thus, this recommendation aligns with the Australian Disability Strategy that states “All health service providers have the capabilities to meet the needs of people with disability” (Commonwealth of Australia, 2021). This recommendation is also compatible with findings from the Disability Royal Commission requiring further training of health professionals to ensure people with disability achieve the right to access health care on an equitable basis to the broader Australian community (Commonwealth of Australia, 2023a. 2023c).

Practice Guidance for MHWs to Support Communication Access. The ability to incorporate multimodal communication strategies was viewed by participants with communication access needs as essential to effective mental health care. When this finding is coupled with the finding that MHWs felt ill equipped to support communication, there is a clear need for greater guidance for MHWs in developing approaches that support communication access in practice. Guidance should come from a range of sources including the Core Competency Framework (3DN, 2016, 2017), published practice guides (3DN, 2014; Hagiliassis et al., 2006; Man & Kangas, 2020), research (Noyes & Wilkinson, 2023; E. Watson et al., 2022), as well as mentoring from other professionals skilled in supporting communication access.

It is recommended that guidance for MHWs be personalised to the individual and provided either by the person, other people who know the person well, or professionals with expertise in supporting communication access. In the case of practice guide manuals, it is important to present a range of potential communication access adjustments and case studies to illustrate applications with a broad range of diagnostic populations. Recent reviews of mental health care indicate that multiple diagnostic populations experience difficulty accessing mental health services due to co-occurring disability and other intersecting issues (NMHC, 2023). Resources designed specifically for diagnostic populations such as people with an intellectual disability or autism may not be perceived by MHWs as being relevant to individuals without these diagnoses.

7.4.7 Develop ECPs’ Capacity to Promote Communication Access and Mental Health Support.

It is recommended that guidance be made available to ECPs, particularly those in paid support roles, to equip them for the role of mental health supporters. Mental health awareness training can improve attitudes and knowledge and promote help-seeking behaviours (Bond et al., 2021). Data from this study indicated that many ECPs also required personalised support from MHWs to adequately support people with communication access needs and co-existing mental ill health.

Developing the Mental Literacy of ECPs Working in Disability Services. This study demonstrated that ECPs with good mental health literacy promote proactive practices, such as offering opportunities to discuss emotional wellbeing, responding to psychological distress, and helping connect with mental health care when necessary. This finding is congruent with other Australian studies identifying connections between mental health awareness of ECPs and support to access mental health care (Man & Kangas, 2019b; E.

Watson et al., 2021). ECPs indicated that under NDIS funding there was contention regarding who should pay for training to meet individual mental health support needs. Findings from this study indicate that ECPs who had participated in mental health training expressed confidence in discussing mental health and offered frequent opportunities for communication about mental health and wellbeing. We recommend investment in the capacity of disability support workers to promote mental health and connect to additional support when required.

Training programs are available to develop the mental health awareness of ECPs working with people with intellectual disability (3DN, n.d.), with a targeted Mental Health First Aid package under development (Bond et al., 2021). However, mental health training programs that specifically address mental health support for people with communication access needs are not available in Australia. We recommend the development of training modules for ECPs that provide information regarding communication diversity and mental health support. Given that some participants with communication access needs encountered attitudinal barriers from ECPs when attempting to gain mental health support, this is another important training consideration.

Guidance for ECPs in their Role as Mental Health Care Supporters. ECPs require specific guidance about how to support communication access at the mental health care interface, including advocacy, communication partner skills, documentation, intervention delivery, and maintaining vocabulary to assist self-management of mental health. Participants with communication access needs and ECPs described a range of beneficial communication strategies to promote access to mental health care. The information provided in the present study forms a basis for the development of a more comprehensive practice guide for ECPs assisting at MHW appointments. Additionally, ECPs and MHW participants indicated that personalised MHW guidance is required to complement general mental health training programs for disability workers. Guidance from MHWs can ensure that ECP support is responsive to individual requirements and can contribute to service planning that prioritises wellbeing.

7.5 Limitations

In reflecting on the limitations of this research project, the constraints imposed by the unprecedented challenges of conducting research during the COVID-19 pandemic must be acknowledged. Responding to a pandemic required adaptations in the research methodology, including reliance on digital recruitment strategies and remote data collection methods, which may have influenced participant engagement and data collection. Furthermore, despite efforts to cast the net wide and recruit a diverse range of participants, a relatively small number of participants were recruited from the lived experience and ECP populations. These limitations impact the generalisability of the findings. The significant number of participants from one geographic location may further limit the transferability of findings in regions with differing mental healthcare systems. The limitations described below are innate to the scope and constraints of the research project; thus, findings must be interpreted within the frame of the limitations.

7.5.1 Covid-19 and Research Design

This research project was conducted during the height of the COVID-19 pandemic. As stated in the methodology chapter, the research project was designed in 2019, with the research proposal presented for feedback in early March 2020. In April 2020 the NHMRC made recommendations for research projects including populations considered vulnerable to COVID-19 (CTPRG, 2020). The recommendations suggested that data collection be moved online, and in-person contact be avoided. Upon receiving this advice, the research design was modified, and aspects of the data collection process were moved online to avoid exposure to the virus. Other researchers using participatory methodologies found that moving to online research protocols provided new opportunities for participants and researchers to connect despite geographic limits (Valdez & Gubrium, 2020). While we were able to engage with survey participants from around the world, people with more significant communication support requirements were excluded from online participation. Once this matter was raised with the researcher, in-person data collection methods were enacted wherever possible. The progression of the COVID-19 pandemic presented a unique array of challenges for experienced researchers and significantly more challenges for a novice PhD researcher (Naumann et al., 2022). Maintaining responsiveness to COVID-19 health advice meant that the project was not as participatory as originally designed, however, opportunities for lived experience inclusion were sought whenever possible within the confines of an unstable research environment.

7.5.2 Recruitment

Recruitment of participants was a slow process. Some issues are inherent to recruiting populations that are dispersed and difficult to locate, such as people with communication access needs. While attempting to recruit online, it was apparent that some people were unable to access the internet independently and were therefore reliant on ECPs to share recruitment materials with them. This can lead to ECPs withholding information if they assume that the person will not be able to participate (Taylor & Balandin, 2020). The MHW group was well represented, and the recruitment targets for this group were reached. However, fewer than projected participants with communication access needs and ECPs were recruited. With fewer participants with communication access needs, the researcher implemented strategies to maintain the priority of lived-experience perspectives in the data analysis phase. Limited participant numbers did lend weight to the qualitative focus of this mixed methods study and enabled a deeper exploration of experiences (Hesse-Biber, 2015). Half of the participants with communication access needs provided data via both survey and interview. This overlap may be viewed as a limitation in recruitment, however the researcher found that providing a second opportunity to contribute their views to the study added richness to the information they shared. Given the significant barriers encountered by people with communication access needs in contributing to research, the mixed methods approach supported equity in participation. Further, providing multiple opportunities to share views and experiences added to the richness of data that people were able to share and allowed for triangulation of interview and survey data.

7.5.3 Population

Most participants in this study were in one geographic location, South Australia. While the survey included some international respondents, all interviewees were based in Australia, with the majority based in metropolitan South Australia. As a result, the findings of this study may not be generalisable or representative of the policies and service models in other locations. However, the communication access strategies discussed by participants were wide-reaching as were those gleaned from the scoping review which incorporated international research. Although the recommendations from this study are embedded within the Australian policy context, the use of the Human Rights Model (Degener, 2016) to frame the research means that findings may be relevant to practitioners and policymakers in other nations that are signatories of the CRPD. However, given the limited sample size, geographic location and policy environment of this study, caution must be exercised when applying these findings to other contexts. An additional limitation was that information about the cultural identity of participants was not collected. Lack of information about the cultural identity of participants with communication access needs meant that the researcher could not comment on the intersectional access issues related to mental health care for First Nations and CALD communities (NMHC,2021; 2022).

7.5.4 Requirement for Further Stakeholder Feedback.

Within the limited timeframe of the PhD research project, it was not possible to obtain a final round of stakeholder feedback on the recommendations presented in the thesis. Feedback was sought from academics with expertise in disability studies and health sciences fields via the final thesis review seminar. However, it is considered a substantial limitation that feedback from stakeholders, particularly people with communication access needs, is not included in this thesis. Stakeholder perspectives and additional feedback on the findings and recommendations will be sought at a later stage, following submission of the thesis.

7.6 Future Research

This was an exploratory study that collected the perspectives of three groups to explore access to mental health care. People with communication access needs have previously been excluded in research generally but perhaps more so in research addressing mental health issues. Researching the nexus of communication access and mental health care has raised further areas for examination. Awareness of the CRPD has developed and statutory obligations are becoming embedded in Australian legislation, policy, and practice. The implementation of CRPD and associated policy has increased attention to the right to equitable standards of health care, with the Disability Royal Commission emphasising the urgency for action to address systemic deficits (Commonwealth of Australia, 2023d, 2023c). As reflected in the proposed areas for future research presented below, the human rights of people with communication access needs must be prioritised in realising quality mental health care.

7.6.1 Participatory Models of Research

The present study took place during the COVID-19 pandemic. Despite the planning and design of a Participatory Action Research project, significant revisions were required to adapt to the restrictions. Although not possible to fully implement, the planning phase of this study demonstrated the feasibility of Participatory Action Research which actively engages people with communication access needs as partners in research. Additionally, the time and financial constraints of conducting PhD research did not allow the researcher to return to the lived-experience research advisors at the analysis stage. Thus the space remains for implementing Participatory Action Research projects which are underpinned by communication inclusion as a core objective. By implementing participatory research projects that prioritise communication access, more can be learned about inclusive research design processes, including defining research questions, selecting suitable data collection methods, and collaborative data analysis strategies. Uncovering access strategies in research that are informed by lived experience at all stages of the research cycle will provide valuable guidance for researchers investigating issues that directly impact the lives of people with communication access needs. Such research would build upon the emerging body of advice for qualitative researchers (Dee-Price, 2023; Dee-Price et al., 2021; Taylor & Balandin, 2020; Walsh et al., 2024), giving focus to the in-depth collaboration necessary for Participatory Action Research (Kemmis et al., 2014).

7.6.2 Communication Accessible Primary Mental Health Resources

The findings of this study suggest that further research is required to ensure mental health education is available to people with communication access needs. Such research can enhance the accessibility of primary and preventative mental health content. Before the advent of the COVID-19 pandemic one of the objectives of this research project had been to work collaboratively with people with communication access needs to identify adjustments to mainstream mental health resources. In its current form, this research project demonstrated specific barriers to accessing preventative and primary mental health care resources. This indicates a necessity for future research to examine adaptations to mainstream primary mental health resources to improve accessibility among people with communication access needs. Projects of this nature present an opportunity for collaborative research with people with communication access needs as co-researchers.

7.6.3 The Role of People with Communication Access Needs in Providing Emotional Support

A novel finding from this research study relates to the role of people with communication access needs in supporting the mental health and wellbeing of friends and family members. Accounts of people with communication access needs providing emotional support to others reinforced the reciprocal nature of emotional support in relationships with ECPs. This is an underexplored area in research. Gaining an understanding of the nature of the support provided by people with communication access needs can inform the development of mental health literacy materials and of AAC resources that enable people to fulfil this important role in their relationships.

7.6.4 Peer Support in Mental Health Care for People with Communication Access Needs

As described in the recommendations section, peer work is an emerging area of research in both AAC (Grace & Raghavendra, 2019) and recovery-oriented mental health care (Cabral et al., 2013; Schweizer et al., 2018). Peer work enables populations to formalise knowledge gained through their experiences to support others in a similar situation (Schweizer et al., 2018). There is scope for research that accompanies the design and development of peer-to-peer mental health support, especially one co-produced in partnership with people with lived experience of communication access needs. Such research could apply a Participatory Action Research approach as described above.

7.6.5 Holistic Models of Mental Health Support

The findings of this study indicate the need for holistic models of mental health care for people with communication access needs. Research is required to address the fragmentation of mental health and disability services by establishing potential models for holistic mental health care. For consistency with Australia's Disability Strategy (Commonwealth of Australia, 2021) a defining feature of any prospective model must be a person-centred approach. Such research would harness trans-disciplinary contributions from psychology, psychiatry, speech and communication, developmental education, and social work, as well as lived-experience perspectives. Promising mental health care models (Baker et al., 2021; Pinals et al., 2022a) trialled in other CRPD nations may be tested for their applicability to the Australian services context.

7.6.6 PBS as an Intervention to Support Mental Health and Wellbeing

Building upon the need for holistic mental health care is the necessity to explore the potential applications of PBS in promoting the mental health of people with communication access needs. This study indicated that some people with communication access needs may be referred to PBS services, rather than mental health care for behavioural issues that are impacted by psychological wellbeing. The scoping review (Chapter 3) demonstrated that PBS models that incorporated access to MHWs, AAC, as well as goals to enhance quality of life had positive benefits for the mental health of people with communication access needs (Cravero et al., 2016; McClean et al., 2007). Interviews indicated that the provision of mental health support within PBS varied depending on the practitioner's skill in identifying potential mental health problems and knowledge of psychoeducational resources. Further research is needed to determine the benefits and applications of PBS to the mental health of people with communication access needs.

7.6.7 Communication Access and Counselling Micro Skills

The scoping review and interviews revealed that people with communication access needs had benefitted from individual counselling and psychotherapy (E. Watson et al., 2022). The present study revealed that MHWs, when providing counselling, are required to adjust the use of micro skills to support communication access. Specifically, the questioning techniques that are typical in counselling may require adjustment to enable the participation of people with communication access needs. MHWs may be challenged in matching which communication access strategies may work best for which individual within the counselling micro-system (Noyes & Wilkinson, 2023). The present study revealed that practitioners must use skilfully and ethically crafted closed and clarifying questions to supplement limited vocabulary availability and minimise fatigue in AAC users. Further research is necessary to define and describe the specific counselling techniques, or micro skills, required to effectively include individuals with communication difficulties in counselling.

7.6.8 Communication Access beyond Diagnostic Confines

To date, research into mental health access has focused predominantly on diagnostic groups, for example, people with intellectual disability (Evans et al., 2012; Man & Kangas, 2019b; Newman et al., 2020; Weise, Fisher, et al., 2020; Whittle et al., 2018), autism (Foley & Trollor, 2015; Nicolaidis et al., 2015), and aphasia (Baker et al., 2021; Sandberg et al., 2021). Among these populations, there is a commonality in the requirement for communication access. In this study MHWs, particularly those employed in psychosocial support settings, indicated a preference for toolkits about supporting communication, rather than focussing on diagnostic populations. The efforts to progress equitable access to mental health care for Australians with intellectual disability are exemplary to researchers aiming to promote awareness of the systemic access requirements of other populations. Future research would benefit from a focus on communication as a central aspect of access to provide more cohesive guidance for professional mental health practice. Such research would further develop the work of (Hagiliassis et al., 2006) and reflect the current context of mental health care provision for people with communication access needs.

7.6.9 Consequences of Access to Effective Mental Health Care

Due to the significant barriers to accessing mental health care, there is very little existing research evidence of the consequences of access to the mental health care system for people with communication access needs. However, given the current policy emphasis on access to mainstream services for mental health care (Commonwealth of Australia, 2021, 2023a, 2023c, 2023e), there is now a clear requirement for research into the consequences of access to the Australian mental health care system. Research into the consequences of access to care must include outcomes for mental health, quality of life, and economic effects, as well as satisfaction with service provision. Undertaking research using varied methods to explore the consequences of realised access to mental health care can inform continual service improvements, and responsive access strategies in a dynamic policy context.

7.7 Chapter Summary

Addressing the central research objective of improving access to mainstream mental health supports for people with communication access needs, this discussion chapter has integrated current research and policy, beginning with an exploration of human rights and social determinants of mental health. The findings of this study elucidate the accessibility challenges encountered by people with communication access needs within the mental health system. By prioritising lived-experience perspectives in the research design and analysis, the study identifies access solutions relevant to the community. With the

Conceptual Model of Access to Health Care (Levesque et al., 2013) as a framework to structure the discussion of barriers and facilitators to mental health support, this chapter emphasises the importance of preserving a human rights orientation in addressing access challenges (Degener, 2016). The chapter concludes with recommendations to enhance mental health care and addresses the limitations of the current research with areas for future research. Through a comprehensive examination of the findings and their alignment with theoretical frameworks, human rights principles, and current policy, this discussion chapter offers new insight into the Australian mental health system as encountered by people with communication access needs.

CHAPTER 8. CONCLUSION

This study explored mental health support for people with communication access needs, with the objective of identifying potential improvements to better access and promote inclusion in mental health care. The study consolidated lived-experience perspectives, alongside those of everyday communication partners (ECPs), and mental health workers (MHWs) to understand the knowledge and experiences of these groups in receiving, observing, or delivering mental health support for people with communication access needs. The significant and original findings from this study include: the identification of the roles and educational requirements of people with communication access needs and ECPs relating to mental health support; identification of the educational needs of MHWs to provide communication access in practice; specifying the access issues encountered by people with communication access needs attempting to navigate the mental health system; and an articulation of the connections between human rights and the mental wellbeing of people with communication access needs. Further, this is the first known use of Levesque et al.'s (2013) Conceptual Model to examine access to mental health care for people with communication access needs. This study also contributes to the development of research designs that actively include people with communication access needs.

People with communication access needs have reciprocal roles in supporting the mental health and emotional wellbeing of others. This study revealed the previously unrecognised role of people with communication access needs as mental health supporters. Emphatically, participants with communication access needs expressed that they wanted resources and education to enable them to support the mental health of others. Further, this study revealed that people with communication access needs do not consistently receive mental health education through schooling, instead, they may rely on life experiences to develop an understanding of mental health and the available care pathways. Developing accessible mental health education is a foundational step in empowering people with communication access needs as active participants in mental health care. Likewise, people with communication access needs want their ECP and other supporters to be informed about mental health to enable support when needed.

While mental health education for ECPs is important, it is essential that ECPs know the person with communication access needs well and value their communication. This study profiled the characteristics, skills, knowledge, attitudes, and behaviours of ECPs who enact mental health support, as perceived by people with lived experience. Lasting connections with responsive ECPs enabled access to regular emotional support, and professional mental health care when needed. Participants with communication access needs and MHWs viewed knowledgeable and trusted ECPs as important partners in mental health care.

MHWs identified the limitations of their training to prepare them to provide communication access in their professional practice. Recently, there has been a recognition of the barriers created by the lack of education for MHWs (Commonwealth of Australia, 2021a, 2023c; Weise et al., 2021). Experiences of working with people with communication access needs enabled many MHWs to develop skills and knowledge to include people with communication access needs in mental health care. Some MHWs were actively sharing their knowledge with other practitioners and students to enhance access to mental health services. The lack of education to adequately equip MHWs to work with people with communication access needs is a by-product of ableism in the mental health system. However, promising efforts to overcome MHW skill deficits and promote access to mental health services are emerging in some jurisdictions (3DN, 2016).

Using the Conceptual Model of Access to Health Care (Levesque et al., 2013) enabled the exploration of accessibility throughout the help-seeking trajectory. This exploration revealed that education was one among many access concerns impacting access to mental health care for people with communication access needs. Access issues were identified at all tiers of mental health care: at the primary level, access to relevant educational resources to promote mental health literacy; at the secondary level, ensuring the availability of early intervention from suitably skilled MHWs, ECPs, GPs, and allied health professionals; and at the tertiary level, provision of specialist multi-disciplinary mental health care in inpatient and community settings. All levels of mental health care must be accessible to people with communication access needs for services to meet statutory obligations and realise the aspirations stated in governmental policy. Planning for mental health care provision must begin with the conception of the right for equitable care among people with communication access needs, and consideration of how this population receives messaging about mental health.

The findings from this study clarify the significance of human rights as a factor in attaining optimum mental health and emotional wellbeing for people with communication access needs. Survey respondents and interviewees with lived experience consistently related their mental health and wellbeing to issues of social justice: autonomy, social connectedness, meaningful work, safe homes, and secure support arrangements. The exclusion of people with communication access needs in mental health care stems from a legacy of siloed services for people with disability and mental illness. Consequently there is a dire need for models of mental health care that recognise the whole person. This study has demonstrated that people with communication access needs contribute unique and valuable perspectives that can improve inclusion in mental health care. Incorporating the perspectives of people with communication access needs in designing systemic mental health care reform can benefit multiple populations who face communication accessibility issues.

This study has implications for policy, service provision, and practice in mental health support for people with communication access needs. It contributes to an emerging body of research that actively seeks to include the lived-experience perspectives of people with communication access needs (Dee-Price et al., 2021; Noyes & Wilkinson, 2023; Sellwood et al., 2022; Walsh et al., 2024; E. Watson et al., 2021). The theoretical framework grounded in the transformative paradigm (Mertens, 2007) and informed by the Human Rights Model of Disability (Degener, 2016) provided a strong conceptual foundation for understanding the interactions between communication and access to mental health care. Using this theoretical framework and methodology to guide data collection, analysis, and interpretation provided a philosophical frame that engaged an ethos of social justice and human rights (Mertens et al., 2016). The detailed description of the research design may assist other researchers in developing inclusive studies that incorporate diverse methods of communication.

The imperative for accessible mental health care has been evidenced throughout this thesis; reflecting the CRPD (2006), as well as contemporary disability policy and legislation (Australian Government, 2010; Commonwealth of Australia, 2021; Disability Discrimination Act, 1992). Australia is at a juncture in disability and mental health care reform – a point at which the system can yield truly person-centred and holistic models of support. The prioritisation of lived-experience perspectives in this study yielded new insights into the issues that influence the mental health of people with communication access needs, as well as the factors that impact inclusion in mental health care. This is a clear indication that people with communication access needs have an important role to play in future research into the efficacy of mental health care. As current policy aims to build the capacity of mainstream mental health services to provide support to Australians with disability (Commonwealth of Australia, 2021, 2023a, 2023e), there is a need for greater collaboration with people with communication access needs and ECPs in designing such services. Future research will benefit from the use of participatory research designs to develop educational resources and models of mental health support that can benefit people with communication access needs.

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APPENDICES

Appendix A: Ethics Approval
Appendix B: Survey Information Sheet for People with Communication Access Needs (Easy English).
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Appendix A: Ethics Approval

3 August 2020

HUMAN RESEARCH ETHICS COMMITTEE

APPROVAL NOTICE

Dear Ms Eleanor Watson,

The below proposed project has been **approved** on the basis of the information contained in the application and its attachments.

Project No: 1885

Project Title: Connecting to Wellbeing: Developing communication accessible mental health supports with people with complex communication needs.

Primary Researcher: Ms Eleanor Watson

Email: eleanor.watson@flinders.edu.au

Approval Date: 03/08/2020

Expiry Date: 31/12/2021

Please note:*Due to the current COVID-19 situation, researchers are strongly advised to develop a research design that aligns with the University's COVID-19 research protocol involving human studies. Where possible, avoid face-to-face testing and consider rescheduling face-to-face testing or undertaking alternative distance/online data or interview collection means. For further information, please go to https://staff.flinders.edu.au/coronavirus-information/research-updates.*

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Participant Documentation**

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the HREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Human Research Ethics Committee (Project Number 1885*). For more information regarding ethics approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.*

2. **Annual Progress / Final Reports**

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research 2007 (updated 2018)* an annual progress report must be submitted each year on the anniversary of the approval date for the duration of the ethics approval using the HREC Annual/Final Report Form available online via the ResearchNow Ethics & Biosafety system.

Please note that no data collection can be undertaken after the ethics approval expiry date listed at the top of this notice. If data is collected after expiry, it will not be covered in terms of ethics. It is the responsibility of the researcher to ensure that annual progress reports are submitted on time; and that no data is collected after ethics has expired.

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please either submit (1) a final report; or (2) an extension of time request (using the HREC Modification Form).

For student projects, the Low Risk Panel recommends that current ethics approval is maintained until a student's thesis has been submitted, assessed and finalised. This is to protect the student in the event that reviewers recommend that additional data be collected from participants.

First Report due date: 3 August 2021

Final Report due date: 31 December 2021

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, researchers and supervisors)
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes to information / documents to be given to potential participants;
- changes to research tools (e.g., survey, interview questions, focus group questions etc);
- extensions of time (i.e. to extend the period of ethics approval past current expiry date).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available online via the ResearchNow Ethics & Biosafety system. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Yours Sincerely,

Andrea Mather

on behalf of

Human Research Ethics Committee
Research Development and Support
human.researchethics@flinders.edu.au
P: (+61-8) 8201 3116

Flinders University
Sturt Road, Bedford Park, South Australia, 5042
GPO Box 2100, Adelaide, South Australia, 5001

http://www.flinders.edu.au/research/researcher-support/ebi/human-ethics/human-ethics_home.cfm

ResearchNow
Ethics & Biosafety

Flinders

Appendix B: Survey Information Sheet for People with Communication Access Needs (Easy English).

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& Health Sciences

Connecting to Wellbeing Research Project

Survey Information Sheet

Easy Read Version

About this information sheet

This information sheet is about a survey.

The survey is part of the **Connecting to Wellbeing** research project.

You can choose if you want to do the survey or not.

Before you can do the survey you need to:

1. Read this information sheet.
2. Understand the information.
3. Decide if you want to do the survey.

Getting help

You can get help to read the information sheet.

You can ask a friend, family member, or support worker for help.

It is important to understand the information sheet.

Then you can make your choice about the survey.

Go to the next page...

Important words

Complex Communication Needs

Complex communication needs makes it hard for a person to communicate with speech.

They might have a condition that makes speech hard, like

- Cerebral Palsy
- Autism
- Brain injury

They might use communication aids or AAC.

Mental Health

Mental health means the health of your mind.

Your mental health affects how you feel, think and act.

Some things that can impact on your mental health are:

- stress,
- being in pain,
- the death of a loved one

Go to the next page...

More important words

Wellbeing

Wellbeing means how you feel about your life overall.

Some things that are linked to good wellbeing are:

- Having your choices are respected.
- Feel safe and comfortable in your home and work.
- Having people that you can trust to help you.
- Having help from health workers when you need it.

Multiple choice question

A question that has a list of answers to choose from.

You can choose one or more answer from the list of choices.

You can choose ‘OTHER’ and type your own answer.

Go to the next page…

The Research Team

PhD Student

Eleanor Watson

✉ Email: eleanor.watson@gmail.com

Supervisors

Associate Professor Pammi Raghavendra

Professor Sharon Lawn

Dr Jo Watson

Go to the next page…

About the research project

- The research project is called **Connecting to Wellbeing.**
- We want to learn about people with complex communication needs and mental health.
- We want to learn from people who have complex communication needs.
- We also want to learn from family, friends and support workers.
- The research project is supported by Flinders University (project 1885).

Go to the next page…

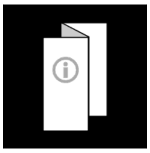
Why are we doing the research project?

We want to learn about:

- How you get help for your mental health.
- How your family, friends and support workers help you with your mental health.
- How mental health workers help people with complex communication needs.
- How can mental health services can include people with complex communication needs.

Go to the next page…

About the survey



You will be asked to

- Do an online survey on your computer, tablet or smart phone.
- Answer multiple choice questions.
- Answer questions about mental health.
- The survey will take between 15-30 minutes.
- You can do the survey at your own pace.

Can I do the Survey?

You can do the survey if you:

- Are over 18 years old.
- Are willing to answer questions about mental health.
- Have complex communication needs.

Go to the next page…

Getting help to do the survey

- You can get help from a support person.
- A support person can be a friend, family or worker.
- The support person should be someone that you trust.
- If someone helps you, they will know your answers.

Your support person can

- Help you set up your computer, tablet, or smart phone.
- Read the survey questions and answers to you.
- Help put the answers into the survey.

Your support person can not

☐ Answer questions for you

☐ There is a separate survey for support people.

☐ Support people can do the survey here.

Or on this web page:

https://qualtrics.flinders.edu.au/jfe/form/SV_55yTvJCYoi7i69f

Go to the next page…

Benefits of doing the survey

- We want to know what you think about mental health services.
- We want to make it easier for people with complex communication needs to get help for mental health.
- Your ideas will help us do this.

Are there risks to doing the survey?

- We want you to feel safe doing this survey.
- The survey asks some questions about your experiences.
- The survey asks some questions about mental health.
- You might feel uncomfortable answering these questions.
- If you feel uncomfortable you can skip a question
- If you feel upset you can stop the survey.

Go to the next page…

If you feel distressed during or after the survey…

You can get help from **Lifeline** or **1800 RESPECT.**

Lifeline and **1800 RESPECT** are free counselling services.

Lifeline

Call: 13 11 14

TTY: call 133 677 then 13 11 14

Speak and Listen: call 1300 555 727 then 13 11 14

National Relay: https://nrschat.nrscall.gov.au/nrs/internetrelay

then request 13 11 14

Chat online:

https://www.lifeline.org.au/get-help/online-services/crisis-chat

1800 RESPECT

Call: 1800 737 732 OR

National Relay: https://nrschat.nrscall.gov.au/nrs/internetrelay

then request 1800 737 732

Chat online: https://chat.1800respect.org.au/#/welcome

Go to the next page…

What if you want to stop doing the survey?

- You can stop the survey by closing the webpage.
- If you stop the survey your answers won’t be recorded.
- When you finish the survey your answers will be recorded.

Keeping your information safe

- We will protect your privacy at all times.
- No one will be able to identify you from the survey.
- Your information will be kept on a password protected computer.
- If you give us your contact details we will not share them.

Go to the next page…

How can I get more information about the project?

- You can email eleanor.watson@flinders.edu.au
- We will give updates about this research project on Facebook.
- You can get updates here.
- Or you can use this web address:

https://www.facebook.com/Connecting2Wellbeing

Making a complaint

Please contact the Flinders University Research Ethics and Compliance Office.

Telephone: 08 8201 3116

Email: human.researchethics@flinders.edu.au.

Go to the next page…

Thank you for reading about the survey

If you do want to do the survey:

- Go back to the survey web page.
- Start answering the questions.

If you don't want to do the survey:

- Close the survey web page.

Appendix C: Survey Information Sheet for People with Communication Access Needs (Standard).

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PARTICIPANT INFORMATION SHEET

Survey:
Lived experience perspectives of people with complex communication needs

Connecting to Wellbeing:

Exploring communication accessible mental health supports with people with complex communication needs

Chief Investigator:
Ms Eleanor Watson
Disability & Community Inclusion Unit
College of Nursing & Health Sciences
Flinders University
eleanor.watson@flinders.edu.au

Supervisors:
Associate Professor Pammi Raghavendra
College of Nursing and Health Sciences
Flinders University
Tel: (08) 8201 3426

Professor Sharon Lawn
College of Medicine and Public Health
Flinders University
Tel: (08) 7221 8476

Dr. Jo Watson
School of Health and Social Development
Deakin University
Tel: (03) 951 7189

Description of the study

This study is part of the project called ***Connecting to Wellbeing: Exploring communication accessible mental health supports with people with complex communication needs*.** In this project the researchers will work with people with complex communication needs, everyday communication partners, and mental health workers to investigate communication access in relation to mental health supports. This project is supported by Flinders University, College of Nursing and Health Sciences.

inspiring achievement

Purpose of the study

Through this project the researchers aim to find out about:

- The issues that impact on people with complex communication needs when they seek help for their mental health;
- The current knowledge, skills and experiences of mental health workers regarding working with people with complex communication needs;
- The things that Everyday Communication Partners and Mental Health Workers do that helps or hinders access to mental health support;
- How mental health supports may be adapted to improve access for people with complex communication needs.

Benefits of the study

Through this project, the researchers are aiming to improve access to mental health supports for people with complex communication needs. They will do this by working with people who experience complex communication needs, as well as other people involved in mental health such as everyday communication partners and mental health workers. Sharing your perspectives and experiences will contribute to better understanding of the factors that improve or prevent access to mental health supports; your information can help us to learn more about existing mental health resources and how these might be adapted to improve access for people who experience complex communication needs.

Who can participate?

The researchers are looking for people who would like to share their views on communication access and support for mental health. To participate in this study, you should be:

- Over 18 years of age,
- identify as experiencing severe difficulties in using speech for communication (or complex communication needs). The primary cause of these communication difficulties is not due to a hearing impairment.
- willing to discuss issues related to mental health,

It is not necessary to have a diagnosis of a mental illness, what is most important is that you feel comfortable to share your views on how you get support for issues that impact on your sense of mental health and wellbeing. This may be informal support (e.g . friends, family, partner) or formal support services (e.g. support workers, psychologist, counsellor, etc).

Participant involvement

If you agree to participate in the research study, you will be asked to:

- Participate in an online survey
- respond to questions about yourself and your views and experiences regarding communication access and mental health supports.

The survey will take about 15 minutes; however, you may undertake the survey at your own pace. Participation is entirely voluntary.

Support to participate in the survey:
You may choose to have a support person assist you to undertake the survey. The support person should be someone that you trust and whom you feel safe discussing your mental health and wellbeing with. The support person will not be able to answer questions on your behalf. A support person may assist by:

- assisting to set up your device or computer to undertake the survey,
- reading the written information and survey questions to you, and/or
- providing physical assistance to input your answers into the survey software.

Be aware, if you have a support person assist you with the survey, your information will not be confidential.

If the support person wants to share their views on communication access and mental health supports there is a separate survey for 'Everyday Communication Partners'. This survey offers an opportunity for family members, friends, partners, and/or support workers to their perspectives about what happens when people with complex communication needs seek help for their mental health and wellbeing. The Everyday Communication Partners survey can be accessed via this web address https://qualtrics.flinders.edu.au/jfe/form/SV_55yTvJCYoi7i69f

Potential risks

The survey will focus on your experiences of addressing issues related to mental health and wellbeing, and what supports have benefited you. The researchers anticipate few risks from your involvement in this interview. However, given the nature of the project, some participants could experience emotional discomfort. Participants have the right to skip question or to stop the survey if they feel uncomfortable at any point. If you experience feelings of distress as a result of participation in this study, please let the research team know immediately via email.

Additionally, these are contact details for some free communication accessible counselling support services:

Lifeline: Crisis support and suicide prevention.

- Call 13 11 14 **OR**
- TTY (teletypewriter): call 133 677 then request 13 11 14 **(open 24 hours)**
- Speak and Listen: call 1300 555 727 then request 13 11 14 **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay
  - then request 13 11 14 **(open 24 hours)**
- Chat online: go to https://www.lifeline.org.au/get-help/online-services/crisis-chat **(7pm – midnight)**

1800 RESPECT: Domestic violence and abuse counselling and support

1800RESPECT has been awarded the Scope Communication Access Symbol. The symbol is awarded to organisations that demonstrate improved access for people with communication difficulties.

- Call 1800 737 732 OR **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay then request 1800 737 732 **(open 24 hours)**
- Chat online: go to https://chat.1800respect.org.au/#/welcome **(open 24 hours)**

Withdrawal Rights

You may, without any penalty, decline to take part in this survey. As the survey is anonymous, if you decide to take part and later change your mind, the researcher will not be able to identify and remove your data. To withdraw, you may just refuse to answer any questions or stop the survey.

Your decision not to participate or to withdraw from this research study will not affect your relationship with Flinders University and its staff and students.

Confidentiality and Privacy

The research outcomes may be presented at conferences, written up for publication or used for other research purposes as described in this information form. However, the privacy and confidentiality of individuals will be protected at all times.

Your survey responses will be anonymous. You may choose to provide your contact details to receive an information pack for a follow up interview. If you give your contact information, your personal details will be stored securely, separate to the survey data, so the survey will not be linked to your details. All information and results obtained in this study will be stored in a secure way, with access restricted to the researchers named in this information sheet.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent.

Data Storage

The information collected may be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All data will be securely transferred to and stored at Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

How will I receive feedback?

On project completion, a short summary of the outcomes will be available to all participants via the research project's Facebook page https://www.facebook.com/Connecting2Wellbeing/

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (project number 1885).

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 3116 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet and if you accept our invitation to be involved, please proceed with the survey.

Appendix D: Interview Information Sheet for People with Communication Access Needs (Easy English)

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& Health Sciences

Connecting to Wellbeing
Research Project

Interview
Information Sheet

Easy Read Version

About this information sheet

This information sheet is about an interview.

The survey is part of the **Connecting to Wellbeing** research project.

You can choose if you want to do the interview or not.

Before you can do the interview you need to:

1. Read this information sheet.
2. Understand the information.
3. Decide if you want to do the interview.
4. Sign the consent form on page 15.

Getting help

You can get help to read the information sheet.

You can ask a friend, family member, or support worker for help.

It is important to understand the information sheet.

Then you can make your choice about the interview.

Go to the next page...

Important words in this document

Complex Communication Needs

Complex communication needs make it hard for a person to communicate with speech.

They might have a condition that makes speech hard, like

- Cerebral Palsy
- Autism
- Brain injury

They might use communication aids or AAC.

Mental Health

Mental health means the health of your mind.

Your mental health affects how you feel, think and act.

Some things that can impact on your mental health are:

- stress,
- being in pain,
- the death of a loved one

Go to the next page...

More important words

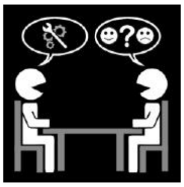
Wellbeing

Wellbeing means how you feel about your life overall.

Some things that are linked to good wellbeing are:

- Having your choices are respected.
- Feel safe and comfortable in your home and work.
- Having people that you can trust to help you.
- Having help from health workers when you need it.

Interview



- An interview is a conversation where one person asks questions and the other person gives answers.
- In research an interview helps the researcher learn.
- The researcher will ask questions about you and your experiences.
- The researcher will record your answers so that they don't forget or make a mistake about what you said.

Go to the next page…

The Research Team

PhD Student

Eleanor Watson

✉ Email: eleanor.watson@gmail.com

Supervisors

Associate Professor Pammi Raghavendra

Professor Sharon Lawn

Dr Jo Watson

Go to the next page…

About the research project

- The research project is called **Connecting to Wellbeing.**
- We want to learn about people with complex communication needs and mental health.
- We want to learn from people who expereince complex communication needs.
- We also want to learn from family, friends and support workers.
- The research project is supported by Flinders University (project 1885).

Why are we doing the research project?

We want to learn about:

- How you get help for your mental health.
- How your family, friends and support workers help you with your mental health.
- How mental health workers help people with complex communication needs.
- How can mental health services can include people with complex communication needs.

Go to the next page…

About the interview

You will be asked to do two interview sessions.

Interview 1 will ask about your life and how you like to communicate.

Interview 1 will take less than 1 hour.

Interview 2 will focus on your experiences of getting help for your emotions and mental health.

Interview 2 will take around 2 hours.

- You can do the interviews in-person or online.
- The researcher will ask your permission to record the interview.
- We will agree on a safe place to do the interview.
- You can do the interview in more than one session if you want to.

To compensate you for your time we will give you a $40 Coles Myer gift voucher.

Go to the next page…

Can I do the interview?

You can do the survey if you:

- Are over 18 years old.
- Are willing to answer questions about mental health.
- Experience complex communication needs.
- Can answer ‘yes’ and ’no’ on your own.
- Have an AAC system that enables you to answer interview questions.

About Augmentative and Alternative Communication (AAC)

- AAC helps you get your message to other people.
- AAC can be a device or a communication aid.
- AAC can be a person, or Communication Assistant

Go to the next page…

Getting help to do the interview

- You can choose to have a support person to help you at your interview.
- We call this support person a **Communication Assistant.**
- A Communication Assistant can be a friend, family or worker.
- Your Communication Assistant should be someone that you trust.
- If someone helps you, they will know your answers.

Your support person can

- Help you with communication.
- Help you think about your answers to the questions.

Your support person can not

- Answer questions for you.

There is a separate interview for support people.

Go to the next page…

Benefits of doing the interview

- We want to know what you think about mental health services.
- We want to make it easier for people with complex communication needs to get help for mental health.
- Your ideas will help us do this.

Are there risks to doing the interview?

- We want you to feel safe doing the interviews.
- We will ask some questions about your experiences.
- We will ask some questions about mental health.
- You might feel uncomfortable answering these questions.
- If you feel uncomfortable you can skip the question
- If you feel upset you can stop the interview.

Go to the next page…

If you feel distressed during or after the interview

You can get help from **Lifeline** or **1800 RESPECT.**

Lifeline and **1800 RESPECT** are free counselling services.

Lifeline

Call: 13 11 14

TTY: call 133 677 then 13 11 14

Speak and Listen: call 1300 555 727 then 13 11 14

National Relay: https://nrschat.nrscall.gov.au/nrs/internetrelay

then request 13 11 14

Chat online:

https://www.lifeline.org.au/get-help/online- services/crisis-chat

1800 RESPECT

Call: 1800 737 732 OR

National Relay: https://nrschat.nrscall.gov.au/nrs/internetrelay

then request 1800 737 732

Chat online: https://chat.1800respect.org.au/#/welcome

Go to the next page…

What if you want to stop doing the interview?

- Your participation in the interviews is your choice.
- You can choose not to do the interview:

Before the interview – You can email Eleanor to cancel your interview.

During the interview - tell Eleanor you want to stop the interview.

After the interview - you can drop out of the interview up to 1 week after the interview.

If you decide to stop the interview your information will be removed. You will not have to return the gift voucher.

Keeping your information safe

- We will protect your privacy at all times.
- All names of people and services will be removed from your interview information.
- Your information will be kept on a password protected computer.
- If you give us your contact details, we will not share them.

Go to the next page…

How can I get more information about the project?

- You can email eleanor.watson@flinders.edu.au
- We will give updates about this research project on Facebook.
- You can get updates here.
- Or you can use this web address:

https://www.facebook.com/Connecting2Wellbeing

Making a complaint

Please contact the Flinders University Research Ethics and Compliance Office.

☎ Telephone: 08 8201 3116

Email: human.researchethics@flinders.edu.au.

Go to the next page…

Thank you for reading about the interview

If you do want to do the interview:

- To get more information, email Eleanor at eleanor.watson@flinders.edu.au, OR
- You can sign the ***consent form*** on page 15 and return it to Eleanor.
- Once you have signed the consent form you can take a photo, or scan the form and email it to eleanor.watson@flinders.edu.au
- If it is hard for you to return the consent form by email, please contact Eleanor to arrange return.

If you don't want to do the interview:

- You don't need to do anything, **OR**
- You can tell Eleanor about your decision by emailing eleanor.watson@flinders.edu.au

Go to the next page…

CONSENT FORM

Consent Statement

☐ I have read and understood the information about the research, and I understand that I can contact the research team if I have further questions about this research.

☐ I am not aware of any condition that would prevent my participation, and I agree to participate in this project.

☐ I understand that I am free to withdraw from the study, as per the information sheet. My withdrawal will not affect my relationship with Flinders University and its staff and students.

☐ I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any concerns about the ethical conduct of this study.

☐ I understand that my involvement is confidential, and that the information collected may be published. I understand that I will not be identified in any research products.

I further consent to:

☐ participating in two interview sessions
☐ having my information audio recorded
☐ having my information video recorded (for online interviews)
☐ sharing my identifiable data with other researchers listed on this information sheet
☐ ***being contacted about other research projects:***
The researchers will conduct workshops to co-design solutions to communication access barriers in mental health supports.

Signed or marked:

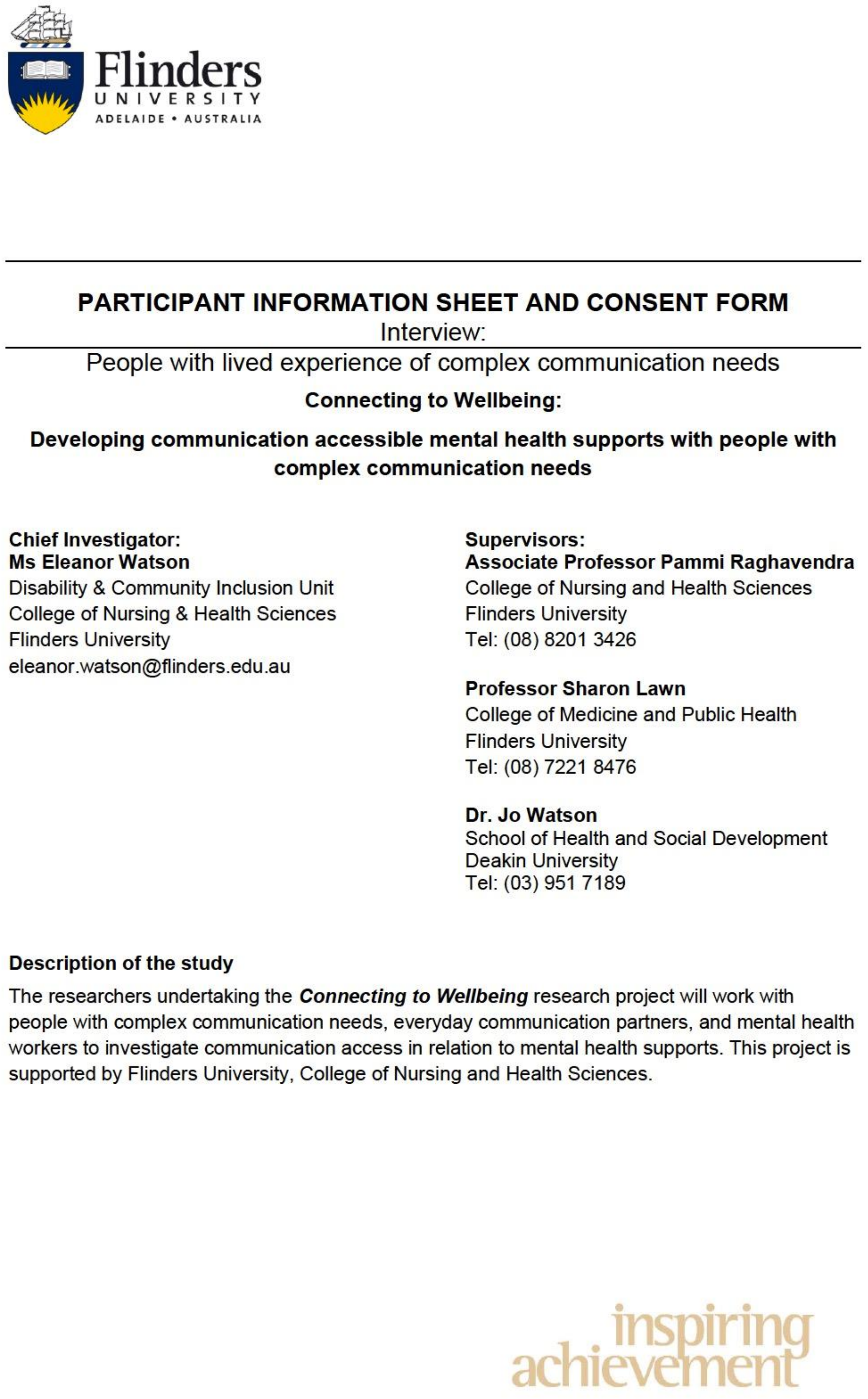
Name:

Date:

You can scan or photograph the form and email it back to eleanor.watson@flinders.edu.au.

If you cannot email the form the researcher will collect it from you at the interview or arrange postage.

Appendix E: Interview Information Sheet for People with Communication Access Needs (Standard)



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PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Interview:

People with lived experience of complex communication needs

Connecting to Wellbeing:

Developing communication accessible mental health supports with people with complex communication needs

Chief Investigator:
Ms Eleanor Watson
Disability & Community Inclusion Unit
College of Nursing & Health Sciences
Flinders University
eleanor.watson@flinders.edu.au

Supervisors:
Associate Professor Pammi Raghavendra
College of Nursing and Health Sciences
Flinders University
Tel: (08) 8201 3426

Professor Sharon Lawn
College of Medicine and Public Health
Flinders University
Tel: (08) 7221 8476

Dr. Jo Watson
School of Health and Social Development
Deakin University
Tel: (03) 951 7189

Description of the study

The researchers undertaking the ***Connecting to Wellbeing*** research project will work with people with complex communication needs, everyday communication partners, and mental health workers to investigate communication access in relation to mental health supports. This project is supported by Flinders University, College of Nursing and Health Sciences.

inspiring
achievement

Purpose of the study

This project aims to find out about:

- The issues that impact on people with complex communication needs when seeking help for their mental health;
- The current knowledge, skills and experiences of mental health workers regarding working with people with complex communication needs;
- The things that everyday communication partners and Mental Health Workers do that help or hinder access to mental health support;
- How mental health supports may be adapted to improve access for people with complex communication needs.

Benefits of the study

This research project aims to improve access to mental health supports by working with people who experience complex communication needs, everyday communication partners and mental health workers. Sharing of your perspective and experiences will contribute to better understanding of the factors that improve or prevent access to mental health supports; your information can help us to learn more about existing mental health resources could be changed to improve access for people who experience complex communication needs.

Who can participate?

The researchers are seeking people who would like to share their views on communication access and support for mental health. To participate in this study, you should:

- Over 18 years of age;
- identify as experiencing severe difficulties in using speech for communication;
- willing to discuss issues related to mental health;
- able to give independent 'yes/no' responses (for a brief informed consent questionnaire), and
- have access to augmentative and alternative communication (AAC) to participate in an interview.
    - AAC is the way that you get your message across to others. It can be a device (communication aid or communication system) or a person (Communication Assistant).

Participant involvement and potential risks

If you agree to participate in the research study, you will be asked to:

- Participate in two interview sessions with a researcher that will be audio and/or video recorded at your discretion. The interview can be conducted online or in-person (within the Adelaide metropolitan area).
- **Interview One** will ask about your life and how you prefer to communicate. It will take no more than 1 hour to complete.
- **Interview Two** will focus on your experiences of getting help for your emotions and mental health. It will take no more than 2 hours to complete.
- At the end of the interview, the researcher will give you a verbal summary of the key points in the interview. You will be able to confirm or correct the researcher's summary.
- All interviews all be conducted in accordance with current COVID-19 requirements.

Participation in the interview is entirely voluntary. If you find the interview process tiring, you can take a break or spread the interview out over multiple shorter sessions.

The interviews may be conducted online or in-person. Whether online or in-person, interviews need to be conducted in a safe and private location where you feel secure to discuss your experiences.

The interviews will focus on your experiences of accessing or attempting to access mental health supports. This content may bring up difficult emotions or discomfort. It is important that you feel safe throughout the interview process. You have the right to choose not to answer questions, to take a break, or to stop the interview if you feel uncomfortable at any point during the interview.

It is important to know that the interviewer, cannot provide you with counselling or advice regarding mental health concerns. There are mental health supports that are available to you at no or low cost.

If you experience feelings of distress following participation in this study, please let the researcher know immediately. If you feel distressed following your interview please contact your usual mental health supporters whether this is a friend, family member, support worker, GP or mental health worker. Additionally, these are contact details for some free counselling support services:

The following free, communication accessible mental supports are available to all interview participants:

Lifeline: Crisis support and suicide prevention.

- Call 13 11 14 **OR**
- TTY (teletypewriter): call 133 677 then request 13 11 14 **(open 24 hours)**
- Speak and Listen: call 1300 555 727 then request 13 11 14 **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay
    - then request 13 11 14 **(open 24 hours)**
- Chat online: go to https://www.lifeline.org.au/get-help/online-services/crisis-chat **(7pm – midnight)**

1800 RESPECT: Domestic violence and abuse counselling and support

**This organisation has strategies to support communication access

- Call 1800 737 732, OR **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay
  then request 1800 737 732 **(open 24 hours)**
- Chat online: go to https://chat.1800respect.org.au/#/welcome **(open 24 hours)**

Mandatory reporting

Please note that the interviewer is a mandated reporter. If, during the interview, you share information that indicates that either yourself or another person is in danger of abuse or harm, this will be reported to someone who can help, such as the National Disability Abuse and Neglect Hotline or the police.

Withdrawal from research
Participation in the interview is voluntary. If you decide not to withdraw from the interview:

- **Before the date of the interview:** please email eleanor.watson@flinders.edu.au to inform us of your decision.
- **During the interview:** state that you would like to cease the interview. Your interview data will not be included in the research project.
- **After the interview:** you may withdraw up to one week after the interview. To withdraw, please email eleanor.watson@flinders.edu.au to inform us of your decision.

In all cases, data collected up to the point of your withdrawal will be securely destroyed.

Support for the interview:
You may choose to have a Communication Assistant, or a support person, attend the interview with you. The Communication Assistant should be someone that you trust and feel safe discussing matters related to mental health with. The Communication Assistant can help you with communication if you want them to. The Communication Assistant cannot answer questions on your behalf. If you have a Communication Assistant at the interview, your information may not be confidential.

There is a separate interview for 'Everyday Communication Partners'. This interview provides family members, friends, partners, and/or support workers with the opportunity to discuss how they help when a person with complex communication needs wants help for their mental health. For more information they may email the Chief Investigator (eleanor.watson@flinders.edu.au).

Confidentiality and Privacy
The research outcomes may be presented at conferences or written up and published. However, the privacy and confidentiality of individuals will always be protected. The interview transcripts will not include your name, workplace, or other identifying information. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to the researchers named in this information sheet.

If you provide your personal contact details they will be stored securely, used only for the purpose specified and will be securely destroyed. You may be asked to provide your contact details for these purposes:

- To have your reimbursement mailed to you; or
- To be contacted about future events related to this research project.

No data will be shared or used in future research projects without your explicit consent.

Data Storage
The information collected will be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes. All data will be securely transferred to and stored at Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

Recognition of Contribution / Time / Travel costs
If you would like to participate, in recognition of your contribution and participation time, you will be provided with a $40.00 Coles Myer gift card. The gift card will be provided to you face-to-face on completion of the interview or mailed to you if you participate in an online interview.

How will I receive feedback?

At the end of the project a short summary of the outcomes will available to all participants and interested parties on the research project's Facebook page www.facebook.com/Connecting2Wellbeing

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (Project Number 1885).

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 3116 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet. If you accept our invitation to be involved, please sign the enclosed Consent Form on page 6 of this document.

CONSENT FORM

Consent Statement

☐ I have read and understood the information about the research, and I understand that I can contact the research team if I have further questions about this research.

☐ I am not aware of any condition that would prevent my participation, and I agree to participate in this project.

☐ I understand that I am free to withdraw from the study, as per the information sheet. My withdrawal will not affect my relationship with Flinders University and its staff and students.

☐ I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any concerns about the ethical conduct of this study.

☐ I understand that my involvement is confidential, and that the information collected may be published. I understand that I will not be identified in any research products.

I further consent to:

☐ participating in two interview sessions
☐ having my information audio recorded
☐ having my information video recorded (for online interviews)
☐ sharing my identifiable data with other researchers listed on this information sheet
☐ ***being contacted about other research projects:***
The researchers will conduct workshops to co-design solutions to communication access barriers in mental health supports.

Signed or marked:

Name:

Date:

You can scan or photograph the form and email it back to *eleanor.watson@flinders.edu.au*.

If you cannot email the form the researcher will collect it from you at the interview or arrange postage.

Appendix F: Survey Information Sheet for ECPs

PARTICIPANT INFORMATION SHEET
Survey:
Everyday Communication Partners

Connecting to Wellbeing:
Exploring communication accessible mental health supports with people with complex communication needs

Chief Investigator:
Ms Eleanor Watson
Disability & Community Inclusion Unit
College of Nursing & Health Sciences
Flinders University
eleanor.watson@flinders.edu.au

Supervisors:
Associate Professor Pammi Raghavendra
College of Nursing and Health Sciences
Flinders University
Tel: (08) 8201 3426

Professor Sharon Lawn
College of Medicine and Public Health
Flinders University
Tel: (08) 7221 8476

Dr. Jo Watson
School of Health and Social Development
Deakin University
Tel: (03) 951 7189

Description of the study

This study is part of the project title ***Connecting to Wellbeing: Exploring communication accessible mental health supports with people with complex communication needs*.** This project will work with people with complex communication needs, everyday communication partners, and mental health workers to investigate communication access in relation to mental health supports. This project is supported by Flinders University, College of Nursing and Health Sciences.

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Purpose of the study

This project aims to find out about:

- The issues that impact on people with complex communication needs when seek help for their mental health;
- The current knowledge, skills and experiences of Mental Health Workers regarding working with people with complex communication needs;
- The things that Everyday Communication Partners and Mental Health Workers do that can help or hinders access to mental health support;
- How mental health supports may be adapted to improve access for people with complex communication needs.

Benefits of the study

The researchers aim to improve access to mental health supports for people with complex communication needs. They will do this by working with people who experience complex communication needs, as well as other people involved in mental health such as everyday communication partners and mental health workers. Sharing your perspectives and experiences will contribute to better understanding of the factors that improve or prevent access to mental health supports; your information can help us to learn more about existing mental health resources and how these might be adapted to improve access for people who experience complex communication needs.

Who can participate?

This study is seeking looking for people who would like to share their views on communication access and support for mental health. To participate in this study, you should:

- Be over 18 years of age,
- have regular communication with a person with complex communication needs (i.e. at least once per week),
- have a relationship of support with a person with complex communication needs, either informal (i.e. friend, family member, partner) or formal (support worker, therapist).

Participant involvement

If you agree to participate in the research study, you will be asked to:

- Participate in an online survey
- respond to questions about yourself, and your views and experiences regarding communication access and mental health supports.

The survey will take about 15 minutes and participation is entirely voluntary.

Potential risks

The survey will focus on your experiences of assisting people with complex communication needs to address issues related to mental health and wellbeing. The researcher anticipates few risks from your involvement in this survey, however, given the nature of the project, some participants could experience emotional discomfort. Participants have the right to skip question or to cease the survey if they feel uncomfortable at any point.

If you experience feelings of distress as a result of participation in this study, please let the research team know via email. Additionally, these are contact details for some free communication accessible counselling support services:

Lifeline: Crisis support and suicide prevention.

- Call 13 11 14 **OR**
- TTY (teletypewriter): call 133 677 then request 13 11 14 **(open 24 hours)**
- Speak and Listen: call 1300 555 727 then request 13 11 14 **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay
    - then request 13 11 14 **(open 24 hours)**
- Chat online: go to https://www.lifeline.org.au/get-help/online-services/crisis-chat **(7pm – midnight)**

1800 RESPECT: Domestic violence and abuse counselling and support

**This organisation has strategies to support communication access

- Call 1800 737 732, OR **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay
  then request 1800 737 732 **(open 24 hours)**
- Chat online: go to https://chat.1800respect.org.au/#/welcome **(open 24 hours)**

Withdrawal Rights
You may, without any penalty, decline to take part in this survey. As the survey is anonymous, if you decide to take part and later change your mind, the researcher will not be able to identify and remove your data. To withdraw, you may just refuse to answer any questions or stop the survey.

Your decision not to participate in this research study will not affect your relationship with Flinders University and its staff and students.

Confidentiality and Privacy
No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent.

Data Storage
The information collected may be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All data will be securely transferred to and stored at Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

How will I receive feedback?

On project completion, a short summary of the outcomes will be available to all participants via the research project's Facebook page https://www.facebook.com/Connecting2Wellbeing/

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (project number 1885)

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 3116 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet and if you accept our invitation to be involved, please proceed with the survey.

Appendix G: Survey Information Sheet for MHWs

PARTICIPANT INFORMATION SHEET
Survey:
Mental Health Workers

Connecting to Wellbeing:
Exploring communication accessible mental health supports with people with complex communication needs

Chief Investigator:
Ms Eleanor Watson
Disability & Community Inclusion Unit
College of Nursing & Health Sciences
Flinders University
eleanor.watson@flinders.edu.au

Supervisors:
Associate Professor Pammi Raghavendra
College of Nursing and Health Sciences
Flinders University
Tel: (08) 8201 3426

Professor Sharon Lawn
College of Medicine and Public Health
Flinders University
Tel: (08) 7221 8476

Dr. Jo Watson
School of Health and Social Development
Deakin University
Tel: (03) 951 7189

Description of the study

This study is part of the project titled ***Connecting to Wellbeing: Exploring communication accessible mental health supports with people with complex communication needs***. In this project the researchers will work with people with complex communication needs, everyday communication partners, and mental health workers to investigate communication access in relation to mental health supports. This project is supported by Flinders University, College of Nursing and Health Sciences.

inspiring achievement

Purpose of the study
This project aims to find out about:

- The issues that impact on people with complex communication needs when seek help for their mental health;
- The current knowledge, skills and experiences of Mental Health Workers regarding working with people with complex communication needs;
- The things that Everyday Communication Partners and Mental Health Workers do that can help or hinders access to mental health support;
- How mental health supports may be adapted to improve access for people with complex communication needs.

Benefits of the study
The researchers aim to improve access to mental health supports by working with people who experience complex communication needs, everyday communication partners, and mental health workers. Sharing your perspective and experiences will contribute to better understanding of the factors that improve or prevent access to mental health supports; your information can help us to learn more about existing mental health resources and how these might be adapted to improve access for people who experience complex communication needs.

Who can participate?
The researcher is seeking Mental Health Workers to participate in this survey. You may be employed in a role such as; community mental health worker, counsellor, mental health nurse, mental health social worker, occupational therapist, peer support worker, psychiatrist, or psychologist.
MHWs must be over 18 years of age at the time of the survey.

Please note that experience working with people with complex communication needs is not essential for participation in this survey.

Participant involvement
If you agree to participate in the research study, you will be asked to:

- Participate in an online survey
- respond to questions regarding your work practices and views and experiences regarding communication access and mental health supports.

The survey will take about 15-30 minutes and participation is entirely voluntary.

Potential risks
The researchers do not expect the questions to cause any harm or discomfort to you. However, if you experience feelings of distress as a result of participation in this study, please let the research team know immediately. The following free, communication accessible mental supports are available to all survey participants:

Lifeline: Crisis support and suicide prevention.

- Call 13 11 14 **OR**
- TTY (teletypewriter): call 133 677 then request 13 11 14 **(open 24 hours)**
- Speak and Listen: call 1300 555 727 then request 13 11 14 **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay

  - then request 13 11 14 **(open 24 hours)**
- Chat online: go to https://www.lifeline.org.au/get-help/online-services/crisis-chat **(7pm – midnight)**

1800 RESPECT: Domestic violence and abuse counselling and support

1800 RESPECT has been awarded the Scope Communication Access Symbol. The symbol is awarded to organisation that demonstrate improves access for people with communication difficulties.

- Call 1800 737 732, OR **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay
  then request 1800 737 732 **(open 24 hours)**
- Chat online: go to https://chat.1800respect.org.au/#/welcome **(open 24 hours)**

Withdrawal Rights

You may, without any penalty, decline to take part in this survey. As the survey is anonymous, if you decide to take part and later change your mind, the researcher will not be able to identify and remove your data. To withdraw, you may just refuse to answer any questions or cease the survey.

Your decision not to participate in this research study will not affect your relationship with Flinders University and its staff and students.

Confidentiality and Privacy

The research outcomes may be presented at conferences, written up for publication or used for other research purposes as described in this information form. However, the privacy and confidentiality of individuals will be protected at all times.

Your survey responses will be anonymous. You may choose to provide your contact details to receive an information pack for a follow up interview. If you give your contact information, your personal details will be stored securely, separate to the survey data, so the information you provide in the survey will not be linked to your details. All information and results obtained in this study will be stored in a secure way, with access restricted to the researchers named in this information sheet.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent.

Data Storage

The information collected may be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All data will be securely transferred to and stored at Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

How will I receive feedback?

On project completion, a short summary of the outcomes will be available to all participants via the research project's Facebook page (https://www.facebook.com/Connecting2Wellbeing/).

Ethics Committee Approval
The project has been approved by Flinders University's Human Research Ethics Committee (Project number 1885)

Queries and Concerns
Queries or concerns regarding the research can be directed to the research team (via the contact details listed on front page). If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 3116 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet and if you accept our invitation to be involved, please proceed to the survey at this web address:
https://qualtrics.flinders.edu.au/jfe/form/SV_6ijOongKNGVtGnj

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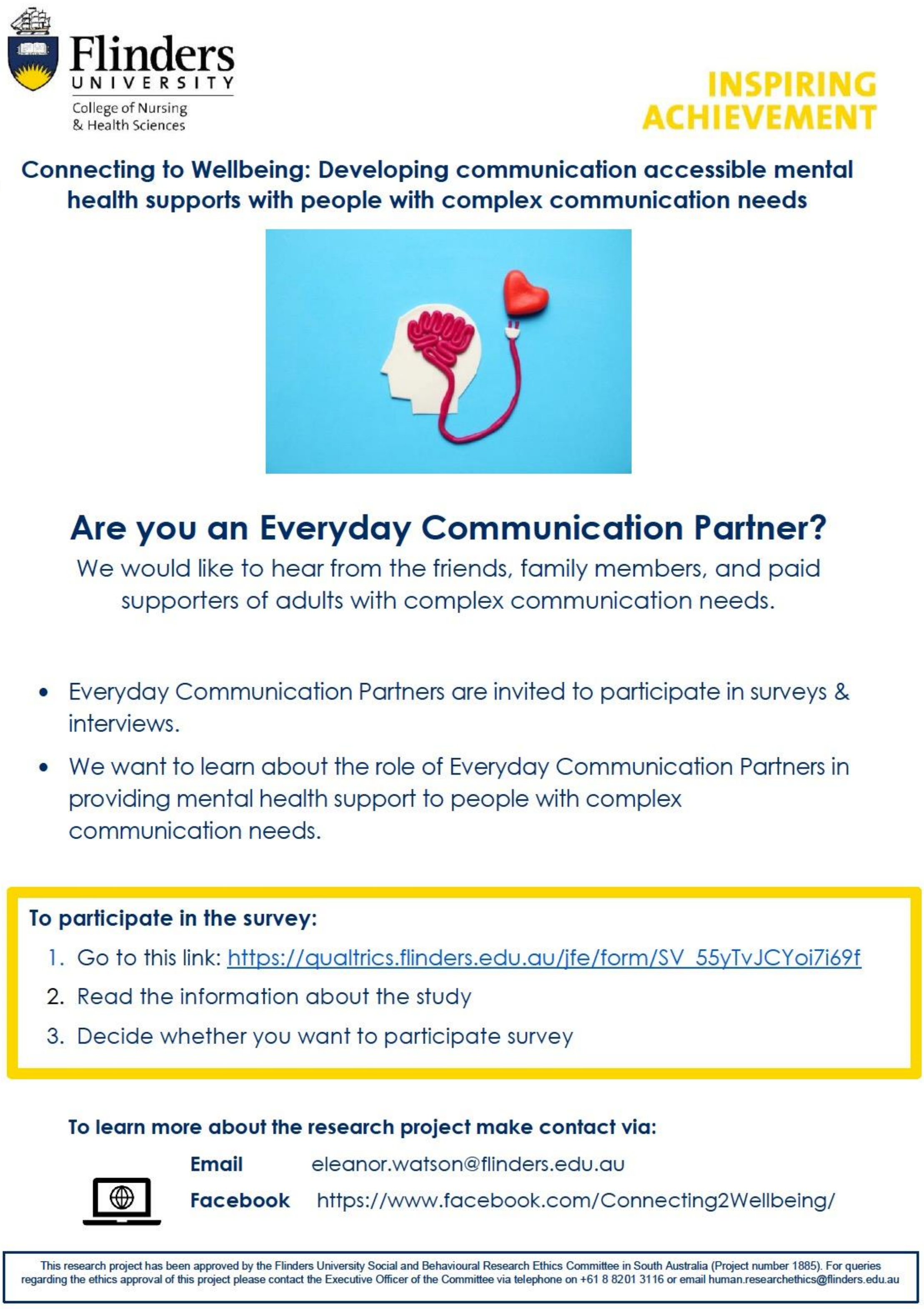
Appendix H: Survey Flyer for People with Communication Access Needs.



Flinders UNIVERSITY
College of Nursing
& Health Sciences

INSPIRING
ACHIEVEMENT

Connecting to Wellbeing: Developing communication accessible mental health supports with people with complex communication needs

Are you an Everyday Communication Partner?

We would like to hear from the friends, family members, and paid supporters of adults with complex communication needs.

- Everyday Communication Partners are invited to participate in surveys & interviews.
- We want to learn about the role of Everyday Communication Partners in providing mental health support to people with complex communication needs.

To participate in the survey:

1. Go to this link: https://qualtrics.flinders.edu.au/jfe/form/SV_55yTvJCYoi7i69f
2. Read the information about the study
3. Decide whether you want to participate survey

To learn more about the research project make contact via:

Email eleanor.watson@flinders.edu.au
Facebook https://www.facebook.com/Connecting2Wellbeing/

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 1885). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix I: Survey Flyer for MHWs.

Flinders UNIVERSITY
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INSPIRING
ACHIEVEMENT

Connecting to Wellbeing:
Developing Communication Accessible Mental Health Supports

Are you a Mental Health Worker?
We would like to hear from you.

- Mental health workers are invited to participate in surveys & interviews.
- We want to learn about Mental Health Workers' practices that may support the inclusion of people with communication disabilities.

Prior experience working with people with communication disabilities is not required.

To participate in the survey:

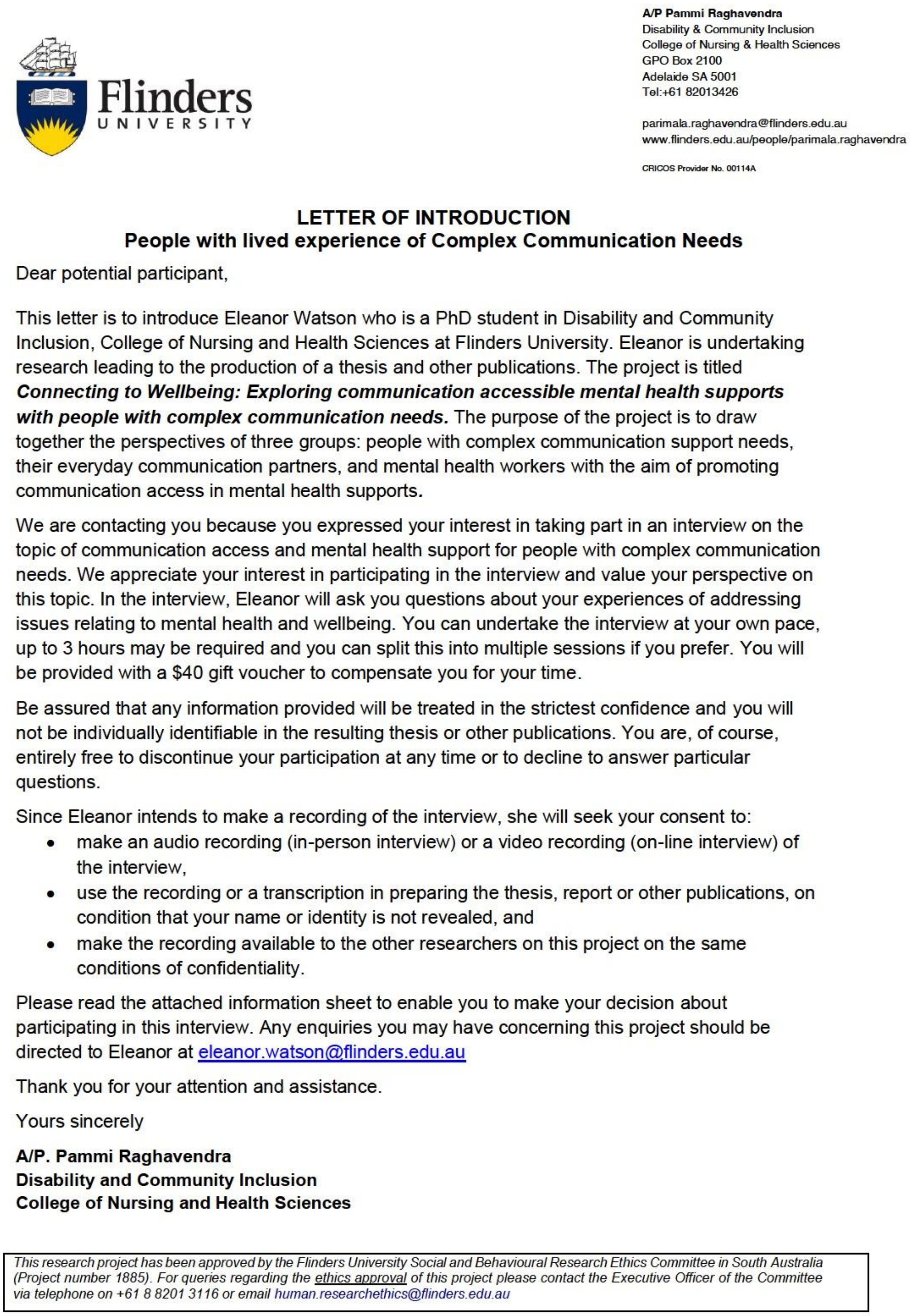
1. go to this link: https://qualtrics.flinders.edu.au/jfe/form/SV_6ijOongKNGVtGnj
2. Read the information about the study
3. Decide whether you want to participate survey

To learn more about the research project make contact via:

- **Email** eleanor.watson@flinders.edu.au
- **Facebook** https://www.facebook.com/Connecting2Wellbeing/

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 1885). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix J: Letter of Introduction.



A/P Pammi Raghavendra
Disability & Community Inclusion
College of Nursing & Health Sciences
GPO Box 2100
Adelaide SA 5001
Tel:+61 82013426

parimala.raghavendra@flinders.edu.au
www.flinders.edu.au/people/parimala.raghavendra

CRICOS Provider No. 00114A

LETTER OF INTRODUCTION
People with lived experience of Complex Communication Needs

Dear potential participant,

This letter is to introduce Eleanor Watson who is a PhD student in Disability and Community Inclusion, College of Nursing and Health Sciences at Flinders University. Eleanor is undertaking research leading to the production of a thesis and other publications. The project is titled ***Connecting to Wellbeing: Exploring communication accessible mental health supports with people with complex communication needs.*** The purpose of the project is to draw together the perspectives of three groups: people with complex communication support needs, their everyday communication partners, and mental health workers with the aim of promoting communication access in mental health supports.

We are contacting you because you expressed your interest in taking part in an interview on the topic of communication access and mental health support for people with complex communication needs. We appreciate your interest in participating in the interview and value your perspective on this topic. In the interview, Eleanor will ask you questions about your experiences of addressing issues relating to mental health and wellbeing. You can undertake the interview at your own pace, up to 3 hours may be required and you can split this into multiple sessions if you prefer. You will be provided with a $40 gift voucher to compensate you for your time.

Be assured that any information provided will be treated in the strictest confidence and you will not be individually identifiable in the resulting thesis or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since Eleanor intends to make a recording of the interview, she will seek your consent to:

- make an audio recording (in-person interview) or a video recording (on-line interview) of the interview,
- use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed, and
- make the recording available to the other researchers on this project on the same conditions of confidentiality.

Please read the attached information sheet to enable you to make your decision about participating in this interview. Any enquiries you may have concerning this project should be directed to Eleanor at eleanor.watson@flinders.edu.au

Thank you for your attention and assistance.

Yours sincerely

A/P. Pammi Raghavendra
Disability and Community Inclusion
College of Nursing and Health Sciences

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 1885). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix K: Interview Information Sheet for ECPs.

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PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Interview:
Everyday Communication Partners

Connecting to Wellbeing:

Developing communication accessible mental health supports with people with complex communication needs

Chief Investigator:
Ms Eleanor Watson
Disability & Community Inclusion Unit
College of Nursing & Health Sciences
Flinders University
eleanor.watson@flinders.edu.au

Supervisors:
Associate Professor Pammi Raghavendra
College of Nursing and Health Sciences
Flinders University
Tel: (08) 8201 3426

Professor Sharon Lawn
College of Medicine and Public Health
Flinders University
Tel: (08) 7221 8476

Dr. Jo Watson
School of Health and Social Development
Deakin University
Tel: (03) 951 7189

Description of the study

The researchers undertaking the ***Connecting to Wellbeing*** research project will work with people with complex communication needs, everyday communication partners, and mental health workers to investigate communication access in relation to mental health supports. This project is supported by Flinders University, College of Nursing and Health Sciences.

inspiring
achievement

Purpose of the study

This project aims to find out about:

- The issues that impact on people with complex communication needs when seeking help for their mental health;
- The current knowledge, skills and experiences of mental health workers regarding working with people with complex communication needs;
- The things that everyday communication partners and Mental Health Workers do that help or hinder access to mental health support;
- How mental health supports may be adapted to improve access for people with complex communication needs.

Benefits of the study

This research project aims to improve access to mental health supports by working with people who experience complex communication needs, everyday communication partners and mental health workers. Sharing of your perspective and experiences will contribute to better understanding of the factors that improve or prevent access to mental health supports; your information can help us to learn more about existing mental health resources could be changed to improve access for people who experience complex communication needs.

Who can participate?

The researchers are seeking people who would like to share their views on communication access and support for mental health. To participate in this study, you should:

- Be over 18 years of age,
- have regular communication with an adult with complex communication needs (i.e. at least once per week),
- have a relationship of support with a person with complex communication needs, either informal (i.e. friend, family member, partner) or formal (support worker, therapist).

Participant involvement and potential risks

If you agree to participate in the research study, you will be asked to:

- Participate in a one-on-one interview with a researcher that will be audio and/or video recorded at your discretion. The interview can be conducted face-to-face or online.
- respond to questions regarding your practice and your perceptions of working with people with complex communication needs.
- At the end of the interview, the researcher will give you a verbal summary of the key points in the interview. You will be able to confirm or correct the researcher's summary.
- All interviews all be conducted in accordance with current COVID-19 requirements.

The interview will take approximately 60 minutes and participation is entirely voluntary.

The interview will focus on your experiences of assisting people with complex communication needs to address issues related to mental health and wellbeing. This content may bring up difficult emotions or discomfort. It is important that you feel safe throughout the interview process. You can choose not to answer questions, to take a break, or to cease the interview if you feel uncomfortable at any point during the interview.

It is important to know that the interviewer, cannot provide you with counselling or advice regarding mental health concerns. There are mental health supports that are available to you at no or low cost.

If you experience feelings of distress following participation in this study, please let the research team know immediately. If you feel distressed following your interview please contact your usual mental health supporters whether this is a friend, family member, support worker, GP or mental health worker. Additionally, these are contact details for some free counselling support services:

The following free, communication accessible mental supports are available to all interview participants:

Lifeline: Crisis support and suicide prevention.

- Call 13 11 14 **OR**
- TTY (teletypewriter): call 133 677 then request 13 11 14 **(open 24 hours)**
- Speak and Listen: call 1300 555 727 then request 13 11 14 **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay
    - then request 13 11 14 **(open 24 hours)**
- Chat online: go to https://www.lifeline.org.au/get-help/online-services/crisis-chat **(7pm – midnight)**

1800 RESPECT: Domestic violence and abuse counselling and support

**This organisation has strategies to support communication access

- Call 1800 737 732, OR **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay then request 1800 737 732 **(open 24 hours)**
- Chat online: go to https://chat.1800respect.org.au/#/welcome **(open 24 hours)**

Mandatory reporting

Please note that the interviewer is a mandated reporter. If, during the interview, you share information that indicates that a person is in danger of abuse or harm, this will be reported to someone who can help, such as the National Disability Abuse and Neglect Hotline or the police.

Withdrawal from research

Participation in the interview is voluntary. If you decide not to withdraw from the interview:

- **Before the date of the interview:** please email eleanor.watson@flinders.edu.au to inform us of your decision.
- **During the interview:** state that you would like to cease the interview. Your interview data will not be included in the research project.
- **After the interview:** you may withdraw up to one week after the interview. To withdraw, please email eleanor.watson@flinders.edu.au to inform us of your decision.

In all cases, data collected up to the point of your withdrawal will be securely destroyed.

Confidentiality and Privacy

The research outcomes may be presented at conferences or written up and published. However, the privacy and confidentiality of individuals will always be protected. The interview transcripts will not include your name, workplace, or other identifying information. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to the researchers named in this information sheet.

If you provide your personal contact details they will be stored securely, used only for the purpose specified and will be securely destroyed. You may be asked to provide your contact details for these purposes:

- To have your reimbursement mailed to you; or
- To be contacted about future events related to this research project.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent.

Data Storage

The information collected will be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes. All data will be securely transferred to and stored at Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

You can choose whether you would like to be contacted regarding opportunities to participate in future research activities. If you give your contact information to the researchers, your personal details will be stored securely, separate to the interview data, so the interview will not be linked to your details.

Recognition of Contribution / Time / Travel costs

If you would like to participate, in recognition of your contribution and participation time, you will be provided with a $20.00 Coles Myer gift card. The gift card will be provided to you face-to-face on completion of the interview or mailed to you if you participate in an online interview.

How will I receive feedback?

At the end of the project a short summary of the outcomes will available to all participants and interested parties on the research project's Facebook page
www.facebook.com/Connecting2Wellbeing

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (Project Number 1885).

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 3116 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet. If you accept our invitation to be involved, please sign the enclosed Consent Form on page 5 of this document.

CONSENT FORM

Consent Statement

☐ I have read and understood the information about the research, and I understand I am being asked to provide informed consent to participate in this research study. I understand that I can contact the research team if I have further questions about this research study.

☐ I am not aware of any condition that would prevent my participation, and I agree to participate in this project.

☐ I understand that I am free to withdraw at any time during the study and that my withdrawal will not affect my relationship with Flinders University and its staff and students.

☐ I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any complaints or reservations about the ethical conduct of this study.

☐ I understand that my involvement is confidential, and that the information collected may be published. I understand that I will not be identified in any research products.

I further consent to:

☐ participating in an interview
☐ having my information audio recorded
☐ having my information video recorded (if conducting the interview via video conferencing)
☐ sharing my identifiable data with other researchers listed on this information sheet
☐ ***being contacted about other research projects:***
This study aims to conduct workshops to co-design solutions to communication access barriers in mental health supports – Can we send you an information pack for this later?

Signed:

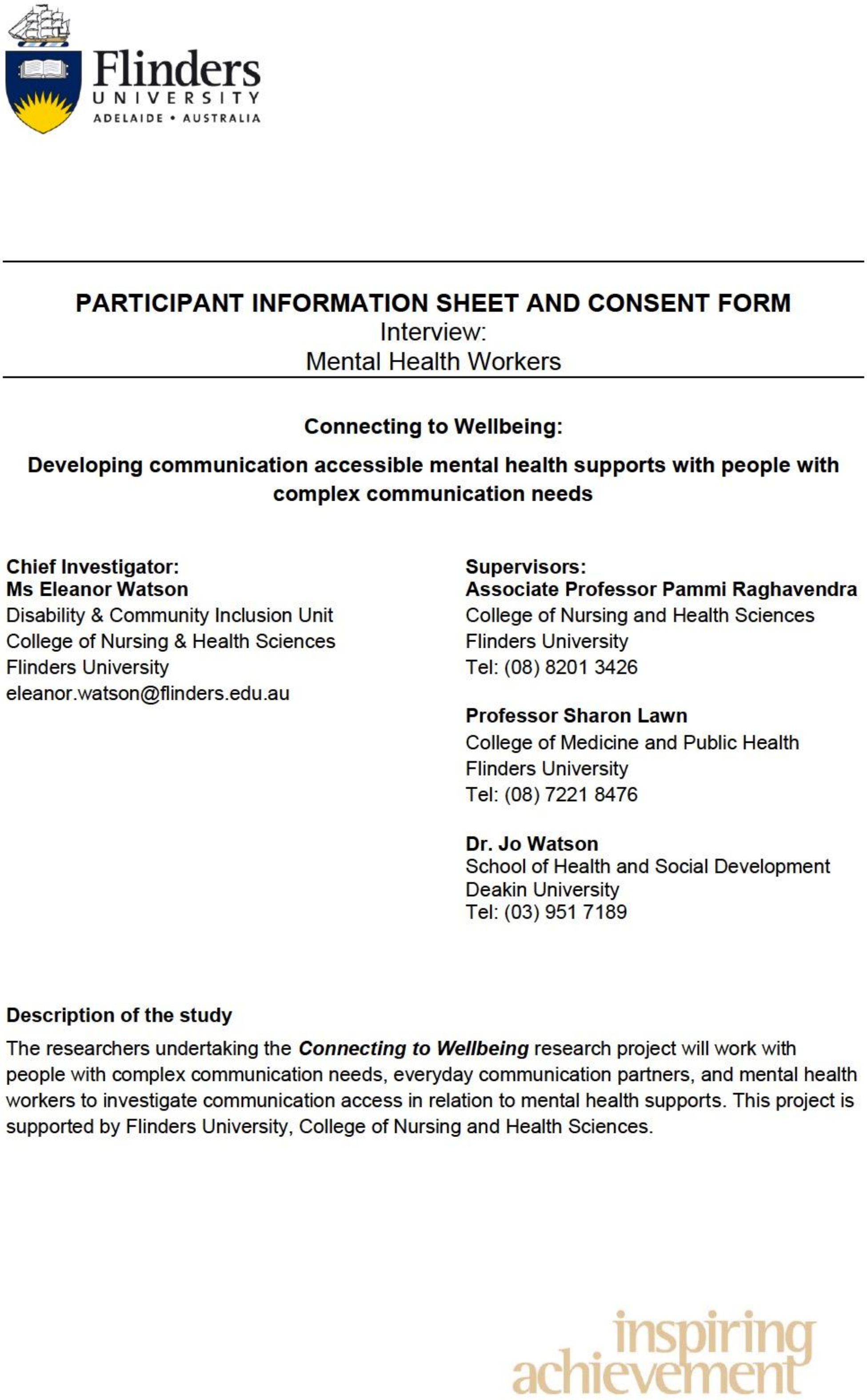
Name:

Date:

You can scan or photograph the form and email it back to *eleanor.watson@flinders.edu.au*.

If you cannot email the form the researcher will collect it from you at the interview or arrange postage.

Appendix L: Interview Information Sheet for MHWs.



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PARTICIPANT INFORMATION SHEET AND CONSENT FORM
Interview:
Mental Health Workers

Connecting to Wellbeing:

Developing communication accessible mental health supports with people with complex communication needs

Chief Investigator:
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Disability & Community Inclusion Unit
College of Nursing & Health Sciences
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Professor Sharon Lawn
College of Medicine and Public Health
Flinders University
Tel: (08) 7221 8476

Dr. Jo Watson
School of Health and Social Development
Deakin University
Tel: (03) 951 7189

Description of the study

The researchers undertaking the ***Connecting to Wellbeing*** research project will work with people with complex communication needs, everyday communication partners, and mental health workers to investigate communication access in relation to mental health supports. This project is supported by Flinders University, College of Nursing and Health Sciences.

inspiring
achievement

Purpose of the study

This project aims to find out about:

- The issues that impact on people with complex communication needs when seeking help for their mental health;
- The current knowledge, skills and experiences of mental health workers regarding working with people with complex communication needs;
- The things that everyday communication partners and Mental Health Workers do that help or hinder access to mental health support;
- How mental health supports may be adapted to improve access for people with complex communication needs.

Benefits of the study

This research project aims to improve access to mental health supports by working with people who experience complex communication needs, everyday communication partners and mental health workers. Sharing of your perspective and experiences will contribute to better understanding of the factors that improve or prevent access to mental health supports; your information can help us to learn more about existing mental health resources and how these might be adapted to improve access for people who experience complex communication needs.

Who can participate?

The researchers are seeking Mental Health Workers to participate in an interview. Mental health workers may be employed in roles such as; community mental health worker, counsellor, mental health nurse, mental health social worker, occupational therapist, peer support worker, psychiatrist, or psychologist. MHWs must be over 18 years of age at the time of the interview.

Participant involvement and potential risks

If you agree to participate in the research study, you will be asked to:

- Participate in a one-on-one interview with a researcher that will be audio and/or video recorded at your discretion. The interview can be conducted online or in-person (within the Adelaide metropolitan region).
- respond to questions regarding your practice and your perceptions of working with people with complex communication needs.
- At the end of the interview, the researcher will give you a verbal summary of the key points in the interview. You will be able to confirm or correct the researcher's summary.
- All interviews all be conducted in accordance with current COVID-19 requirements.

The interview will take approximately 60 minutes and participation is entirely voluntary.

The researchers do not expect the questions to cause any harm or discomfort to you. However, if you experience feelings of distress as a result of participation in this study, please let the research team know immediately. You may refuse to answer a question if you wish.

Provision of counselling and advice is beyond the scope of this interview. You may contact the counselling support services listed on the following page if you experience emotional distress following the interview.

The following free, communication accessible mental supports are available to all interview participants:

Lifeline: Crisis support and suicide prevention.

- Call 13 11 14 **OR**
- TTY (teletypewriter): call 133 677 then request 13 11 14 **(open 24 hours)**
- Speak and Listen: call 1300 555 727 then request 13 11 14 **(open 24 hours)**
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Withdrawal from research

Participation in the interview is voluntary. If you decide not to withdraw from the interview:

- **Before the date of the interview:** please email eleanor.watson@flinders.edu.au to inform us of your decision.
- **During the interview:** state that you would like to cease the interview. Your interview data will not be included in the research project.
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Confidentiality and Privacy

The research outcomes may be presented at conferences or written up and published. However, the privacy and confidentiality of individuals will always be protected. The interview transcripts will not include your name, workplace, or other identifying information. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to the researchers named in this information sheet.

If you provide your personal contact details they will be stored securely, used only for the purpose specified and will be securely destroyed. You may be asked to provide your contact details for these purposes:

- To have your reimbursement mailed to you; or
- To be contacted about future events related to this research project.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent.

Data Storage

The information collected will be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes. All data will be securely transferred to and stored at Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

You can choose whether you would like to be contacted regarding opportunities to participate in future research activities. If you give your contact information to the researchers, your personal details will be stored securely, separate to the interview data, so the interview will not be linked to your details.

Recognition of Contribution / Time / Travel costs

If you would like to participate, in recognition of your contribution and participation time, you will be provided with a $20.00 Coles Myer gift card. The gift card will be provided to you face-to-face on completion of the interview or mailed to you if you participate in an online interview.

How will I receive feedback?

At the end of the project a short summary of the outcomes will available to all participants and interested parties on the research project's Facebook page www.facebook.com/Connecting2Wellbeing

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee (Project Number 1885).

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 3116 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet. If you accept our invitation to be involved, please sign the enclosed Consent Form on page 5 of this document.

CONSENT FORM

Consent Statement

☐ I have read and understood the information about the research, and I understand I am being asked to provide informed consent to participate in this research study. I understand that I can contact the research team if I have further questions about this research study.

☐ I am not aware of any condition that would prevent my participation, and I agree to participate in this project.

☐ I understand that I am free to withdraw at any time during the study and that my withdrawal will not affect my relationship with Flinders University and its staff and students.

☐ I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any complaints or reservations about the ethical conduct of this study.

☐ I understand that my involvement is confidential, and that the information collected may be published. I understand that I will not be identified in any research products.

I further consent to:

☐ participating in an interview
☐ having my information audio recorded
☐ having my information video recorded (if conducting the interview via video conferencing)
☐ sharing my identifiable data with other researchers listed on this information sheet
☐ ***being contacted about other research projects:***
This study aims to conduct workshops to co-design solutions to communication access barriers in mental health supports – Can we send you an information pack for this later?

Signed:

Name:

Date:

You can scan or photograph the form and email it back to *eleanor.watson@flinders.edu.au*.

If you cannot email the form the researcher will collect it from you at the interview or arrange postage.

Appendix M: Interview Flyer for People with Communication Access Needs and ECPs.

Connecting to Wellbeing: Developing communication accessible mental health supports

We would like to ask you about communication access & mental health support.

Do you experience complex communication needs (CCN)?

OR

Are you a friend, relative, or supporter of someone with CCN?

Are you:

- Over 18 years of age, and
- willing to share your experiences of discussing emotional wellbeing and/or mental health, and
- interested in participating in an interview (in-person or online).

Interviews are now open.

To get an information pack please contact Eleanor Watson at:

Email: eleanor.watson@flinders.edu.au

Facebook: www.facebook.com/Connecting2Wellbeing/

Flinders UNIVERSITY

This research project has been approved by Flinders University's Human Research Ethics Committee (Project No. 1885). Flinders University's Research Ethics & Compliance Office team email human.researchethics@flinders.edu.au

Appendix N: Interview Recruitment Flyer for MHWs.

Connecting to Wellbeing: Developing communication accessible mental health supports

We would like to ask you about communication access & mental health support.

Are you a Mental Health Worker?

- Mental Health Workers are invited to participate in interviews.
- We want to learn about Mental Health Workers' practices that may support the inclusion of people with communication disabilities.

Prior experience working with people with communication disabilities is not required.

Interviews are now open.

To get an information pack please contact Eleanor Watson at:

Email: eleanor.watson@flinders.edu.au

Facebook: www.facebook.com/Connecting2Wellbeing/

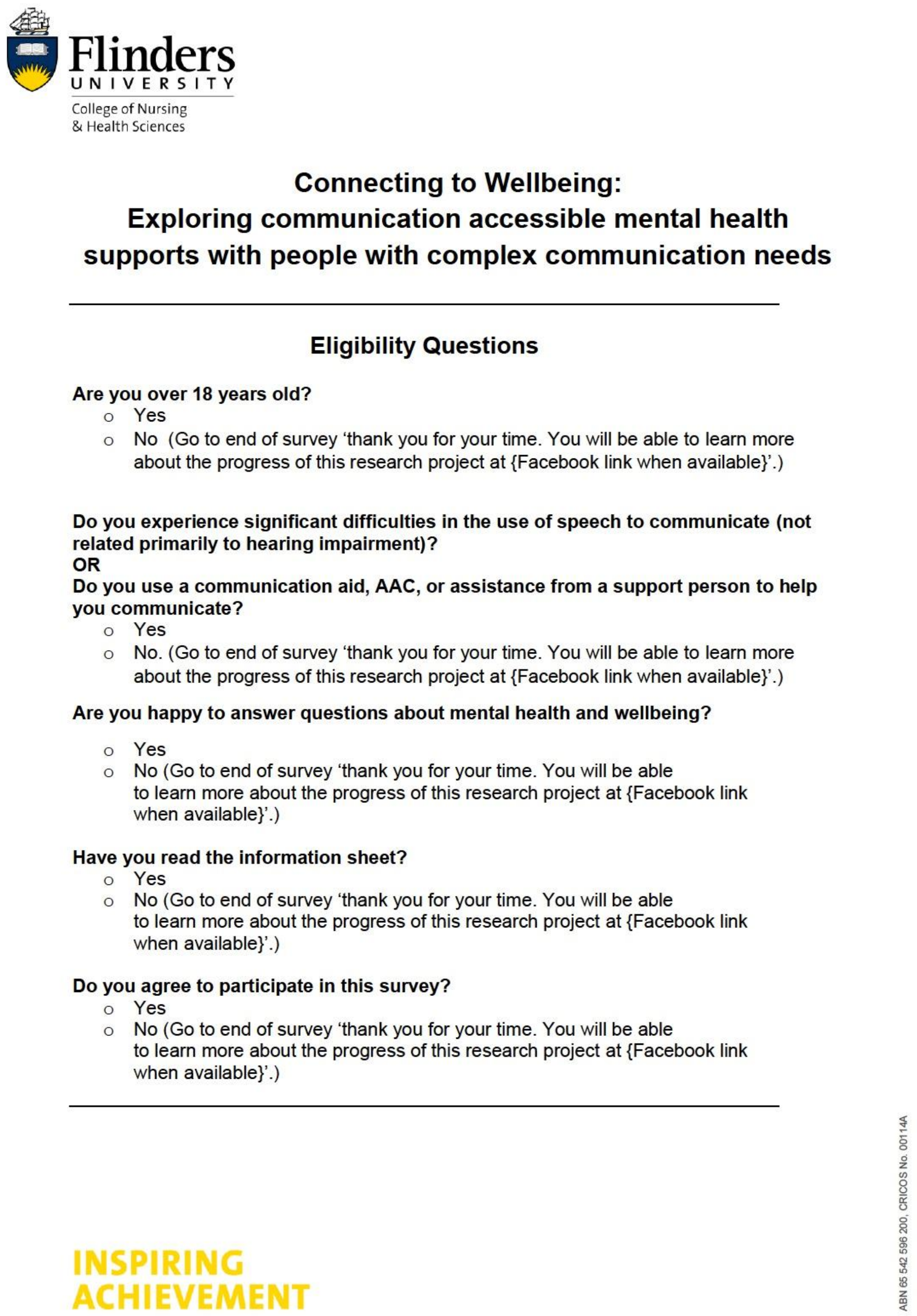
Flinders UNIVERSITY

This research project has been approved by Flinders University's Human Research Ethics Committee (Project No. 1885). Flinders University's Research Ethics & Compliance Office team email human.researchethics@flinders.edu.au

Appendix O: Caveat for ECP Surveys and Interviews.

Script: *This interview seeks to explore your experiences of communicating about emotions, and/or seeking mental health support with individuals with complex communication needs. It is the researchers' view that mental health support is a resource that should be provided to all people should they want it. We do not suggest that people with (communication access needs) experience mental health problems more or less than other people, but rather communication about emotions and mental health is an ordinary human experience.*

Appendix P: Survey Questions for People with Communication Access Needs.



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& Health Sciences

Connecting to Wellbeing:
Exploring communication accessible mental health supports with people with complex communication needs

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Eligibility Questions

Are you over 18 years old?

- ○ Yes
- ○ No (Go to end of survey 'thank you for your time. You will be able to learn more about the progress of this research project at {Facebook link when available}'.)

Do you experience significant difficulties in the use of speech to communicate (not related primarily to hearing impairment)?
OR
Do you use a communication aid, AAC, or assistance from a support person to help you communicate?

- ○ Yes
- ○ No. (Go to end of survey 'thank you for your time. You will be able to learn more about the progress of this research project at {Facebook link when available}'.)

Are you happy to answer questions about mental health and wellbeing?

- ○ Yes
- ○ No (Go to end of survey 'thank you for your time. You will be able to learn more about the progress of this research project at {Facebook link when available}'.)

Have you read the information sheet?

- ○ Yes
- ○ No (Go to end of survey 'thank you for your time. You will be able to learn more about the progress of this research project at {Facebook link when available}'.)

Do you agree to participate in this survey?

- ○ Yes
- ○ No (Go to end of survey 'thank you for your time. You will be able to learn more about the progress of this research project at {Facebook link when available}'.)

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Demographic Questions

1. **What is your age?** (specify age)

2. **How do you identify your gender?**
    - Female
    - Male
    - Non-binary
    - Prefer not to say

3. **What state do you live in?**
    - Australian Capital Territory
    - New South Wales
    - Northern Territory
    - Queensland
    - South Australia
    - Tasmania
    - Victoria
    - Western Australia

4. **How long have you experienced CCN?**
    - All my life
    - Less than 5 years
    - 5-10 years
    - 11-15 years
    - 16-20 years
    - 21-25 years
    - 26-30 years
    - More than 30 years

5. **Education**

    5.1.:Did you go to a mainstream or specialist school?
    - I attended a mainstream school
    - I attended a specialist education school
    - OTHER:

    5.2.: What is the highest level of education you have completed?
    - Year 10
    - Year 11
    - Year 12
    - Certificate level (TAFE or VET qualification)
    - Diploma level
    - Bachelor's degree
    - Graduate Certificate/ Diploma
    - Master's degree
    - Doctorate

6. **Occupation: What are your daily activities?**
   Studying
   Attending a recreation program (day options)
   Self-employed/ freelance
   Employed - Casual
   Employed - Part Time
   Employed - Full-time
   OTHER:

   6.1 Overall, do you enjoy your daily activities?
   All of the time
   Most of the time
   Some of the time
   Never

7. **Living arrangements:**
   I live on my own
   I live with my family
   I live with housemates (I chose my house mates)
   I live with housemates (I did not choose my housemates)
   I live in a home with support workers (supported accommodation)
   I live in a nursing home
   OTHER:

   7.1 Overall, are you happy with your living arrangements?
   All of the time
   Most of the time
   Some of the time
   Never

Background information

What is mental health?

The World Health Organisation says that mental health is a state of emotional and physical wellbeing in which people can:

- *Recognise their abilities and strengths,*
- *can cope with the stress in their life,*
- *can work productively and fruitfully,*
- *and are able to contribute to their community*

(World Health Organization & Calouste Gulbenkian Foundation, 2017)

Mental health refers to the health and wellbeing of your mind. Your mental health affects how you feel, think and act.

Some things that can impact on your mental health are:

- *stress,*
- *being in pain,*
- *hormonal changes,*
- *being bullied or excluded,*
- *ending a relationship, or*
- *the death of a loved one.*

The health of your mind is just as important as health of your body.

Survey Questions

1. **Have you ever learned about mental health?**
   Learning about mental health means that someone has given you information about mental health. The learning may have happened in a formal way, like learning about mental health at a school, university, or online course, or an informal way, learning about mental health from a friend, family member, or support worker.
   ○ No

   ○ Yes

What did you learn about?

Different mental health problems
How to improve your mental health
Ways to help you relax and be less stressed or anxious
How to get help for a mental health problem
Identifying and naming different emotions
OTHER:

Who taught you about mental health?

Parent

Friend

Colleague/ Peer

Teacher/ Lecturer

Support Worker

Website or online community

General Practitioner

Mental Health Worker

OTHER:

2. Where do you get your information about mental health?

Mental health information may be information about different mental health problems and treatments, or strategies to help wellbeing.

Friends

Family

General Practitioner

Mental Health Professional

Attending courses

Website

Online community (Social media)

Print Media – television, newspapers, magazines

OTHER:

3. What would you like to know more about mental health?
Choose all that apply

Different types of mental health problems
Different therapies to improve mental health
Ways to relax and be less stressed or anxious
How to get help for a mental health problem (not an emergency)
How to get help in a mental health emergency (e.g. thinking about suicide)
How to manage my own mental health problems
How to help other people with mental health problems
Identifying and naming different emotions

- Learning about resilience or how to ‘bounce back’ from hard times.
- OTHER:

4. **What issues impacts most on your mental health?** (Choose as many as you want)

   Not feeling included
   Experiences of discrimination
   Experiences of abuse or neglect
   Not having choices
   Not having my choices respected
   Not liking where I live
   Not feeling safe
   Not liking my work
   Feeling bored
   Not happy with my support workers
   Not having enough support
   Having physical pain
   Having health problems
   Funding or money worries
   Family problems
   Alcohol and/or drugs
   Not having enough friends
   Not having the romantic/sexual relationships that I want
   Not being able to communicate
   Not being understood
   OTHER:

5. **Do you think you ever experienced a mental health problem?**
   Mental health problems affect a person's thoughts, feelings, perceptions, behaviour, and may impact on their relationships and quality of life. Mental health problems include high prevalence conditions such as anxiety and depression as well as less common mental illness such as bi-polar disorder, schizophrenia and personality disorders. People with complex communication needs may face barriers to accessing diagnosis and treatment for mental health problems.

   ○ No
   Why do think you have not experienced any mental health problems?
   ENTER TEXT

   ○ Yes

   How would you describe this mental health problem?
   This is a list of common mental health problems with an explaination. You may have your own way to describe a mental health problem. If you choose 'other' you can describe the problem yourself

   Anxiety – A lot of stress, worry, anger, or panic that stops you from doing the things you want to.
   Depression – sad or 'down' feelings that stop you from doing things that you like to do.
   Bipolar - having big changes of mood; very high mood to very low mood.
   Schizophrenia – Seeing, hearing or experiencing things that are not there.

Personality disorder – Parts of a person's personality that can make it more difficult to cope with life and interactions with people
Drug and/or Alcohol problems
OTHER, I have my own description:

6. **When you are struggling with difficult feelings, moods, emotions or a mental health problem, what helps you?**
   Choose all that apply
   Catching-up with friends
   Exercising or playing sport
   Eating healthy food
   Asking for help from someone I trust
   Planning something to look forward to like a holiday or outing
   Trying to get a good sleep
   Taking a bath
   Entertaining myself with music, movies or books
   Reducing my use of social media
   Relaxation or meditation
   Spending time in nature
   Getting help from a mental health professional
   Doing something creative (art, writing)
   I take prescribed medication
   OTHER

References/ Resources:

Headspace (2020). Learn how to handle tough times. https://headspace.org.au/
Black Dog Institute (2020). Healthy Mind https://www.blackdoginstitute.org.au/resources-support/digital-tools-apps/healthy-mind/
Mental Health Foundation (2020). Feeling down: Looking after my mental health. https://www.mentalhealth.org.uk/sites/default/files/feeling-down-guide.pdf

7. **Who do you share your feelings, concerns, and emotions with?**
   Friend
   Partner
   Family Member
   Colleague or peer (if working or studying)
   Support Worker
   Online community
   Professional (non-mental health – GP, Speech Pathologist, etc)
   Mental Health Worker (Counsellor, psychologist, peer worker, etc.)
   I don't have anyone to share my feelings, concerns and emotions with.
   OTHER:

8. **When you share your feelings, concerns, and emotions, how useful are each of these communication partner behaviours?**
   Rate from 1 (not useful) to 5 (very useful).
   Approach me and ask if I am okay
   Take time to hear what I want to communicate
   Check what I said to make sure they got it right
   Speak directly to me (not a family member or support worker)
   Help me to use my communication aid/AAC

Learn about how I communicate
Help me sort the problem out
Use manners
Respect my point of view/ choices
Have a kind, compassionate attitude
Distract me from my worries
Check back later to see how I am doing
Keep our conversations private
Give me enough time
Give me written information in Easy English
Tell other people about what I said
Book a longer appointment so that we have enough time

8.1 Do you have any other suggestions for useful things that communication partners can do when you are communicating about your feelings, emotions and mental health?

List as many useful things as you would like to.

ENTER TEXT

9. Have you ever sought help for a mental health problem?

- No

  What were the barriers to getting help?

  I haven't experienced any mental health problems
  I didn't want help
  I didn't know help was available
  No one offered me any help
  I was worried what other people would think
  People didn't understand me
  I didn't have access to the vocabulary I needed to express the problem.
  OTHER

- Yes

  Where did you try to get help from?

  Family
  Friends
  Partner
  Support worker
  General practitioner
  Counsellor
  Psychologist
  Psychiatrist
  Social Worker
  E-mental health (website or online mental health program)
  Mental health support phone lines (e.g. Lifeline, Beyond Blue, etc)
  Mental health support chat rooms/ instant messaging (e.g. Lifeline, Beyond Blue, etc)
  OTHER:

10. What mental health supports have you used?
Select all that apply
○ I haven't used mental health supports

i. Think of a time that you have used a general health service, what did the staff and professionals do to ensure that you were able to communicate?

ENTER TEXT

E-mental health (website or online mental health program)
Mental health support phone lines (e.g. Lifeline, Beyond Blue, etc)
Mental health support chat rooms/ instant messaging (e.g. Lifeline, Beyond Blue, etc)
Counselling (face to face)
Counselling (tele-health)
Psychology (face to face)
Psychology (tele-health)
Psychiatry (face to face)
Psychiatry (tele-health)
Medication
Community-based mental health program
Crisis support (e.g. Psychiatric Emergency Team, CATT, Mental Health Triage)
Hospital (e.g Inpatient Psychiatry)
OTHER:

ii. Think of a time that you have used mental health service, what did the staff and professionals do to ensure that you were able to communicate?

ENTER TEXT

iii. Overall, how satisfied were you with the mental health support that you received?
○ Not at all satisfied
○ Somewhat satisfied
○ Completely satisfied

11. How accessible do you think mental health phonelines (e.g. Lifeline, Beyond Blue) are for people with CCN?
Some mental health organisations have free counselling over the phone. Mental health phone lines also have teletypewriter (TTY), Speak and Listen, and Voice Relay Service.
Completely inaccessible
Somewhat inaccessible
Somewhat accessible
Completely accessible

12. How likely are you use a mental health phone line?
○ Very likely
○ Somewhat likely
○ Somewhat unlikely
○ Not at all likely

13. How accessible do you think mental health chat rooms are (e.g. Lifeline, Beyond Blue) for people with CCN?
Most mental health hotlines now offer an online chat option.

○ Not at all accessible
○ Somewhat inaccessible
○ Somewhat accessible
○ Completely accessible

14. How likely are you use a mental health chat room?

○ Very likely
○ Somewhat likely
○ Somewhat unlikely
○ Not at all likely

15. What is the relevance of 'Positive Behaviour Support' in mental health support?

Note: Positive Behaviour Support is an evidence-based approach commonly used in the support of people with disabilities. Its primary aim is to increase the quality of life of the person, and secondarily to reduce the use of 'behaviours of concern' (e.g. self-injury, aggression, disruption, property damage, etc). More information on Positive Behaviour Support is available here.

○ PBS is only relevant to with people with disability.

○ PBS is relevant to all people (including people with disability).

○ PBS is not relevant in mental health support.

○ I don't know enough about PBS to say.

16. How do you think mental health support could be made more accessible for people with communication difficulties?

ENTER TEXT

If you experience feelings of distress as a result of participation in this study, please let the research team know via email. Additionally, these are contact details for some free communication accessible counselling support services:

Lifeline: Crisis support and suicide prevention.

- Call 13 11 14 **OR**
- TTY (teletypewriter): call 133 677 then request 13 11 14 **(open 24 hours)**
- Speak and Listen: call 1300 555 727 then request 13 11 14 **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay
  - then request 13 11 14 **(open 24 hours)**
- Chat online: go to https://www.lifeline.org.au/get-help/online-services/crisis-chat **(7pm – midnight)**

1800 RESPECT: Domestic violence and abuse counselling and support

**This organisation has strategies to support communication access

- Call 1800 737 732, OR **(open 24 hours)**
- National Relay Service: go to https://nrschat.nrscall.gov.au/nrs/internetrelay
  then request 1800 737 732 **(open 24 hours)**
- Chat online: go to https://chat.1800respect.org.au/#/welcome **(open 24 hours)**

Thank you for participating in this survey.
Feedback about this research project will be made available via (link to Facebook page for the project).

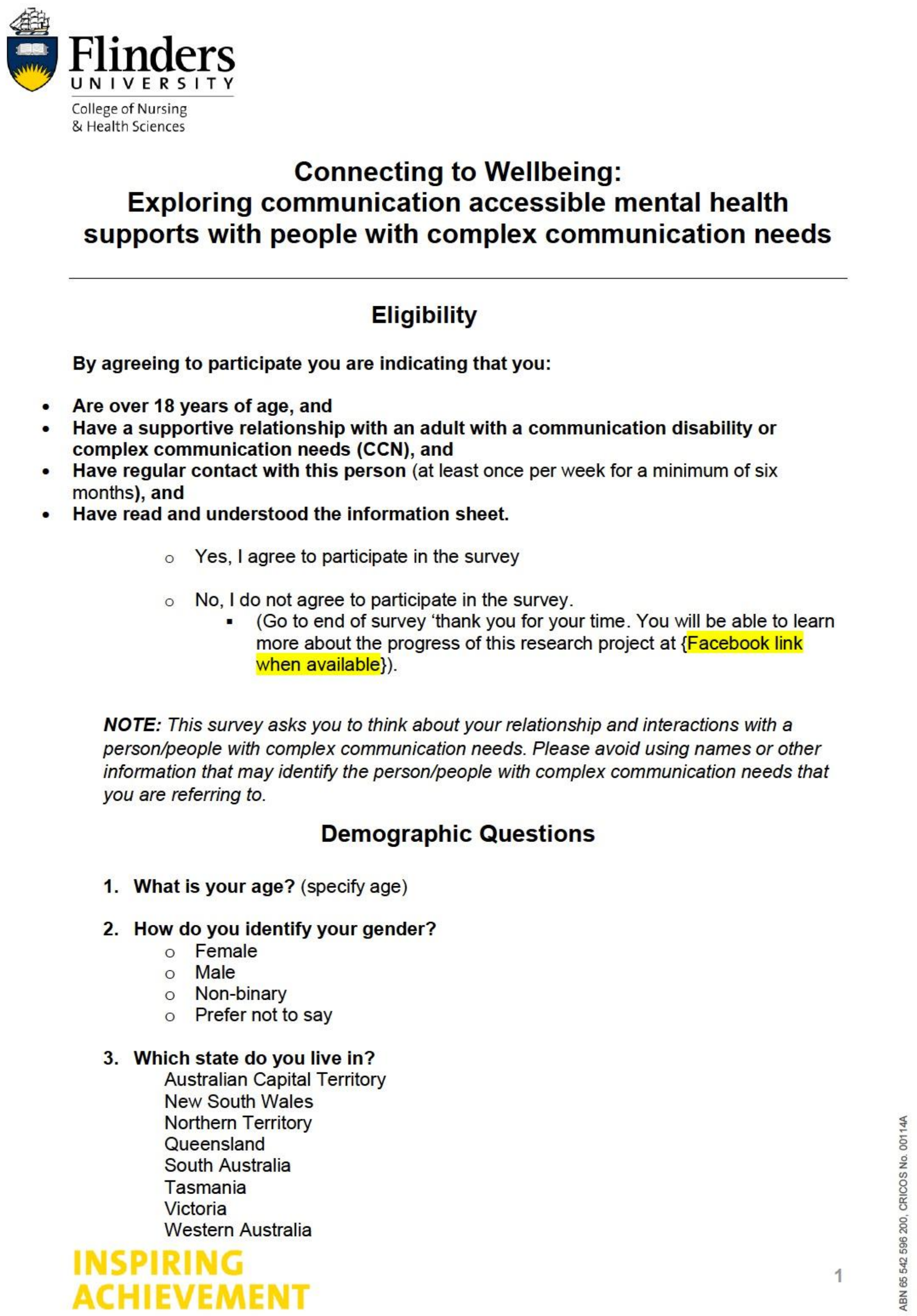
Would you be interested in being part of an interview to share your thoughts and opinions about mental health and how access to supports could be improved for people with complex communication needs?

- Yes
  - Please share your contact details here to receive an information pack:
    Name:
    Email:
    OR Postal address:
    Phone number:

  Note: Your contact details will not be used for any other purpose.

- No
  - **Thank you for participating in the Connecting to Wellbeing survey.**

Appendix Q: Survey Questions for ECPs



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Exploring communication accessible mental health supports with people with complex communication needs

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Eligibility

By agreeing to participate you are indicating that you:

- **Are over 18 years of age, and**
- **Have a supportive relationship with an adult with a communication disability or complex communication needs (CCN), and**
- **Have regular contact with this person** (at least once per week for a minimum of six months**), and**
- **Have read and understood the information sheet.**

○ Yes, I agree to participate in the survey

○ No, I do not agree to participate in the survey.
  - (Go to end of survey 'thank you for your time. You will be able to learn more about the progress of this research project at {Facebook link when available}).

NOTE: *This survey asks you to think about your relationship and interactions with a person/people with complex communication needs. Please avoid using names or other information that may identify the person/people with complex communication needs that you are referring to.*

Demographic Questions

1. **What is your age?** (specify age)

2. **How do you identify your gender?**
   - ○ Female
   - ○ Male
   - ○ Non-binary
   - ○ Prefer not to say

3. **Which state do you live in?**
   Australian Capital Territory
   New South Wales
   Northern Territory
   Queensland
   South Australia
   Tasmania
   Victoria
   Western Australia

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ABN 65 542 596 200, CRICOS No. 00114A

4. **How many years have you known the person with complex communication needs?** (Specify years)

5. **What is your relationship to the person?**
    - Family member
    - Friend
    - Partner
    - Housemate
    - Colleague/ peer
    - Support worker
    - OTHER:

6. **Education:**
   What is the highest level of education that you have completed?
    - Year 10
    - Year 11
    - Year 12
    - Certificate level (TAFE or VET qualification)
    - Diploma level
    - Bachelor's degree
    - Graduate Certificate/ Diploma
    - Master's degree
    - Doctorate

Background information

What is mental health?

The World Health Organisation says that mental health is a state of emotional and physical wellbeing in which people can:

- *Recognise their abilities and strengths,*
- *can cope with the stress in their life,*
- *can work productively and fruitfully,*
- *and are able to contribute to their community*

(World Health Organization & Calouste Gulbenkian Foundation, 2017)

Mental health refers to the health and wellbeing of your mind. Your mental health affects how you feel, think and act.

Some things that can impact on your mental health are:

- *stress,*
- *being in pain,*

- *hormonal changes,*
- *being bullied or excluded,*
- *ending a relationship, or*
- *the death of a loved one.*

The health of your mind is just as important as health of your body.

Survey Questions

1. **Do you think that people with complex communication needs can experience mental health problems?**

   Mental health problems affect a person's thoughts, feelings, perceptions, behaviour, and may impact on their relationships and quality of life. Mental health problems include high prevalence conditions such as anxiety and depression as well as less common mental illness such as bi-polar disorder, schizophrenia and personality disorders.

   - Yes
   - No
   - Not sure

2. **Have you ever participated in education (e.g. a course or information session) about mental health?**

   - No
   - Yes

   What did you learn about?

     - Different mental health problems
     - How to improve your mental health
     - Ways to help you relax and be less stressed or anxious
     - How to get help for a mental health problem
     - Identifying and naming different emotions
     - OTHER:

3. **Where do you get information about mental health?**

   - Friends
   - Family
   - General Practitioner
   - Mental Health Professional
   - Attending courses
   - Website
   - Online community (Social media)
   - Print Media – television, newspapers, magazines
   - OTHER:

4. **What would you like to know more about mental health?**
   Choose all that apply

- Different types of mental health problems
- Different therapies to improve mental health
- Ways to relax and be less stressed or anxious
- How to get help for a mental health problem (not an emergency)
- How to get help in a mental health emergency (e.g. someone thinking about suicide)
- How to manage my own mental health problems
- How to help other people with mental health problems
- Identifying and naming different emotions
- Learning about resilience or how to 'bounce back' from hard times.
- OTHER:

NOTE: For the next part of this survey asks you to think about your relationship and interactions with a person/people with complex communication needs (CCN). Please avoid using names or other information that may identify the person/people with complex communication needs that you are referring to.

5. **How does the person with CCN communicate with you about feelings, emotions and mental health?**
   ○ They tell me with their natural voice
   ○ They tell me using their AAC
   ○ They tell me with their behaviour
   ○ They don't communicate about feelings and emotions
   ○ OTHER:

6. **How easy do you find it to understand the person's communication about feelings, emotions and mental health?**
   ○ Very easy
   ○ Somewhat easy
   ○ Somewhat difficult
   ○ Very difficult

7. **How often do you communicate with the person with CCN about feelings, emotions and mental health?**
   ○ Multiple times a day
   ○ Once a day
   ○ Every few days
   ○ Every week
   ○ Every few weeks
   ○ Every month
   ○ Less than once a month
   ○ Not at all

8. What are most useful things that you can do when the person with CCN communicates about their feelings, emotions and mental health?

Rate from 1 (not useful) to 5 (very useful).

○ Approach the person and ask if they are okay
○ Take time to hear what the person wants to communicate
○ Check what the person said to make sure you got it right
○ Speak directly to the person (not a family member or support worker)
○ Help the person to use their communication aid/AAC
○ Learn about how the person communicates
○ Help the person sort the problem out
○ Use manners
○ Respect the person's point of view/ choices
○ Convey a kind, compassionate attitude
○ Distract the person from their worries
○ Check back later to see how the person is doing
○ Keep your conversations with the person private
○ Give the person enough time
○ Give the person written information in Easy English
○ Tell other people about what the person said
○ Book longer appointments to make sure there is enough time to communicate.

9. Do you have any other suggestions for useful things that communication partners can do when a person with CCN communicates about their feelings, emotions and mental health?

ENTER TEXT

10. What doesn't help when the person with CCN is trying to communicate about their feelings, emotions and mental health?

ENTER TEXT

11. Has the person with CCN experienced a mental health problem?

Mental health problems affect a person's thoughts, feelings, perceptions, behaviour, and may impact on their relationships and quality of life. Mental health problems include high prevalence conditions such as anxiety and depression as well as less common mental illness such as bi-polar disorder, schizophrenia and personality disorders. People with complex communication needs may face barriers to accessing diagnosis and treatment for mental health problems.

Yes, but it isn't diagnosed.
Yes, it has been diagnosed by a mental health professional.
No, the person has not experienced any mental health problems.
I don't know

12. Has the person with CCN ever sought help for a mental health problem?

- No

  Why not?
  - The person hasn't experienced any mental health problems
  - The person didn't want help
  - No one offered any help
  - I/we didn't know how to help
  - I/we worried what other people/services would think
  - People didn't understand the person when they tried to get help
  - OTHER

- Yes

  Where did the person get help from?
  - Family
  - Friends
  - Partner
  - Support worker
  - General practitioner
  - Counsellor
  - Psychologist
  - Psychiatrist
  - Social Worker
  - E-mental health (website or online mental health support program)
  - Mental health support phone lines (e.g. Lifeline, Beyond Blue, etc)
  - Mental health support chat rooms/ instant messaging (e.g. Lifeline, Beyond Blue, etc)
  - OTHER:

13. What mental health supports has the person with CCN used to help them with their mental health?

- They haven't used any mental health supports

  i. Think of a time that you have assisted the person with CCN to attend a general health service, what did the staff and professionals do to ensure that the person was able to communicate?

  ENTER TEXT

E-mental health (website or online mental health support program)
Mental health support phone lines (e.g. Lifeline, Beyond Blue, etc)
Mental health support chat rooms/ instant messaging (e.g. Lifeline, Beyond Blue, etc)
Counselling (face to face)
Counselling (tele-health)
Psychology (face to face)
Psychology (tele-health)
Psychiatry (face to face)
Psychiatry (tele-health)
Medication
Community-based mental health program
Crisis support (e.g. Psychiatric Emergency Team, CATT, Mental Health Triage)

Hospital (e.g. Inpatient Psychiatry)
OTHER:

ii. **What methods did the staff and professionals use to ensure that the person with CCN could communicate?**

ENTER TEXT

iii. **Overall, how satisfied were you with the mental health support that the person you with CCN received?**

- ○ Not at all satisfied
- ○ Somewhat satisfied
- ○ Completely satisfied

14. Have you ever sought advice from a mental health professional to assist you in your support of a person with CCN?

- ○ Yes, I have
- ○ No, I haven't needed to
- ○ No, but I have thought about it
- ○ No, I don't think that they can help

15. What is the role of 'Positive Behaviour Support' in mental health support?

Note: Positive Behaviour Support is an evidence-based approach commonly used in the support of people with disabilities. Its primary aim is to increase the quality of life of the person, and secondarily to reduce the use of 'behaviours of concern' (e.g. self-injury, aggression, disruption, property damage, etc). More information on Positive Behaviour Support is available here.

- ○ PBS is only relevant to with people with disability.
- ○ PBS is relevant to all people (including people with disability).
- ○ PBS is not relevant in mental health support.
- ○ I don't know enough about PBS to say.

16. How do you think mental health support could be made more accessible for people with communication difficulties?

ENTER TEXT

Thank you for participating in this survey.

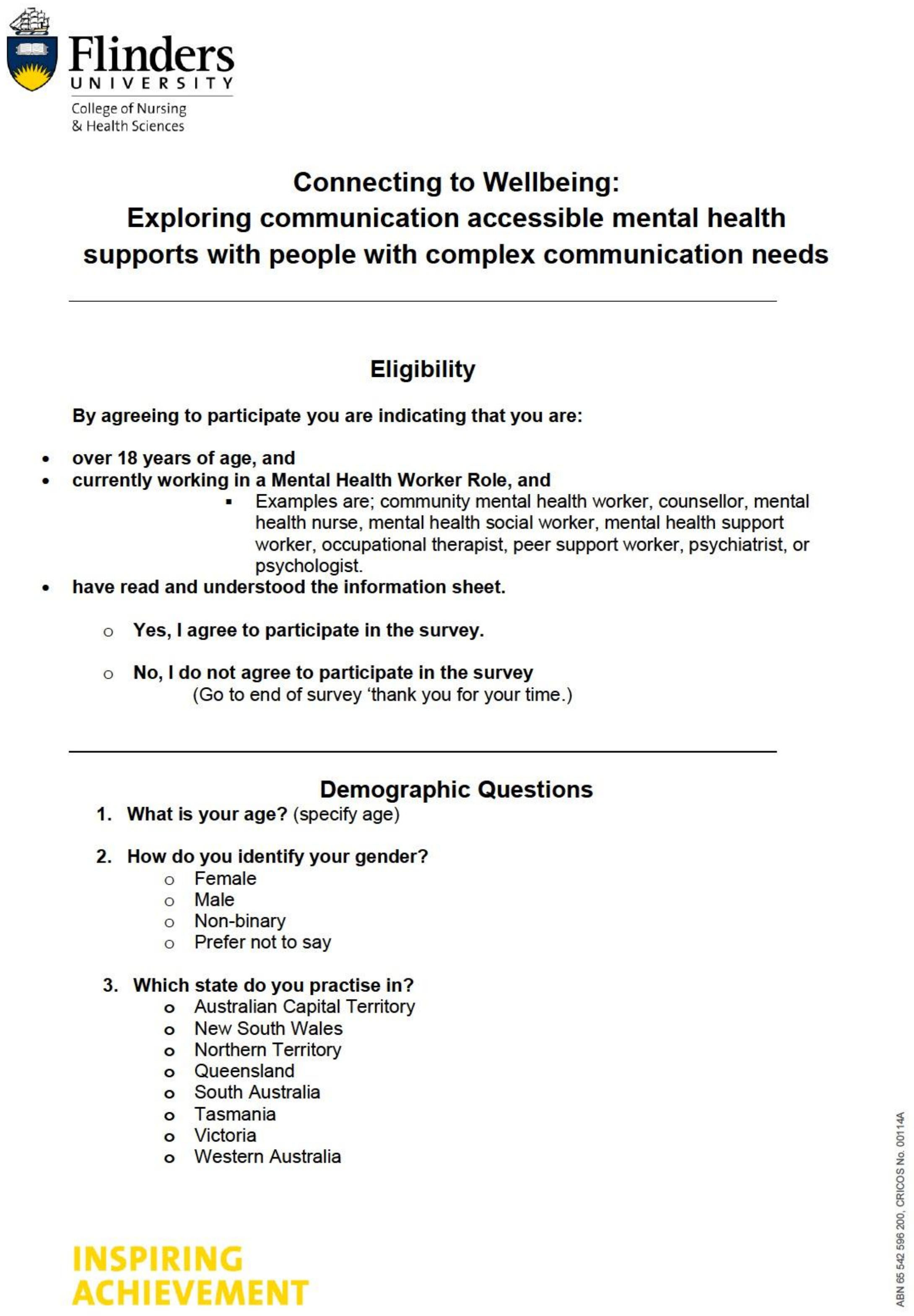
Would you be interested in being part of an interview to share your thoughts and opinions about mental health and how access to supports could be improved for people with complex communication needs?

- Yes
    - Please share your contact details here to receive an information pack:
      Name:
      Email:
      OR Postal address:
      Phone number:

  Note: Your contact details will not be used for any other purpose.

- No
    - **Thank you for participating in the Connecting to Wellbeing survey.**

Appendix R: Survey Questions for MHWs.



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Connecting to Wellbeing:
Exploring communication accessible mental health supports with people with complex communication needs

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Eligibility

By agreeing to participate you are indicating that you are:

- **over 18 years of age, and**
- **currently working in a Mental Health Worker Role, and**
    - Examples are; community mental health worker, counsellor, mental health nurse, mental health social worker, mental health support worker, occupational therapist, peer support worker, psychiatrist, or psychologist.
- **have read and understood the information sheet.**

○ **Yes, I agree to participate in the survey.**

○ **No, I do not agree to participate in the survey**
(Go to end of survey 'thank you for your time.)

Demographic Questions

1. **What is your age?** (specify age)

2. **How do you identify your gender?**
    - ○ Female
    - ○ Male
    - ○ Non-binary
    - ○ Prefer not to say

3. **Which state do you practise in?**
    - ○ Australian Capital Territory
    - ○ New South Wales
    - ○ Northern Territory
    - ○ Queensland
    - ○ South Australia
    - ○ Tasmania
    - ○ Victoria
    - ○ Western Australia

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4. **What is your highest education?**
   - Year 12
   - Certificate level (TAFE or vocational education qualification)
   - Diploma level
   - Bachelor's degree
   - Graduate Certificate/ Diploma
   - Master's degree
   - Doctorate

5. **Which best describes your job title?**
   - community mental health worker
   - counsellor
   - mental health nurse
   - mental health social worker
   - mental health support worker
   - occupational therapist
   - peer support worker
   - psychiatrist
   - psychologist
   - OTHER:

6. **How long have you been working in the mental health sector?** (Specify years)

7. **Which populations do you work with primarily?**

Identify up to three of the community groups listed below.
- Aboriginal and Torres Strait Islander communities
- Children
- Culturally and linguistically diverse communities
- LGBTQIA+
- Older People
- Youth
- OTHER:

8. **What areas do you specialise in within mental health?**
   Select all that apply to you
   - Addiction
   - Alcohol and other drugs
   - Anxiety
   - Autism
   - Depression
   - Disability
   - Disordered Eating
   - Family support
   - Forensics
   - Lived experience/ Peer support
   - Relationships
   - Recovery-oriented support
   - Severe and persistent mental illness
   - OTHER

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Background information

Who are people with complex communication needs (CCN)?

People with CCN experience significant challenges in the use of speech and may have difficulties in meeting the everyday demands of communication such as sharing information, expression of wants and needs, and establishing and maintaining social relationships. The communication challenges are not due to deafness or hearing impairment. CCN may be caused by motoric, cognitive, sensory, psychological or environmental factors They may be temporary (e.g. Resulting from intubation for a surgical procedure), acquired (e.g. occurring later in life due to a brain injury or progressive neuromuscular condition), or lifelong (e.g. occurring alongside a developmental condition such as cerebral palsy, intellectual disability, or autism). The population of people with CCN are diverse; comprising of people from a range of ages, and social, cultural and linguistic groups

NOTE: Previous experience working with people with CCN is not essential for participation in this survey.

Survey Questions

1. **Do you think that people with CCN can experience mental health problems?**
   ○ Yes

   ○ No

   ○ Not sure

2. **Have your ever undertaken any training regarding mental health and people with disability?**
   ○ No

   ○ Yes

   What was the name of the course?...

3. **Do you have experience working with people with CCN?**
    - Yes

    - No
        - **Reasons:**
            - No referrals- People with CCN haven't approached our service.
            - I don't think people with CCN would benefit from our service.
            - People with CCN aren't my client group.
            - Too complex
            - OTHER
4. **Do you feel equipped to work with someone with CCN?**
    - Very under equipped
    - Somewhat under equipped
    - Somewhat equipped
    - Well equipped

5. **When working with a person with CCN, how much effort would be required to provide communication access compared to your usual practices?**
    - Substantial effort
    - Moderate effort
    - Very little effort

6. **When working with a person with CCN, how do you adapt your practice?**
    - I haven't worked with people with CCN
    - I don't adapt my practice
    - Use of visual aids (e.g. pictographic symbols, illustrations, or photos)
    - Use of augmentative and alternative communication (AAC)
    - Reducing distractions
    - Simplifying the objectives of the sessions
    - Allowing additional time for the session
    - Checking for recall of information within sessions
    - Checking for recall of information between sessions
    - Increased rate of 'checking-in'
    - Offering frequent breaks
    - Giving only one piece of new information at a time
    - Repeating information when necessary
    - Reducing the reliance on verbal communication
    - Having the client nominate a second person to help with consultations
    - Using a formal communication assistant
    - OTHER:

7. **What are the most important skills and knowledge for MHWs working with people with complex communication needs?**

ENTER TEXT

8. **What 5 specific communication skills do you think are necessary when working with a person with complex communication needs?**

- ○
- ○
- ○
- ○
- ○

9. **What are the most important attitudes for MHWs working with people with complex communication needs?**

ENTER TEXT

10. **Generally, what therapeutic approaches have you used that reduce the requirement of speech to convey emotional states?**

ENTER TEXT

11. **What is the role of 'Positive Behaviour Support' in mental health support?**

Note: Positive Behaviour Support is an evidence-based approach commonly used in the support of people with disabilities. Its primary aim is to increase the quality of life of the person, and secondarily to reduce the use of 'behaviours of concern' (e.g. self-injury, aggression, disruption, property damage, etc). More information on Positive Behaviour Support is available here.

PBS is only relevant to with people with disability.

PBS is relevant to all people (including people with disability).

PBS is not relevant in mental health support.

I don't know enough about PBS to say.

12. **How do you think mental health support could be made more accessible for people with communication difficulties?**

ENTER TEXT

Thank you for participating in this survey.

Would you be interested in being part of an interview to share your thoughts and opinions about mental health and how access to supports could be improved for people with complex communication needs?

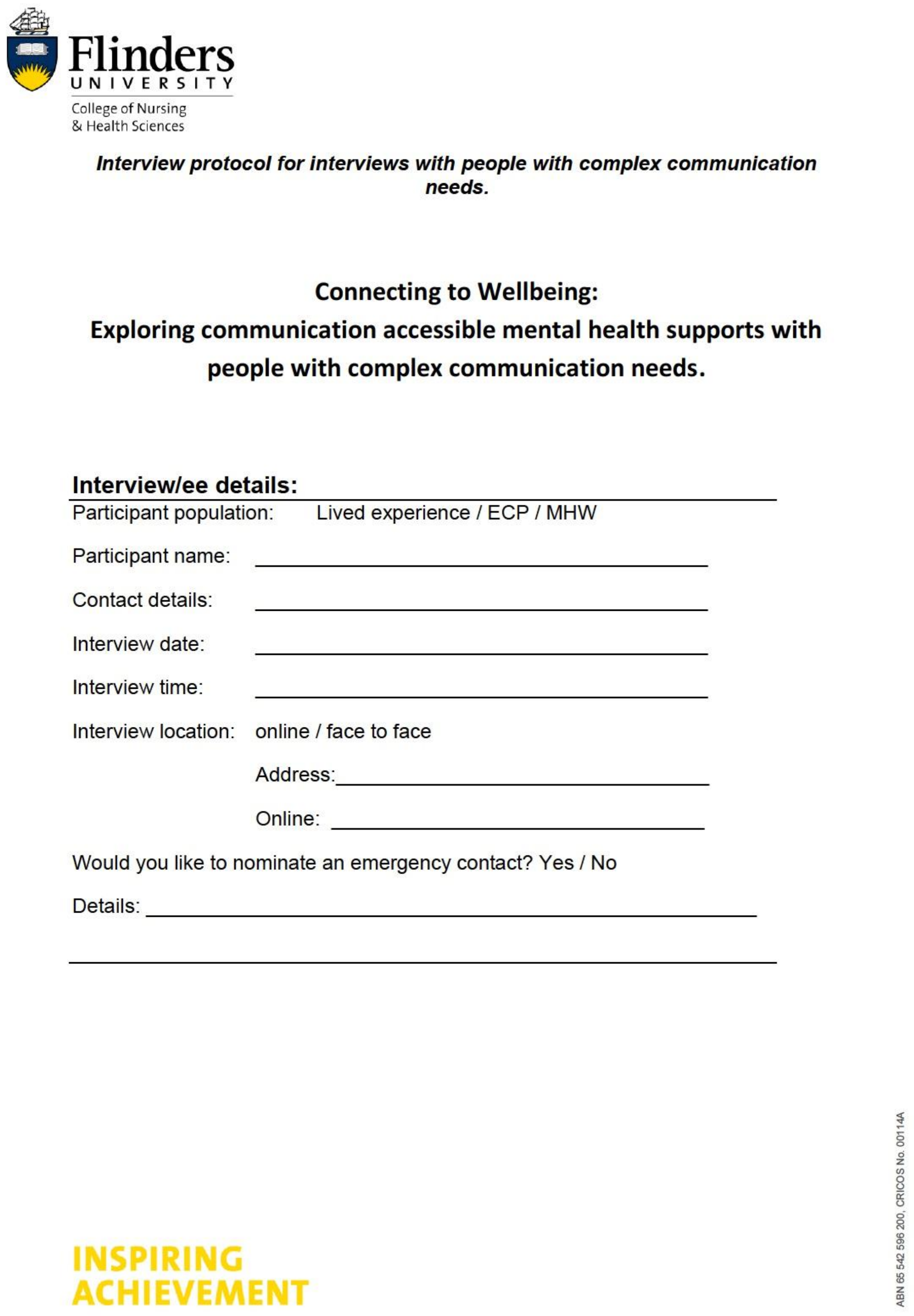
- Yes
    - Please share your contact details here to receive an information pack:
      Name:
      Email:
      OR Postal address:
      Phone number:

  Note: Your contact details will not be used for any other purpose.

- No

  Thank you for participating in the Connecting to Wellbeing survey.

Appendix S: Interview protocol - People with Communication Access Needs.



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Interview protocol for interviews with people with complex communication needs.

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Exploring communication accessible mental health supports with people with complex communication needs.

Interview/ee details:

Participant population: Lived experience / ECP / MHW

Participant name: ______________________________

Contact details: ______________________________

Interview date: ______________________________

Interview time: ______________________________

Interview location: online / face to face

Address:______________________________

Online: ______________________________

Would you like to nominate an emergency contact? Yes / No

Details: ____

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Interview Preparation

TASK	NOTES	DATE
Provide the participant information pack.		
Confirm receipt of information pack • After 1 week if no further correspondence.		
Arrange interview date/ location		
Provide Interview question overview		
Log interview time and location in outlook and share with supervisor (safety measure).		
Request information re: preferred methods of communication.		
Confirm interview • 24-48 hours prior to interview • Contact interviewee and check the interview arrangements • Check latest SA Health notifications and make arrangements as needed		
Confirm preferred methods of communication. • Are additional resources required?		
Gather interview materials • Spare info sheet • Consent form • Audio recorder (check it is charged) • Protocol sheet • PPE (sanitiser, wipes and mask if required) • $40 gift voucher		
On arrival at interview location notify supervisor via text message. • Face to face interviews only		

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Prior to interview commencement
Screening Questions

Covid-19 screening questions (face to face interviews)

Question	Response
Have you returned from overseas travel in the last 14 days?	YES/NO
Have you visited and of the known Covid-19 contact points? • Check SA Health for the most recent information and list for the interviewee.	YES/NO
Have you had any close contact with confirmed COVID-19 positive case?	YES/NO
Do you have any COVID-19 symptoms? *Symptoms can include:* • *fever OR chills (with no alternative illness that explains these symptoms)* • *cough* • *sore throat* • *runny nose* • *shortness of breath* • *loss of taste or smell.*	YES/NO

Brief questionnaire to ascertain informed consent.

Question	*Participant response*	*Correct response*
Have you been given the information pack?	YES/NO	**Yes**
Can the researcher make you participate in the study 'Connecting to Wellbeing'?	YES/NO	**No**
Can you skip a question if you feel uncomfortable to answer it?	YES/NO	**Yes**
Can you stop the interview if you feel distressed?	YES/NO	**Yes**
Will the researchers share your information with other people outside of the research team?	YES/NO	**No**
Will the researcher destroy your personal information when the study is finished?	YES/NO	**Yes**

Based on Balandin et al. (2006).

If the participant is unable to answer the informed consent questionnaire – **do not proceed**.

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Script:
"We can't begin the interview yet. I need to ensure that you are fully informed of your rights and responsibilities before we begin. Would you like me to re-read the information sheet with you and answer any questions that you may have? Then we can go through the questionnaire again."

The Researcher will re-read the information sheet with the individual and then readminister the **brief questionnaire to ascertain informed consent.** If the individual is able to respond to questions correctly the interview will proceed. If not, the researcher will read the following script and cease the interview process.

Script:
"We will need to stop the interview. It's very important that that you are fully aware of your rights and responsibilities in the research process, and that you consent willing to participate in the research project. I thank you for your time and your interest in the project. Please feel free to continue to follow the progress of the research project on Facebook."

****Complete the consent form at the back of the information sheet before proceeding with interview****

Interview Part 1: Demographic questions

Script: *This interview seeks to explore your experiences of communicating about emotions and/or seeking help to maintain your mental health. It is the researchers' view that mental health support is resource that should be provided to all people should they want it. We do not suggest that people with complex communication needs experience mental health problems more or less than other people, rather that communication about emotions and mental health is an ordinary human experience.*

Question	Notes
1. **What is your age?** Select age range	18-29 years. 30-39 years. 40-49 years. 50-59 years. 60-69 years. 70-79 years. 80-89 years. 90-99 years
2. **How do you identify your gender?**	
3. **Where do you live?** INTERVIEWER PROMPT: • Location and living arrangements	
4. **How do you describe your disability?**	

Question	**Notes**
INTERVIEWER PROMPT: • What is the predominant cause of your communication difficulties? • How long have you experienced complex communication needs?	
4. What are your preferred methods of communication?	
5. What schooling and other education have you completed? INTERVIEWER PROMPT: • Did you attend a mainstream school or specialist school? • What is the highest level of education that you have achieved?	
6. Occupation: INTERVIEWER PROMPT: • What are the main activities that you do each day? e.g. work, study, recreation	
7. Support arrangements: INTERVIEWER PROMPT: What supports do you have? • Informal (unpaid) • Formal (paid)	

That is the end of Part One of the Interview. Would you like to continue, or we can arrange another time to complete the rest of the interview?

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Interview 2 –Experiential Questions

NOTE: The purpose of this interview is to explore your experiences of communicating about emotions, concerns and/or seeking help for mental health. It is the researchers' view that mental health support should be available to all people should they want it. We do not suggest that all people with complex communication needs experience mental health problems more or less than other members of the community, rather that communication about emotions and mental health is an ordinary human experience.

Interview question	Notes
1. **What does mental health mean to you?**	
2. **How did you learn about mental health?** INTERVIEWER PROMPTS ○ What did you learn about? ○ Who taught you? ○ Where did you go, e.g. to a class or online? ○ How was the information presented, was it accessible?	
3. **How do you keep up to date with information about mental health?** e.g. self-help, different services, therapies INTERVIEWER PROMPT ○ How do you get information about mental health?	
4. **Can you tell me about the things that have a positive impact on your mental health?** INTERVIEWER PROMPTS ○ What do you do for self-care/ to look after your emotions? ○ What do you do when you are feeling stressed out?	
5. **Can you tell me about what sorts of things impact negatively upon your state of mental health?** INTERVIEWER PROMPTS • What are the things that cause you to feel distressed/sad/worried?	
6. **How does communication factor in your mental health?** INTERVIEWER PROMPTS ○ How have you expressed your emotions in the past? ○ How do feel about expressing your feelings, emotions, and concerns?	
○	

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Interview question	Notes
7. Can you tell me about a time when your wanted to address an issue that was impacting upon your mental health? INTERVIEWER PROMPTS ○ How do you express your emotions and concerns? ○ Who do you share your feelings with? ○ Where do you go for help? ○ How do you express your feelings, emotions and concerns?	
8. How did people respond when you expressed your feelings, emotions and concerns? INTERVIEWER PROMPTS ○ How do they validate your feelings? ○ How do they show that they are listening to you? ○ Were you offered any further help/ MH professional help?	
9. Have you tried any of the following interventions for mental health? ○ Anger management ○ Cognitive behaviour therapy ○ Dignity therapy ○ Expressive disclosure (keeping a journal) ○ Group therapy ○ Hypnosis ○ Individual psychotherapy/ counselling ○ Multi-family Group Therapy ○ Music therapy ○ Narrative therapy ○ Positive behaviour support ○ Resilience and adjustment therapy ○ Psychomotor therapy INTERVIEWER PROMPT: provide a brief description of each intervention. **What was your experience of that intervention/s?**	
10. If no to the listed interventions, what were the mental health services or supports that you have used? INTERVIEWER PROMPT ○ What was different about those supports? ○ What was it that worked/didn't work well for you?	

11. Have mental health workers made any of the following accommodations when you are getting help for mental health?

- Personalisation of intervention
    - **Person centred approach to developing intervention goals and delivery.**
- Communication access –
    - **Incorporating the person's existing AAC in the intervention delivery**
    - **Introducing new AAC to the person**
    - **Behavioural assessment**
    - **Inclusion of other professionals in the interventions (Multi-Disciplinary approach)**
    - **Easy English/plain language resources**
    - **Symbolised resources and visual aids**
    - **Use of memory aids**
    - **Recapping information**
    - **Inclusion of family members or support workers in intervention** (ECPMulti
    - **Adapted teaching strategies (e.g. use of roleplay)**
    - **Allowing additional time for intervention**
- Use interventions that rely less on spoken communication.
    - **E.g., Art therapy, hypnosis, Psychomotor therapy**

11.a What are your thoughts of each of those adaptations?

INTERVIEWER PROMPT

- **What sorts of accommodations worked well in your opinion?**

12. If no, what sorts of strategies have you noticed mental health professionals use to promote communication access?

INTERVIEWER PROMPT

- What worked well for you? What didn't?
- Did you have to initiate the strategy or did they?
- Were accommodations addressed explicitly?

13. Under what circumstances do you think should everyday communication partners be included in the mental health intervention?

14. What would you like to know more about in relation to mental health?

15. Do you have any other comments about communication access and mental health support?	

That is the end of the long answer questions.
Thank you very much for sharing your thoughts and experiences with me.
May I provide you with a brief summary of the interview?

Now we have a few more administrative items to discuss

Closing Interview

Transcript information:

Your interview will be typed up and you will have a chance to check it to make sure the information is accurate. The typed-up copy of the interview is called a transcript. Once the transcript is provided to you, you will have 14 days to review it, make corrections and send it back to the researcher. If the researcher doesn't receive any communication from you, they will assume that you are satisfied with the transcript.

How would you like to receive your transcript?

Email:

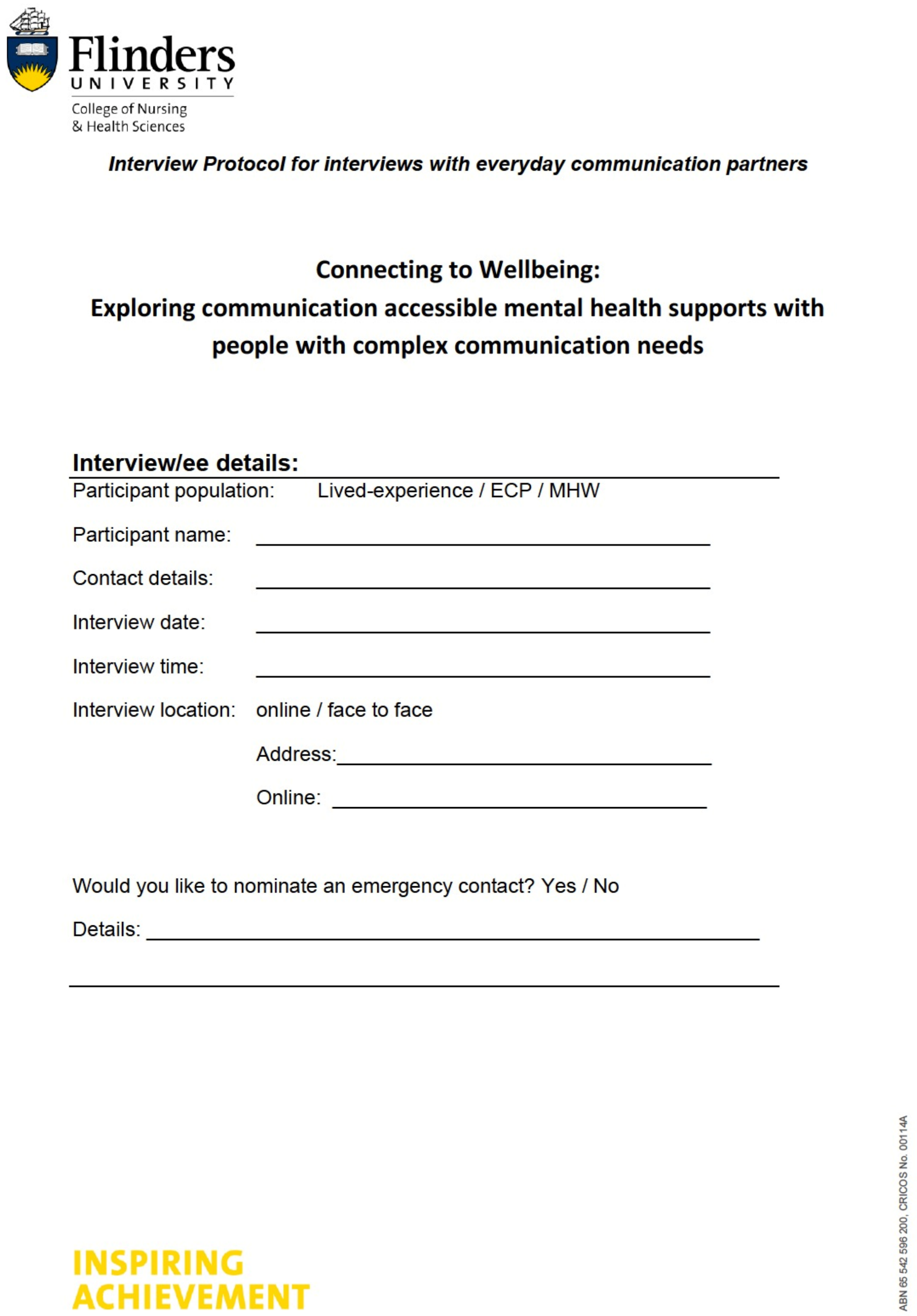
Postal address:

Do you require any assistance/resources/ alternative formats to read your transcript?

Would you like to select your own pseudonym?

- No, the researcher may allocate a pseudonym.
- Yes: ___________________________________

Appendix T: Interview Protocol - ECPs.



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Interview Protocol for interviews with everyday communication partners

Connecting to Wellbeing:
Exploring communication accessible mental health supports with people with complex communication needs

Interview/ee details:

Participant population: Lived-experience / ECP / MHW

Participant name: ____________________________________

Contact details: ____________________________________

Interview date: ____________________________________

Interview time: ____________________________________

Interview location: online / face to face

Address:________________________________

Online: ________________________________

Would you like to nominate an emergency contact? Yes / No

Details: ____

____

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Interview Preparation

TASK	NOTES	DATE
Provide the participant information pack.		
Confirm receipt of information pack • After 1 week if no further correspondence.		
Arrange interview date/ location		
Provide Interview question overview		
Log interview time and location in outlook and share with supervisor (safety measure).		
Request information re: preferred methods of communication.		
Confirm interview • 24-48 hours prior to interview • Contact interviewee and check the interview arrangements • Check latest SA Health notifications and make arrangements as needed		
Confirm preferred methods of communication. • Are additional resources required?		
Gather interview materials • Spare info sheet • Consent form • Audio recorder (check it is charged) • Protocol sheet • PPE (sanitiser, wipes and mask if required) • $20 gift voucher		
On arrival at interview location notify supervisor via text message. • Face to face interviews only		

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Prior to interview commencement
Screening Questions

Covid-19 screening questions (face to face interviews)

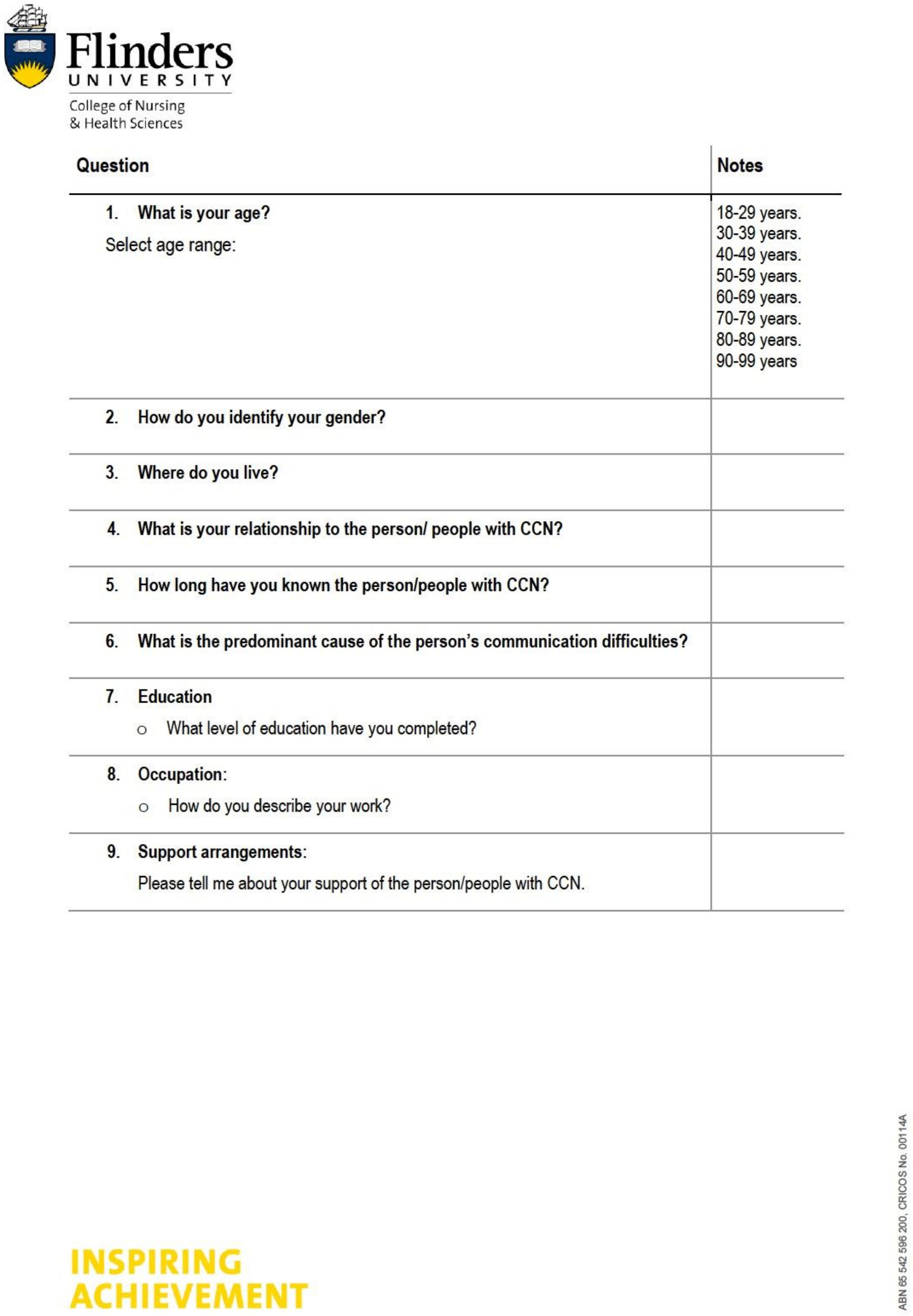
Question	**Response**
Have you returned from overseas travel in the last 14 days?	YES/NO
Have you visited and of the known Covid-19 contact points? • Check SA Health for the most recent information and list for the interviewee.	YES/NO
Have you had any close contact with confirmed COVID-19 positive case?	YES/NO
Do you have any COVID-19 symptoms? *Symptoms can include:* • *fever OR chills (with no alternative illness that explains these symptoms)* • *cough* • *sore throat* • *runny nose* • *shortness of breath* • *loss of taste or smell.*	YES/NO

****Complete the consent form before proceeding with interview****

Interview Questions – Demographics

Script:
This interview seeks to explore your experiences of communicating about emotions, and/or seeking mental health support with individuals with complex communication needs. It is the researchers' view that mental health support is resource that should be provided to all people should they want it. We do not suggest that people with complex communication needs experience mental health problems more or less than other people, rather that communication about emotions and mental health is an ordinary human experience.

In this interview the researcher will ask you to think about your relationship and interactions with a person, or people with complex communication needs. Please avoid using names or other information that may identify the person/people with complex communication needs that you are referring to.



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Question	Notes
1. **What is your age?** Select age range:	18-29 years. 30-39 years. 40-49 years. 50-59 years. 60-69 years. 70-79 years. 80-89 years. 90-99 years
2. **How do you identify your gender?**	
3. **Where do you live?**	
4. **What is your relationship to the person/ people with CCN?**	
5. **How long have you known the person/people with CCN?**	
6. **What is the predominant cause of the person's communication difficulties?**	
7. **Education** o What level of education have you completed?	
8. **Occupation**: o How do you describe your work?	
9. **Support arrangements**: Please tell me about your support of the person/people with CCN.	

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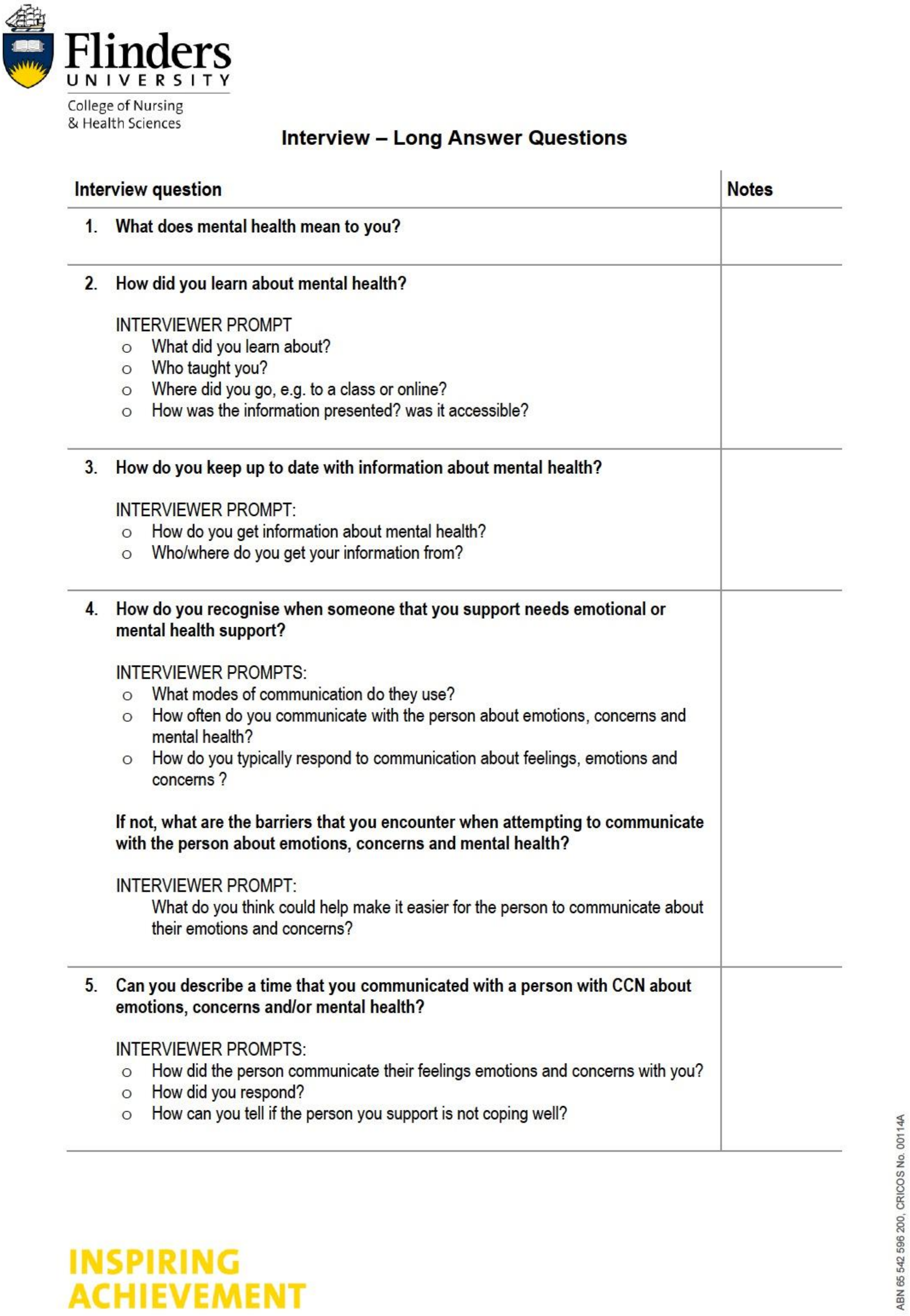

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Interview – Long Answer Questions

Interview question	Notes
1. **What does mental health mean to you?**	
2. **How did you learn about mental health?** INTERVIEWER PROMPT o What did you learn about? o Who taught you? o Where did you go, e.g. to a class or online? o How was the information presented? was it accessible?	
3. **How do you keep up to date with information about mental health?** INTERVIEWER PROMPT: o How do you get information about mental health? o Who/where do you get your information from?	
4. **How do you recognise when someone that you support needs emotional or mental health support?** INTERVIEWER PROMPTS: o What modes of communication do they use? o How often do you communicate with the person about emotions, concerns and mental health? o How do you typically respond to communication about feelings, emotions and concerns ? **If not, what are the barriers that you encounter when attempting to communicate with the person about emotions, concerns and mental health?** INTERVIEWER PROMPT: What do you think could help make it easier for the person to communicate about their emotions and concerns?	
5. **Can you describe a time that you communicated with a person with CCN about emotions, concerns and/or mental health?** INTERVIEWER PROMPTS: o How did the person communicate their feelings emotions and concerns with you? o How did you respond? o How can you tell if the person you support is not coping well?	

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6. **How do you perceive your role in supporting someone with CCN to communicate about their emotions and/or matters relating to mental health?**

INTERVIEWER PROMPT:
- What are the specific strategies that you use?
- Who do you refer to if further help is needed?

7. **How confident do you feel about addressing issues relating to emotions and/ or mental health with the person that you support?**

INTERVIEWER PROMPTS:
- What are some of the challenges to communication about feelings and emotions?
- How do you feel in addressing emotional distress?
- If you notice the person is not coping well, how do you initiate communication about what is distressing them?

8. **Have you heard of any of the following interventions for mental health being used with people with communication difficulties?**

- Anger management
- Cognitive behaviour therapy
- Dignity therapy
- Expressive disclosure (keeping a journal)
- Group therapy
- Hypnosis
- Individual psychotherapy/ counselling
- Multi-family Group Therapy
- Music therapy
- Narrative therapy
- Positive behaviour support
- Resilience and adjustment therapy
- Psychomotor therapy

8.a. Please describe your experience/ understanding of each intervention that you named.

8.b. Are there other interventions that you have observed?

INTERVIEWER PROMPTS:
What are your thoughts regarding the accessibility of those interventions?

9. Have you observed mental health workers to make any of the following accommodations when working with someone with communication difficulties?

- ***Personalisation of intervention***
  - Person centred approach to developing intervention goals.
  - Consideration of general access requirements.

- ***Use of communication access strategies***
  - Incorporating the person's existing AAC in the intervention delivery
  - Introducing new AAC to the person
  - Behavioural assessment
  - Inclusion of everyday communication partners in the intervention.
  - Inclusion of other professionals in the interventions (Multi-Disciplinary approach)
  - Easy English/plain language resources
  - Symbolised resources
  - Use of visual aids
  - Recapping information
  - Inclusion of family members or support workers in intervention
  - Adapted teaching strategies (e.g. use of roleplay)
  - Allowing additional time for intervention

- ***Use interventions that rely less on spoken communication.***
  - E.g., Art therapy, hypnosis, Psychomotor therapy

9.a What are your thoughts of each of those adaptations?

INTERVIEWER PROMPT

- What sorts of accommodations worked well in your opinion?

---

10. What other accommodations would you suggest that would promote the accessibility of mental health services or supports?

INTERVIEWER PROMPT

- What was it that worked/didn't work well?
- What was different about those supports?

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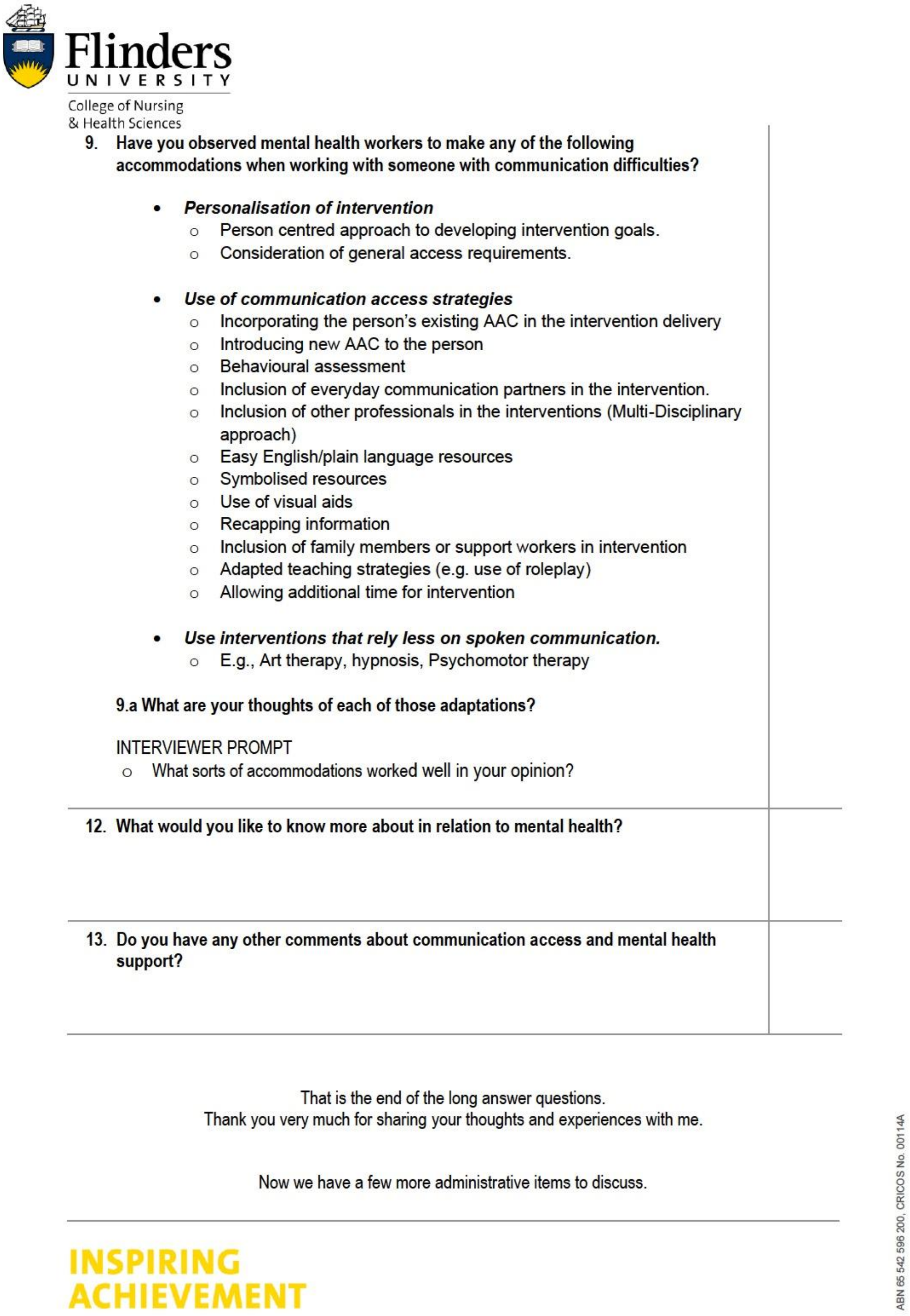
11. What are your thoughts about the involvement of family members or support people in mental health interventions for people with communication difficulties?



9. **Have you observed mental health workers to make any of the following accommodations when working with someone with communication difficulties?**

- ***Personalisation of intervention***
    - Person centred approach to developing intervention goals.
    - Consideration of general access requirements.

- ***Use of communication access strategies***
    - Incorporating the person's existing AAC in the intervention delivery
    - Introducing new AAC to the person
    - Behavioural assessment
    - Inclusion of everyday communication partners in the intervention.
    - Inclusion of other professionals in the interventions (Multi-Disciplinary approach)
    - Easy English/plain language resources
    - Symbolised resources
    - Use of visual aids
    - Recapping information
    - Inclusion of family members or support workers in intervention
    - Adapted teaching strategies (e.g. use of roleplay)
    - Allowing additional time for intervention

- ***Use interventions that rely less on spoken communication.***
    - E.g., Art therapy, hypnosis, Psychomotor therapy

9.a What are your thoughts of each of those adaptations?

INTERVIEWER PROMPT

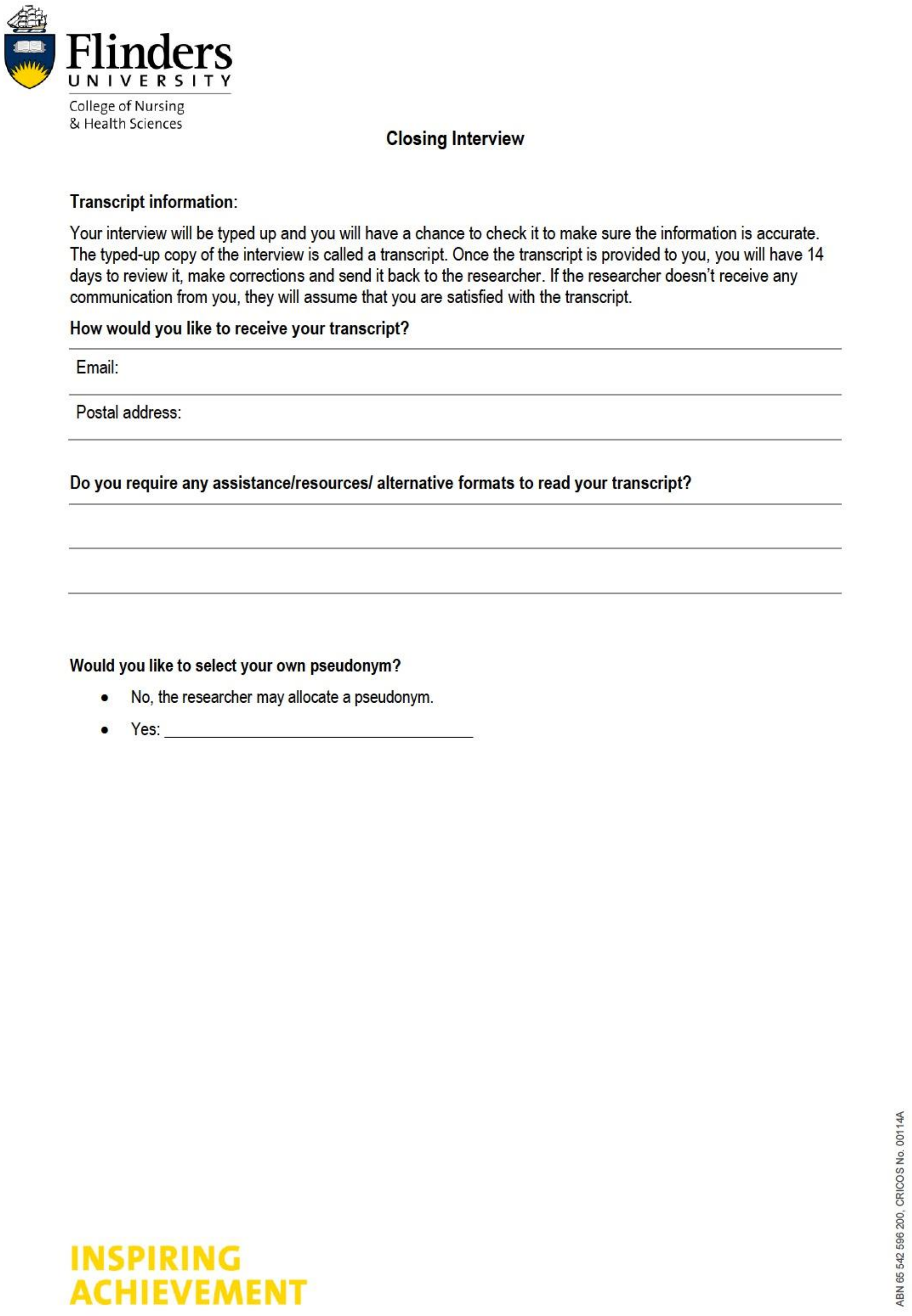
- What sorts of accommodations worked well in your opinion?

12. **What would you like to know more about in relation to mental health?**

13. **Do you have any other comments about communication access and mental health support?**

That is the end of the long answer questions.
Thank you very much for sharing your thoughts and experiences with me.

Now we have a few more administrative items to discuss.



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Closing Interview

Transcript information:

Your interview will be typed up and you will have a chance to check it to make sure the information is accurate. The typed-up copy of the interview is called a transcript. Once the transcript is provided to you, you will have 14 days to review it, make corrections and send it back to the researcher. If the researcher doesn't receive any communication from you, they will assume that you are satisfied with the transcript.

How would you like to receive your transcript?

Email:

Postal address:

Do you require any assistance/resources/ alternative formats to read your transcript?

Would you like to select your own pseudonym?

- No, the researcher may allocate a pseudonym.
- Yes: ____________________________________

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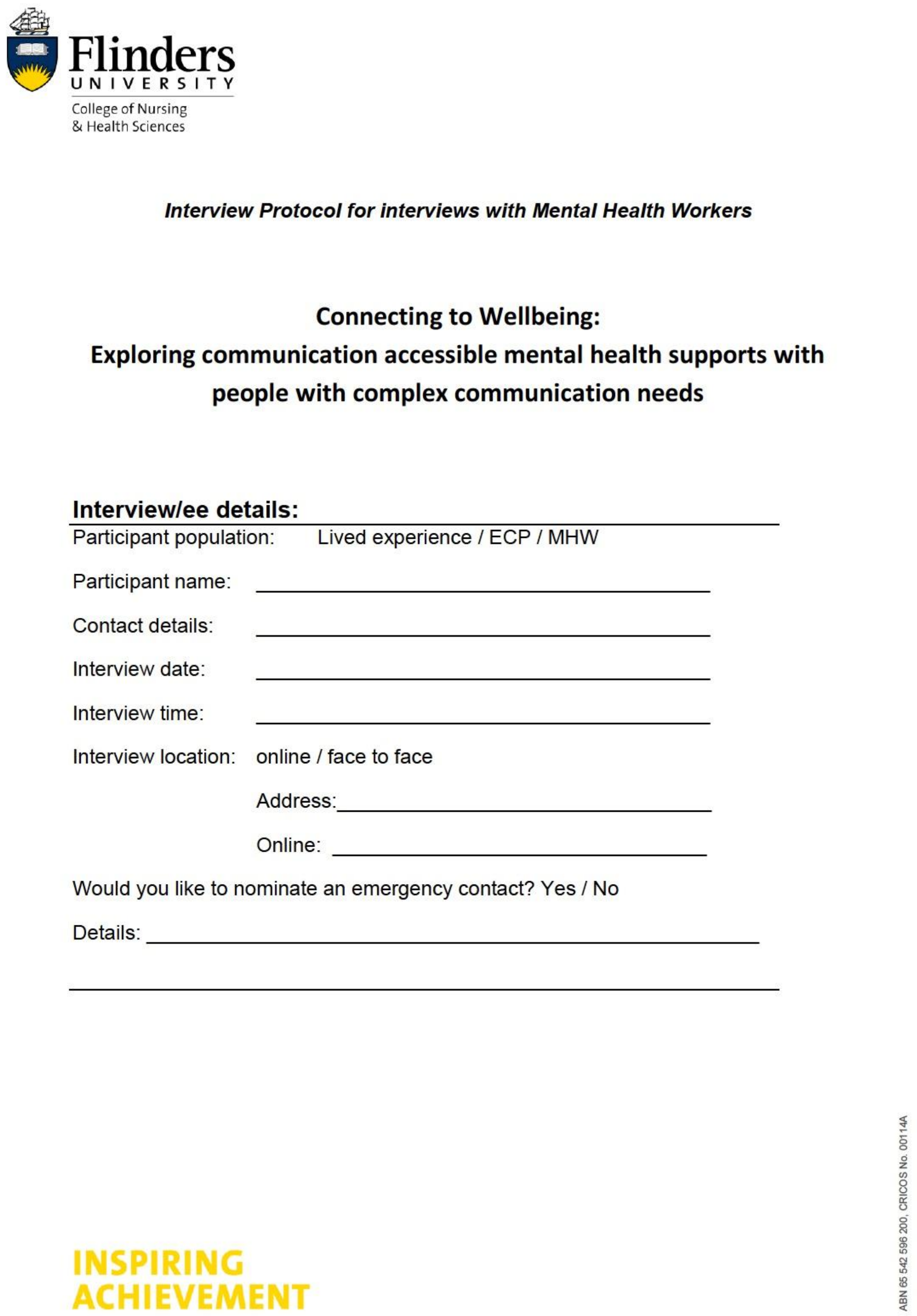
Appendix U: Interview Protocol - MHWs.



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Interview Protocol for interviews with Mental Health Workers

Connecting to Wellbeing:
Exploring communication accessible mental health supports with people with complex communication needs

Interview/ee details:

Participant population: Lived experience / ECP / MHW

Participant name: ____________________

Contact details: ____________________

Interview date: ____________________

Interview time: ____________________

Interview location: online / face to face

Address: ____________________

Online: ____________________

Would you like to nominate an emergency contact? Yes / No

Details: ____________________

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Interview Preparation

TASK	NOTES	DATE
Provide the participant information pack.		
Confirm receipt of information pack • After 1 week if no further correspondence.		
Arrange interview date/ location		
Provide Interview question overview		
Log interview time and location in outlook and share with supervisor (safety measure).		
Request information re: preferred methods of communication.		
Confirm interview • 24-48 hours prior to interview • Contact interviewee and check the interview arrangements • Check latest SA Health notifications and make arrangements as needed		
Confirm preferred methods of communication. • Are additional resources required?		
Gather interview materials • Spare info sheet • Consent form • Audio recorder (check it is charged) • Protocol sheet • PPE (sanitiser, wipes and mask if required) • $20 gift voucher		
On arrival at interview location notify supervisor via text message. • Face to face interviews only		

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Prior to interview commencement
Screening Questions

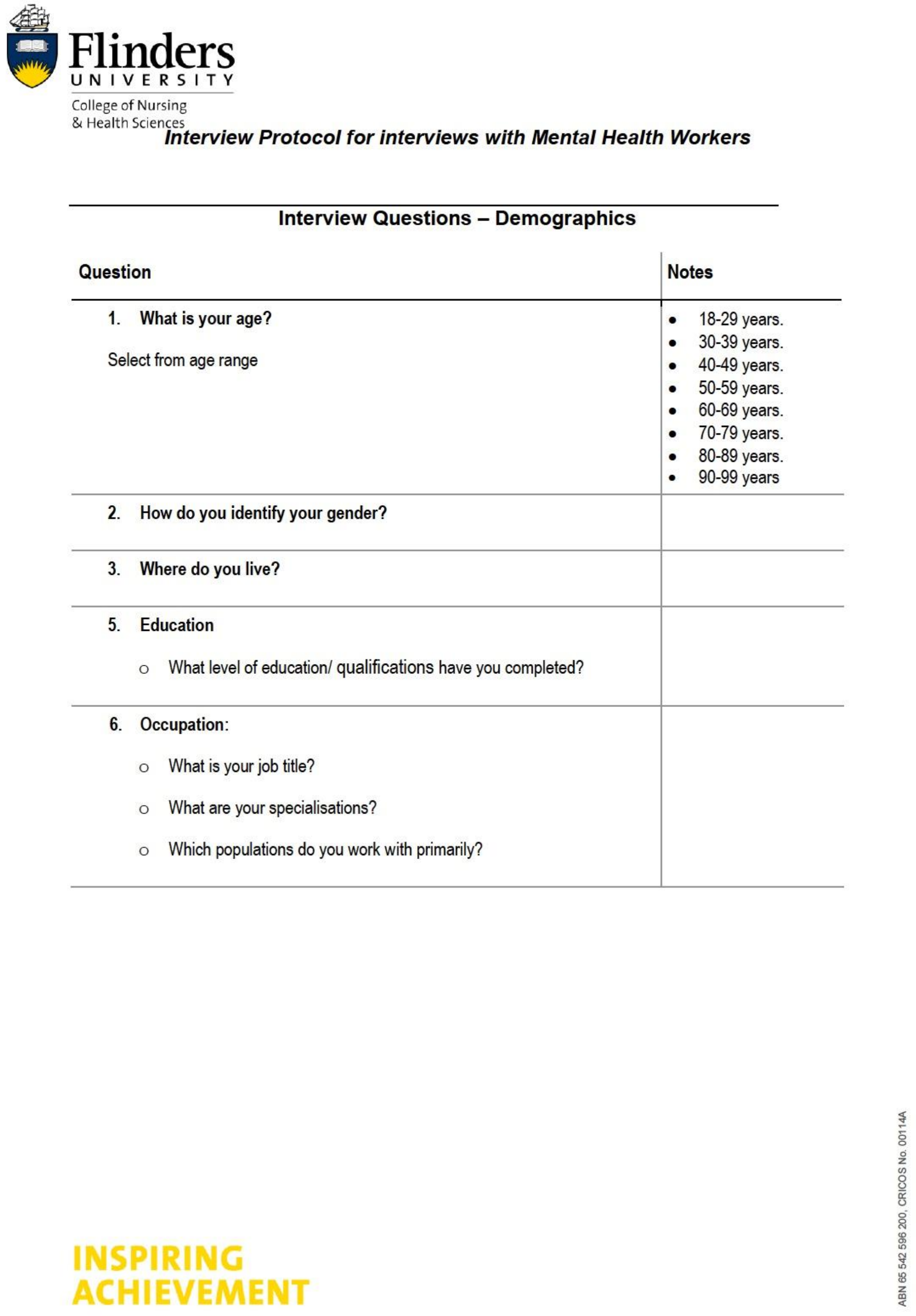
Covid-19 screening questions (face to face interviews)

Question	Response
Have you returned from overseas travel in the last 14 days?	YES/NO
Have you visited and of the known Covid-19 contact points? • Check SA Health for the most recent information and list for the interviewee.	YES/NO
Have you had any close contact with confirmed COVID-19 positive case?	YES/NO
Do you have any COVID-19 symptoms? *Symptoms can include:* • *fever OR chills (with no alternative illness that explains these symptoms)* • *cough* • *sore throat* • *runny nose* • *shortness of breath* • *loss of taste or smell.*	YES/NO

Eligibility and Consent Questions

Are you over 18 years old?	YES/NO
Are you currently working in a Mental Health Worker role?	YES/NO
Have you read the information sheet?	YES/NO
Do you agree to participate in this interview?	YES/NO

****Complete the consent form before proceeding with interview****



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& Health Sciences

Interview Protocol for interviews with Mental Health Workers

Interview Questions – Demographics

Question	Notes
1. **What is your age?** Select from age range	• 18-29 years. • 30-39 years. • 40-49 years. • 50-59 years. • 60-69 years. • 70-79 years. • 80-89 years. • 90-99 years
2. **How do you identify your gender?**	
3. **Where do you live?**	
5. **Education** ○ What level of education/ qualifications have you completed?	
6. **Occupation**: ○ What is your job title? ○ What are your specialisations? ○ Which populations do you work with primarily?	

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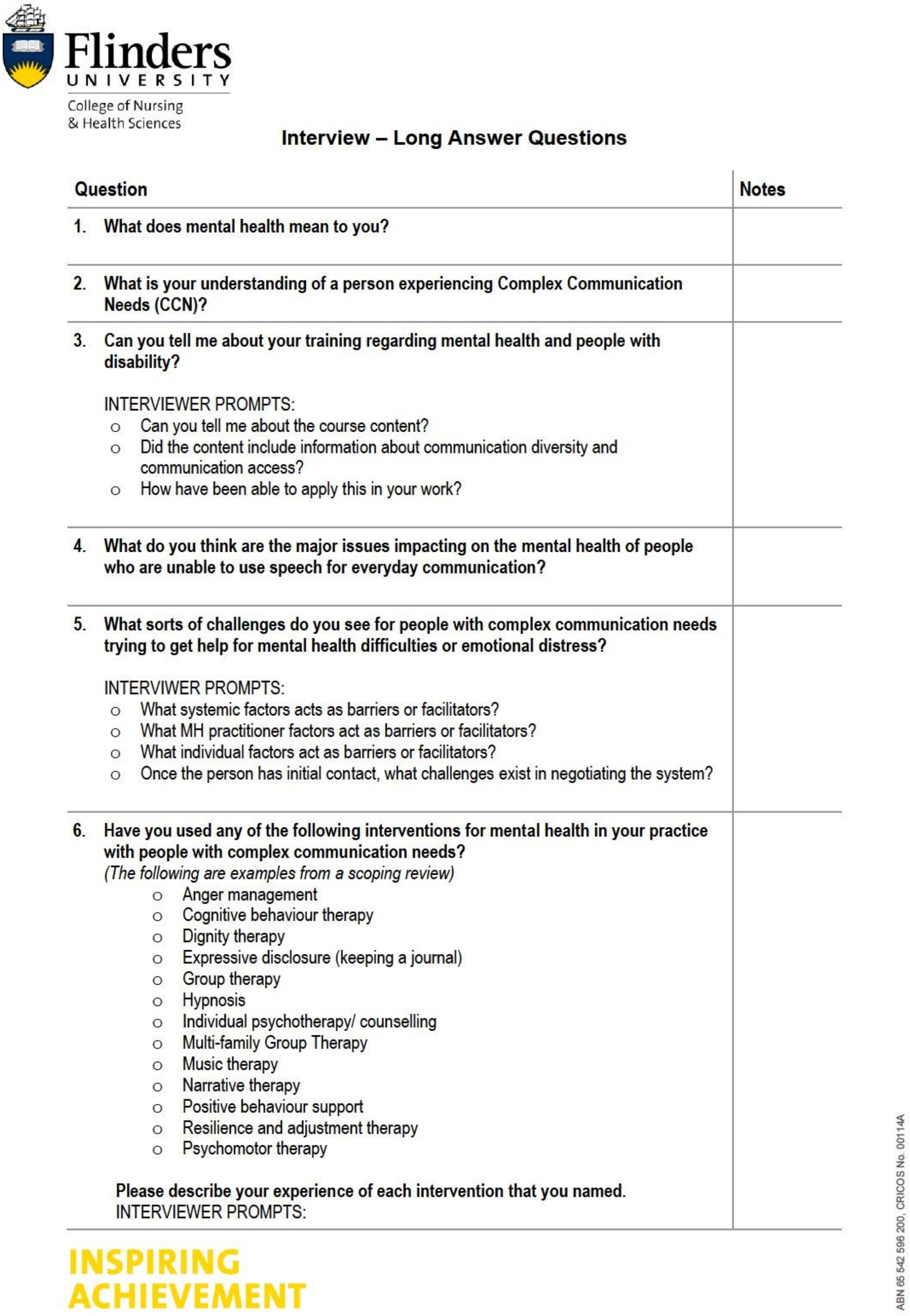

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Interview – Long Answer Questions

Question	Notes
1. What does mental health mean to you?	
2. What is your understanding of a person experiencing Complex Communication Needs (CCN)?	
3. Can you tell me about your training regarding mental health and people with disability? INTERVIEWER PROMPTS: ○ Can you tell me about the course content? ○ Did the content include information about communication diversity and communication access? ○ How have been able to apply this in your work?	
4. What do you think are the major issues impacting on the mental health of people who are unable to use speech for everyday communication?	
5. What sorts of challenges do you see for people with complex communication needs trying to get help for mental health difficulties or emotional distress? INTERVIWER PROMPTS: ○ What systemic factors acts as barriers or facilitators? ○ What MH practitioner factors act as barriers or facilitators? ○ What individual factors act as barriers or facilitators? ○ Once the person has initial contact, what challenges exist in negotiating the system?	
6. Have you used any of the following interventions for mental health in your practice with people with complex communication needs? *(The following are examples from a scoping review)* ○ Anger management ○ Cognitive behaviour therapy ○ Dignity therapy ○ Expressive disclosure (keeping a journal) ○ Group therapy ○ Hypnosis ○ Individual psychotherapy/ counselling ○ Multi-family Group Therapy ○ Music therapy ○ Narrative therapy ○ Positive behaviour support ○ Resilience and adjustment therapy ○ Psychomotor therapy **Please describe your experience of each intervention that you named.** INTERVIEWER PROMPTS:	

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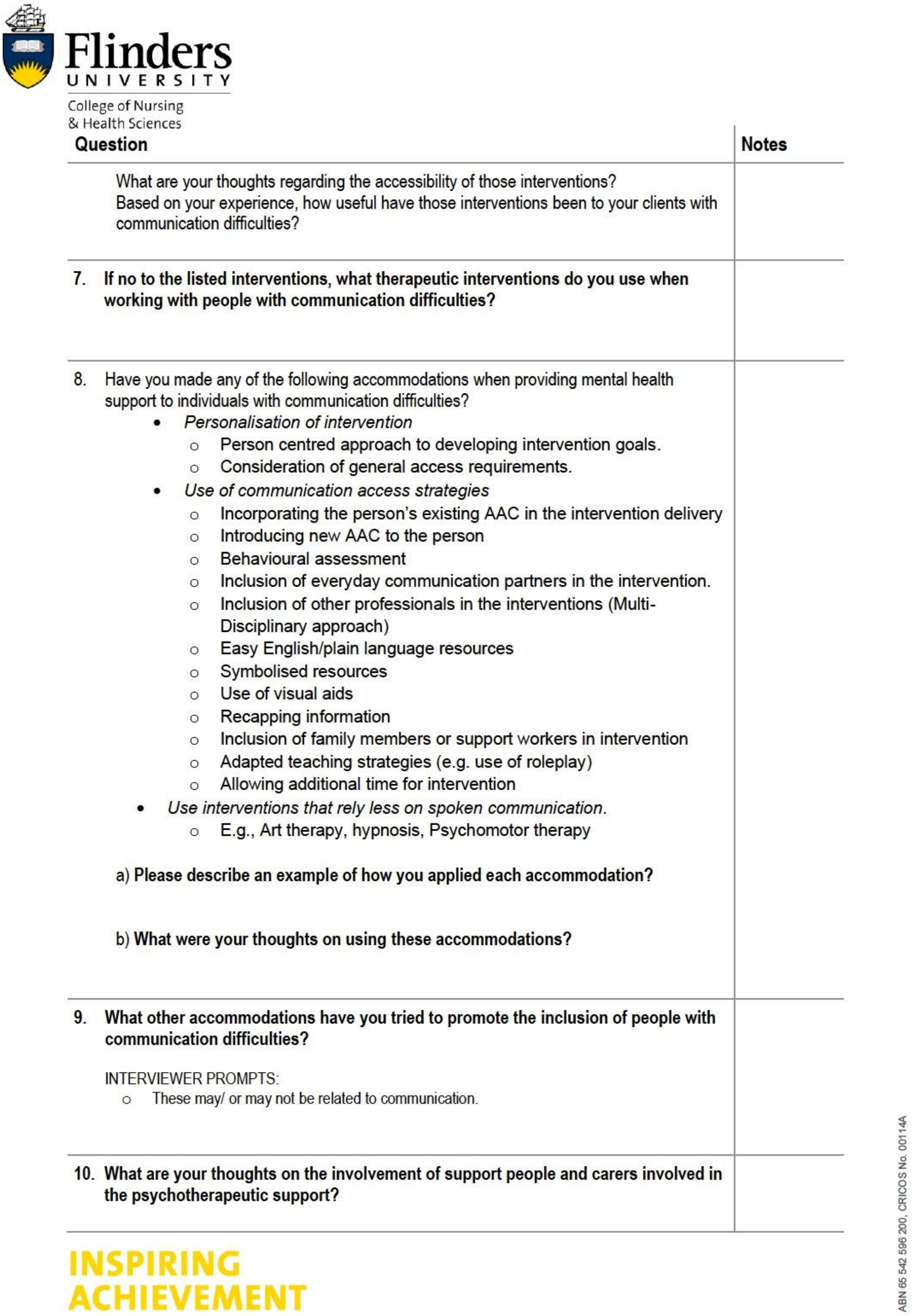

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Question	**Notes**
What are your thoughts regarding the accessibility of those interventions? Based on your experience, how useful have those interventions been to your clients with communication difficulties?	
7. If no to the listed interventions, what therapeutic interventions do you use when working with people with communication difficulties?	
8. Have you made any of the following accommodations when providing mental health support to individuals with communication difficulties? • *Personalisation of intervention* o Person centred approach to developing intervention goals. o Consideration of general access requirements. • *Use of communication access strategies* o Incorporating the person's existing AAC in the intervention delivery o Introducing new AAC to the person o Behavioural assessment o Inclusion of everyday communication partners in the intervention. o Inclusion of other professionals in the interventions (Multi-Disciplinary approach) o Easy English/plain language resources o Symbolised resources o Use of visual aids o Recapping information o Inclusion of family members or support workers in intervention o Adapted teaching strategies (e.g. use of roleplay) o Allowing additional time for intervention • *Use interventions that rely less on spoken communication.* o E.g., Art therapy, hypnosis, Psychomotor therapy a) **Please describe an example of how you applied each accommodation?** b) **What were your thoughts on using these accommodations?**	
9. What other accommodations have you tried to promote the inclusion of people with communication difficulties? INTERVIEWER PROMPTS: o These may/ or may not be related to communication.	
10. What are your thoughts on the involvement of support people and carers involved in the psychotherapeutic support?	

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Question	Notes
INTERVIEWER PROMPTS: ○ How is this similar/different for people with complex communication needs? ○ What would you do to manage power in where a second person is involved in sessions?	
11. What would you like to know more about regarding communication access in mental health support provision?	
12. Do you have any other comments about communication access and mental health support?	

That is the end of the long answer questions.
Thank you very much for sharing your thoughts and experiences with me.

Now we have a few more administrative items to discuss

Closing Interview

Transcript information:

Your interview will be typed up and you will have a chance to check it to make sure the information is accurate. The typed-up copy of the interview is called a transcript. Once the transcript is provided to you, you will have 14 days to review it, make corrections and send it back to the researcher. If the researcher doesn't receive any communication from you, they will assume that you are satisfied with the transcript.

How would you like to receive your transcript?

Email:

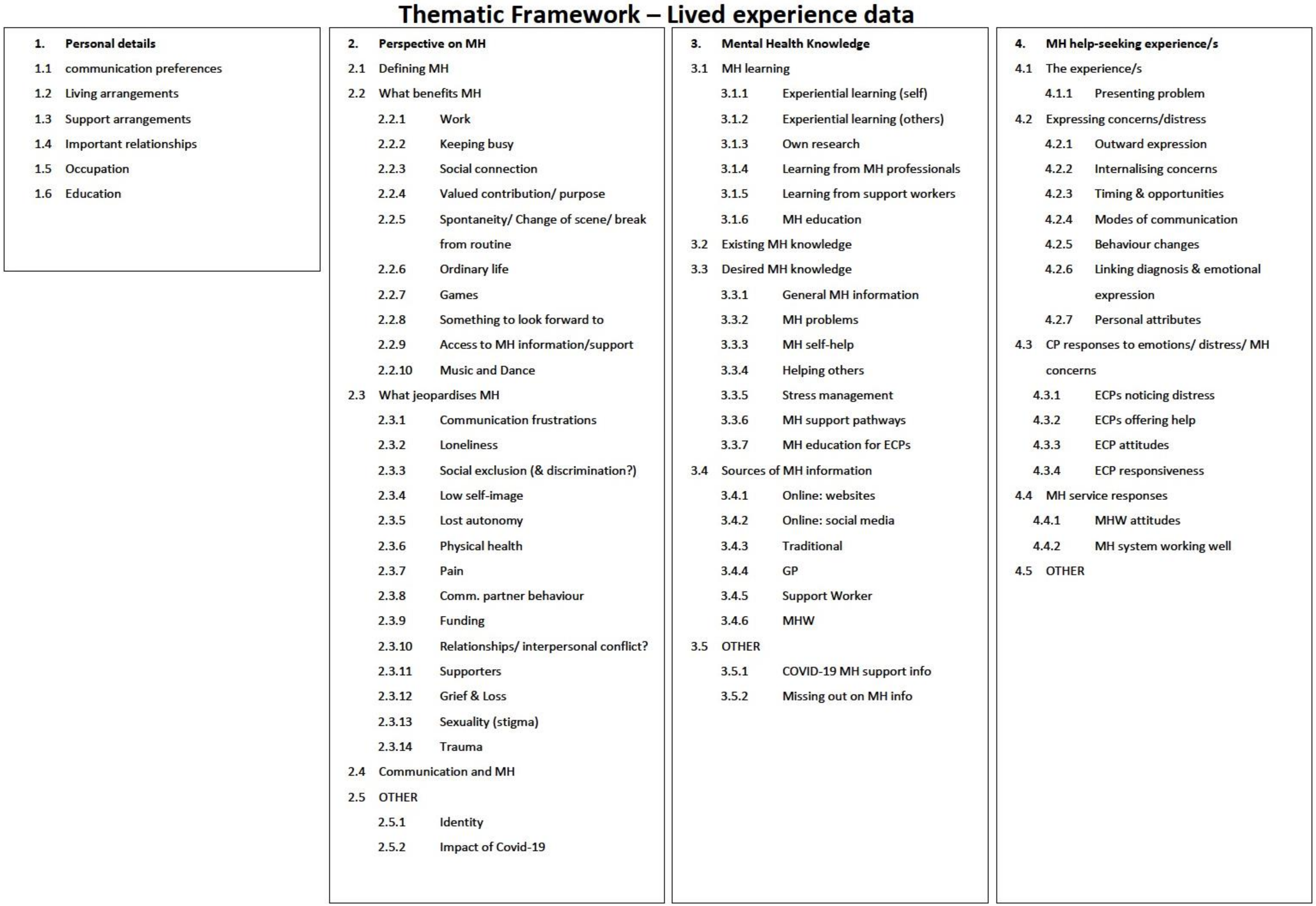
Postal address:

Do you require any assistance/resources/ alternative formats to read your transcript?

Would you like to select your own pseudonym?

- No, the researcher may allocate a pseudonym.
- Yes: ___________________________________

Appendix V: Thematic Framework v.1 Lived Experience Data.



Thematic Framework – Lived experience data

1. Personal details

1.1 communication preferences
1.2 Living arrangements
1.3 Support arrangements
1.4 Important relationships
1.5 Occupation
1.6 Education

2. Perspective on MH

2.1 Defining MH
2.2 What benefits MH
  2.2.1 Work
  2.2.2 Keeping busy
  2.2.3 Social connection
  2.2.4 Valued contribution/ purpose
  2.2.5 Spontaneity/ Change of scene/ break from routine
  2.2.6 Ordinary life
  2.2.7 Games
  2.2.8 Something to look forward to
  2.2.9 Access to MH information/support
  2.2.10 Music and Dance
2.3 What jeopardises MH
  2.3.1 Communication frustrations
  2.3.2 Loneliness
  2.3.3 Social exclusion (& discrimination?)
  2.3.4 Low self-image
  2.3.5 Lost autonomy
  2.3.6 Physical health
  2.3.7 Pain
  2.3.8 Comm. partner behaviour
  2.3.9 Funding
  2.3.10 Relationships/ interpersonal conflict?
  2.3.11 Supporters
  2.3.12 Grief & Loss
  2.3.13 Sexuality (stigma)
  2.3.14 Trauma
2.4 Communication and MH
2.5 OTHER
  2.5.1 Identity
  2.5.2 Impact of Covid-19

3. Mental Health Knowledge

3.1 MH learning
  3.1.1 Experiential learning (self)
  3.1.2 Experiential learning (others)
  3.1.3 Own research
  3.1.4 Learning from MH professionals
  3.1.5 Learning from support workers
  3.1.6 MH education
3.2 Existing MH knowledge
3.3 Desired MH knowledge
  3.3.1 General MH information
  3.3.2 MH problems
  3.3.3 MH self-help
  3.3.4 Helping others
  3.3.5 Stress management
  3.3.6 MH support pathways
  3.3.7 MH education for ECPs
3.4 Sources of MH information
  3.4.1 Online: websites
  3.4.2 Online: social media
  3.4.3 Traditional
  3.4.4 GP
  3.4.5 Support Worker
  3.4.6 MHW
3.5 OTHER
  3.5.1 COVID-19 MH support info
  3.5.2 Missing out on MH info

4. MH help-seeking experience/s

4.1 The experience/s
  4.1.1 Presenting problem
4.2 Expressing concerns/distress
  4.2.1 Outward expression
  4.2.2 Internalising concerns
  4.2.3 Timing & opportunities
  4.2.4 Modes of communication
  4.2.5 Behaviour changes
  4.2.6 Linking diagnosis & emotional expression
  4.2.7 Personal attributes
4.3 CP responses to emotions/ distress/ MH concerns
  4.3.1 ECPs noticing distress
  4.3.2 ECPs offering help
  4.3.3 ECP attitudes
  4.3.4 ECP responsiveness
4.4 MH service responses
  4.4.1 MHW attitudes
  4.4.2 MH system working well
4.5 OTHER

Thematic Framework – Lived experience data

5. MH support

- 5.1 Informal supports
- 5.2 Formal supports (non-MH worker)
  - 5.2.1 Speechie (SLP)
  - 5.2.2 GP
  - 5.2.3 Support Worker (disability)
  - 5.2.4 Developmental Educator
- 5.3 Formal supports
  - 5.3.1 Psychologist
  - 5.3.2 Psychiatrist
  - 5.3.3 Counsellor
  - 5.3.4 Community Mental Health Service
  - 5.3.5 Hospital
- 5.4 Therapeutic approaches tried
  - 5.4.1 CBT
  - 5.4.2 Expressive disclosure
  - 5.4.3 Counselling & psychotherapy
  - 5.4.4 ACT
  - 5.4.5 Medication
  - 5.4.6 Music therapy
  - 5.4.7 PBS
  - 5.4.8 Other intervention
- 5.5 Therapeutic approaches of interest
- 5.6 Coping strategies and self-care
- 5.7 Satisfaction with formal MH support
- 5.8 Suggested improvements for formal MH support
- 5.9 OTHER

6. MH Access Facilitators

- 6.1 Facilitating factors
  - 6.1.1 Human Assistance
  - 6.1.2 Adequate time
  - 6.1.3 Timing
  - 6.1.4 Learn about comm. preferences
  - 6.1.5 Person centred approach
  - 6.1.6 Physical access
  - 6.1.7 Incorporating AAC
  - 6.1.8 Simplified language
  - 6.1.9 Easy English/Plain language
  - 6.1.10 Visual aids
  - 6.1.11 Recapping
  - 6.1.12 Feeling understood
  - 6.1.13 Home visits
  - 6.1.14 Telehealth
  - 6.1.15 Holistic approach
  - 6.1.16 Funding
  - 6.1.17 Self-advocacy
  - 6.1.18 Other advocates
  - 6.1.19 Continuity of supports
  - 6.1.20 Reliable AAC
  - 6.1.21 Consent
  - 6.1.22 ECPs
  - 6.1.23 MH knowledge
- 6.2 OTHER

7. MH access barriers

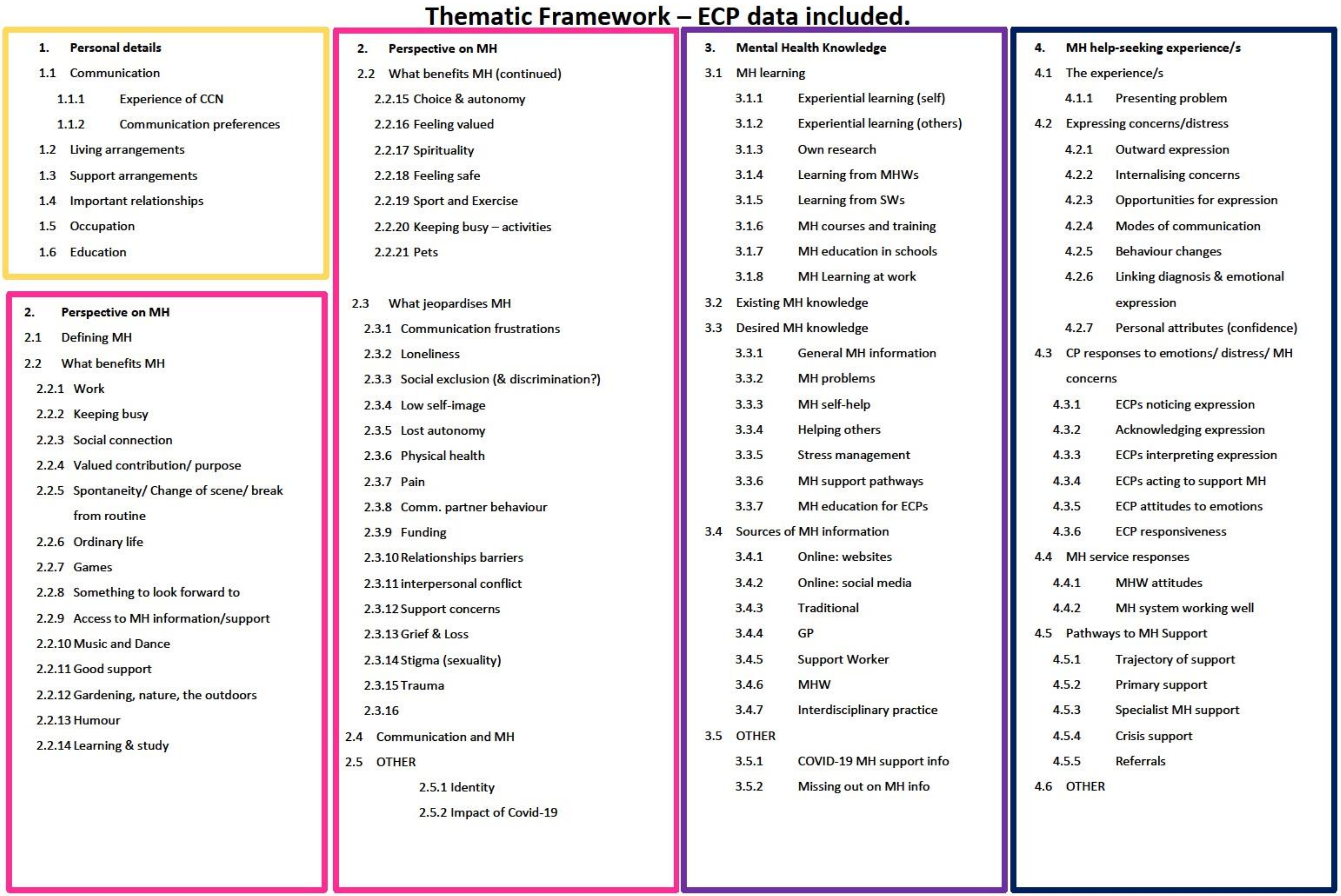
- 7.1 Barriers/Challenges
  - 7.1.1 Poor physical access
  - 7.1.2 Time constraints
  - 7.1.3 Lack of funding
  - 7.1.4 Lack of reliable AAC
  - 7.1.5 Stigma (attitude barrier)
  - 7.1.6 Low literacy
  - 7.1.7 MHW reliance on speech
  - 7.1.8 Opportunities to give feedback
  - 7.1.9 Practitioner skills
  - 7.1.10 Motivation
  - 7.1.11 Few opportunities to discuss emotions and issues relating to MH
  - 7.1.12 Lacking awareness of MH services
  - 7.1.13 People didn't understand
  - 7.1.14 Lack of trusted CPs
- 7.2 OTHER

8. ECPs

- 8.1 Inclusion of ECPs in formal MH support
- 8.2 The qualities of good MH supporters
  - 8.2.1 The 'right person' for the job
  - 8.2.2 Attitudes
  - 8.2.3 Trust
  - 8.2.4 'They know me well'
  - 8.2.5 Persistence
  - 8.2.6 Providing comfort/safety
  - 8.2.7 Supporting privacy/ confidentiality
  - 8.2.8 ECP MH knowledge
  - 8.2.9 Providing opportunities
  - 8.2.10 Promoting autonomy
- 8.3 ECPs as conduits to MH support
  - 8.3.1 Taking action
  - 8.3.2 ECPs support at MH interface
  - 8.3.3 Co-constructing messages
  - 8.3.4 Collaborative approach
  - 8.3.5 Maintaining/developing MH vocab
  - 8.3.6 Support before appointments
  - 8.3.7 Education for ECPs
- 8.4 ECP issues
  - 8.4.1 Lack of trust with ECPs
  - 8.4.2 ECP Attitudes
  - 8.4.3 Lack of MH knowledge
- 8.5 OTHER

9. Other important themes

Appendix W: Thematic Framework v.2 Lived Experience and ECP Data.



Thematic Framework – ECP data included.

1. Personal details
- 1.1 Communication
  - 1.1.1 Experience of CCN
  - 1.1.2 Communication preferences
- 1.2 Living arrangements
- 1.3 Support arrangements
- 1.4 Important relationships
- 1.5 Occupation
- 1.6 Education

2. Perspective on MH
- 2.1 Defining MH
- 2.2 What benefits MH
  - 2.2.1 Work
  - 2.2.2 Keeping busy
  - 2.2.3 Social connection
  - 2.2.4 Valued contribution/ purpose
  - 2.2.5 Spontaneity/ Change of scene/ break from routine
  - 2.2.6 Ordinary life
  - 2.2.7 Games
  - 2.2.8 Something to look forward to
  - 2.2.9 Access to MH information/support
  - 2.2.10 Music and Dance
  - 2.2.11 Good support
  - 2.2.12 Gardening, nature, the outdoors
  - 2.2.13 Humour
  - 2.2.14 Learning & study

2. Perspective on MH
- 2.2 What benefits MH (continued)
  - 2.2.15 Choice & autonomy
  - 2.2.16 Feeling valued
  - 2.2.17 Spirituality
  - 2.2.18 Feeling safe
  - 2.2.19 Sport and Exercise
  - 2.2.20 Keeping busy – activities
  - 2.2.21 Pets
- 2.3 What jeopardises MH
  - 2.3.1 Communication frustrations
  - 2.3.2 Loneliness
  - 2.3.3 Social exclusion (& discrimination?)
  - 2.3.4 Low self-image
  - 2.3.5 Lost autonomy
  - 2.3.6 Physical health
  - 2.3.7 Pain
  - 2.3.8 Comm. partner behaviour
  - 2.3.9 Funding
  - 2.3.10 Relationships barriers
  - 2.3.11 interpersonal conflict
  - 2.3.12 Support concerns
  - 2.3.13 Grief & Loss
  - 2.3.14 Stigma (sexuality)
  - 2.3.15 Trauma
  - 2.3.16
- 2.4 Communication and MH
- 2.5 OTHER
  - 2.5.1 Identity
  - 2.5.2 Impact of Covid-19

3. Mental Health Knowledge
- 3.1 MH learning
  - 3.1.1 Experiential learning (self)
  - 3.1.2 Experiential learning (others)
  - 3.1.3 Own research
  - 3.1.4 Learning from MHWs
  - 3.1.5 Learning from SWs
  - 3.1.6 MH courses and training
  - 3.1.7 MH education in schools
  - 3.1.8 MH Learning at work
- 3.2 Existing MH knowledge
- 3.3 Desired MH knowledge
  - 3.3.1 General MH information
  - 3.3.2 MH problems
  - 3.3.3 MH self-help
  - 3.3.4 Helping others
  - 3.3.5 Stress management
  - 3.3.6 MH support pathways
  - 3.3.7 MH education for ECPs
- 3.4 Sources of MH information
  - 3.4.1 Online: websites
  - 3.4.2 Online: social media
  - 3.4.3 Traditional
  - 3.4.4 GP
  - 3.4.5 Support Worker
  - 3.4.6 MHW
  - 3.4.7 Interdisciplinary practice
- 3.5 OTHER
  - 3.5.1 COVID-19 MH support info
  - 3.5.2 Missing out on MH info

4. MH help-seeking experience/s
- 4.1 The experience/s
  - 4.1.1 Presenting problem
- 4.2 Expressing concerns/distress
  - 4.2.1 Outward expression
  - 4.2.2 Internalising concerns
  - 4.2.3 Opportunities for expression
  - 4.2.4 Modes of communication
  - 4.2.5 Behaviour changes
  - 4.2.6 Linking diagnosis & emotional expression
  - 4.2.7 Personal attributes (confidence)
- 4.3 CP responses to emotions/ distress/ MH concerns
  - 4.3.1 ECPs noticing expression
  - 4.3.2 Acknowledging expression
  - 4.3.3 ECPs interpreting expression
  - 4.3.4 ECPs acting to support MH
  - 4.3.5 ECP attitudes to emotions
  - 4.3.6 ECP responsiveness
- 4.4 MH service responses
  - 4.4.1 MHW attitudes
  - 4.4.2 MH system working well
- 4.5 Pathways to MH Support
  - 4.5.1 Trajectory of support
  - 4.5.2 Primary support
  - 4.5.3 Specialist MH support
  - 4.5.4 Crisis support
  - 4.5.5 Referrals
- 4.6 OTHER

Thematic Framework – ECP data included.

5. MH support

5.1 Informal supports
5.2 Formal supports (non-MH worker)
  5.2.1 Speechie (SLP)
  5.2.2 GP
  5.2.3 Support Worker (disability)
  5.2.4 Developmental Educator
5.3 Formal supports
  5.3.1 Psychologist
  5.3.2 Psychiatrist
  5.3.3 Counsellor
  5.3.4 Community MH Service
  5.3.5 Hospital
5.4 Therapeutic approaches tried
  5.4.1 CBT
  5.4.2 Expressive disclosure
  5.4.3 Counselling & psychotherapy
  5.4.4 ACT
  5.4.5 Medication
  5.4.6 Music therapy
  5.4.7 PBS
  5.4.8 PBS as MH support
  5.4.9 Other intervention
5.5 Therapeutic approaches of interest
5.6 Coping strategies and self-care
5.7 Satisfaction with formal MH support
5.8 Suggested improvements for formal MH support
5.9 Disability orgs. MH support providers
  5.9.1 Providing primary support
  5.9.2 Organisational culture
  5.9.3 Work practices that support MH
5.10 OTHER
  5.10.1 Pw.CCN as MH supporters

6. MH Access Facilitators

6.1 Facilitating factors
  6.1.1 Human Assistance
  6.1.2 Adequate time
  6.1.3 Timing
  6.1.4 Learn about comm. preferences
  6.1.5 Person centred approach
  6.1.6 Physical access
  6.1.7 Incorporating AAC
  6.1.8 Simplified language
  6.1.9 Easy English/Plain language
  6.1.10 Visual aids
  6.1.11 Recapping
  6.1.12 Feeling understood
  6.1.13 Home visits
  6.1.14 Telehealth
  6.1.15 Holistic approach
  6.1.16 Funding
  6.1.17 Self-advocacy
  6.1.18 Other advocates
  6.1.19 Continuity of supports
  6.1.20 Consent
  6.1.21 ECPs
  6.1.22 MH knowledge
  6.1.23 Reliable AAC
  6.1.24 Persistence of Pw.CCN
  6.1.25 Multi-disciplinary team
  6.1.26 ECP attitudes to MH support
  6.1.27 Customised MH/AAC tools
6.2 OTHER

7. MH access barriers

7.1 Barriers/Challenges
  7.1.1 Poor physical access
  7.1.2 Time constraints
  7.1.3 Funding barriers (non-responsive funding)
  7.1.4 Lack of reliable AAC
  7.1.5 Stigma (attitude barrier)
  7.1.6 Low literacy
  7.1.7 MHW reliance on speech
  7.1.8 Opportunities to give feedback
  7.1.9 Lack of practitioner skills & knowledge
  7.1.10 Motivation
  7.1.11 Few opportunities to discuss emotions and issues relating to MH
  7.1.12 Lacking awareness of MH services
  7.1.13 People didn't understand
  7.1.14 Lack of trusted CPs
  7.1.15 Intervention objectives not agreed.
  7.1.16 ECP attitudes preventing access
  7.1.17 Diagnostic overshadowing
  7.1.18 Delays to support/ support too late
  7.1.19 Lack of referral pathways
  7.1.20 Over-reliance on medication
  7.1.21 Lack of MH practitioners
7.2 OTHER

9. NDIS

9.1 Safeguarding
9.2 Restrictive practices
9.3 Funding
9.4 Responsiveness of NDIS system
9.5 Demonstrating eligibility for support

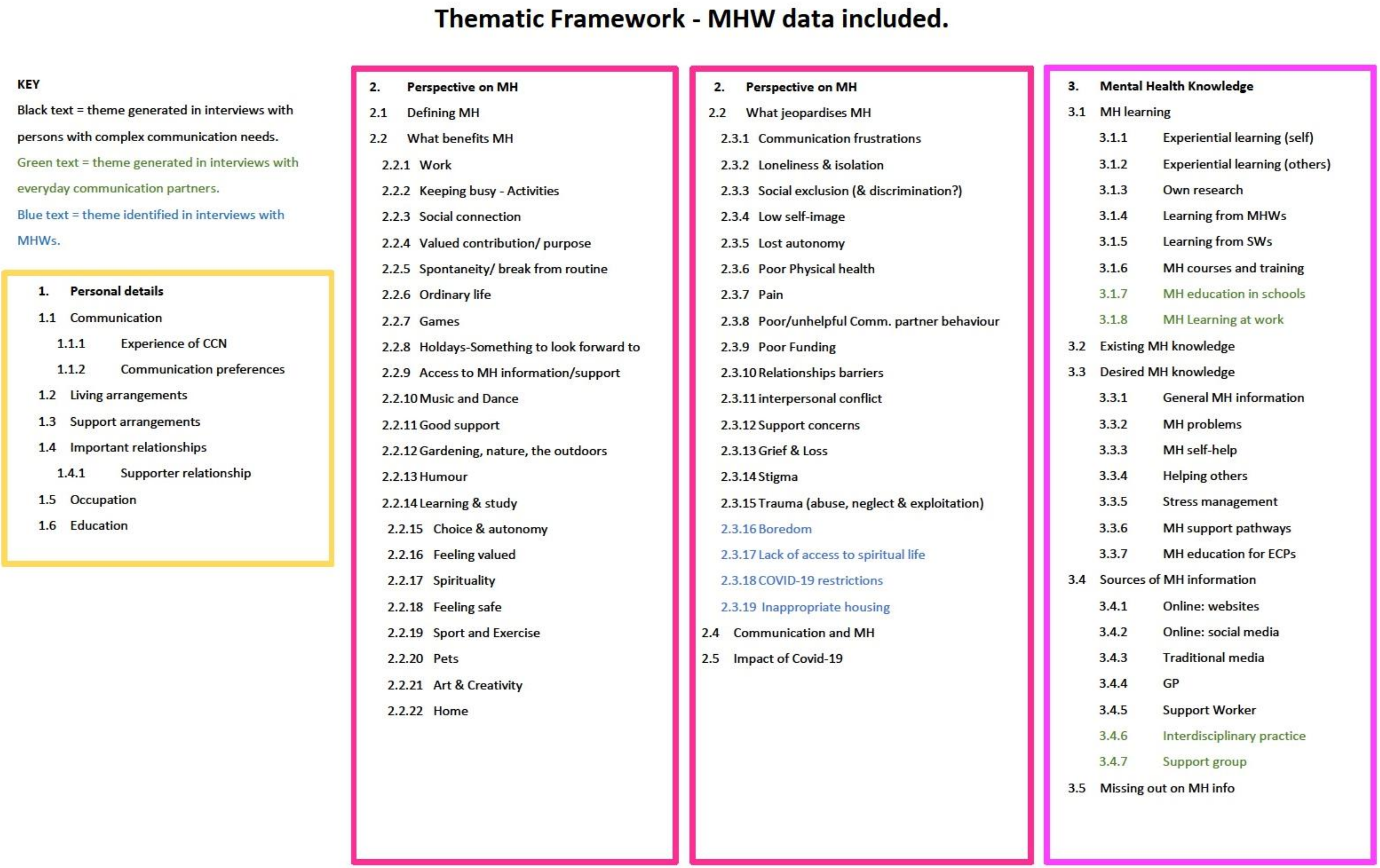
8. ECPs

8.1 Inclusion of ECPs in formal MH support
8.2 The qualities of good MH supporters
  8.2.1 The 'right person' for the job
  8.2.2 Attitudes
  8.2.3 Trust/ Rapport
  8.2.4 'They know me well'
  8.2.5 Persistence
  8.2.6 Providing comfort/safety
  8.2.7 Supporting privacy/ confidentiality
  8.2.8 ECP MH knowledge
  8.2.9 Providing opportunities for MH comm.
  8.2.10 Promoting autonomy
8.3 ECPs as conduits to MH support
  8.3.1 Taking action
  8.3.2 ECPs support at MH interface
  8.3.3 Co-constructing messages
  8.3.4 Collaborative approach
  8.3.5 Maintaining/developing MH vocab
  8.3.6 Support before appointments
  8.3.7 Implementing MH support strategies
8.4 Building the Capacity of ECPs
  8.4.1 Individualised MH information
  8.4.2 Workforce capacity building
8.5 ECP attitudes:
  8.5.1 Behaviour is communication
  8.5.2 Person-centred attitude
8.6 OTHER ECP issues
  8.6.1 Lack of trust with ECPs
  8.6.2 Lack of MH knowledge
  8.6.3 Confidence in discussing MH

10. Other important themes

10.1 Human rights
10.2 System silos

Appendix X: Thematic Framework v.3 Lived Experience, ECP and MHW Data.



Thematic Framework - MHW data included.

KEY

Black text = theme generated in interviews with persons with complex communication needs.

Green text = theme generated in interviews with everyday communication partners.

Blue text = theme identified in interviews with MHWs.

1. Personal details
- 1.1 Communication
  - 1.1.1 Experience of CCN
  - 1.1.2 Communication preferences
- 1.2 Living arrangements
- 1.3 Support arrangements
- 1.4 Important relationships
  - 1.4.1 Supporter relationship
- 1.5 Occupation
- 1.6 Education

2. Perspective on MH
- 2.1 Defining MH
- 2.2 What benefits MH
  - 2.2.1 Work
  - 2.2.2 Keeping busy - Activities
  - 2.2.3 Social connection
  - 2.2.4 Valued contribution/ purpose
  - 2.2.5 Spontaneity/ break from routine
  - 2.2.6 Ordinary life
  - 2.2.7 Games
  - 2.2.8 Holdays-Something to look forward to
  - 2.2.9 Access to MH information/support
  - 2.2.10 Music and Dance
  - 2.2.11 Good support
  - 2.2.12 Gardening, nature, the outdoors
  - 2.2.13 Humour
  - 2.2.14 Learning & study
  - 2.2.15 Choice & autonomy
  - 2.2.16 Feeling valued
  - 2.2.17 Spirituality
  - 2.2.18 Feeling safe
  - 2.2.19 Sport and Exercise
  - 2.2.20 Pets
  - 2.2.21 Art & Creativity
  - 2.2.22 Home

2. Perspective on MH
- 2.2 What jeopardises MH
  - 2.3.1 Communication frustrations
  - 2.3.2 Loneliness & isolation
  - 2.3.3 Social exclusion (& discrimination?)
  - 2.3.4 Low self-image
  - 2.3.5 Lost autonomy
  - 2.3.6 Poor Physical health
  - 2.3.7 Pain
  - 2.3.8 Poor/unhelpful Comm. partner behaviour
  - 2.3.9 Poor Funding
  - 2.3.10 Relationships barriers
  - 2.3.11 interpersonal conflict
  - 2.3.12 Support concerns
  - 2.3.13 Grief & Loss
  - 2.3.14 Stigma
  - 2.3.15 Trauma (abuse, neglect & exploitation)
  - 2.3.16 Boredom
  - 2.3.17 Lack of access to spiritual life
  - 2.3.18 COVID-19 restrictions
  - 2.3.19 Inappropriate housing
- 2.4 Communication and MH
- 2.5 Impact of Covid-19

3. Mental Health Knowledge
- 3.1 MH learning
  - 3.1.1 Experiential learning (self)
  - 3.1.2 Experiential learning (others)
  - 3.1.3 Own research
  - 3.1.4 Learning from MHWs
  - 3.1.5 Learning from SWs
  - 3.1.6 MH courses and training
  - 3.1.7 MH education in schools
  - 3.1.8 MH Learning at work
- 3.2 Existing MH knowledge
- 3.3 Desired MH knowledge
  - 3.3.1 General MH information
  - 3.3.2 MH problems
  - 3.3.3 MH self-help
  - 3.3.4 Helping others
  - 3.3.5 Stress management
  - 3.3.6 MH support pathways
  - 3.3.7 MH education for ECPs
- 3.4 Sources of MH information
  - 3.4.1 Online: websites
  - 3.4.2 Online: social media
  - 3.4.3 Traditional media
  - 3.4.4 GP
  - 3.4.5 Support Worker
  - 3.4.6 Interdisciplinary practice
  - 3.4.7 Support group
- 3.5 Missing out on MH info

Thematic Framework - MHW data included.

4. MH help-seeking experience/s

- 4.1 The experience/s
  - 4.1.1 Presenting problem
- 4.2 Expressing concerns/distress
  - 4.2.1 Outward expression
  - 4.2.2 Internalising concerns
  - 4.2.3 Opportunities for expression
  - 4.2.4 Modes of communication
  - 4.2.5 Behaviour changes
  - 4.2.6 Linking diagnosis & emotional expression
  - 4.2.7 Personal attributes (confidence)
  - 4.2.8 Behaviour and perceived risk
- 4.3 CP responses to emotions/ distress/ MH concerns
  - 4.3.1 ECPs noticing expression
  - 4.3.2 Acknowledging expression
  - 4.3.3 ECPs interpreting expression
  - 4.3.4 ECPs acting to support MH
  - 4.3.5 ECP attitudes to emotions
  - 4.3.6 ECP responsiveness
- 4.4 Referrals & support pathways
- 4.5 Trajectory of support

5. MH support

- 5.1 Informal supports
- 5.2 Formal supports (non-MH worker)
  - 5.2.1 Speechie (SLP)
  - 5.2.2 GP
  - 5.2.3 Support Worker (disability)
  - 5.2.4 Developmental Educator
  - 5.2.5 Support coordinator
  - 5.2.6 PBS practitioner
- 5.3 Formal supports (MH workers)
  - 5.3.1 Psychologist
  - 5.3.2 Psychiatrist
  - 5.3.3 Counsellor
  - 5.3.4 MH Peer-Worker
  - 5.3.5 Community MH Service
  - 5.3.6 Hospital & Crisis
  - 5.3.7 Social worker
  - 5.3.8 MH Groups Facilitator
  - 5.3.9 Mental Health Nurse
- 5.4 Therapeutic approaches tried
  - 5.4.1 CBT
  - 5.4.2 Expressive disclosure
  - 5.4.3 Counselling & psychotherapy
  - 5.4.4 ACT
  - 5.4.5 Medication
  - 5.4.6 Music therapy
  - 5.4.7 PBS
  - 5.4.8 PBS as MH support
  - 5.4.9 Anger Management
  - 5.4.10 Mindfulness, MBSR
  - 5.4.11 MHFA – MH literacy
  - 5.4.12 Group interventions
  - 5.4.13 Other intervention
- 5.5 Therapeutic approaches of interest
- 5.6 Coping strategies and self-care
- 5.7 Satisfaction with MH support
- 5.8 Suggested improvements MH support
- 5.9 Disability orgs. MH support providers
  - 5.9.1 Providing primary support
  - 5.9.2 Organisational culture
  - 5.9.3 Work practices that support MH
- 5.10 The MH Support System **(Check this)**
  - 5.10.1 MH system working well (from 4.4.2)
  - 5.10.2 System silos (Moved from 10.2)
  - 5.10.3 MH/Dis. services culture clash
- 5.11 Pw.CCN as MH supporters

6. MH Access Facilitators

- 6.1 Facilitating factors
  - 6.1.1 Human Assistance
  - 6.1.2 Adequate time
  - 6.1.3 MHW CP Skills
  - 6.1.4 Learn about comm. preferences
  - 6.1.5 Person centred approach
  - 6.1.6 Physical access
  - 6.1.7 Incorporating AAC
  - 6.1.8 Simplified language
  - 6.1.9 Accessible written information
  - 6.1.10 Visual aids
  - 6.1.11 Recapping
  - 6.1.12 Feeling understood
  - 6.1.13 Home visits
  - 6.1.14 Telehealth
  - 6.1.15 Holistic approach
  - 6.1.16 Funding
  - 6.1.17 Self-advocacy
  - 6.1.18 Other advocates
  - 6.1.19 Continuity of supports
  - 6.1.20 Consent
  - 6.1.21 ECPs as conduits
  - 6.1.22 MH knowledge
  - 6.1.23 Relevant resources
  - 6.1.24 Reliable AAC
  - 6.1.25 Persistence of Pw.CCN
  - 6.1.26 Multi-disciplinary team
  - 6.1.27 ECP attitudes to MH support
  - 6.1.28 Customised MH/AAC tools
  - 6.1.29 Responsive ECPs
  - 6.1.30 Assuming capacity for MH support
  - 6.1.31 Teaching strategies
  - 6.1.32 Examining behaviour
  - 6.1.33 Collaborative approach (w. ECPs)
  - 6.1.34 Good rapport
  - 6.1.35 Referrals process
  - 6.1.36 MH + Dis system collaboration
  - 6.1.37 Opportunities to discuss MH
  - 6.1.38 Appropriate diagnostic tools

7. MH access barriers

- 7.1 Barriers/Challenges
  - 7.1.1 Poor physical access
  - 7.1.2 Time constraints
  - 7.1.3 Funding barriers (non-responsive funding)
  - 7.1.4 Lack of reliable AAC
  - 7.1.5 Stigma (attitude barrier)
  - 7.1.6 Low literacy
  - 7.1.7 MHW reliance on speech
  - 7.1.8 Lack of Opportunities to give feedback
  - 7.1.9 Lack of practitioner skills & knowledge
  - 7.1.10 Low motivation
  - 7.1.11 Few opportunities to discuss MH
  - 7.1.12 Lacking awareness of MH services
  - 7.1.13 People didn't understand
  - 7.1.14 Lack of trusted CPs
  - 7.1.15 Intervention objectives not agreed.
  - 7.1.16 ECP attitudes preventing access
  - 7.1.17 Diagnostic overshadowing
  - 7.1.18 Delays to support/ support too late
  - 7.1.19 Lack of referral pathways
  - 7.1.20 Over-reliance on medication
  - 7.1.21 Lack of MH practitioners
  - 7.1.22 Barriers to diagnosis
  - 7.1.23 Perceived complexity
  - 7.1.24 Exclusion PwD by the MH system
  - 7.1.25 Lack of accessible written information
  - 7.1.26 Misconceptions about capacity
  - 7.1.27 Lack of CP skills
  - 7.1.28 Lack of Rapport
  - 7.1.29 ECPs not included/respected
  - 7.1.30 Prioritisation of physical health
  - 7.1.31 Substitute decision makers
  - 7.1.32 Lost histories

Thematic Framework - MHW data included.

8. ECPs

- 8.1 Inclusion of ECPs in formal MH support
- 8.2 The qualities of good MH supporters
  - 8.2.1 The 'right person' for the job
  - 8.2.2 Attitudes
  - 8.2.3 Trust/ Rapport
  - 8.2.4 'They know me well'
  - 8.2.5 Persistence
  - 8.2.6 Providing comfort/safety
  - 8.2.7 Supporting privacy/ confidentiality
  - 8.2.8 ECP MH knowledge
  - 8.2.9 Providing opportunities for MH comm.
  - 8.2.10 Promoting autonomy
- 8.3 ECPs as conduits to MH support
  - 8.3.1 Taking action
  - 8.3.2 ECPs support at MH interface
  - 8.3.3 Co-constructing messages (scaffolding)
  - 8.3.4 Collaborative approach
  - 8.3.5 Maintaining/developing MH vocab
  - 8.3.6 Support before appointments
  - 8.3.7 Implementing MH support strategies
  - 8.3.8 Preparing for appointments
  - 8.3.9 Documenting
- 8.4 Building the Capacity of ECPs
  - 8.4.1 Individualised MH information
  - 8.4.2 Workforce capacity building
  - 8.4.3 Developing MH literacy of ECPs
  - 8.4.4 ECP self-care
- 8.5 ECP attitudes:
  - 8.5.1 Behaviour is communication
  - 8.5.2 Person-centred attitude
  - 8.5.3 Assumptions about capacity
- 8.6 Lack of MH knowledge
- 8.7 Confidence in discussing MH
- 8.8 ECP concept of the MH supporter role
- 8.9 OTHER critical ECP issues

9. MHWs

- 9.1 MHW Experiences
  - 9.1.1 Of working with Pw.CCN
  - 9.1.2 Of comm. diversity
  - 9.1.3 Of including ECPs
  - 9.1.4 Diverse work experience
  - 9.1.5 Access challenges
- 9.2 MHW Attitudes
  - 9.2.1 Capacity of Pw.CCN
  - 9.2.2 Recognition of personhood
  - 9.2.3 Person-centred attitude
  - 9.2.4 Confidence in working with Pw. CCN
  - 9.2.5 Openness to comm. diversity
  - 9.2.6 Perception of complexity
  - 9.2.7 To the inclusion of ECPs
  - 9.2.8 Behaviour as communication
- 9.3 MHW Skills
  - 9.3.1 CP skills
  - 9.3.2 Adjusting communication
  - 9.3.3 Personalising intervention
  - 9.3.4 Rapport building
  - 9.3.5 Using MM comm strategies
- 9.4 MHW Knowledge
  - 9.4.1 MHW qualifications, courses, trainings
  - 9.4.2 About Pw.CCN
  - 9.4.3 Comm. access strategies
  - 9.4.4 About MH & Disability/CCN
  - 9.4.5 Knowledge from experience
  - 9.4.6 Knowledge from other practitioners
  - 9.4.7 Navigating the MH system
  - 9.4.8 Desired knowledge
  - 9.4.9 MHW resources
  - 9.4.10 Generating knowledge
- 9.5 Recommended access strategies
  - 9.5.1 Accessible resources
  - 9.5.2 Strategic closed questions
  - 9.5.3 Observing communication strategies
  - 9.5.4 Assessment & collateral information
  - 9.5.5 CP skills
- 9.6 MHW understanding of the experience of CCN

9. NDIS

- 10.1 Safeguarding
- 10.2 Restrictive practices
  - 10.2.1 Reducing use of medical restraint
- 10.3 Funding
  - 10.3.1 Appealing to MHWs
  - 10.3.2 Security (safe funding)
- 10.4 Responsiveness of NDIS system
- 10.5 Demonstrating eligibility for support
- 10.6 NDIS closing the gap Dis. and MH supports.
  - 10.6.1 Co-location of services
  - 10.6.2 Support Coordinators know Dis/MH
  - 10.6.3 MHWs doing PBS
  - 10.6.4 NDIS training for MHWs
- 10.7 Compliance measures
  - 10.7.1 Bureaucracy/ paperwork
  - 10.7.2 Safety v innovation