NDIS Participants with Psychosocial Disabilities: Investigating their Formal Supports Following a Life-Limiting Diagnosis

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CONTENTS

ABSTRACT

The National Disability Insurance Scheme (NDIS) has supported Australians with disabilities for almost a decade. Approximately 4.4 million Australians live with disabilities. Projections indicate the number of NDIS participants will reach 1,030,337, with 86,712 participants with primary psychosocial disabilities (PwPDs) being supported by the NDIS by 2033. To ensure the sustainability of the NDIS, Australian Governments have agreed that where services are best funded under universal service obligations or via another service system, such as health or mental health, the NDIS will not fund those supports. However, there is an expectation that NDIS participants will be supported seamlessly across service systems. The Applied Principles and Tables of Support (APTOS) loosely describe these agreements and responsibilities.

Many NDIS participants are likely to be diagnosed with life-limiting conditions necessitating support from multiple systems, particularly within the health, mental health and disability sectors. This research found that there has been limited exploration of how formal support systems plan to assist NDIS participants once they develop life-limiting conditions, particularly those without pre-existing physical disabilities. There is substantial confusion in the disability, mental health and health sectors about how to support PwPDs when they experience functional declines associated with life-limiting conditions, and the NDIS has created a more complex end-of-life experience for them.

This research’s significant and original contribution to knowledge is its detailed analysis of the types of support that formal systems currently provide PwPDs and life-limiting conditions, whether the support ensures equity and seamlessness between systems, and identifies the gaps and barriers that are likely to impact their experiences as they are dying. Further, this research highlights the specific support that PwPDs and their informal and formal supports feel will be necessary to improve their end-of-life experiences. This research exposes the nationwide cross-sector confusion about applying the APTOS. Finally, the research findings regarding the gaps between systems, barriers to optimal support during life stages, and issues regarding the marketisation of disability support created by the NDIS should inform policymakers internationally as they consider introducing more person-centred approaches to disability support.

Health and human services within Australia are siloed, and the NDIS has created another silo for participants to navigate. Additionally, while positive experiences were reported, there is an over-reliance on advocacy and the goodwill of the workforce; positive outcomes are “a happy accident”. The research found inequity in support around life-limiting conditions and substantial gaps between systems. NDIS does not fund case conferencing for most NDIS participants, contributing significantly to the gaps and barriers experienced by PwPDs. Research interviewees also reported significant issues with the quality of NDIS supports and nefarious NDIS providers.

The National Disability Insurance Agency communicates poorly with PwPDs and their informal and formal supports, lacks transparency and provides inconsistent planning outcomes. There is limited understanding of and significant confusion and divergent opinions about what supports each system offers and why. The guidance found in the APTOS regarding system responsibilities is unclear, leading to potential and actual poor outcomes for PwPDs and life-limiting conditions. In line with the recent *NDIS Review: Working together to deliver the NDIS*, this research recommended that the APTOS be replaced, and Australian governments should enter into new agreements where each system's funded supports should be clearly mapped, including the Review's proposed foundational supports. Additional recommendations include case-management funding in NDIS plans, particularly following diagnoses of life-limiting conditions, capability uplift across all systems, and trusted worker portability to ensure that PwPDs have end-of-life experiences not vitiated by poor communication and gaps between systems.

ORIGINAL OUTPUT ARISING FROM THIS THESIS

Research Presentation to the Department of Social Services

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Publications and Statements of Contributions

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This publication is included within this Thesis in Chapter 2 – Scoping Review. Co-authorship approvals for the HDR Thesis Examination can be found in Appendix 3.

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Authors: Boschen, K.

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Link: https://theconversation.com/the-ndis-promises-lifelong-support-but-what-about-end-of-life-support-for-people-with-disability-199990

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Authors: Boschen, K. Phelan, C.

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Contribution: K.B., C.P. writing—original draft preparation, K.B.; writing—review and editing, K.B., C.P. Both authors read and agreed to the published version of the manuscript.

Link: https://theconversation.com/brain-tumours-can-bring-long-term-disability-but-some-diagnosed-are-being-refused-ndis-support-216534

I, Professor Sharon Lawn, certify that the student statements regarding their contributions to each of the PhD thesis chapters and related publications are correct.

Primary PhD Supervisor: ***Sharon Lawn*** ***Date: 26th August 2024***

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....... Katherine Boschen....

Date.........28 August 2024...

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GLOSSARY OF TERMS

Throughout this thesis, the language and terminology used to describe individuals with disabilities and mental health conditions have been carefully chosen to be respectful, incorporating either person-first or identity-first language based on the preferences of the individuals or the communities in which they identify. The language surrounding disability and mental health is fluid, and both its usage and understanding have evolved throughout the research, with expectations of further change. At the heart of this study are participants of the National Disability Insurance Scheme (NDIS) with psychosocial disabilities. While acronyms are generally discouraged, due to the size of the thesis, the abbreviation "PwPD" (Participants with Psychosocial Disabilities) has been used for ease of reading.

Term	Guide
Australian Governments	Commonwealth, State and Territory Governments of Australia
Agency	The National Disability Insurance Agency
Applied Principles and Tables of Support (APTOS)	The general principles agreed upon by Australian Governments and the tables that outline each service system's responsibilities. • Health • Mental health • Early childhood development • Child protection and family support • School education • Higher education and Vocational Education and Training (VET • Employment • Housing and community infrastructure • Transport • Justice • Aged care

Term	Guide
End of Life (EOL) care	End-of-life care is health care for people nearing the end of their lives, the advanced stage of a terminal illness.
Formal Supports	Any funded support provided to people with disabilities from either the NDIS or other service system; health, mental health, early childhood development, child protection and family support, school education, higher education and VET, employment, housing and community infrastructure, transport, justice and aged care.
Gaps (System Gaps)	Gaps are the difference between the desired and current state of service delivery within and across systems.
ILO (Independent Living Options)	An NDIS package of supports (similar to Supported Independent Living) allows participants to live in homes of their choosing outside of Specialist Disability Accommodation.
Informal Supports	Carers, family and friends that do not receive specific disability funding to support an NDIS Participant. They may receive a carer's payment from Centrelink.
IS Interviewees	Informal supports that have been interviewed for this research.
Life limiting illness	Chronic diseases or conditions that cannot be cured and results in terminal diagnoses.
Local Area Coordinators (LAC/Partners)	• Assist with access and information about the NDIS. • Work with local communities around accessibility and inclusion. • Assist people with disabilities (NDIS and others) connect to non-NDIS funded supports in the community. • Develop NDIS Plans with NDIS Participants (An NDIS Planner [delegate] must approve NDIS Plans)

Term	Guide
Mainstream supports	Formal supports not funded by the NDIS.
Mental Health System	Commonwealth, State and Territory funded community mental health care services [1].
Mental Health Clinicians	Psychiatrists, psychologists, occupational therapists, social workers and mental health nurses working in defined roles in the state or territory health systems can work in acute hospital settings, residential treatment facilities, forensic mental health facilities, and community mental health programmes. These may be delivered directly or outsourced to non-government or for-profit organisations.
MH Clinicians	Mental health clinicians who have been interviewed for this research.
Mental Health Workers	Mental health workers are often certificate-trained professionals but can also include graduates, and undergraduate or postgraduate students. They usually work in community mental health programmes and are usually outsourced to non-government or for-profit organisations. The state and territory governments may deliver the services directly in rural and remote areas where no other organisations exist.
National Disability Insurance Agency	Commonwealth government department that administers the NDIS. It holds all funds contributed by Australian Governments, manages access to the scheme and approves the payment of individual support plans and fraud matters.
National Disability Insurance Scheme (NDIS)	Australian Government funding for individualised disability supports for Australians with severe and enduring functional impairment brought about disabilities and psychiatric conditions.

Term	Guide
NDIS Participants	Australian citizens with a disability who received individual funding for disability supports from the NDIS
NDIS Plan	A statement of an NDIS Participant’s goals and aspirations and linked allocated funds for participants to purchase NDIS funded supports to meet their goals. Outlined in Chapter 3, Part 2 of the NDIS Act (2013).
NDIS Planner	Directly employed by the NDIA and prepare NDIS Plans – usually for NDIS Participants with more complex support needs. Have delegation to approve NDIS Plans.
NDIS Quality and Safeguards Commission (NDIS Commission)	An independent agency tasked to ensure the quality and safety of NDIS supports and services: regulates NDIS providers and provides oversight on restrictive practices, behaviour support, and reportable incidents. Also, it manages complaints against NDIS providers and has compliance and investigations functions.
NDIS Support Worker	Workers who provide direct support to NDIS Participants and are funded by NDIS.
NGO (Non-Government Organisation)	A non-profit organisation that Australian governments usually fund; they report to, but operate independently of government.
Palliative Care	Interdisciplinary approach to care aimed at optimising the quality of life and reducing suffering for people with life-limiting conditions
Palliative Care Clinicians	Psychiatrists, psychologists, occupational therapists, social workers and palliative care nurses working in defined roles in the state or territory health systems can work in hospice, hospital, and community settings. These may be delivered directly or outsourced to non-government or for-profit organisations.

Term	Guide
PC Clinicians	Palliative care clinicians who have been interviewed for this research.
Psychosocial Disability	Diagnosis of a significant mental disorder that results in a significant reduction in function for a person's lifetime and where supports are best funded by the NDIS and not other services systems. Meets the requirement of Section 21 of the NDIS Act (2013).
Participants with psychosocial disabilities (PwPDs)	NDIS participants with a primary disability that is an enduring and severe psychiatric condition that causes substantial functional impairment.
PwPD Interviewee	NDIS participants with psychosocial disabilities interviewed for this research
PR Interviewee	An NDIS worker, manager, or NDIS provider business owner who was interviewed for this research.
Registered NDIS Provider (Registered Provider)	A provider that has passed a quality audit against the NDIS Practice standards; has been registered by the NDIS Quality and Safeguards Commission can provide all types of supports to NDIS Participants on approval.
Research Cohort	Research interviewees that participated in this research 1. NDIS Participants with primary psychosocial disabilities. 2. Informal supports of NDIS Participants with primary psychosocial disabilities. 3. Mainstream Mental Health Providers 4. Palliative Care providers, 5. NDIS Providers.

Term	Guide
Research interviewees	Any person who has been interviewed for this research from any or all of the cohorts interviewed. As the word “participant” is used to describe people with disabilities that receive NDIS funding, the word “interviewee” has been used to avoid confusion.
Scheme	The National Disability Insurance Scheme
SDA (Specialist Disability Accommodation)	Specialist disability accommodation (SDA) is a specific housing designed for people with extreme functional impairment or very high support needs.
SIL (Supported Independent Living)	In-home support for people with extreme functional impairment and usually provided in specialist disability accommodation and, commonly within a group housing setting with other NDIS Participants.
Silo (System Silo)	Boundaries that arise between the health and human services systems that support Australians. These silos and boundaries often evolve due to government funding allocations.
Specialist Support Coordinator	A capacity-building support funded by the NDIS that can assist NDIS Participants with complex support needs to connect with both NDIS and other support systems. Must be working as or for a registered NDIS Provider and demonstrate an appropriate qualification or experience to the NDIS Quality and Safeguards Commission.
SPMI and SMI	Serious and persistent mental illness - diagnosis of a significant mental disorder, disability and duration for longer than two years.
Support Coordinator	A capacity-building support funded by the NDIS that can assist NDIS Participants to connect with both NDIS and other support

Term	Guide
	systems. No qualifications or registration is required unless the NDIS Participant is agency-managed.
SRF or SRS	Usually, a for-profit facility that is chiefly funded by participants' disability support pensions. They may receive a stipend from local councils and, at times, NDIS or aged care funding. These are often called boarding houses and may also have residents who do not have NDIS or aged care funding.
Unregistered NDIS Provider (Unregistered Provider)	An NDIS provider that is not registered by the NDIS Qualit and Safeguards Commission. These providers can provide support to self-managed and plan-managed participants who do not require restrictive practice in their supports. Unregistered providers cannot offer high risk supports, specialist disability accommodation (SDA) supports.

CHAPTER 1 – INTRODUCTION AND BACKGROUND

1.1 Introduction

Introduced in 2013, the National Disability Insurance Scheme (NDIS) is a world-first, once-in-a-generation reform to Australia's disability sector [2]. There are approximately 4.4 million people in Australia living with disabilities [3], and as of June 2023, the NDIS was supporting 610,502 participants with a total estimated expenditure in 2022-2023 of $36.7 billion. By 2033, the NDIS is projected to support an estimated 1,030,337 NDIS participants, and approximately 86,712 (8.4%) will enter the Scheme with a primary psychosocial disability (predominantly related to severe and persistent mental illness) [4]. These projections have fluctuated significantly since the introduction of the NDIS, ranging from the 2018 [5] prediction of 716,800 total NDIS participants by 2045 and the 2023 prediction of 102,026 NDIS participants with psychosocial disabilities (PwPDs) by 2032 [6]. Australians with disabilities whom the NDIS does not support may receive support from the aged care system or state health systems, or they may receive limited or no support as their functional impairments may not meet the threshold for support from the NDIS (as outlined and interpreted in Section 24 of the NDIS Act (2013)[7]). To ensure the sustainability of the NDIS, the Commonwealth Government and the six state and two territory governments have agreed that where services are best funded under another service system, such as health or mental health, the NDIS will not fund those supports. However, there is an expectation that the NDIS will support participants seamlessly across service systems [8].

There has been little consideration about how formal support systems intend to support NDIS participants who receive life-limiting diagnoses [9-12]. It is essential to understand whether the current service models around NDIS participants with life-limiting conditions must support them and ensure quality of life and optimal care and outcomes. Most NDIS participants do not have primary physical disabilities. Of the 649,623 NDIS participants in the third quarter of the 23/24 financial year, there were 232,646 NDIS participants with autism spectrum disorder, 96,048 children with developmental delays, 90,945 participants with intellectual disabilities and 63,469 PwPDs [13]. As the National Disability Insurance Agency (NDIA) only discloses participants' primary disabilities and does not publish data about any additional disabilities supported by the NDIS, a complete support picture cannot be investigated. However, if NDIS participants do not have a physical disability that requires functional supports, such as personal or intimate care and equipment for mobility, they are unlikely to have these supports funded by the NDIS if they develop life-limiting conditions.

Around 80% of people who die in Australia are aged over 65 [14]. Therefore, palliative care programmes and support are usually geared towards the over-65's. However, people with severe and persistent mental illnesses often die up to 20 years sooner than the average [15-23]. Further, there is a paucity of research into the death, dying and palliative care experiences of people living with severe and persistent mental illness [15, 24-34]. The limited research shows that people with psychosocial disabilities experience stigmatising, siloed, disjointed systems and substantial gaps in their supports. Therefore, these issues are amplified when they are dying, and their end-of-life (EOL) experiences are typically bleak and inequitable [26, 27, 31, 35-38]. System silos are boundaries that arise between the health and human services systems that support Australians that evolve from government funding allocations. Gaps are the difference between the desired and current state of service delivery within and across systems. This research's significant and original contribution to knowledge will be the exploration of the systems that support NDIS participants with primary psychosocial disabilities who receive a life-limiting diagnosis. The research will seek to understand whether the NDIS creates a more equitable end-of-life experience or further complicates it by simply adding another silo to navigate.

The NDIS and its impact on the Australian disability community and other systems within the country is, as revealed by this research, a rapidly changing phenomenon. Therefore, it is important to highlight that the thesis's information is current as of the 23rd of July, 2024.

1.2 Background – The Disability Landscape in Australia

Prior to the introduction of the NDIS, disability services were delivered very differently and inequitably across the six states and two territories; where people with disabilities lived determined the kinds of support that they would receive. The state and territory governments (hereafter state governments) funded the majority of disability support, with the balance being funded by the Commonwealth Government. Most supports were directly provided by the state government or outsourced to local governments, not-for-profit and for-profit organisations. Services were block-funded, grants were awarded for pre-determined services, and disability service providers had to meet certain conditions and win tenders to deliver them. There were some limited individualised funding options available prior to the introduction of the NDIS [39].

1.2.1 The United Nations Convention on the Rights of Persons with Disabilities

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was adopted on the 13th of December 2006. Australia ratified the UNCRPD on the 17th of July 2008, and it entered into force on the 16th of August 2008. The Optional Protocol, which includes inquiry and complaints procedures, was enacted in 2009 [40]. Article 1 of the UNCRPD states that its purpose is to:

> *"…promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. " [41]*

Whilst Australia became one of the original signatories of the UNCRPD, and the NDIS is underpinned by it, the United Nations reported in 2019 [42] that there are significant concerns about Australia not meeting its obligations. These include the complex NDIS access process, a heavy reliance on the medical model of disability, the lack of provision for older persons with disabilities and people with psychosocial disabilities and the lack of advocacy programmes. Further, the report noted that people with disabilities, including psychosocial disabilities, often live below the poverty line and are:

> *"… in significantly poorer health and have less access to information and adequate, affordable and accessible health services and equipment" [42]*

1.2.2. Grassroots Action, the National Disability Strategy and the Productivity Commission Inquiry

In 2011, Every Australian Counts, a grassroots campaign consisting of Australians with disabilities and their informal and formal supports, was formed, and it fought to introduce a fairer disability support system [43]. The National Disability Strategy 2010-2020 [44] was also released in 2011, and it was a commitment from all governments (at that time called the Council of Australian Governments (COAG), which was later replaced by National Cabinet in 2020) for a unified approach and shared responsibility to support Australians with disabilities that worked toward:

> *"...an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens."* [44 p. 8]

The purpose of the Disability Strategy was to guide mainstream and disability-specific high-level policy, improve the performance of mainstream services, highlight disability issues and provide leadership on greater disability inclusion. The Strategy's policy areas include inclusive and accessible communities, protection of rights, justice and legislation, economic security, personal and community support, learning and skills and health and wellbeing [44 p. 10]. The Disability Strategy acknowledged that people with disabilities have poor health outcomes and looked to improve disability education within the health sector. The next iteration of the National Disability Strategy, 2021-2031, was launched in December 2021, with a stronger policy focus on housing, safety, employment and community attitudes and a view to health promotion and early health interventions [45].

In that same year, the Australian Productivity Commission (PC) released its Inquiry into Disability Care and Support, which reported that the existing service systems were “*inequitable, unfair, fragmented, and inefficient*” [46 p. 5]. The PC is a Commonwealth Government-funded “*independent research and advisory body*” [47] that proports to be apolitical; however, this assertion has been contested [48, 49]. The PC recommended, in line with Australia’s obligations under the UNCRPD, that the NDIS be created, with its primary function being to fund long-term, high-quality support for approximately 410,000 Australians (p. 2) who acquired their disabilities before they reach the “*age pension age”* [46 p. 14]. (Age pension eligibility in Australia was raised to 67 on the 1st of July 2023; however, the NDIS and the aged care system still use the age 65 as a delimiter.) The PC envisioned a more inclusive society and a broader ecosystem of supports for people with disabilities from university mainstream and community services that would lessen the need for individual support.

The NDIS, as envisaged by the PC, would be the assessor and the funder of supports, but the provision of care would be outsourced to disability providers that included:

> *“non-government organisations, disability service organisations, state and territory disability service providers, individuals and mainstream businesses”* [46 p. 2]

People with disabilities would have increased choices in their supports and care providers. Further, the PC recommended that the NDIS should not be means tested [46 p. 22] and should use an insurance model where a long-term view of support was taken, that there would be an emphasis on early intervention to improve function and minimise future costs “*spend dollars to save dollars*” [46 p.11]. Advocacy would be funded outside of the NDIS. The PC included functional support for people with psychosocial disabilities, noting that clinical services should continue to be received through the mental health system [46 p. 26 – 27].

1.2.3. National Disability Insurance Scheme

COAG negotiated the National Disability Insurance Act (2013), and it was passed through the houses of parliament with bi-partisan support on the 21st of March 2013. Not without significant debate regarding funding, the Scheme was rolled out in stages from 2013 and was available to all Australians on the 1st of July 2020 [50]. The NDIA administers the NDIS, and the NDIS funds functional supports related to the disabilities accepted by the NDIA.

To gain access to the NDIS, a person must be under 65 (Section 22) and an Australian citizen, a permanent resident, or a special category visa holder (Section 23). Section 24 of the NDIS Act (2013) [7] states that applicants must:

1. have a disability that is either psychological, intellectual, cognitive, neurological, sensory or physical, and
2. have a permanent disability, and
   (Proving permanence of disability is a significant issue for applicants to the NDIS, particularly for people with psychosocial disabilities, due to the fluctuating nature of mental illness and the use of recovery language in the mental health system.)
3. demonstrate that the impairment(s) must impact their function substantially in one or more of the following: communication, social interaction, learning, mobility (for example, the use of arms and legs), self-care or self-management, and
   (Substantial impact must be demonstrated in each domain, and impacts cannot be cumulated across the domains to meet the requirement of substantial functional impairment.)
4. demonstrate that their impairments affect their capacity for social or economic participation, and
5. the person is likely to require the support of the NDIS for their lifetime.
   (This eligibility requirement can refer to someone's functional impairment improving over time or can be used to indicate that the responsibility of their care falls under the domain of another service system).

There is also recognition within Section 24 that impairments may be episodic, can fluctuate and vary in intensity, and this does not preclude them from accessing the Scheme. It is important to note that many NDIS participants have multiple disabilities, but not all of them will be supported by the NDIS. For example, if a person has chronic back pain and a psychosocial disability, they must prove that both conditions meet the access criteria set out by Sections 24 and 25 of the NDIS Act (2013) [7]. If the psychosocial disability is assessed as meeting the access criteria but the chronic back pain does not, supports, such as physiotherapy or equipment for the back pain, will not be funded by the NDIS.

For this thesis, only Section 24 will be referred to when discussing access to the NDIS. Section 25 refers to early intervention access, and COAG agreed that the mental health systems across the country would retain carriage of mental health early intervention [8 p. 7].

The NDIS Quality and Safeguards Commission, the independent statutory body that regulates the quality and safeguards of NDIS supports and services, was introduced in 2018 and has supported all NDIS participants since the 1st of July 2020 [51].

The NDIS has been subject to multiple reviews and inquiries since its inception, with the first on the capabilities of the NDIA published in January 2014 [50] and the most recent comprehensive review of the NDIS published in December 2023 [52]. The reviews have included issues regarding costs, workforce, and participant experiences. The Joint Standing Committee on the NDIS was established in December 2013, and as well as discussing general issues, it has completed 21 specific inquiries on issues; the last inquiry explicitly focussed on PwPDs and was completed on the 15th of August 2017 [53].

The NDIS Review, *Working together to deliver the NDIS*, made 26 recommendations with 139 supporting actions [52]. This review instigated the *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024* [54], which was introduced on the 27th of March 2024 and received 205 submissions from individuals, providers and governments, is on its third reading and is before the Senate at the time of writing.

1.2.4. Psychosocial Disabilities and the NDIS

Approximately one in five Australians has a mental illness at some point in their lives [55], and it is estimated that 1.1 million Australians live with psychosocial disability [56]. Of those 1.1 million, approximately 86,712 (8.4%) [4] will enter the Scheme with a primary psychosocial disability, though many people with other disability types will have co-occurring psychosocial disabilities [56]. The NDIS was not initially intended to support Australians with psychosocial disabilities; however, with grassroots advocacy, it was agreed that the NDIS could support some Australians with SPMI, and this is seen as a recognition that, for some, SPMIs can cause substantial functional impairment. The inclusion of PwPDs was seen as an opportunity to offer greater support, choice and control. However, NDIS support for psychosocial disabilities has not always been successful [52, 57-61], with the misalignment of the recovery model of mental health and the deficits model of the NDIS. There are substantial issues with access and planning, and the NDIA staff and NDIS workforce do not have the appropriate training and skills to work with PwPDs, and there is fragmented and inadequate support outside the NDIS.

1.2.5. The Applied Principles and Tables of Support to Determine the Responsibilities of the NDIS and Other Service Systems

In 2013, the COAG entered into agreements regarding the responsibilities of the NDIS and other systems. On the 27th of November 2015, the Applied Principles and Tables of Support to Determine the Responsibilities of the NDIS and Other Service Systems (APTOS) [8] was published. This 26-page document provides loose guidance about the supports the NDIS will fund and which supports are the responsibility of other systems, which includes: health, mental health, early childhood development, child protection and family support, school education, higher education and Vocational Education and Training (VET), employment, housing and community infrastructure, transport, justice and aged care. There has never been any clarity or detail regarding specific supports, which has created significant issues within each system.

Particular sections of APTOS that are pertinent to this research are:

Palliative Care

With regard to palliative care, the following are the statements concerning the responsibilities of the NDIS and the health system.

> Other Parties
>
> *"Sub-acute services (palliative care, geriatric evaluation and management and psychogeriatric care) including inpatient and out-patient services delivered in the person's home or clinical settings."* [8 p. 4]
>
> *NDIS*
>
> *"In relation to palliative care, functional supports as part of an NDIS participant's plan may continue to be provided at the same time as palliative care services, recognising that supports may need to be adjusted in scope or frequency as a result of the need to align with the core palliative care being delivered through sub-acute health services*." [8 p. 5]

Mental Health

With regard to mental health services, the following are the statements concerning the responsibilities of the NDIS and the health system.

> Other Parties
>
> *"Services and therapies in which the primary function is to provide treatment* of mental illness targeted towards people affected by mental illness or a psychiatric condition,*

> *including acute and non- acute residential services, mental health crisis assessment services, hospital avoidance services and post-acute care services.*
>
> ** Treatment is defined here as activities associated with stabilisation and management of mental illness (including crisis, symptom and medication management) and establishment of pathways for longer term recovery. "* [8 p. 7]
>
> NDIS
>
> *"The NDIS will be responsible for ongoing psychosocial recovery supports that focus on a person's functional ability, including those that enable people with mental illness or a psychiatric condition to undertake activities of daily living and participate in the community and in social and economic life. This may also include provision of family and carer supports to support them in their carer role, and family therapy, as they may facilitate the person's ability to participate in the community and in social and economic life.* [8 p. 7]

Importantly, PwPDs can receive allied health and therapies to assist them, including psychology supports. However, these are quite limited in scope.

> *"Allied health and other therapy directly related to managing and/or reducing the impact on a person's functional capacity of impairment/s attributable to a psychiatric condition, including social and communication skills development, routine symptom and medication management, and behavioural and cognitive interventions."* [8 p. 7]

Principle 6 of APTOS states that:

> *The interactions of people with disability with the NDIS and other service systems should be as seamless as possible, where integrated planning and coordinated supports, referrals and transitions are promoted, supported by a no wrong door approach.* [8 p1]

Reviewing the APTOS, the key supports that PwPDs and life-limiting conditions may require are indicated against each system below.

Mental Health System

1. Treatment of mental health conditions "*activities associated with stabilisation and management of mental illness (including crisis, symptom and medication management) and establishment of pathways for longer term recovery*." This includes inpatient, ambulatory, rehabilitation/recovery, early intervention and clinical support for adolescent developmental needs [8 p.7].
2. Acute and non-acute residential services that are time-limited follow-up linked to treatment or diversion [8 p. 6]
3. Mental health facilities [8 p. 6]
4. Mental health crisis assessment services [8 p.7].
5. Hospital avoidance services [8 p.7].
6. Post-acute services [8 p.7].
7. Treatment for drug and alcohol issues [8 p.6].
8. "Intensive case coordination operated by the mental health system where a significant component of case coordination is related to the mental illness ." [8 p.7]

Health System

1. *"Responsible for the diagnosis, early intervention and treatment of health conditions, including ongoing or chronic health conditions. This may involve general practitioner services, medical specialist services, dental care, nursing, allied health services, preventive health care, care in public and private hospitals, and pharmaceuticals (available through the PBS)"* [8 p. 3].
2. "*Responsible for funding time limited, recovery-oriented services and therapies (rehabilitation) aimed primarily at restoring the person's health and improving the person's functioning after a recent medical or surgical treatment intervention. This includes where treatment and rehabilitation is required episodically*" [8 p. 3].
3. Medical, nursing and allied health services related to the health condition [8 p. 3].
4. Emergency services [8 p. 3].
5. Assessment and diagnosis [8 p. 3].
6. "*Intensive case coordination operated by the health system where a significant component of case coordination is related to the health support* [8 p. 5]."
7. "*Sub-acute services (palliative care, geriatric evaluation and management and psychogeriatric care) including inpatient and out-patient services delivered in the person's home or clinical settings*. [8 p. 4]."

NDIS System

1. "*Any funding in a person's package would continue for supports for people with complex communication needs or challenging behaviours while accessing health services, including hospitals and inpatient facilities* [8 pp. 4-5]."
2. "*Support for community reintegration and day to day living including development of skills, assistance with planning, decision-making, personal hygiene, household tasks, social relationships, financial management, transport, support for accommodation access, and community connections provided other than where provided as an integral part of an established treatment program* [8 p. 7]"
3. "*Allied health and other therapy directly related to managing and/or reducing the impact on a person's functional capacity of impairment/s* ***attributable to a psychiatric condition*** *(emphasis added), including social and communication skills development, routine symptom and medication management, and behavioural and cognitive interventions*." [8 p. 7]
4. "*Community supports aimed at increasing a person's ability to live independently in the community or to participate in social and economic activities, including in-home and centre-based care, recreational activities, day centre services and holiday care, community access (including life skills and social skills day programs)* [8 p. 7]."
5. "*In relation to palliative care, functional supports as part of an NDIS participant's plan may continue to be provided at the same time as palliative care services, recognising that supports may need to be adjusted in scope or frequency as a result of the need to align with the core palliative care being delivered through sub-acute health services* [8 p. 5]."
6. The coordination of NDIS supports with supports offered by the health and mental health systems and other relevant service systems [8 pp. 5, 7]

1.3 Background – Mental Health Services in Australia

Mental health services in Australia are a convoluted conglomeration of public and private systems. Funding is shared between the Commonwealth, state governments, private health insurers and self-funding by patients.

1.3.1 Commonwealth Government

Along with funding the NDIS, the Commonwealth Government provides funding for consultations with general practitioners (GPs) and eligibility-restricted subsidies for psychiatrists, psychologists, and other allied health practitioners [62]. Due to the low subsidy rates, practitioners usually charge a substantial additional gap fee, which must be paid on the day of treatment. Most mental health services in Australia are delivered by GPs, who prescribe and refer as required, with GP consults usually being under 20 minutes long; however, many are undercharging for their time [63].

The Pharmaceutical Benefits Scheme (PBS) is another Commonwealth programme that subsidises medications for most medical and mental health conditions. There is a co-payment of up to $31.60 for most medications and $7.70 for concession card holders. The upper annual co-pay limit is $1,647.90 and $277.20 for concession card holders. PwPDs and other Australians with mental illnesses incur substantial out-of-pocket expenses for mental health treatments.

The Commonwealth Government also funds 31 Primary Health Networks (PHN), which commission services for local mental health initiatives. The PHNs assess the needs of the communities within their jurisdiction and help fill gaps in service provision, particularly in rural communities. Although these mental health services are not nationally consistent, they align with system reform platforms focusing on early intervention, digital mental health, and delivering services within a stepped-care approach and are "*funded on the basis of need*". Non-government and private service providers deliver these services, including peak bodies, primary healthcare providers, Aboriginal Community Controlled Organisations and primary mental healthcare service providers [62]. Responsibility for ensuring awareness of these programmes and services generally sits with GPs or through individual marketing initiatives by those commissioned to provide the services.

The Commonwealth Government currently has seven active policies and plans for Australians' mental health. These include the Fifth National Mental Health and Suicide Prevention Plan, the National Mental Health and Suicide Prevention Agreement, Vision 2030, the National Mental Health Policy, The National Mental Health and Wellbeing Pandemic Response Plan, the COVID-19 National Health Plan and e The National Mental Health Workforce Strategy 2022-2032. Each state government also has mental health policies and plans.

1.3.2 State Governments

State governments fund mental health services within public hospitals, emergency departments, and residential and community mental health care. Community mental health services can be provided directly by state governments, or the services can be outsourced to not-for-profit and for-profit organisations. These services do not incur a co-payment. Community mental health teams are responsible for assessing and treating mental health conditions, including managing community treatment orders, crisis intervention, and care planning and coordination [62]. Often, the limited service availability and the costs of mental health services leave Australians with "*nowhere else to go*" but to attend hospital emergency departments in crisis [64, 65]. The Australasian College for Emergency Medicine reported that this is harmful, inefficient and expensive [64].

1.3.3 Private and Community Sectors

The health system in Australia is a hybrid of public and private health funding. All Australians have access to the public health system, and about 55% have some form of private health cover [66]. The public hospital system has no additional costs that need to be paid, but wait lists for elective surgery are often very long and have limited dental and allied health services. For this reason, many Australians choose to take out private health coverage. Private coverage can be for hospital cover only or hospital plus "extras", which includes coverage such as psychology, dental care, optometry, physiotherapy, or just extras cover alone. Australians can select the level of coverage and agree on the excess they will pay when they pay for private health insurance. The public and private systems have limitations on the types of healthcare they fund. Private health insurers often fund private inpatient services and services in public hospitals, including psychologists and other allied health professionals [62]. In Australia, the average annual cost of private health insurance to fund inpatient and out-of-hospital health services, such as psychology, is $3,434 per person [67]. There are also out-of-pocket gaps for payments when obtaining services using private health insurance.

Non-government organisations (not-for-profit and for-profit) also run crisis support and information services, well-being programmes and functional mental health programmes that provide support that is not clinically focused [62]; these are usually funded by government grants and supported by charity efforts.

1.4 Background - Palliative Care in Australia

Palliative care is not well defined in Australia, and many Australians are uncertain about what the term means, with many equating it with end-of-life care. The National Palliative Care Strategy defines palliative care as:

> *"[P]alliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification*

> *and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual."*[14 p4].

Palliative care is an approach to care, rather than defined supports offered by a single system, for people when they are diagnosed with a life-limiting illness, and they may receive it for years, whereas end-of-life care is care in the last few weeks of life [68].

Specialist Palliative Care services are delivered by government agencies and non-government organisations (for-profit and not-for-profit). Services can be delivered in public and private hospitals, community and residential aged care services, and specialist inpatient and community-based palliative care services. The Australian Health and Welfare government website also lists "*disability services*"; however, this research indicates that further clarity is necessary [69]. The state health systems manage clinical treatments and symptom management services in public hospitals, community outreach services and hospices. As with the mental health system, the Commonwealth Government subsidises medications via the PBS and general practitioners out of hospital [69]. If clinically appropriate, functional supports such as equipment, personal or intimate care, cleaning, gardening, and assistance with shopping and meal preparation can help people stay out of the hospital for as long as possible and die at home if that is their wish. For Australians over 65 and over 50, if Aboriginal or Torres Strait Islander Peoples will be able to receive these kinds of functional supports from the aged care system (hereafter, if the terms under 65 and over 65 are used, it is with the understanding that eligibility age delimiter for these communities is 50). Most Australians under 65, however, do not receive those functional supports until their last weeks and, in some cases, months of life [10]. When reviewing the responsibilities outlined by APTOS, PwPDs and other NDIS Participants without primary physical disabilities who develop life-limiting conditions will not have their equipment and personal or intimate care needs funded by the NDIS.

1.5. Voluntary Assisted Dying

Voluntary assisted dying (VAD) is available in all six states at the time of writing, but the Australian Capital Territory and the Northern Territory do not yet have these laws in place. Eligibility in each state is similar, and the criteria are strict. Disability and mental illness do not preclude Australians from accessing VAD. However, they must be assessed as having decision-making capacity, elect VAD without coercion and have a co-occurring life-limiting illness likely to cause death within either 6 or 12 months, depending on the location [70].

1.4. Research Significance

Database searches in March 2021 and January 2024 revealed that there had been no research or grey literature publications regarding the death, dying and palliative care experiences of NDIS Participants with primary psychosocial disabilities. This research explores the formal supports that PwPDs receive if they develop a life-limiting condition, identifies systemic issues, and, if required, informs a framework to improve the death, dying and palliative care experiences of PwPD, other NDIS participants and Australians under 65. The Scheme is immature and rapidly evolving, and research around the experiences of NDIS Participants is essential to ensure that the NDIS and other systems can provide efficient, best-practice support throughout their lifetime, particularly during key life events. Using a transformative systems change framework, this research offers recommendations and future research ideas to improve the outcomes for NDIS participants with life-limiting conditions. Additionally, the research findings regarding the gaps between systems, barriers to optimal support during life stages, and issues regarding the marketisation of disability support created by the NDIS should inform policymakers internationally as they consider introducing more person-centred approaches to disability support.

1.5 Research Question

What are the death, dying and palliative care experiences of National Disability Insurance Scheme (NDIS) Participants with primary psychosocial disabilities?

Sub-questions:

1. What support do NDIS Participants with primary psychosocial disabilities receive from their formal service systems once diagnosed with a life-limiting condition?
2. Are the death, dying, and palliative care experiences of NDIS Participants with primary psychosocial disabilities equitable to the experience of non-NDIS Participants with a severe and persistent mental illness and/or other Australians without a pre-existing severe and persistent mental illness?
3. Is the support received by NDIS Participants with primary psychosocial disabilities seamless between systems, both their existing NDIS and mainstream supports? Once they receive a life-limiting diagnosis, do participants receive integrated planning and coordinated supports, referrals and transitions between services? If so, what works? If not, what are the gaps and barriers?

1.5 Thesis Outline

1.5.1 Chapter 1: Introduction

This chapter provides context and rationale for the thesis.

1.5.2 Chapter 2: Scoping Review

This chapter presents the two scoping reviews of the available academic and grey literature and policy documents that were undertaken to discover key characteristics related to the experiences of NDIS participants with psychosocial disabilities and life-limiting conditions. As no specific publications were found in the area of interest, three lines of enquiry were developed to provide context around the phenomenon.

1. What information is available regarding the NDIS experiences of participants living with psychosocial disabilities?
2. What information is available regarding the death, dying, and palliative care supports and experiences of NDIS participants?
3. What information is available regarding the death, dying, and palliative care experiences of people living with psychosocial disabilities?

The initial database searches were conducted in March 2021, and the open-access scoping review was published in the International Journal of Environmental Research and Public Health on the 16th of August 2022 [11]. A supplementary search was conducted in January 2024 and was reported from Section 2.15 to Section 2.23.

1.5.3 Chapter 3: Research Design and Methodology

Chapter 3 describes the ontology, epistemology and qualitative research design and methodology. A qualitative systems dynamics approach was adopted where in-depth qualitative interviews inform and enable preliminary systems modelling across systems. Chapter 3 summarises the theoretical perspectives, the qualitative data collection methodology, and the analysis of the data, using a transformative change framework to understand and identify the levers of change.

1.5.4 Chapter 4: NDIS Participants with Psychosocial Disability Interview Results

The results of nine qualitative interviews with PwPD Interviewees can be found in Chapter 4. PwPD Interviewees shared their experiences with the NDIS and used their knowledge and expertise regarding the systems to predict the death, dying and palliative care experience and supports likely to be received by PwPDs with life-limiting conditions.

1.5.5 Chapter 5: Informal Support Interview Results

The results of seven qualitative interviews with Informal Support Interviewees (IS Interviewees) can be found in Chapter 5. IS Interviewees shared their experiences with the NDIS and used their knowledge and expertise regarding the systems to predict the death, dying, and palliative care experience and supports likely to be received by PwPDs with life-limiting conditions. Chapter 5 includes the case study of Barbara, a palliative patient (and eventual PwPD) and her sister Leoni.

1.5.6 Chapter 6: NDIS Provider Interview Results

The results of nine qualitative interviews with Provider Interviewees (PR Interviewees) can be found in Chapter 6. PR Interviewees, who consisted of workers, managers and owners of NDIS providers businesses, shared their experiences with the NDIS and used their knowledge and expertise regarding the systems to predict the death, dying, and palliative care experience and supports likely to be received by PwPDs with life-limiting conditions. Chapter 6 includes the case study of Margaret, a PwPD, and her worker, Heidi.

1.5.7 Chapter 7: Mental Health Clinician Interview Results

The results of three qualitative interviews with Mental Health Clinicians (MH Clinicians) can be found in Chapter 7. MH Clinicians, two mental health nurses, and an occupational therapist shared their experiences with the NDIS and used their knowledge and expertise regarding the systems to predict the death, dying, and palliative care experience and supports likely to be received by PwPDs with life-limiting conditions.

1.5.8 Chapter 8: Palliative Care Clinician Interview Results

The results of five qualitative interviews with Palliative Care Clinicians (PC Clinicians) can be found in Chapter 8. PC Clinicians, two social workers, an occupational therapist, a nurse practitioner, and a palliative care medical specialist shared their direct experiences with the intersection of the NDIS and palliative care systems. They discussed PwPDs and life-limiting conditions, other NDIS participants and other Australians with disabilities.

1.5.9 Chapter 9: Discussion

This chapter explores the combined results of the scoping review and the interviews with the five cohorts through the lens of dynamic systems theory. Foster-Fishman’s transformative systems change framework is used to analyse and understand the systems’ functioning and interactions.

1.5.10 Chapter 10: Conclusion

This chapter summarises key findings from the thesis and presents the transformative systems framework’s final stage, identification of levers for change. Feasible recommendations are made based on the evidence with the aim of improving the outcomes for PwPDs, other NDIS participants and Australians with life-limiting conditions.

CHAPTER 2 – SCOPING REVIEW

2.1 Introduction

The exploratory nature of this research intends to discover critical concepts, system gaps and inform future research and policy. Therefore, a scoping review of the available policy documents, academic and grey literature was undertaken to discover key characteristics related to this concept and provide context around the phenomenon. The initial database searches were conducted in March 2021, and the open access scoping review was published in the International Journal of Environmental Research and Public Health on the 16th of August 2022 [11]. It is presented below in Sections 2.2 to 2.14. A supplementary search was conducted in January 2024 in order to update the evidence. The results from the updated review are reported in Sections 2.15 to 2.23.

2.2 Published Paper

Bochen K, Phelan C, Lawn S. NDIS Participants with Psychosocial Disabilities and Life-Limiting Diagnoses: A Scoping Review. International Journal of Environmental Research and Public Health. 2022, 19(16).

2.2.1 Authors' Contributions

Conceptualisation, K.B., C.P. and S.L.; methodology, K.B., C.P. and S.L.; validation, K.B., C.P. and S.L.; formal analysis, K.B.; data curation, K.B. and C.P.; writing—original draft preparation, K.B.; writing—review and editing, K.B., C.P. and S.L.; supervision, S.L. and C.P.; project administration, K.B. All authors have read and agreed to the published version of the manuscript.

Acknowledgments: Research Centre for Palliative Care, Death, and Dying, Research Librarian Raechel Damarell.

2.3 Abstract

This research aimed to map evidence about system supports and gaps for Australians with psychosocial disabilities and life-limiting diagnoses. A scoping review of available policy documents, academic, and grey literature was completed to discover key characteristics of this concept and provide context around the phenomenon. Our focus was on Australia's National Disability Insurance Scheme (NDIS), a key reform providing support to the disability population nationally. No peer-reviewed or grey literature was retrieved on the phenomena. Therefore, three lines of enquiry were developed: experiences of NDIS participants living with psychosocial disabilities; the death, dying, and palliative care supports and experiences of NDIS participants of any disability type; and the experiences for people living with severe and persistent mental illness (SPMI) and life-limiting diagnoses. Five themes were identified: (1) the person; (2) advocacy; (3) informal supports;(4) formal supports; and (5) existing research. NDIS participants living with SPMI and their informal and formal support systems are still struggling to navigate the NDIS. While there are no specific publications about their end-of-life experiences, people with SPMI often experience poor end-of-life outcomes. Rigorous research into their death, dying, and palliative care experiences is needed to inform improved support to them, including their end-of-life care.

Keywords: National Disability Insurance Scheme (NDIS); psychosocial disability; severe and persistent mental illness; life-limiting; palliative care

2.4 Introduction

Introduced in 2013, the National Disability Insurance Scheme (NDIS) is a world-first, once-in-a-generation reform to the Australian disability sector[2]. To ensure the sustainability of the NDIS, Australian Governments have agreed that where services are best funded under another service system, the NDIS will not fund those supports. However, there is an expectation that the NDIS will support ‘participants’ in the scheme seamlessly across service systems:

> *The interactions of people with disability with the NDIS and other service systems should be as seamless as possible, where integrated planning and coordinated supports, referrals and transitions are promoted, supported by a no wrong door approach.[8] (p1)*

By 2030, the NDIS will support an estimated 859,328 participants, and approximately 88,180 (10.3%) will enter the scheme with a primary psychosocial disability (predominantly related to severe and persistent mental illness)[71]. There appears to have been little consideration about how formal support systems intend to support NDIS participants who receive life-limiting diagnoses [72]. It is essential to understand whether the current service systems, NDIS, health, and mental health around these NDIS participants adequately support them once they receive a life-limiting diagnosis. People with severe and persistent mental illnesses often die up to 20 years sooner than the average [15-19, 21-23, 73]. However, as around 80% of people who die in Australia are over 65 years, most palliative care programmes and support appear to be geared towards the over-65s. Further, there is a paucity of research into the death, dying, and palliative care experiences of people living with severe and persistent mental illness [15, 24-31, 33, 34, 74]. This limited research also shows that people with psychosocial disabilities experience stigmatising, siloed, disjointed systems, and substantial support gaps. Therefore, these issues are amplified when they are palliating, and their end-of-life (EOL) experiences are typically bleak and inequitable [26, 27, 31, 35-37, 75, 76]. This scoping review seeks to discover existing publications regarding NDIS participants with psychosocial disabilities and life-limiting illnesses and identify concepts and the characteristics of any systems gaps to inform future research.

2.5 Methods

NDIS March 2022 data reveals that participant numbers are sitting at ~60% [77] of the total estimated number of participants. Consequently, comprehensive quality research regarding a full-scheme NDIS is limited. Therefore, the most appropriate way to understand the available information is a scoping review to map the available evidence about the phenomena of interest to identify gaps in knowledge [78]. Using Arksey and O'Malley's framework, a scoping review of the available policy documents and academic and grey literature was undertaken to discover key characteristics of this concept and provide context around the phenomenon[79, 80]. The Scoping Review-Prisma-ScR Checklist can be found at Appendix B.

2.5.1 Development of Key Lines of Enquiry

Search strategies were developed with the assistance of a research librarian, and database searches were subsequently performed within the CINAHL, Scopus, Medline via Ovid, and Psychinfo databases. Further review of the National Disability Insurance Agency (NDIA), NDIS Quality and Safeguards Commission (NDIS Commission), Australasian Legal Information Institute (AustLII), and Department of Social Services and Australian university websites were undertaken to search for relevant web pages, guidelines, and government position statements. The database search resulted in no peer-reviewed studies, published opinions, grey literature, or policy documents regarding NDIS participants with a primary psychosocial disability who have been diagnosed with a life-limiting illness. Three key lines of enquiry were subsequently derived from the research question to review the literature from the following perspectives:

4. What information is available regarding the NDIS experiences of participants living with psychosocial disabilities?
5. What information is available regarding the death, dying, and palliative care supports and experiences of NDIS participants?
6. What information is available regarding the death, dying, and palliative care experiences of people living with psychosocial disabilities?

2.5.2 Publication Search Considerations

A subsequent search, using the three key lines of inquiry, was completed 14 March 2021 using CINAHL, Scopus, Medline via Ovid, and Psychinfo. The authors developed the following inclusion and exclusion criteria.

Exclusions: Searches of the databases and websites used the three identified themes and excluded publications before 2013 (prior to the NDIS's commencement). The Australian Government enacted the National Disability Insurance Scheme in 2013, and the Australian Palliative Care Standards 5th Edition and the Fifth National Mental Health and Suicide Prevention Plan were also released that year. Thus, 2013 represents contemporaneous paradigm shifts in the disability, mental health, and palliative care sectors that reflect current practice and perspectives. As part of the establishment of NDIS, the Council of Australian Governments (COAG) agreed that all early intervention supports for mental health conditions are best funded by mental health. While early intervention is not limited to people under 18, most people under 18 should be receiving early intervention supports through the mental health system [8]. Therefore, all publications regarding under 18-year-olds were excluded from the study. Publications not in English, and publications that were epidemiology or health promotion focused, were also excluded.

Inclusions: The term "serious and persistent mental illness" was used in the palliative care publications to enable the sector to identify that patients/clients had a mental illness that was not secondary to their life-limiting diagnoses. Search terms for each database and theme are detailed in Appendix A.

2.5.3 Publication Selection

Initial searches resulted in 5701 papers; after removing duplicate publications, 5061 were identified for title and abstract screening, and 272 for full-text screening. Two authors (K.B. and C.P.) independently reviewed included publications, supported by the Covidence "Better systematic review management" document 2018 (available from: https://www. covidence.org/home (accessed 14 March 2021)). All conflicts were resolved without the need for adjudication. Additional texts were included through citation tracking and new publication alerts. The scoping literature review contains 49 publications under the NDIS and psychosocial disability line of enquiry; 66 publications under the SPMI, death, dying, and palliative care line of enquiry; and two publications under the NDIS and death, dying, and palliative care line of enquiry. A total of 117 publications were therefore included. Publication selection flow chart diagrams, based on the Prisma Report for each line of enquiry, can be found in Figures 1–3.

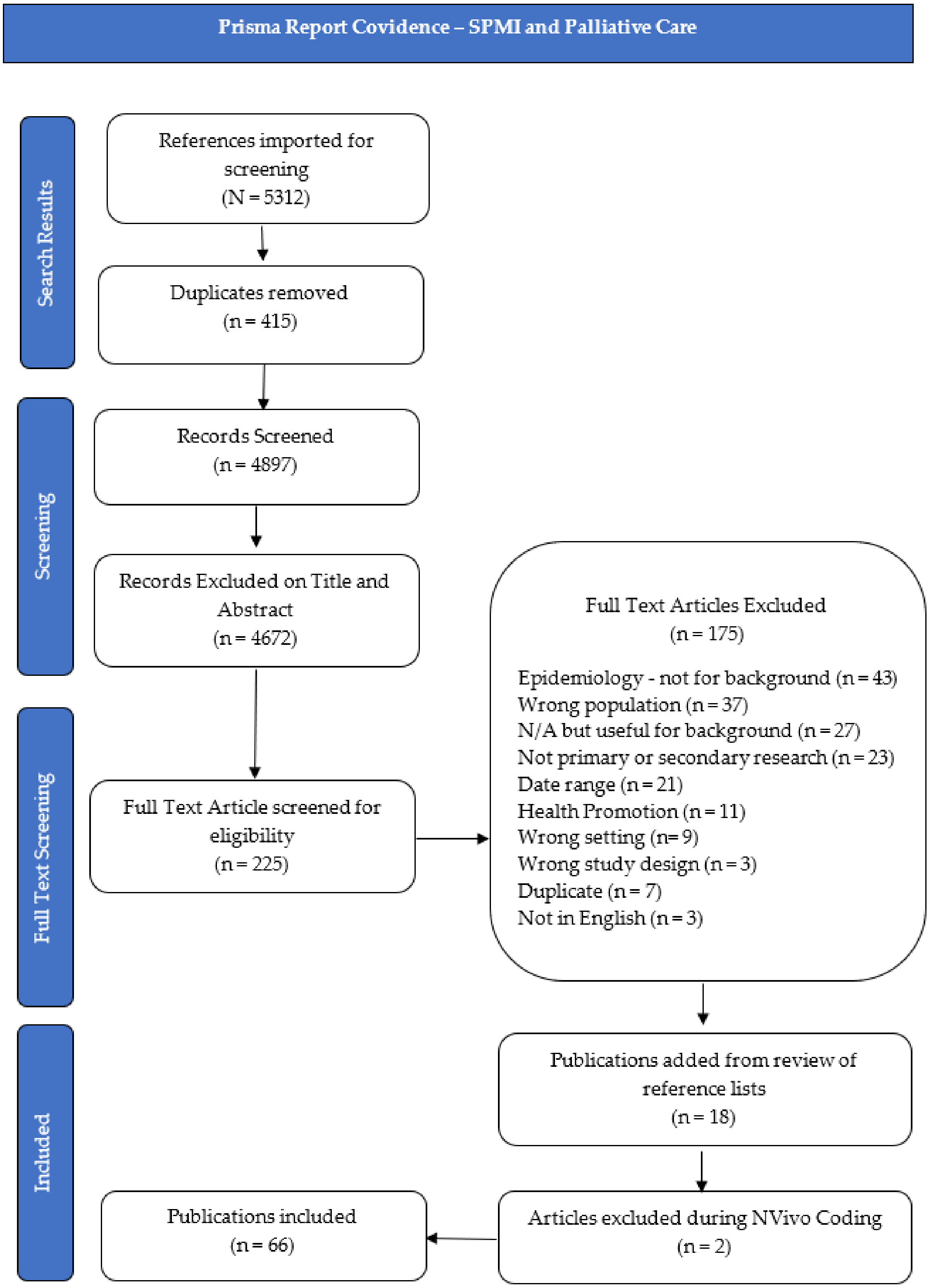

Figure 1: Prisma Report Covidence—SPMI and Palliative Care

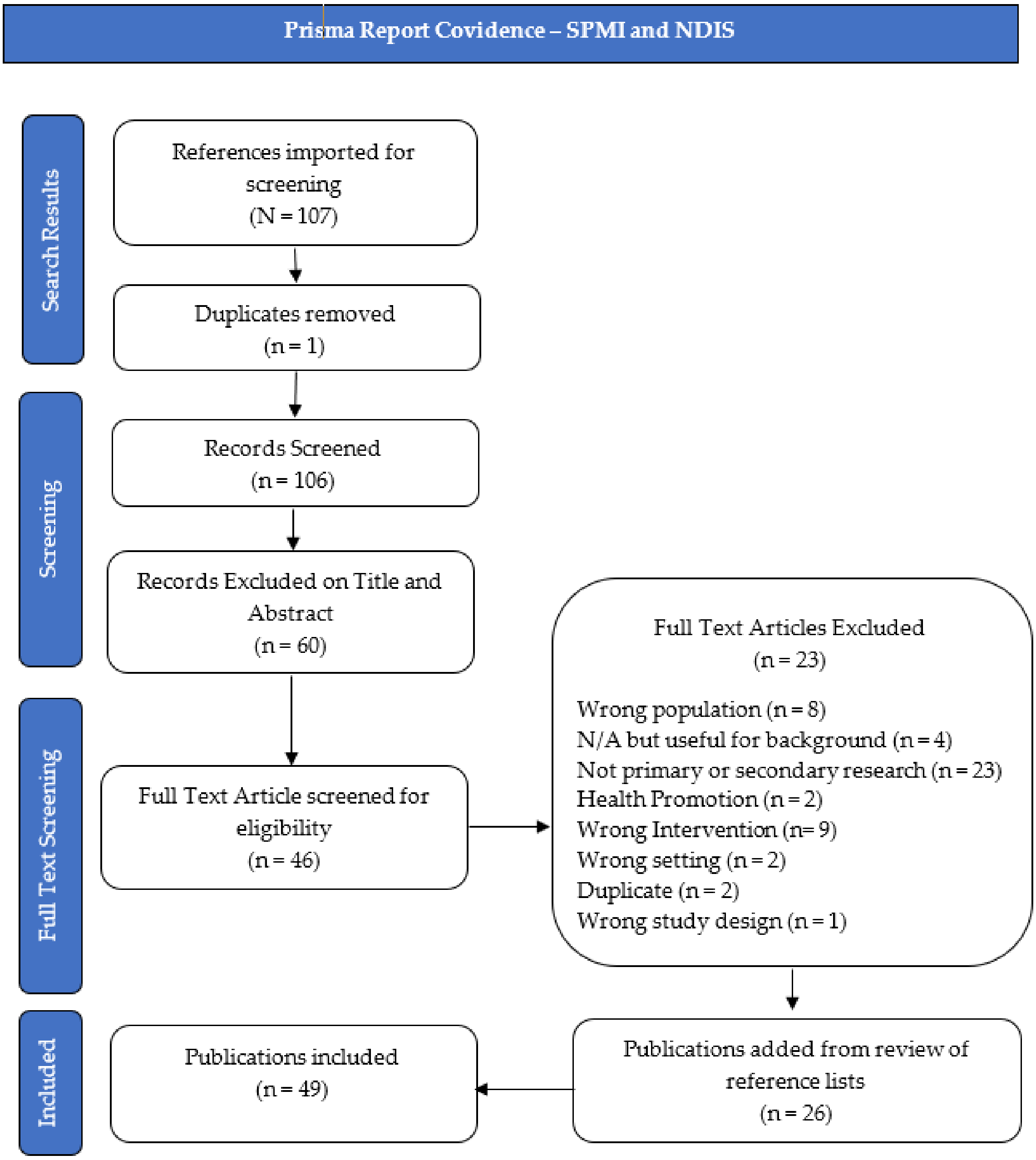

Figure 2: Prisma Report Covidence—SPMI and NDIS

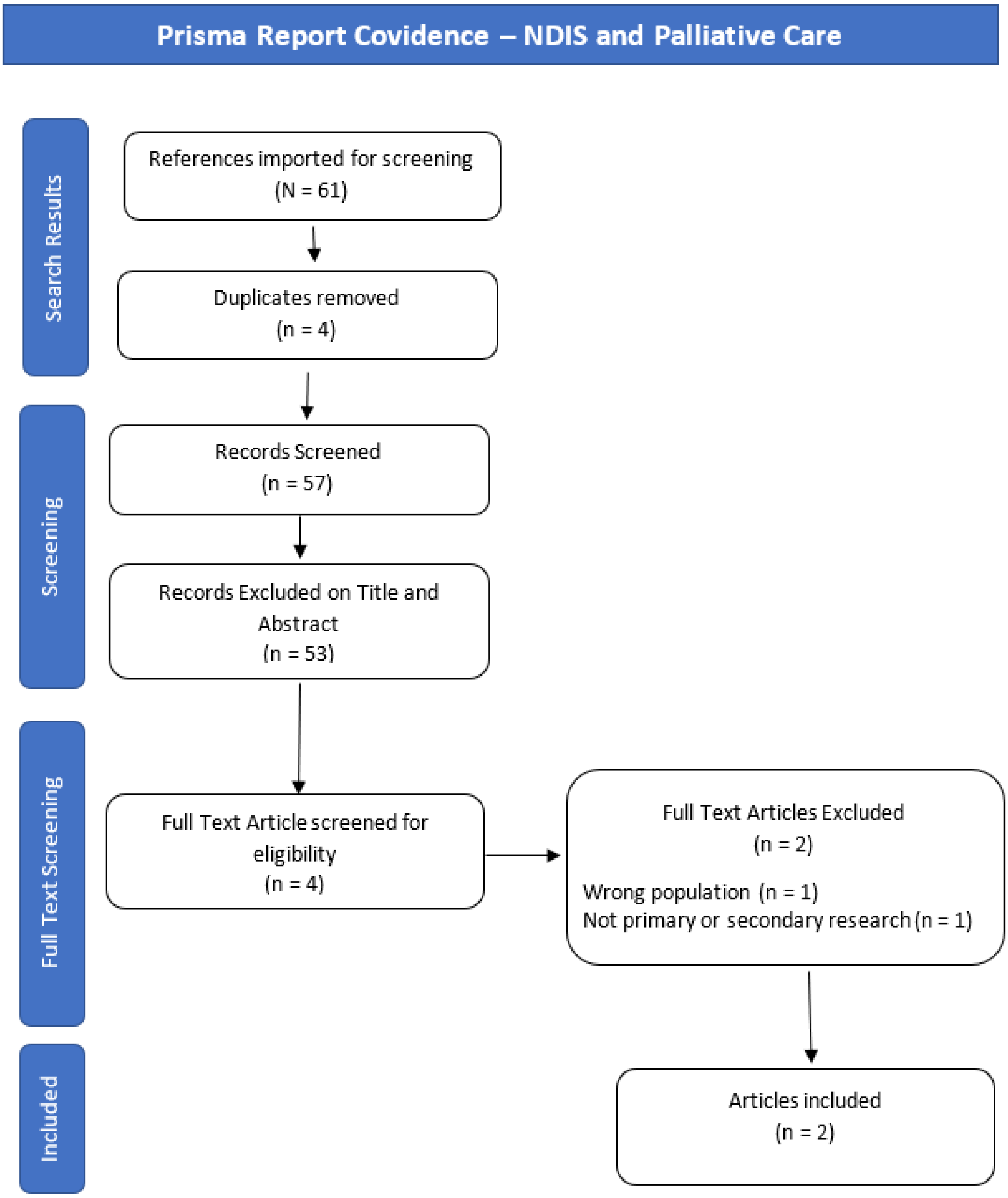

Figure 3: Prisma Report Covidence—NDIS and Palliative Care

2.6 Results

The NVivo software tool was used to code and sort the literature. Common themes and connections were identified and analysed against the three lines of enquiry that were derived from the initial scoping review question:

1. What information is available regarding the NDIS experiences of participants living with psychosocial disabilities?
2. What information is available regarding the death, dying, and palliative care supports and experiences of NDIS participants?
3. What information is available regarding the death, dying, and palliative care experiences of people living with psychosocial disabilities?

Across the literature, common themes were discovered regardless of the literature's service system, issue, or intent. Data were, therefore, coded into these common themes. Five key themes and a range of sub-themes within three of the themes were developed as described in Figure 4:

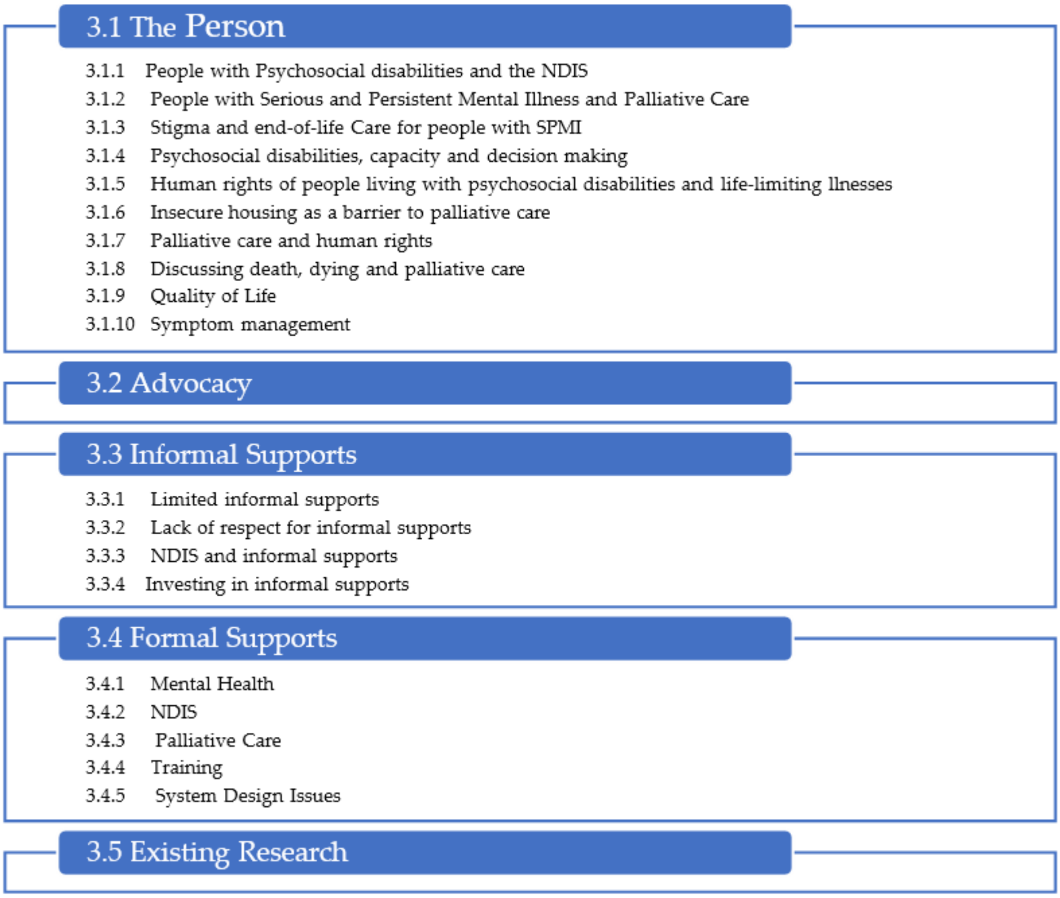

Figure 4: Scoping Review—Themes

2.7 The Person

2.7.1 People with Psychosocial Disabilities and the NDIS

Psychosocial disabilities were a late addition to the NDIS [61], and the scheme's impact on the lives of people living with psychosocial disabilities is yet to be fully understood. To access the NDIS, a person living with a psychosocial disability needs to meet the disability requirements found in Section 24 of the National Disability Insurance Scheme Act (2013) [7]. Mental illness is one of the leading causes of disability nationally and internationally [29, 81]. However, there has been significant, cogent discourse in the mental health community about the appropriateness of the NDIS for Australians living with mental illness. Most notably, it was found that there has been further fragmentation of the support systems experienced by people with SPMI [60].

2.7.2 People with Serious and Persistent Mental Illness and Palliative Care

The term "psychosocial disability" is not commonly used in the palliative care literature. Instead, the terms "severe and persistent mental illness" (SPMI) and "severe mental illness" (SMI) identify patients/clients with significant mental illnesses that are preexisting and not secondary to their life-limiting diagnoses [27, 36, 82-85].

People living with SPMI have increased somatic risks, higher cancer mortality rates [86], poorer clinical outcomes [82, 87], and die significantly earlier due to factors attributable to their mental illnesses. These factors include the side effects of psychotropic medications, unhealthy lifestyles [82], alcohol and other drug use, poor health monitoring [88-90], and reduced health prevention and screening, leading to under-detection and late diagnosis of disease [28, 35, 36, 74, 83, 84, 89-92]. People with SPMI are particularly vulnerable to shorter life expectancy [84, 93] as they are often victims of violence [94], healthcare system neglect [35, 89], and can be excluded from mainstream service support due to barriers such as homelessness [36, 37, 95], cultural insensitivity [96], poverty, and stigmatisation [15, 24, 25, 27, 28, 31, 34-37, 74, 83, 91, 93, 95, 97-99].

2.7.3 Stigma and End-of-Life Care for People with SPMI

Fear of discrimination due to past experiences of stigma often leads people with SPMI to disconnect from services and supports [93], resulting in unmet needs across a range of areas, including mental and physical healthcare, housing, and alcohol and other drugs (AOD) treatment. In addition, this fear of discrimination can lead to ambivalence regarding receiving treatment and end-of-life and palliative care [24, 31, 36, 74, 83, 95, 100]. There is, however, across the research ample confirmation that people with SPMI are almost universally stigmatised within health and palliative care settings, resulting in substantial inequity, unmet need, reduced access to care, and poor end-of-life outcomes [15, 24, 25, 28, 31, 34-37, 74, 75, 83, 93, 95, 97, 98, 101-103].

2.7.4 Psychosocial Disabilities, Capacity and Decision-Making

A frequent discussion about people with both disabilities and SPMI within the palliative care, mental health, and NDIS literature [96, 104-106] was their cognitive capacity and ability to make decisions about their supports, palliative care, and end-of-life care. Many of the studies discussed the presumptions within medical and mental health settings that people with SPMI were, due to capacity issues, unable to make decisions or that the symptoms of their mental illness made discussions about death, dying, and palliativ care overwhelming [15, 25-28, 81-84, 102]. Promoting and respecting existing relationships, such as with carers and multidisciplinary health/mental health teams, is key to ensuring that people with psychosocial disabilities are well supported as they die [15, 25, 26, 34, 74, 107]. Where capacity exists, people with SPMI have the same rights as others to make poor decisions [84]. Notably, the NDIS Practice Standards uphold this concept of, and right to, dignity of risk [108].

2.7.5 Human Rights of People Living with Psychosocial Disabilities and Life-Limiting Illnesses

Multiple studies reveal that healthcare for people with SPMI is not equitable [24-27, 29, 31, 35, 36, 83, 89, 109-113]. Ethical challenges such as withheld treatments due to SPMIs and concerns about risks to other patients [111], fewer referrals and admissions to palliative and quality end-of-life care [24-26, 35, 89, 112], and being subjected to more invasive end-of-life treatments, such as intubation, CPR, and feeding tubes [91], and being denied access to mental health care teams in their healthcare setting [26] were described. The United Nations Convention on the Rights of Persons with Disabilities' (UNCRPD) purpose is to "*promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms*" and to "*promote respect for their inherent dignity of people with disabilities*" [41p. 4]. The Objects and Principles of the NDIS Act give effect to the UNCRPD [7]. However, concerns regarding the human rights of people with disabilities [94, 114, 115], and/or SPMI, living with life-limiting diagnoses are expressed frequently throughout the literature [24, 25, 37, 82, 83, 116]. Grassi and Riba [83] state that dignity is incompatible with stigma. The stigma of mental illness that has been pervasive throughout people's lifetimes is compounded by intrinsic and extrinsic factors when managing significant health conditions [36].

Healthcare supports also have additional ethical complications when people with SPMI decline or withdraw from treatment [35]. Concerns regarding patient capacity, vulnerability, and risk often override their right to healthcare choices and advance care planning, and result in them being subjected to involuntary treatments [35].

Unfortunately, the NDIS has not been the promised panacea for people with disabilities since its introduction. Instead, Australia has seen an uptick in guardianship applications and financial management orders [104]. Additionally, carers of people with disabilities report that the NDIA/Local Area Coordinators (LAC) staff have inadequate levels of understanding of disability and do not have the requisite empathy and compassion that would ameliorate this inexperience [117].

This scoping review found that the human rights of people living with SPMI and a life-limiting illness are not being upheld, particularly the rights of equity, freedom of discrimination, dignity, the right to housing, and equitable access to healthcare.

2.7.6 Insecure Housing as a Barrier to Palliative Care

As a signatory to the UNCRPD, Australia recognises the right to and, therefore, should ensure [41] that all people with disabilities have access to public housing. However, the responsibility of housing sits within each state and territory governments' jurisdiction. The NDIS, therefore, does not ensure that NDIS participants are guaranteed housing if their support needs do not meet the threshold for supported disability accommodation [8]. Globally, people with SPMI are at a high risk of homelessness, and housing insecurity is recognised across the literature as a significant barrier to palliative care [24, 26, 28, 36, 37, 83, 84, 95, 100]. Where people are not street living, they may be living in hostels, supported residential facilities, mental health facilities or in shared accommodation settings that make the delivery of in-home palliative care unrealisable or challenging [28].

2.7.7 Palliative Care and Human Rights

Quality palliative care is a recognised human right [118, 119]. However, the literature identified that people with disabilities and SPMI often experience inequity and have significant unmet needs [35, 37, 76, 93] and barriers to palliative care [24, 27, 28, 37, 84, 91, 93, 112].

2.7.8 Discussing Death, Dying and Palliative Care

Formal mental health and palliative care support providers expressed significant concern regarding discussing death and dying with people with SPMI; they also expressed concern that this would exacerbate the symptoms of their mental illness [28, 37, 74]. However, when researchers conducted interviews with people living with SPMI, the concerns and themes were inconsistent with clinician concerns [74]. Indeed, in one study, people with SPMI advised that they were aware of this avoidance by clinicians, increasing their sense of abandonment [74]. Another study found that, contrary to clinician beliefs that their research participants did not experience fear of death, many people with SPMI found it a relief to talk about and that themes of death had been regularly contemplated throughout their lives [81]. Skilled companionship at the end of their lives was identified as crucial to improving end-of-life experiences for people with SPMI [81]. Additionally, the loss of their providers of mental health supports, who many view as "*de facto family*" is the source of significant distress [93, 97, 120]. People with SPMI highlighted the importance of their formal supports being trained, in some form, in both mental health and palliative care, ensuring people with SPMI and life-limiting conditions are treated holistically and do not have their care compartmentalised or avoided due to clinician discomfort [74, 81, 97].

2.7.9 Quality of Life

"*Improving quality of life . . . as well as reducing physical and mental stress*" [14 p. 4] is fundamental to palliative care. People with SPMI often have a reduced quality of life throughout their lifetime, further compounded by a life-limiting diagnosis [35, 81, 121]. Many people with SPMI have struggled with service systems that do not respect their autonomy. When diagnosed with life-limiting conditions, there can be further declines in agency and physical capabilities with increased dependence on or being a burden to loved ones or others [81, 84].

2.7.10 Symptom Management

There is often a misattribution of symptoms, diagnostic overshadowing occurs, and care teams believe physical symptoms are due to a patient's mental illness due to their communication style [26, 36, 81, 95, 116] However, a study by Jerwood et al. [74] found that people with SPMI may hide their symptoms due to the difficulties of building new therapeutic relationships with new care teams. Communication issues with and underlying stigmatising beliefs held by health professionals can also lead to under-prescribing pain medications for people with SPMI at the end of their lives [26, 35, 36, 97]. Quality of life during palliative and end-of-life care can be supported by managing pain [14], and research has identified this as a significant issue for people with SPMI [81, 84, 97, 122]. Unfortunately, there appears to be confusion within the literature regarding perceptions of pain for people with SPMI. Many publications refer to a decreased response to pain [25, 82] or an inability to talk about their pain in a way that others can understand [81, 95, 116].

2.8 Advocacy

NDIS participants and their informal supports require significant system knowledge and negotiation capabilities to navigate the NDIS. A lack of confidence or capacity to understand the NDIS can result in participants not receiving the support they need [104]. Carey, Malbon and Blackwell [96] advise that personalisation systems such as the NDIS require prodigious amounts of self-advocacy. Participants must understand their support needs and figure out how the NDIS can meet them [123]. Participants must know how to set NDIS goals in support plans and demonstrate that supports for that goal are not best funded by another support system, and communicate their goals and connect their support needs, and NDIS supports, to those goals [124]. Additionally, Carey, Malbon and Blackwell [96] found that paid advocacy results in increased funding within NDIS plans. A lack of advocacy is highlighted as a contributing factor to poor outcomes for people with psychosocial disabilities in the NDIS and palliative care systems. The acknowledged importance, yet underfunding of advocacy organisations in Australia [125], would further contribute to this issue.

2.9 Informal Supports

2.9.1 Limited Informal Supports

Many people living with SPMI have little to no informal support; this can be family or friends that undertake an unpaid carer role throughout their lives. This loss can add further complexity when they are diagnosed with a severe medical condition or life-limiting illness [24, 26, 28, 36, 74, 75, 82-84, 91, 93, 112, 116, 126-128] and attempting to navigate systems on their own [24]. Advocacy is essential to respect end-of-life advance care directives when a person has no informal supports [28, 93]. Substitute decision-makers are often state-funded guardians, and there can be limitations on their powers. Decisions may be required from tribunals or courts, causing unacceptable delays in care [36, 129]. Psychiatric nurses describe being considered substitute family members [15], and mental health teams often have close relationships with their clients [128]. However, people with SPMI are likely to be separated from these essential supports when they enter the health system due to their life-limiting illness [25].

2.9.2 Lack of Respect for Informal Supports

Informal supports or carers describe a lack of respect by formal support services when supporting a person with SPMI and a life-limiting condition [74, 130]. Health and mental healthcare providers expect them to display expertise in the medical and psychiatric conditions of the person they are caring for, to be their advocate, and attend to their personal and intimate care needs [34, 74], even though informal supports are often perceived as problematic by formal supports [15, 28, 74]. Informal supports safeguard people with SPMI from the gaps between silos [120]. However, they describe having to keep extensive records and being ignored when they had concerns about the person they were caring for; only heard if they expressed that they could no longer cope [131].

2.9.3 NDIS and Informal Supports

The shift to the NDIS has caused a decline in support for informal carers of people living with mental illness in Australia [61, 132]. Informal supports describe extensive difficulties negotiating with NDIA [61]. LACs and planners have been described as judgmental, dismissive, and possessing limited capabilities to work collaboratively with informal supports of NDIS participants [117]. As part of the NDIS process, carers are often excluded from planning meetings, resulting in unmet participant support needs. Supports and service funding once used to support carer wellbeing have been redirected into the NDIS; however, NDIS funds, for the most part, provide support to NDIS participants [61], not informal supports. Other government carer supports are minimal [61], and searches through the Carer Gateway, a government website dedicated to supporting carers, provide no clear answers about carer support. Attempting to navigate these systems substantially strains relationships between the NDIS participants and their informal and formal supports [61].

2.9.4 Investing in Informal Supports

The emotional and physical burdens and social isolation experienced by informal supports is significant [130], and it is important to acknowledge their significant economic contribution. Diminic et al.’s [132] research into the caring hours provided by informal supports of people living with SPMI in Australia estimated that they provide 186 million hours of unpaid work each year. Without these informal supports, people with SPMI would need to have more of their support needs funded by the NDIS, including the high-cost supported independent living (SIL) or independent living options (ILO). If these hours were to be funded by the NDIS, at the minimum 2021 hourly support rate of AUD 57.10, the cost of replacing informal supports would be around AUD 10.62 billion. These figures do not count any weekend, public holiday, afternoon and night shift loading, or rural or remote loading per the NDIS pricing arrangements [133]. Indeed, the “Mind the Gap” report estimated the cost of replacing unpaid carer hours at AUD 13.2 billion in 2018 and advised that not investing in unpaid carers would severely impact the funding and delivery of social services in Australia [61].

2.10 Formal Supports

There is limited research into the formal support systems of NDIS participants with psychosocial disabilities and NDIS participants with any disability who are dying, and none regarding the formal support of NDIS participants with a psychosocial disability who are dying. There has also been a dearth of research regarding how organisations can best support people with SPMI who receive a life-limiting diagnosis. However, this limited research reveals that formal support systems are inadequate [15, 26, 28, 74, 98] despite the multiple service providers involved in the lives of people with SPMI [24, 27, 95]. Furthermore, even though mental health, NDIS, and palliative care providers share person-centred values [25, 29, 84, 134, 135], collaboration between providers, though highly recommended and encouraged, is poor, limited or non-existent [25, 26, 28, 31, 37, 57, 74, 82, 84, 97, 134-140]. The NDIS does not fund case management or care coordination, a recognised and highly valued role in mental health systems [141, 142], to the detriment of NDIS participants with complex support needs. Support coordination, specialist support coordination, and LAC roles do not have clear guidelines on how to provide support, nor the funding nor jurisdiction to provide this complex support [136, 143]. The NDIA briefly explains the role of specialist support coordinators on its website; however, the criteria for obtaining funding for specialist coordination in an NDIS plan are not provided [144]. However, many NDIS participants and their informal supports are uncertain of what is available and how to request particular support [96]. There is no publicly available data on how many NDIS participants are receiving specialist support coordination or how many hours are funded. Isaacs and Firdous’s [137] review of the now defunded Partners in Recovery program demonstrated that care coordination was cost-effective and efficient in supporting people living with SPMI while maintaining recovery-orientated practice. While the NDIA has co-opted recovery terminology, there is little evidence or capacity for recovery-oriented practice within the NDIS, due to its deficits-based approach [145-147].

Traditionally, mental health systems case-managed people with SPMI; however, resource limitations often no longer provide this comprehensive case management and are usually restricted to monitoring medication and compliance [146]. For people with SPMI who are dying, lack of care coordination [28, 37, 74, 84] and appropriate standardised tools [25, 82, 97] are barriers to palliative care and contribute to poor end-of-life experience. General practitioners find navigating the NDIS [148] and palliative care systems [93] challenging, and they may have little time to spend with [93] or be responsive to the needs of [131] their patients with SPMI. The complex care needs of people with SPMI with life-limiting conditions, and a lack of appropriate referrals to specialist palliative care, results in unmet needs, distressing end-of-life outcomes, and the inability to develop trust, a therapeutic alliance, and advance care directives [28, 37, 74, 93, 97, 112, 128]. Workers in the palliative care [24, 149], mental health [28], and NDIS sectors [94] need to "*bend the rules*", work unpaid hours and go above and beyond their system's funding to support people with SPMI throughout their lives and as they die [26, 35, 37, 82, 105, 136, 150]. The literature describes concerns about the risks to and safety of staff and other patients that can negatively impact the delivery of palliative and end-of-life care to people with SPMI [15, 24, 28, 36, 74, 83, 151], sometimes leading to the need for restrictive practices such as chemical or physical restraint [84, 151]. There are, at this time, no publications or guidelines available regarding practices restrictive of people with disabilities that discuss the requirements of the NDIS Commission combined with the requirements of the various state health systems or My Aged Care. Further, no available publications or operational guidelines discuss supporting NDIS participants with psychosocial disabilities to die at home, whether in their own home or supported disability accommodation.

2.10.1 Mental Health

In Australia, mental health systems consist of government-run/funded mental health systems and non-government organisations that may receive funding from either federal or state programs. The reallocation of resources to the NDIS has reduced funding in the community mental health systems around the country to varying degrees [61]. Secondary losses include loss of qualified staff and rural and remote programs, a casualised workforce, and hybrid providers that provide NDIS and fund other mental health supports, resulting in streamlining and loss of supports offered [60].

These losses of qualified supports are concerning, given that people with SPMI and life-limiting illnesses often lose access to their mental health services due to being absorbed into the health systems [97]. As a result, they can be discharged from mental health services without notice or have supports reduced. The literature shows that this leaves people with SPMI and life-limiting conditions feeling abandoned and dying alone in unfamiliar environments [74, 121]. The literature also highlights the need for continuity of care and continued support from a multidisciplinary team where preexisting therapeutic relationships are maintained and fostered, and medication management responsibilities are shared [34, 74, 97, 121, 136]. However, the research indicates that the mental health workforce often finds working with dying patients/clients challenging [15, 26, 75]. In addition, many organisational guidelines are not conducive to palliative care in mental health settings [28]. Mental health services have difficulties supporting dying clients [15, 25, 28, 37, 84, 93, 97, 151-154]

This may be due to an inability to provide high-level somatic care, funding models or operational guidelines that see people with SPMI discharged from mental health supports when they enter the health system [28]. Mental health system staff advise that they are apprehensive about supporting their clients as they die, as the skills required are not within their standard care practice and discussions about death can be confronting [28]. For some people with SPMI in Australia, mental health facilities and SDAs are considered their homes, and dying in familiar surroundings is important for some people with SPMI [81]. People with SPMI have advised that they have not been provided with information about palliative care by their mental health teams even as they withdrew their support [74].

2.10.2 NDIS

Similar to trends in human services in some European countries, the Australian Government designed the NDIS to deliver individualised or self-directed support to people with disabilities [57, 58]. These funding models help empower NDIS participants [155] and ratify Australia's obligations under the UNCRPD [7] However, the implementation of the NDIS has spawned many issues since it commenced transition in 2013. The NDIS is built on a foundation of middle-class norms that may lead to high administrative burdens and poorer outcomes for those from more marginalised communities [96]. David and West [114] advise a lack of "*nuanced empirical data about the long-term effects of marketisation in the disability sector*" [p. 333]. They suggest that market-driven approaches to social services may be regressive. Cortis and van Toon [156] expressed concern regarding the private market and self-regulation of providers, and "*loose parameters of oversight*" [p. 122].

The NDIA has struggled to effectively support NDIS participants with psychosocial disabilities [2, 61]. The literature identifies issues such as the inability to plan around fluctuating conditions, and the dichotomy of the disability model and deficits-based language with the recovery model and its associated terminology used by the mental health systems [60, 61]. Systemic power imbalances cultivated within the NDIA continue through to the service delivery landscape. NDIS workers are paid less in the NDIS system than in other systems [61, 147]. Many support workers have few or no qualifications, particularly in mental health, and are subjected to insecure work arrangements. There are few opportunities for professional development, and many feel they will not continue working in the disability sector. This, ultimately, will limit choice and control, further disempowering NDIS participants, particularly those in rural and remote areas [60, 61, 94, 117, 124, 157-160].

Providers are reporting that they must work around the NDIS rules to survive financially [61]. The conflict between quality and profit has negatively impacted their organisations' missions, making NDIS participant relationships transactional [57, 61]. Due to insecurity around income, the financial risks to businesses have caused NDIS providers to restructure their business models to ensure financial viability. As NDIS participants can change NDIS providers with limited notice, they are curating the types of disability supports offered to reduce these financial risks [57, 158].

NDIS providers report that the caps and lower remuneration from the NDIS have resulted in difficulties with recruiting and retaining qualified staff [117, 134, 158], particularly those with mental health training [60, 61]. They advise that the needs of NDIS participants already exceed the system's ability to supply the supports required, particularly in rural and remote areas [57, 117]. In addition, thin market issues have not been alleviated by the new, inexperienced NDIS providers entering the sector [57]. Competition is also impacting NDIS providers' collaboration: while Foster et al. report that providers reducing the types of services offered has increased collaboration [140], competition often negatively impacts interagency cooperation [57, 136]. Even though the NDIS stresses the importance of collaboration between NDIS providers and other service systems, no funding, policy or legislation frameworks support this [136].

2.10.3 Palliative Care

Support for palliative care remains the health system's responsibility [2, 8]; however, it is essential to clarify how the various systems interpret palliative care, illness, and disability. For example, there are several genetic conditions on List A, the NDIA's list of conditions that are likely to meet the disability requirements in Section 24 of the NDIS Act [7] that are life-limiting [161]. However, no published framework or guideline describes how the NDIA determines whether the palliative care system or NDIS best funds a support need [72]. The 2021–2031 National Disability Strategy policy priority [162] advises that people with disabilities should be able to choose where they live. As dying at home is the choice of many Australians and including people with SPMI [28], it is crucial to understand how the NDIS and the healthcare system intend to fund an NDIS participant's choice and control when they are dying.

While there are no publications regarding providing palliative care support to NDIS participants with primary psychosocial disabilities, palliative care providers globally experience difficulties supporting people with SPMI [15, 25, 28, 37, 84, 93, 97, 116, 120, 151-153, 163]. Many people with SPMI are not receiving palliative care and often present to the hospital in the final stages of their life-limiting conditions [24, 25, 27, 83, 97]. They may die in acute care settings without receiving palliative care support [24, 83, 113].This may be due to problems with identifying their illness [24, 25, 82] or that just surviving each day, and attempting to meet their basic needs of food and shelter lowers the priority of caring for their health [24]. Subsequently, they may only present for medical assistance when their symptoms become unbearable [24, 83].

The siloed nature of mental health, health, and palliative care systems has been highlighted as a barrier to palliative care for people with SPMI [15, 24, 25, 27, 28, 31, 37, 82, 83, 93, 151]. Often there are no ongoing relationships with medical teams or distrust of medical professionals [84, 93]. GPs can be an excellent support for this cohort; however, this is not consistent, and they may also act as a barrier to palliative care [37]. Due to funding allocations, a limited number of patients are admitted into specialist palliative care, and few facilities can manage the complexity of patients with SPMI [15, 25, 28, 153]. The diagnosis of SPMI itself may be a barrier to referral to palliative care [27, 83]. The literature demonstrates that palliative care is usually structured to support normative populations [24, 82]. Subsequently, clinicians struggle to support people with SPMI adequately within existing systems.

Medical professionals may struggle with diagnostic overshadowing and prescribe fewer pain medications to people with SPMI [26, 35, 36, 164] either due to stigma toward them by health professionals [36, 83], or communication issues [95, 116] and misattribution of symptoms [95]. Multiple publications indicate that palliative care patients with SPMI experience less pain or communicate pain differently to other people [36, 82, 95]. However, Jerwood et al. [74] and Sweers et al. [81] advise that people with SPMI may not be experiencing less pain. The inequity of palliative care leads to distress and poor symptom management for people with SPMI; this can also cause long-lasting harm to informal supports and friends [31].

People with SPMI are discharged from palliative care settings due to their SPMI symptoms impacting somatic care [35, 83, 84, 112] and risk to other patients and staff [15, 24, 37]. In a similar challenge to clinicians from the mental health sector, palliative care clinicians may feel uncomfortable supporting people with a preexisting mental illness and may feel alarmed by the active symptoms of an SPMI [83]. In addition, without knowing a patient with SPMI’s usual presentation or treatment regimen, it can be challenging to support them adequately [93, 97] or manage medication interactions effectively [25, 29, 91, 95]. Further challenges can include that some patients with SPMI can be ambivalent about dying or their end-of-life care [24, 95], refuse treatment [35], and there may be uncertainty about the patient’s capacity for advance care planning [26-28]. However, studies have indicated that people with SPMI often have that capacity [37, 82, 122] and appreciate flexible, supported decision-making to develop their advance care directives [26, 28, 74, 81, 150, 165].

2.11 Training

The literature identified that people with a life-limiting diagnosis and a preexisting SPMI benefit from a cohesive multidisciplinary team to support them as they die [35, 83, 93, 97]. Therefore, best practice would be that mental health teams continue to support people with SPMI once they enter other systems [151, 166]. However, both mental health and palliative care clinicians recognise that they lack the necessary skills and require additional, targeted training opportunities to ensure they can confidently provide competent and caring support for this complex cohort [15, 26, 28, 31, 37, 82, 84, 93, 97, 120, 153, 167].

2.12 System Design Issues

Each state and territory government entered into bilateral agreements with the Commonwealth Government regarding how the NDIS would be funded and delivered in each state and territory. The bilateral agreements have been amended at various stages of the implementation of the NDIS, and each state and territory has negotiated slightly different arrangements with the Commonwealth (detail can be found on the NDIA website [168]). In 2015, the COAG (now National Cabinet) developed the NDIS Principles to determine the responsibilities of the NDIS and other service systems [8]. However, while these set out funding models and responsibilities, there is no clear framework or pathways where these systems intersect [136, 160]. Historically the state and federal governments have been responsible for different systems. The recognised issue with gaps between siloed systems [15, 24, 27, 28, 31, 36, 37, 46, 72, 74, 82, 83, 93, 97, 104, 112, 120, 131, 134, 136, 137, 139, 169] has been exacerbated, rather than resolved, with the addition of the NDIS [93, 136, 143, 160].

The design of the NDIS, while attempting to focus on the individual, has resulted in "*Taylorist administration*" leading to "*routinisation and data-driven planning*" [104]. Carey et al.'s [96] scoping review found that the NDIS has been designed and works best for middle-class, white people. It is administratively burdensome and difficult to navigate [96, 170] and excludes or provides less support for NDIS participants who are not from this social class. Neoliberal approaches to human services reduce the ability of people with disabilities and providers to work together to advocate for improved support [145]. Hummell et al.'s [136] rapid review found that while the design and intent of the NDIS was to increase collaboration between systems, there has been a reduction in information sharing and collaboration due to increasing competition. There needs to be a significant cultural shift to change the administration and policy directions of the NDIS [96] to overcome gaps in the NDIS and health system frameworks.

2.13 Existing Research

Despite the significant issues raised within the literature about the death, dying, and palliative care experiences of people with SPMI, there has been limited research nationally and internationally [15, 24, 26-31, 33, 34, 36, 74, 84, 171]. There is recognition that the perspective of the person with comorbid SPMI and life-limiting diagnosis is largely missing from existing research. It is acknowledged that it is necessary to conduct further research that includes their and their informal supports' perspectives [28, 74, 81, 172]. Research into the NDIS is usually directed toward difficulties regarding access and obtaining funded supports and workforce and NDIS provider issues. There has been limited research where NDIS participants have been offered the opportunity to contribute to our understanding of the NDIS [60] and none about the death, dying, and palliative care experiences of NDIS participants with primary psychosocial disabilities [60].

2.14 Conclusions

This scoping review revealed that there has been no research into the death, dying, and palliative care experiences of NDIS participants with psychosocial disabilities and life-limiting diagnoses. Furthermore, there was minimal literature across the three key lines of inquiry regarding experiences of NDIS participants living with psychosocial disabilities, the death, dying, and palliative care supports and experiences of NDIS participants of any disability type, and the death, dying, and palliative care experiences of people living with severe and persistent mental illness psychosocial disabilities. The experiences of NDIS participants are still highly variable, and the impact on NDIS participants with psychosocial disability and their workforce across the NDIS and other service systems has been significant. Additionally, this limited information demonstrated that while there are no publications about their end-of-life experiences, people with SPMI often experience poor end-of-life outcomes. The scoping review also discovered that the three lines of enquiry, training, cross-training, and mapping across the service systems are recommended to improve NDIS participant service experiences and EOL support. This mapping would be ideal for all NDIS participants where there may be intersections with other services. Another key finding is the importance of investment to strengthen and sustain informal support networks and advocacy services to ensure that NDIS participants can be well supported at the end of life in both the NDIS and other service systems.

Hamilton et al. [60] identified in their scoping review of the NDIS and psychosocial disability that there is a need for independent and rigorous research into the NDIS. It is essential to consider that while 88,180 participants are expected to enter the NDIS with primary psychosocial disabilities, many NDIS participants may enter the scheme with secondary psychosocial disabilities. Data regarding the number of NDIS participants with declared secondary psychosocial disabilities have not been made publicly available through the NDIS Data website. Therefore, it is difficult to understand the impact of co-occurring disabilities on EOL experiences. Further research must also extend to the death, dying, and palliative care experiences of NDIS participants of any disability type and consider the formal support they will receive from the NDIS and the other services systems. The NDIA must support research into this phenomenon to ensure that, in line with the goals of palliative care, the suffering of NDIS participants and their families is relieved and that they experience the best possible quality of life and equity in death.

2.15 An Update of the Literature

The search for the initial scoping review was conducted in April 2022. Due to the rapidly changing nature of the NDIS and, therefore, its intersection with other service systems, a supplementary literature search was completed in January 2024. Key lines of enquiry, search considerations and publication selection strategies were consistent with the initial database searches. The updated searches from 01 April 2022 to January 2024 resulted in 2,538 further papers; after removing duplicate publications, 2,504 were identified for title and abstract screening and 126 for full-text screening. The same team performed screening as the initial scoping review, and all conflicts were resolved without adjudication. Additional texts were included through citation tracking and new publication alerts. Our publication listed in 2.2 above was the only publication within the literature that addressed NDIS participants with psychosocial disabilities (PwPD) and life-limiting conditions. This supplementary scoping review contains 43 publications under the SPMI, death, dying, and palliative care line of enquiry; 21 publications under the NDIS and psychosocial disability line of enquiry; and four publications under the NDIS and death, dying, and palliative care line of enquiry. A total of 68 publications were therefore included in the supplementary review. Publication selection flow chart diagrams, based on the Prisma Report for each line of enquiry, can be found in Figures 5-7 below.

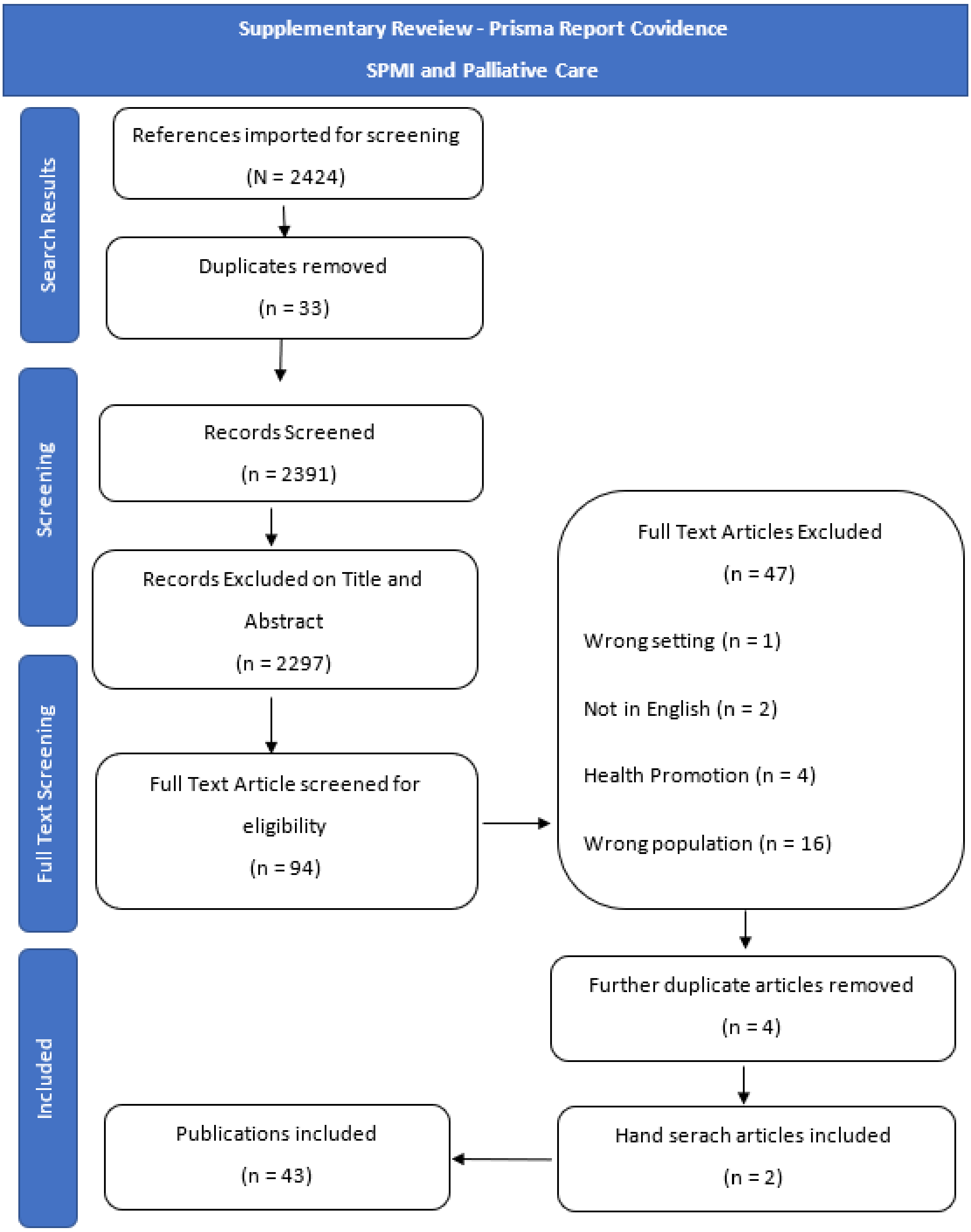

Figure 5: Supplementary Prisma Report Covidence—SPMI and Palliative Care

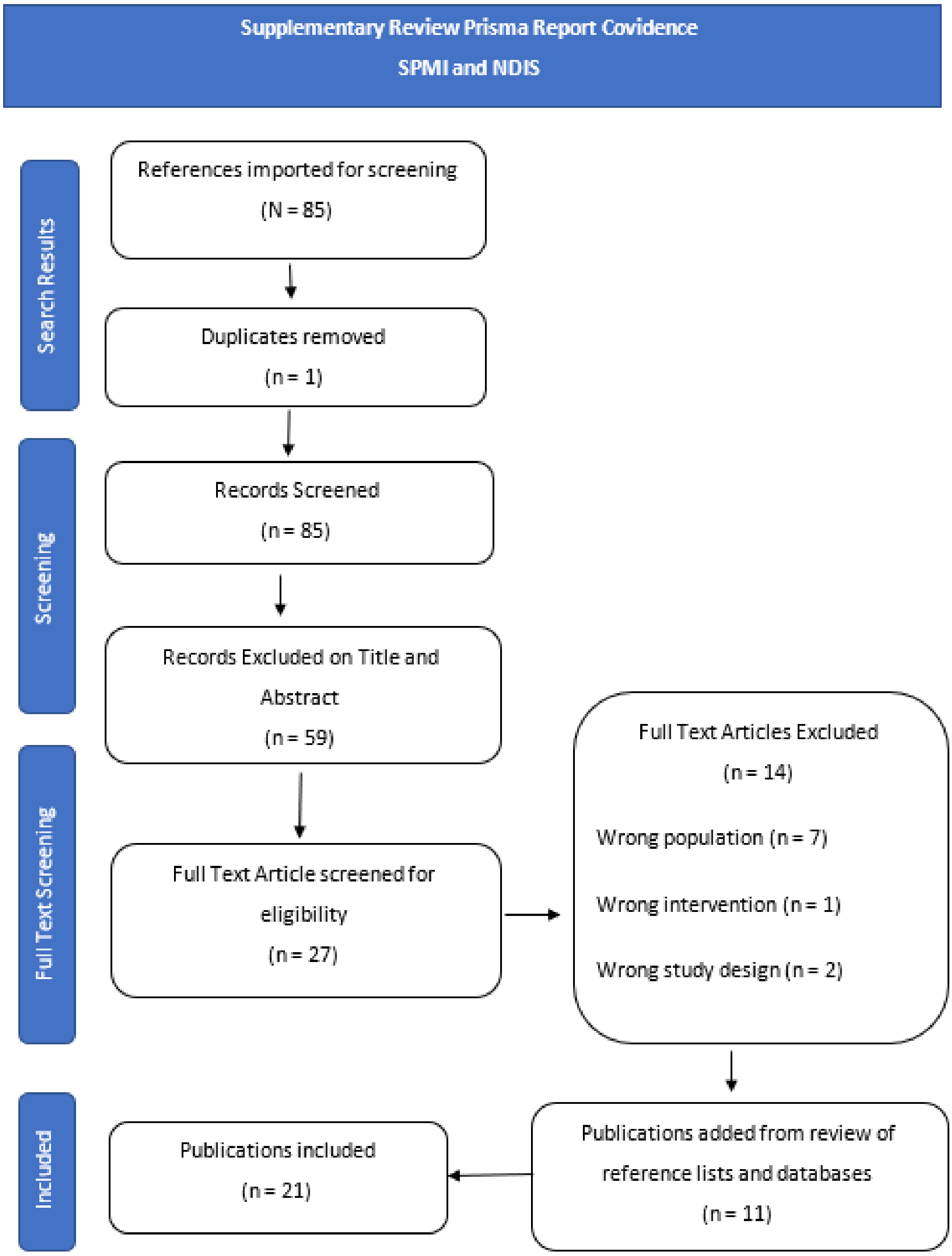

Figure 6: Supplementary Prisma Report Covidence—SPMI and NDIS

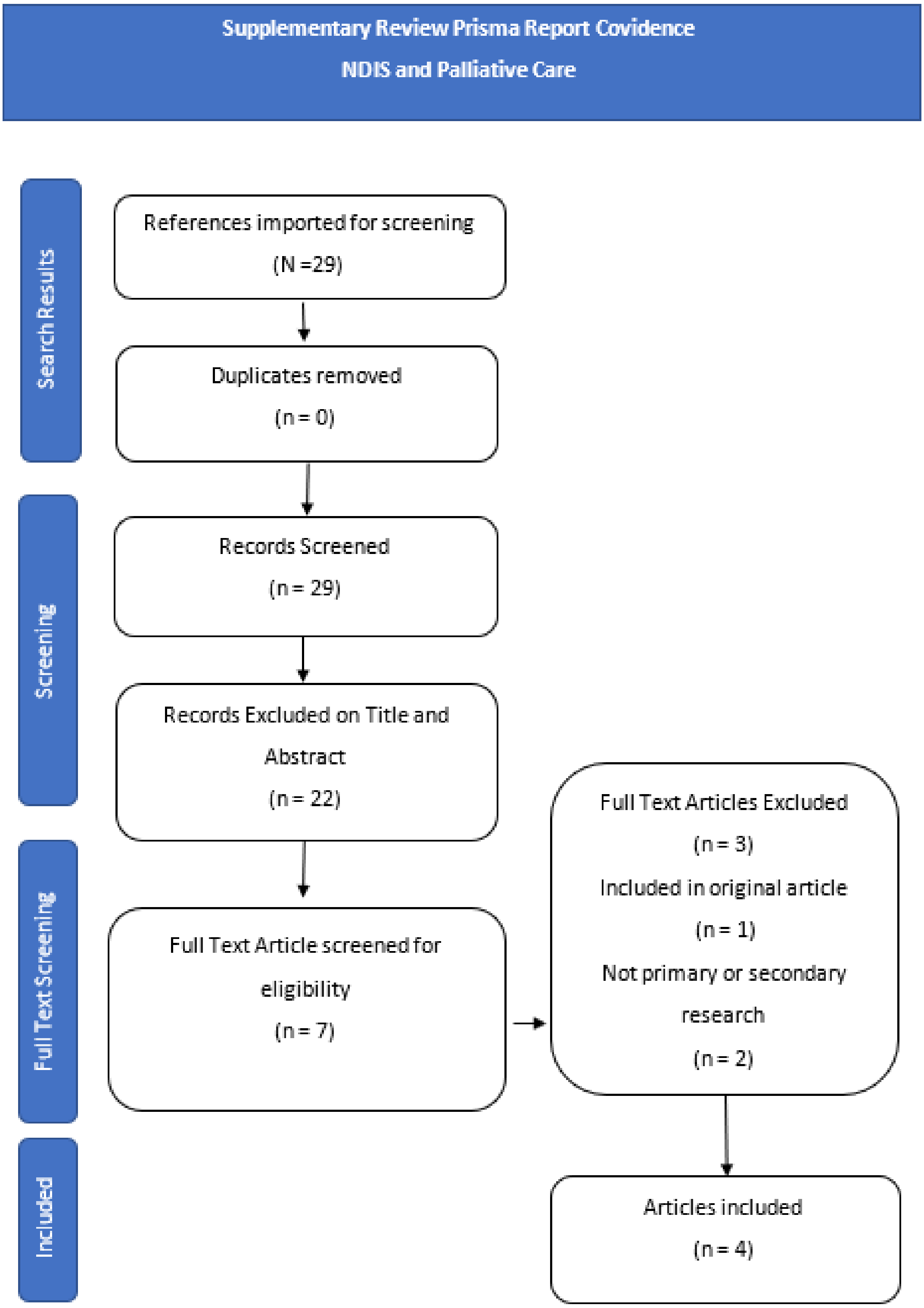

Figure 7: Supplementary Prisma Report Covidence—NDIS and Palliative Care

Repeating the methods found in Section 2.6 above, the NVivo software tool was used to code and sort the literature. The five key themes described in Figure 4 remained relatively consistent across the literature and are described below.

2.16 The Person

Consistent with the initial publication, people with disabilities have been found to have worse cancer care and poorer outcomes [173] and present to emergency departments twice as often as other Australians [65]. People with SPMI or psychosocial disabilities have significant differences in life expectancy than others in their communities. Although there is a significant focus on suicide mortality, the majority die earlier due to physical diseases such as cancer and cardiovascular and respiratory diseases [174-197]. This was attributed to multiple causes, which can be challenging to isolate [198] but include lower quality screening and care [177, 194], socioeconomic factors and quality of life [199], and the side effects of pharmacological interventions [199].

2.16.1 People with Psychosocial Disabilities and the NDIS

Three studies in the supplementary review demonstrated that people with SPMI still find it difficult or are reluctant to identify as having a disability [200-202]. This reluctance may stem from the experience of stigma [164, 165], or they may feel that the concept may not be relevant to them [201]. Dickinson and colleagues [200] found that this particularly impacts people in the prison system where their behaviours that may stem from trauma or intellectual impairment have been "*explained as criminogenic"* rather than disability-related. This may delay diagnosis [203] and, therefore, access to the NDIS [12]. Behaviours of concern can limit choice and control for PwPDs as NDIS providers have more freedom to choose whom they wish to support. This may lead to the exclusion of more complex participants who may not obtain the support they need as there is no longer a provider of last resort in most jurisdictions [52, 200] p 46. Negotiating with the NDIA continues to cause PwPDs significant distress, and the NDIA processes and how NDIA and partner staff speak to them can be "*triggering*" and negatively impact mental health [59, 65].

The importance of trust between PwPDs and their formal support networks was emphasised in the literature [59, 201, 202]. Trust can take a very long time to earn [201], and the loss of regular trusted workers due to implementing the NDIS has been a source of grief for PwPDs [202]. The 2023 NDIS Review [52 p. i] emphasised the need for the NDIS to rebuild the trust of the disability community.

2.16.2 People with Serious and Persistent Mental Illness and Palliative Care

As with the initial review, there are many additional considerations for PwPDs and life-limiting conditions. People with SPMI and life-limiting conditions may suffer additional challenges associated with their shortened lives. The cumulative impact of the "*multiple losses and trauma*" they have experienced during their lives may increase the experience of spiritual distress as they are dying [204]. Additionally, people with SPMI can be highly vulnerable; however, this is not always the case. This perception of vulnerability may contribute to healthcare professionals feeling fearful about discussing the end of life and can create a culture of paternalism and coercion [203]. Behaviours of concern and co-occurring conditions such as substance abuse disorder can make supporting a person with SPMI and life-limiting conditions within palliative care services very complex. Managing symptoms of pain can be difficult due to prior or concurrent use of alcohol or other drugs [203].

2.16.3 Stigma and Marginalisation

Stigma and marginalisation are continuing themes across the lines of enquiry [59, 176, 197, 201, 203-210]. Stigma has been found to impact physical health [176], disability support, housing and health services [201]. Barriers to online information about the NDIS can negatively impact mental health and contribute to increased marginalisation of people with SPMI [210]. PwPDs are still reporting poor experiences with NDIA staff and, partners and NDIS providers, leaving them feeling judged and discriminated against [59]. During a sizeable advocacy-focussed project supporting marginalised people to access the NDIS, it was found that building trusting relationships with service providers was essential to ensure that they do not feel further stigmatised [201]. Those with SPMI and life-limiting conditions are the "*most vulnerable and marginalized groups in contemporary society*"[204]. The stigmatisation they experience from the health system [197, 203, 206-208] can prevent people with SPMI from accessing or receiving optimal support from palliative care services [197]. This can impact the provision of palliative sedation, the preparation of do-not-resuscitate orders and access to voluntary assisted dying (VAD) or euthanasia [203]. Further, if the person with SPMI is deemed to be "*non-compliant*" with medication or treatment, they "*get lost*" in processes and systems [207, 209].

2.16.4 Psychosocial Disabilities, Capacity and Decision-Making

People with SPMI and life-limiting conditions continue to experience discrimination regarding their capacity to make decisions, particularly around advance care planning [203, 211, 212]. Moureau et al. [203] highlighted that the end-of-life choices of people with SPMI are not dissimilar to others; however, there are concerns regarding determining legal capacity, authentic choice versus clinical picture and the "*fluctuating nature of decision-making competence*". PwPDs with greater social capital, particularly those with resourceful and educated informal supports, are more likely to have supported decision-making and less likely to live under restrictive guardianship orders [205]. The 2023 NDIS Review [52 p.7] recommended that NDIS participants be provided better support with their decision-making. Further, the Review recommended assessments on the need for decision-making support, capacity building around decision making and specific training for "*decision-supporters*".

2.16.5 Human Rights of People Living with Psychosocial Disabilities

The general principles of the UNCRPD [41] state that people with disabilities shall have full and effective participation in society. However, the Australian National Psychosis Survey and several other studies found that despite the NDIS and mainstream mental health programmes around the country, social isolation still impacts many Australians with psychosocial disabilities [59, 202, 213, 214].

Stable accommodation is associated with having good physical health [180, 214], and Article 19 of the UNCRPD states that people with disabilities have the right to choose their place of residence [41]. While there have been some improvements [215], access to suitable housing options is often not within the grasp of many Australians living with SPMI, leading to them being unhoused [201, 207, 216]. Often, the only housing option for PwPDs is still supported residential services (SRS), which are private congregate care settings. Many are now also providing NDIS-funded supports. A study by Dearn and colleagues [216] found that these settings impact PwPDs choice and control over their lives, notably where they can live and the supports they can receive. Research participants advised that they were not offered a real choice, that their options would be an SRS or a nursing home, and that residing in an SRS had been imposed as a "*site of containment"* under bail conditions or within community treatment orders. Many palliative patients with preexisting SPMI are homeless, and this negatively impacts them with symptom and medication management [207]. The NDIS review [52] has recognised that genuine housing choices for participants is not fully realised under the NDIS and has recommended actions that "*support participants to exercise genuine choice and control over their living arrangement*" [p. 9].

The right to equitable health care is not being realised for people with SPMI [217, 218]; they are not receiving equitable access to palliative and hospice care internationally [219], and guardians, whilst their presence is strongly supported, have been found "*second-guessin*g" the recommendations of medical professionals [220]. Carney [205] reported that it can be challenging to establish when there are breaches or a lack of compliance with socio-economic human rights, such as the right to health, including equity in the right to health or mental health services.

2.16.6 Quality of Life

Dunn et al. [221] reported that healthcare professionals often assume that people with SPMI have a poorer quality of life, despite this not necessarily always being the case. People with preexisting disabilities, like others, often experience a significant reduction in the quality of their lives when they develop a life-limiting condition. A personalised approach must be taken to ensure that patients' emotional and spiritual needs are addressed and the quality of life is maintained or enhanced [220]. This includes supporting the wishes of people with SPMI to die at home, as many do not wish to die in a hospital [211].

2.17 Advocacy

The supplementary review indicated that the importance of advocacy is a continuing theme throughout the literature [59, 65, 200-203, 206, 207, 216, 222]. Many Australians with SPMI still require advocacy to access the NDIS [59, 200-202]. PwPDs advise that gathering evidence of their disability is fraught and stressful, and they do not feel confident that their health professionals could adequately support them without the involvement of others to advocate [59]. Additionally, the NDIS's ability to offer choice and control depends on PwPDs' ability to advocate for themselves or the presence and capacity of others, both informal and formal, to advocate for them [59, 200, 216]. Without advocacy, PwPDs and people living with SPMI are "*contained*" long-term in SRSs [216], unable to secure other housing [200, 202], and struggling to stay out of prison [200]. A PwPD needs to be "*lucky*" to have the right blend of family and formal supports to advocate for them and navigate the NDIS [202]. Despite specialist support, such as justice liaison officers, being provided by the NDIA, these are still not meeting the needs of people with disabilities trying to access the NDIS and secure plans that can support them appropriately [200]. Specialist outreach advocacy services that can build trust are better placed to advocate for more hard-to-reach communities [201]. This need for advocacy for people with SPMI and life-limiting conditions and their families was also a theme within the palliative care literature [207, 222]. Those without families are often "*lost in the system*" [206] and need the advocacy of their care teams to ensure that they have the support they need as they are dying [203, 206].

2.18 Informal Supports

As found in the intial scoping review, informal support networks were recognised as vital to good outcomes for people with SPMI, life-limiting conditions, and PwPDs [200, 202]. However, limited or turbulent informal supports were continuing themes found in the supplementary search of the databases [200, 203, 206-208]. Informal supports can be appointed as plan nominees, who, once appointed, can make decisions on behalf of NDIS participants [223]. The NDIS Review [52 p. 7] has recommended reforming the appointment process and improving training for NDIS plan nominees. Devine and colleagues found that experienced and educated plan nominees who could navigate multiple systems reported greater satisfaction with the NDIS [202].

2.19 Formal Supports

The second review of publications found that the formal support systems of health, the NDIS, and mental health continue to be inadequate in their support of PwPDs and people with SPMI and life-limiting conditions [59, 173, 197, 201, 202, 209, 213, 214, 220, 224-229]. Due to capacity issues, it can be difficult for service providers to deliver on their promises, and this can impact trust and lead to people with SPMI and PwPDs getting lost in the gaps between systems [201]. Workers and providers need to build strong and trusting relationships with people with SPMI and life-limiting conditions [203], PwPD and NDIS participants with other disabilities [224]. Having those relationships and being able to support people with SPMI when they enter hospitals and emergency departments can lessen their distress [209]. Formal support providers and workers often provide unpaid or unacknowledged services [204, 220, 224]. The impact of workload and difficulties supporting PwPD and people with SPMI and life-limiting conditions on the health, mental health, and disability workforces cannot be understated, with research reporting that they are overwhelmed, stressed, and burnt out [204, 209, 224].

There continue to be significant issues and gaps between the NDIS and the health systems across Australia [59, 230]. There are substantial delays in hospital discharge for PwPDs due to complications with plan implementation for those with complex needs, particularly with housing [230]. Hamilton and colleagues' study found that PwPDs are struggling with health practitioners, particularly GPs, who do not provide the necessary evidence to obtain the support they need from the NDIS [59]. Mental health nurses report significant concerns when transferring their clients from mental health facilities to hospitals and encounter negative attitudes and stigma from the hospital staff supporting their clients [209]. Their ability to advocate can also be limited by health system hierarchies [209], and they work under the grid, sometimes "*breaking the rules*" in order to provide patient-centred care to people with SPMI and life-limiting conditions [204]. The NDIS Review [52 p.8] has recommended that the interface between mental health systems and the NDIS be strengthened and that more mental health supports should be funded by all governments beyond those offered by the NDIS.

2.19.1 NDIS

Despite some reports of good outcomes [200, 202, 215], as with the initial scoping review, there are still significant issues with the NDIS for people with SPMI and PwPDs. The loss of mainstream service funding due to the implementation of the NDIS continues to be flagged [215, 222], as does the inflexibility of the NDIS [202], limited choice and control [59, 200, 216, 224, 230, 231] and poor plan utilisation[202]. Some PwPDs are unaware of what kinds of supports are available under the NDIS [59, 200, 201] and are often fearful of losing existing supports [59, 200-202, 210, 214, 232]. The changing demands and inconsistency of decisions by the NDIA [59, 65] and the high administrative burden [135, 162, 167, 189] negatively impact PwPDs' mental health [59, 65]. The review processes are confusing for participants, informal and formal supports, and, as Townsend reported, the Administrative Appeals Tribunal members and legal scholars [233]. Access criteria and processes are still causing considerable distress [200, 201], and the NDIS Review has recommended that changes be made to improve clarity, transparency and consistency [52 p. 91]. PwPDs feel disempowered by the NDIA and their partner organisations, particularly with their staff's poor understanding of psychosocial disabilities [59, 65, 202, 213] and deficits-based approach [65], which often results in insufficient NDIS plans [59, 200]. Communication issues, particularly the use of policy language [201], a lack of clarity [233] and jargon used [59] by the staff of NDIA and their partners alongside a difficult-to-navigate NDIS website [210], were listed as critical areas of concern.

Foley and colleagues [224] explored the "*uncomfortable relationship between profit and care*", the quality of NDIS supports and the safeguarding of NDIS participants. The limited capacity of the NDIS Quality and Safeguards Commission to adequately regulate the market is causing increased vulnerability and harm for NDIS participants, was identified as a key area of concern in the 2023 NDIS Review and several other publications [52, 215, 216, 224, 231]. The NDIS Review recommended that "*substantial actions be taken to "strengthen the regulatory response to long-standing and emerging quality and safeguards issues*" [52 p. 13]. Too few providers and support options, or a "*thin market*", is still a concern, particularly in rural areas [59, 200, 210, 224, 234]. Further, the lack of a "*provider of last resort*" for highly complex participants is particularly concerning [200]. There are concerns that providers are either unwilling to take on complex participants [200, 224] or accept referrals due to high budgets but cannot provide high-level supports [200], which can put both participants and workers at risk of harm. The need for increased market stewardship to manage these inequities has been underscored [52, 200, 210, 234], and the NDIS Review has recommended that all governments coordinate NDIS market monitoring and develop tools and strategies to manage supply gaps [52]. The changing, market-based disability reform has left some informal supports and participants feeling that business and financial interests now take priority over the quality of services. However, in the same study, NDIS providers reported placing participant needs above financial interest [224]. PwPDs report that NDIS providers are rigid about the kinds of supports they will provide [59], and some advised Foley and colleagues that they refuse to provide functional assessments in the format the NDIA demands [224]. Dearn et al. expressed concerns about NDIS providers, namely SRSs, offering multiple in-house supports, limiting choice and control and not managing issues with conflict of interest [216]. There have been significant workforce issues, with high staff turnover [59, 200], no opportunity for PwPD to choose their workers [59], and staff that have no understanding of psychosocial disability [59, 202, 215, 224]. The NDIS Review has recommended that a "*support-specific Practice Standard*" be developed and that all NDIS providers delivering psychosocial supports should be registered and compliant with the standard [52 p8].

Two studies addressed end-of-life care by NDIS Providers: Walker et al.[222] researched end-of-life care for NDIS Participants with physical disabilities, and Wark et al. [220] studied the quality of life of NDIS participants with intellectual disabilities and life-limiting conditions. Critical issues identified within these studies were fragmented systems, communication with participants, carers and other system workers, the capacity to manage symptoms, the availability of suitable providers, and the need for trained and skilled workers.

2.19.3 Palliative Care

As with the previous review, people with SPMI and disability are still experiencing significant barriers to optimal palliative care and specialist palliative care services [173, 203, 207, 208, 219, 220, 235, 236], leaving them with "*no right place to die"* [206, 209]. The confusion about what palliative care is remains [207]. Grindrod [236] stated that palliative care providers must modify their practice to provide better end-of-life care for people with disabilities. Communication issues [173, 203] and the fear of discussing death and dying with a person with SPMI continue to trouble palliative care clinicians [203, 207]. Ethical dilemmas [203, 207], and perceived or actual vulnerability of people with SPMI may lead to paternalism and a "*framework of coercion*" around end-of-life choices [203], advanced care planning [212], and voluntary assisted dying [203]. As discussed in Section 2.10.3, symptom control for people with SMPI and life-limiting conditions can be more complex around pain management and co-occurring AOD use [203], poly-pharmacy issues, combining mental health and pain medications [208] and medications for breathlessness [219]. The perception that people with SPMI experience pain differently than others persists, although others understand that this may be an issue of communication [203]. There continues to be reported clinician discomfort caring for people with SMPI and life-limiting conditions due to unpredictable behaviours, drug use and violence [207, 236, 237]. Prioritising people with SPMI being able to die in the place of their choosing is critical; this may be well supported with the investment of foundational support that has been recommended by the NDIS Review, which may enable people with SPMI and PwPD to gain additional home care support and equipment beyond those provided by the NDIS if they develop a life-limiting illness [52 p4].

2.20 Training

Across the literature, there is an emphasis on insufficient training for the health, mental health and disability workforces. As found with the initial database searches, recommendations included palliative care and mental health clinicians learning how to better support people with SPMI and life-limiting conditions [203, 206, 207, 235]; NDIS training for health workers [65] and the need to upskill the NDIS workforce regarding psychosocial disabilities [59]. Importantly, Walker et al. [222] and Grindrod [236] found that disability support workers seek training around end-of-life care trajectories. Upskilling of the NDIS workforce has been recommended in the NDIS Review [52 pp. ii & 12]. Recent projections now indicate that there will be a total of 1,030,337 NDIS participants [4], many of whom are likely also to have poor mental health [238], and specifically, there will be 86,712 NDIS participants with a primary psychosocial disability [4]. Despite recognising that the NDIS workforce is often unskilled and requires additional training to support people with psychosocial disabilities, it is interesting to note that they have not been considered in the National Mental Workforce Strategy (2022 – 2032) [239], demonstrating the continued siloing of various parts of the system (mental health, disability and palliative care) and their workforces.

2.21 System Design Issues

Again, issues with siloing and a lack of integrated care were prominent in the literature [59, 65, 200-203, 206, 230, 231, 235, 236, 240]. Limited knowledge about other systems' service provisions [65] leads to people with SPMI and PwPD being shunted between services [59, 65] and falling into the gaps between systems [200-203]. It was reported that PwPD and people with SPMI have better outcomes when regular workers and clinicians support them in health settings [65, 209]. Integrated and comprehensive case or care management was advanced as best practice to support PwPD and people with SPMI with complex needs across systems [200, 201, 207, 222, 230]. It is also crucial to include the person with SMPI where possible [180]. Foster and colleagues advocated investing in one-to-one support to achieve optimal results in care planning [230]. As with the initial scoping review, there were multiple calls within the literature for increased collaboration and communication between systems [65, 173, 200-202, 207, 222, 231, 236]. However, understanding and operationalising the NDIS principles to determine the responsibilities of the NDIS and other service systems can be challenging [200]. There were recommendations for governments to simplify systems to improve user navigation [165] and map services to monitor the effects of significant reforms [210, 234]. The NDIS Review also recommended that the NDIA develop tools to support NDIS participants and service navigators to help them demonstrate participant needs and pool NDIS supports [52 p. 11]. It is essential that service users and providers actively participate in system improvements [203]; however, the current funding within ILC grants is insufficient to facilitate this process [236]. The NDIS Review [52] has strongly recommended that all governments work together to improve coordination between systems and that:

> *"National Cabinet should agree to a multilateral schedule to a new Disability Intergovernmental Agreement that replaces the principles for determining the responsibilities of the NDIS and other service systems, including the Applied Principles and Tables of Supports to better clarify respective responsibilities."* [52 p. 5]

2.22 Research

The paucity of research on the experiences of people with SPMI and life-limiting conditions, the need for further research on differences in treatment, capacity around end-of-life decision making and mortality outcomes [173, 174, 177, 181-184, 186, 188, 190, 194, 196, 198, 212, 217, 218, 230, 237, 241] continue to be reoccurring themes across multiple articles and government publications. Further research on the experiences of PwPDs and the NDIS [59, 65, 202, 213, 230, 232, 242] and the views and experiences of palliative care clinicians [219], person-centred care for people with SMPI and life-limiting conditions [208] and on stigma within palliative care settings was recommended [197]. The need to include the voices of people with lived experience in research [197, 203, 206, 231, 232, 243] was emphasised. Additional recommendations were made for future research on the online experiences of NDIS participants and applicants [210] and the impact of delayed discharge on participants, particularly exploring regional differences [230] and disability and palliative care sector partnerships [235, 236]. The NDIS Review recommended improved disability reporting mechanisms and establishing a Disability and Research Fund to enable further research and independent evaluation of the NDIS that the Commonwealth and the States would jointly fund [52 p. 15].

2.23 Final Conclusion

The database searches conducted in April 2022 and January 2024 confirmed that there has been no research into the death, dying, and palliative care experiences of NDIS participants with psychosocial disabilities and life-limiting diagnoses, demonstrating the pressing need to understand this experience. Early mortality due to physical diseases, stigma, and poor quality of life continue to plague people with SPMI, and it is essential to ensure a streamlined pathway between the multitude of systems within Australia’s formal support systems. Unfortunately, clinician discomfort working with people with SPMI and life-limiting conditions continues to be a concern. PwPD, their informal and formal supports, still struggle to understand the NDIS and do not receive consistent and transparent communication and decisions from the NDIA.

The two scoping reviews found that concerns continue regarding the impact of the marketisation of disability support, particularly around the quality of supports and safeguarding NDIS participants. Cross-training on palliative care and psychosocial disability for workers in the NDIS, health, mental health and other mainstream systems has been recommended by researchers and by the 2023 NDIS Review. The NDIS Review has recommended actions to ensure greater transparency, clarity and training. Notably, “Recommendation 2” [52] calls for replacing the current principles for determining the responsibilities of the NDIS and other service systems with a multi-lateral schedule. The supplementary review found two specific studies on the end-of-life experiences of NDIS participants, one that included participants with physical disabilities [222] and the other included participants with intellectual disabilities [220]. Both studies identified significant systems-based issues and recommended future research in this space. This scoping literature review has highlighted the need for further research into the experiences of PwPD and life-limiting conditions and demonstrates the importance of stakeholder engagement, including the input of PwPD, their informal supports, and the health, mental health, and NDIS workforce in research and in developing the new multi-lateral schedule and the proposed foundational supports.

CHAPTER 3 – RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

The scoping review found that NDIS participants with psychosocial disabilities (PwPDs) have variable experiences with the National Disability Insurance Scheme (NDIS). Significant issues exist with NDIS access, planning, provider availability, workforce training, and experience. Internationally, people with severe and persistent mental illnesses have poor end-of-life experiences. The scoping review found that, to date, there has been no research into the palliative and end-of-life experiences of PwPDs and life-limiting conditions. This study explores the formal support PwPDs are likely to receive once they develop life-limiting conditions.

A progressive rollout of the NDIS across the country commenced in 2013 and was available to all Australians (full scheme) on 1st July 2020. Therefore, this phenomenon and the collaboration between formal systems and PwPDs experiences are not yet understood. A qualitative systems dynamics approach was adopted where in-depth qualitative interviews inform and enable preliminary systems modelling across systems. Below is a summary of dynamic systems theory or systems thinking outlined by Meadows and Wright [244], the qualitative data collection methodology of qualitative description outlined by Sandelwoski [245, 246], reflexive thematic analysis as described by Braun and Clarke [247] and a framework for understanding and changing systems as described by Foster-Fishman et al. [248].

3.2 Dynamic Systems Theory or Systems Thinking

Primarily developed in the 20th century, systems thinking has multiple disciplinary origins, including biology, psychology, mathematics, management, anthropology, computer science, and physics [249]. Donella Meadows was a pioneer in dynamic systems theory and practice [250] and was keen to see that it was used in analysing real-world problems [244 p. X]. This theory holds that systems are more than the sum of their parts; the flow of information impacts the interconnections within systems; systems behaviours stem from their structures; and it takes time for a system's behaviour to be revealed [p188]. Meadows and Wright [244] describe systems as more than the sum of their parts; they consist of elements, interconnections, and functions or purposes.

> *"A set of elements or parts that is coherently organised and inter-connected in a pattern or structure that produces a characteristic set of behaviours, often classified as its "function" or "purpose". [244](p188)*

To date, simple, linear cause-and-effect models have not addressed the more complex issues that plague public health and human services [251]. As evidenced in the scoping review, siloing and fragmentation of services between and within health and human service systems is a well-known complexity experienced in Australia and internationally. Further, the scoping review found that PwPDs and other people with severe and persistent mental illnesses (SPMI) experience significant gaps at the intersection between systems, and this adds to the complexity of their experiences. Therefore, it is crucial to acknowledge that many elements can impact the phenomenon of formal systems that support PwPDs and life-limiting illnesses. To adequately inform disability and health policy on complex problems, research must provide governments with evidence that accounts for the interplay of elements that impact the phenomenon. As systems are dynamic, effective policy change should be an iterative process. It is essential to learn from incremental changes to systems as often the impacts of change may not be fully understood prior to implementation [251]. Post-implementation feedback and evaluation should continuously occur to understand how each system element responds to the change and its impact on the whole system [251]. Policy decisions based on linear models intent on improving outcomes, efficiency, and cost-effectiveness can lead to runaway feedback loops [244] that negatively impact the whole system [252].

The most relevant systems principles that inform this study are outlined below.

3.2.1 Stocks, Flows and Dynamic Equilibrium

The foundation of every system is stocks, a quantity of material or information that can be seen, felt, measured, and counted and can be as simple as the amount of water in a bathtub and the number of workers in a workforce or as abstract as the reserve of goodwill held by a business. Stocks alter through, often multiple, inflows and outflows. If the inflows equal the outflows, a dynamic equilibrium occurs where the stock levels remain more or less steady. However, if the outflow exceeds the inflow, the system stocks will be reduced. Without corrective action, stocks can be depleted entirely. Equally, if the inflow exceeds the outflow the stocks can become too large. Stocks provide a buffer within systems, allowing for changes in inflow and outflow and corrective action to occur to maintain a dynamic equilibrium. As stock levels usually change quite slowly, there is often sufficient time to apply corrective action/s to help maintain systems. However, if corrective actions occur too quickly or slowly or are not appropriate, there can be catastrophic outcomes, including systems that are out of control, have unintended consequences, or collapse [244] [pp17-20].

Some stocks, such as NDIS or health funding, the NDIS workforce, or the NDIS marketplace (NDIS providers), can easily be conceived. For example, NDIS "stock" levels can maintain their equilibrium by ensuring that inflow (NDIS funding) matches outflow (funding allocated to the NDIS Participants' plans). However, if NDIS costs are higher than anticipated, to ensure adequate stocks (funding) are maintained, there will need to be either an increased inflow (more funding received from governments) or a decreased outflow (less funding allocated to NDIS participants' plans).

Other stocks, such as worker skillsets and goodwill, NDIS participants' and Australian society's trust in the NDIS and government, may be less tangible. The stock of goodwill and trust of Australians with disabilities increased through the introduction of the NDIS, a scheme that aligned with the United Nations Convention on the Rights of People with Disabilities [41]; however, that stock can decrease through policy debate between political parties and sustained media reporting about negative participant experiences and the cost of the NDIS. Sufficient stock can act as a buffer in the system, i.e. if there is an abundance of goodwill and trust in the NDIS, it can be sustained even if there are some news reports that the system is not operating well.

3.2.2 Feedback Loops

> *"A feedback loop is a closed chain of causal connections from a stock, through a set of decisions or rules or physical laws or additions that are dependent on the level of stock and back again through a flow to change the stock. "*[244 p. 189]

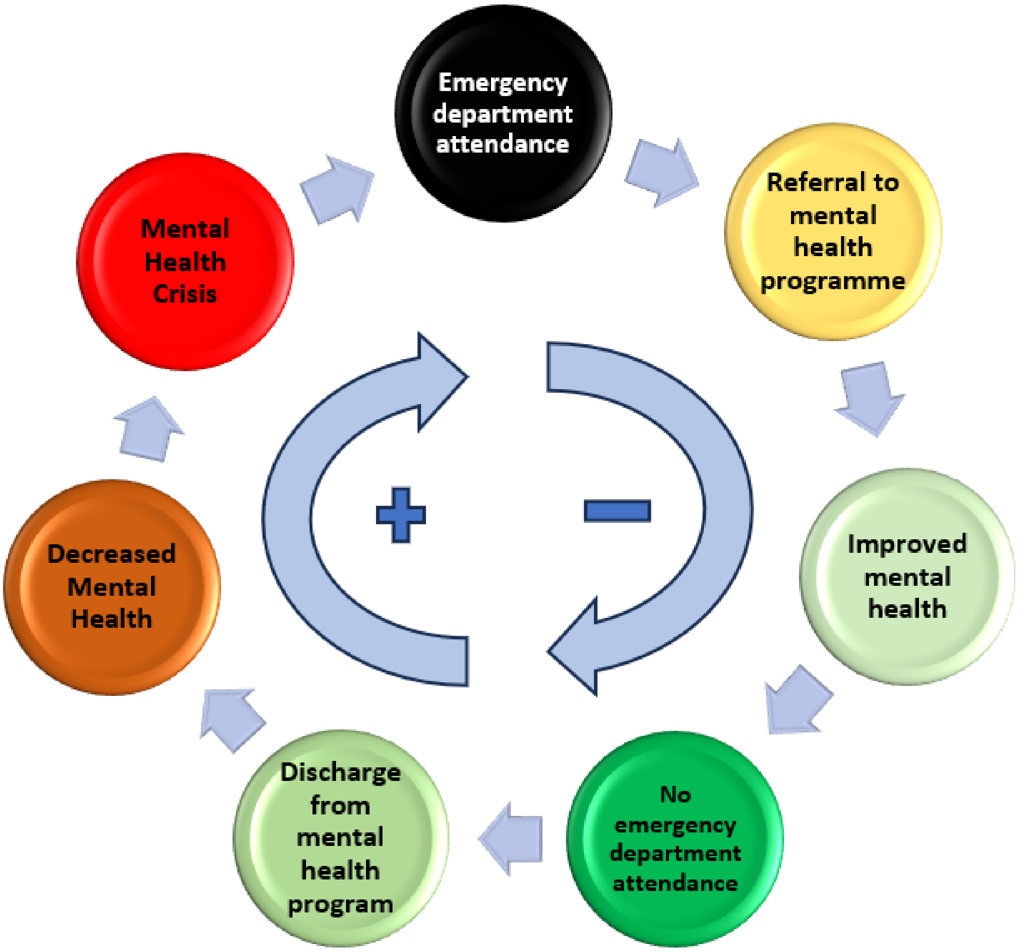

Figure 8: Balancing Feedback Loop Mental Health Presentations in the Emergency Department

Balancing feedback loops keeps systems stable; a simplified example of a balancing loop would be Figure 8 – Balancing Feedback Loop Mental Health Presentations in the Emergency Department.

Reinforcing feedback loops are "*self-enhancing*" and occur when events or behaviours inside the loop reinforce one another, as demonstrated in Figure 9. Reinforcing feedback loops can lead to "*exponential growth or runaway collapses*". Feedback loops can only impact the future behaviour of systems, which is an important consideration when implementing system changes. Feedback loops cannot supply information fast enough to enable corrections within current feedback [244 p. 189] and long delays in feedback loops require actors to predict and prepare for potential oscillations [244 p. 105].

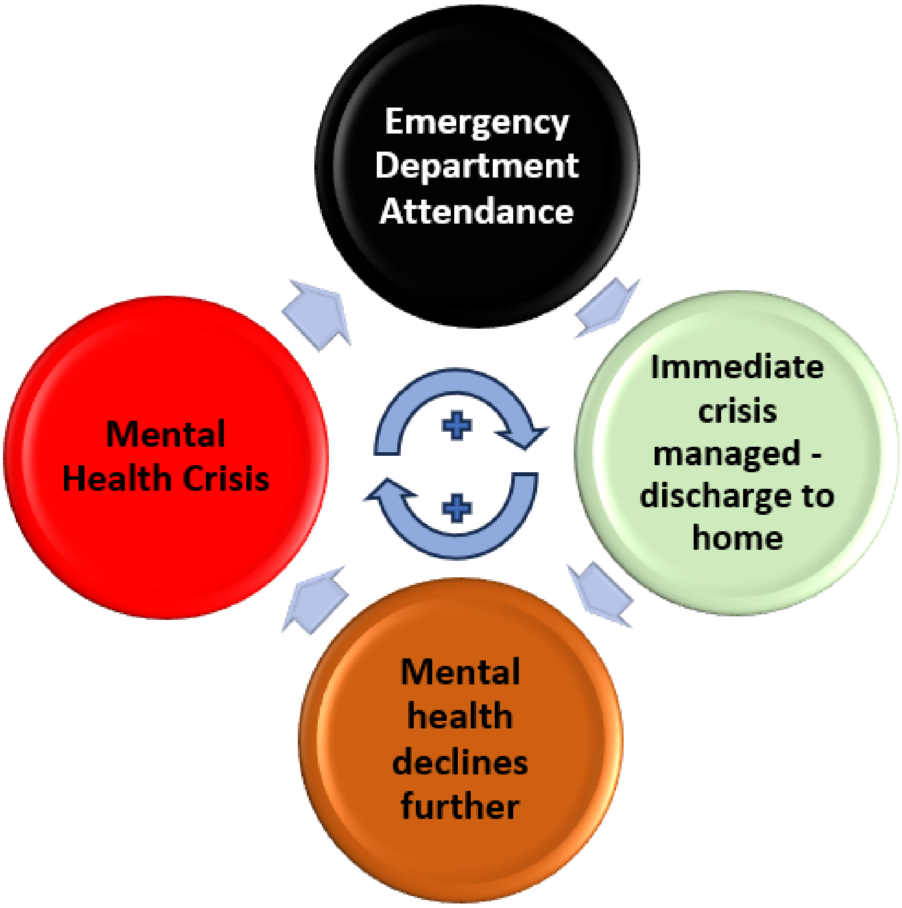

Figure 9: Reinforcing Feedback Loop Mental Health Presentations in the Emergency Department

Another example of a reinforcing feedback loop is disability support in Australia. The 2023 NDIS Review [52] found that the redirection of funding from other effective programs to the NDIS and the closure or reduced support of other mainstream services for people with disability has resulted in the NDIS becoming "*an oasis in the desert*" [52 p.24]. These issues have resulted in people with disabilities only having the NDIS as the only system where they can gain support. These issues have led to more NDIS applicants and participants, increased support requests within NDIS plans, exponentially rising costs, and sustainability issues for the scheme due to these reinforcing feedback loops. Additionally, unmet needs are being widened for populations that are not eligible or receiving the NDIS [253].

3.2.3 Shifting Dominance, Delays and Oscillations

Changes and delays in feedback loops can make a system's behaviour oscillate unpredictably. Changing policies and processes very quickly or in the wrong direction to correct an issue can cause oscillations in system behaviour that can make it difficult to interpret how the system is and will respond to further changes. The lengths of delays in feedback loops can also change system behaviour, making it much more complex. The strength dominance of the multiple feedback loops may also alter as the system behaviour changes [244 p. 45]. The 2023 NDIS Review is a five-year sequenced and staged implementation of its recommendations [52 p 50]. The Review stated this was "*to learn from implementation and make necessary changes and adjustments*" [52 p.215]. The approach recommended by the review should assist with understanding feedback loops and system behaviour before implementing the next raft of policy changes. PwPDs and life-limiting conditions need to utilise multiple systems, each with internal shifting dominance, delays, and oscillations. The impact of these factors across multiple systems is likely to have an exponential impact on the PwPDs with life-limiting conditions, as each system's reactions may have unpredictable flow-on effects on other systems.

3.2.4 Constraints in Systems

Systems cannot grow forever, and resources either flow-limited (can only occur at a specific rate) or are stock-limited (such as oil reserves). Systems with reinforcing loops need balancing loops to constrain growth [244]. For example, there are limited tax-payer-funded budgets for health, mental health and the NDIS. Although governments regularly meet to increase annual budgets, these systems cannot grow or provide services beyond their allocated budgets or beyond what the Australian economy can manage. Competition for funding between systems, political cycles and public opinion further constrain and cause oscillations within the NDIS and other systems.

3.2.5 Resilience, Self-Organisation and Hierarchy

Systems must be flexible and resilient and withstand variations and oscillations to survive. If systems are too rigid and inflexible, they become fragile. A resilient system often has multiple feedback loops that can work independently through different mechanisms, so there is no single point of failure. There are limits to resilience [244 p 76].

Systems self-organise, Meadows and Wright describe this as:

> *"…the ability to structure themselves , to create new structure, to learn, diversify, and complexify. Even complex forms of self-organisation may arise from relatively simple organising rules – or may not." [244 p. 81]*

NDIS providers self-organise; they organise and reorganise in response to rules, rule changes, or oscillations within systems. For example, the introduction in 2018 of the National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules [254] saw providers reorganising their businesses and deciding whether they would continue providing support to NDIS participants that required restrictive practices. They reorganised their business models, educated their workforce, and changed their systems, policies, and procedures to adapt to the changed legislation and requirements. These decisions may have caused unintended consequences for the NDIS.

Systems have hierarchies, which Meadows and Wright advise should be built from the bottom up, and the purpose of the upper levels of the hierarchy is to serve the lower levels. Subsystems can develop and work independently of the upper levels of hierarchies; this can also mean that it is possible to restructure parts of a system, the upper layers or other subsystems without having a significant impact on all of the subsystems contained within the system [244 pp 83-84]. For example, an NDIS provider can restructure their board without impacting its support workers' day-to-day operations.

3.2.6 Other Relevant System Principles

Dynamic system theory holds that "*the world is a continuum*" [244 p. 190] and that systems' boundaries are usually by agreement. The Applied Principles and Tables of Support of the NDIS and Other Systems (APTOS) [8], which was agreed upon between the state, territory, and Commonwealth governments in 2015, loosely describing the boundaries of Australian health and human services, is an example of this kind of agreement.

Relationships within and between systems are not linear

> *"Many relationships in systems are non-linear. Their relative strengths shift in disproportionate amounts as the stocks in the system shift. Nonlinearities in feedback systems produce shifting dominance loops and many complexities in system behavior."* [244 p. 94]

Meadows and Wright further argue that, "*There will always be limits to growth*" [p 190], and there are usually layers of limits within complex systems. The input into a system that is most important is the one that is, at that particular time, limiting the system.

3.2.7 Bounded Rationality

Meadows and Wright [244 pp.105-110] include bounded rationality theory, as described by Herbert Simon, in their systems principles. This theory posits that people, rather than making what would be considered perfectly rational choices, make decisions that are reasonable to them based on the information that they have at the time. When making decisions, people attempt to satisfy their immediate needs or short-term best interests (which may be rational or otherwise and likely are based on varying degrees of evidence) and often do not consider the full range of possibilities or long-term consequences on systems. This is particularly relevant when considering what may happen for PwPDs and life-limiting conditions. For example, upon learning that their patient is an NDIS participant, an overworked and underfunded clinician within the health system may assume that the NDIS will fund all of their disability needs without further input from their system. From their perspective, that worker would not have to undertake their usual extensive activities (meeting their immediate need) trying to locate equipment or other functional supports for their patients. Without considering the full range of possibilities, the impact on the PwPDs and life-limiting conditions could be catastrophic, not only because they would likely not receive the support that they need at the end of their lives but also because these additional stressors may make their end-of-life experiences unreasonably distressing.

3.2.8 System Traps

Meadows and Wright [244] (pp115-116) describe a variety of system traps that occur in dynamic systems. Below are some system traps that may impact the NDIS and other mainstream systems.

- A particularly relevant trap for this research is *policy resistance*. When policies are changed to improve outcomes, balancing feedback loops can cause resistance. Each subsystem or actor's bounded rationalities may see them attempt to "correct" situations to maintain their own goals, which may not align with the goals of the policy change. For example, to ensure that PwPDs and life-limiting conditions obtain the support they need as they die, NDIS providers, palliative care clinicians, and NDIA planners may bend the rules to obtain or approve equipment and supports that are not within the NDIS budget. This funding creep, along with masking funding deficits within other systems, meeting these short-term goals, which are patient-centred and objectively decent, does not align with the policy goals of the NDIS and may impact the long-term sustainability of the NDIS.

- With the concerns about the sustainability and claims of abuse of the NDIS [52], *the tragedy of the commons* is undoubtedly a system trap worth consideration. The tragedy of the commons is when users who benefit from a resource also share the cost of the abuse or overuse of that resource. When abuse of the NDIS, such as providers overservicing or individual participants or informal supports using NDIS funding for everyday items, there may be less funding for participant plans in the longer term, or fewer disability types or supports may be included within the NDIS.
- When there is a perception that systems are performing poorly, it can create a reinforcing feedback loop where performance goals are progressively eroded and corrective actions are not implemented, causing the system trap of a *Drift to Low Performance*.
- *Escalation* is a reinforcing loop in the other direction, where stocks attempt to surpass each other, leading to exponential growth and the eventual collapse of a system. An example of this system trap may be that a lack of support outside of the NDIS is driving greater numbers of Australians to obtain access and support from the NDIS. Once a person becomes an NDIS participant, they may learn of the support options other NDIS participants receive and apply for these higher levels of support regardless of whether their support needs are the same. These requests may be instigated by NDIS providers intent on survival and growth, recommending that all of their participants apply for certain types of supports within their plans.
- The NDIS attempts to offer choice and control for NDIS participants by ensuring a diverse range and quantity of providers to choose from. This should lead to greater competition in the disability markets. However, the *Success to the Successful* system trap may impact this. The system trap is a reinforcing feedback loop where the winners in competitive markets are systematically rewarded for winning again, and "losers" are eliminated from the market.
- The system trap/reinforcing feedback of *Shifting the Burden* to the Intervenor is where "*the intervention designed to correct a problem causes the self-maintaining capacity of the original system to atrophy or erode*" [244 p. 135]. The NDIS Review found that this has already occurred, with the NDIS becoming the only disability support available, and that the rest of the disability ecosystem has eroded [52 pp. 24-25].
- *Rule beating* is another system trap where the rules that govern systems can lead to situations where actors appear compliant but act in ways that distort the system. Minister for the National Disability Insurance Scheme, The Hon Bill Shorten MP and the Assistant Minister for Competition, Charities and Treasury, Hon Dr Andrew Leigh MP, released a joint statement that claimed in NDIS providers are charging "*exorbitantly jacked up prices for essential services, supports and equipment*" [255]. If these claims are correct, NDIS providers were engaging in activities that, at that time, were compliant with the rules but were acting in ways that distorted the NDIS. The ministers advised that the NDIS rules would be changing to prevent over-charging participants and, by extension, the NDIS.

- *Seeking the wrong goal* is a system trap where inaccurate or incomplete goal definitions can lead to outcomes that are not in line with the system's intent despite all parties following the rules of that system. The NDIS funds reasonable and necessary supports for NDIS participants; however, the 2023 NDIS review found that the term and concepts are poorly defined. The review found that this had led to outcomes such as "…*stressful, time-consuming and poor planning experiences, inconsistent and inequitable decisions about funding and disputes between participants and the Agency*" [256].

3.3 Qualitative Research

Qualitative studies are beneficial when little is known about a topic [1 p.18], and this, therefore, is an ideal method for exploring the formal supports and experiences of PwPDs and life-limiting conditions, as there has been no prior research on the phenomenon. Qualitative research allows in-depth exploration of a phenomenon and allows the researcher to generate themes from the data. There are often assumptions about qualitative research, such as that it is "not scientific", can only produce subjective accounts, and cannot contribute to an evidence base for broader practice and policy [257 pp. 22-27]. Through disciplined data collection methods and analysis, ensuring critical scrutiny of assumptions and maintaining critical distance, qualitative research enables us to understand more about the phenomenon in question [257 p4]; it aims to explore and understand research participants' experiences, perspectives and opinions [257 p12]. Further, it is an iterative, inductive, and flexible approach that allows multiple meanings and understandings, and each perspective is treated as valid rather than seeking a single "truth" [247 p. 6.]

Ontologically and epistemologically, this study is based on a pragmatic perspective, which acknowledges that human actions cannot be separated from past experiences and that people consider the possible consequences before taking action and use the outcomes of prior actions to predict the consequences of similar actions. Pragmatism holds that knowledge is socially constructed, that reality is not static and that "*Truth is whatever proves itself good or what has stood the scrutiny of individual use over time*" [258]. Pragmatic researchers do not have to commit to a particular research method and "*address their research questions with any methodological tool available*" [258]. The rise in the "*what works*" approach of pragmatism has been criticised as veering towards a positivist approach [259] and "*delinks pragmatism from its important philosophical roots" [260].* However, the "*what works*" approach can help validate the research question, allow for multiple truths and help focus on the interviewees' perspectives regarding what is working or not working [260]. Therefore, the pragmatic approach is particularly useful for this research as the model of transformative systems change being utilised requires "*an integration of conceptual orientations*" of soft systems methodologies, dynamic systems theory and qualitative description [248].

3.3.1 Qualitative Description

As outlined by Sandelowski [245, 246], qualitative description is a pragmatic starting point to provide an account that is "*valid at the level of description",* which Green states enables further thematic and theoretical analysis [257 p. 257]. Whilst qualitative description has been criticised or lauded as simple reproduction, it is still interpretive [245]. Unlike other qualitative research forms, such as grounded theory, ethnography, and phenomenology, it does not require "*a conceptual or highly abstract rendering of the data*". Qualitative description studies allow the researcher to "*present a comprehensive summary of an event in the everyday terms of those events"* [245, 246] in a manner that is appropriate for its intended audience. However, qualitative descriptive studies are still more interpretive and subjective than quantitative studies, which are more restrictive and limited by the boundaries imposed by the researcher and cannot provide the additional context that can be found with qualitative research.

3.3.2 Thematic Analysis

Thematic analysis is a valuable qualitative approach to inform policy and practice in health and human services [261]. It is a form of data analysis that builds findings inductively from raw data to conceptual themes and presents them in a straightforward way that is accessible to most audiences [261]. Thematic analysis is not bound to particular theories and can be considered a "*theoretically flexible method rather than a theoretically delimited methodology*" [247 p 5]. Critical reflection on researchers' roles, pre-existing knowledge and social status is vital in reflexive thematic analysis. In qualitative research, researcher subjectivity is viewed positively and engaged with in an explicit way [247 p 8].

3.4 Transformative Systems Change Framework

Recognising that there was a dearth of frameworks to assist with positive change for human services and community systems, Foster-Fishman and colleagues [248] designed a broad framework that provides stakeholders and researchers with a guide to analyse, evaluate and understand system functioning and "*identify levers for change"*. This approach incorporates the qualitative methodology and dynamic systems principles, such as those described by Meadows and Wright [244].

The approach has four steps, as listed in Table 1 below, adapted from Foster-Fishman et al.'s Fig. 3 Essential components of transformative systems change [248].

Table 1: Foster-Fishman et al.'s Essential Components of Transformative Systems Change

Components of Transformative Systems Change		Component Addressed
Bounding the System	• Problem definition • Identification of the levels, niches, organisations, and actors relevant to the problem.	The scoping review found in Chapter 2 explored the systems and potential gaps in knowledge and assisted in the generation of the research question and identifies the levels, niches organisations and actors relevant to the problem, which can be found in Chapter 3 - Section 3.6.1. A deeper and richer understanding of system problems, levels, and boundaries was gained through the interviews and the analysis of transcripts in Chapters 4 to 8, which are detailed in Chapter 9 , Section 9.4.1.
Understanding Fundamental System Parts as Potential Root Causes	• System norms • System resources • System regulations • System operations	Prior knowledge of the researcher and the scoping review provided some understanding of system norms, resources, regulations and operations and assisted with the research design described in this chapter. The research interviews and the analysis of transcripts in Chapters 4 to 8 helped to deepen this understanding further and are detailed in Chapter 9, Section 9.4.2.
Assessing System Interactions	• Reinforcing and balancing interdependencies. • System feedback and self-regulation • Interaction delays	Assessing the system interactions is described in this chapter, Section 3.6.6, and detailed in Chapter 9, Section 9.4.3.

Components of Transformative Systems Change		Component Addressed
Identifying Levers For Change	Identifying Parts to Leverage for Change • Exerts or could exert cross-level influences • Directs system behaviour • Feasible to change Identifying Interactions and Patterns to Leverage for Change • System differences that create niches compatible with systems change goal • Gaps in system feedback mechanisms Cross-level/sector connections that are needed	These are detailed in Chapter 9, Section 9.4.4.

3.5 Situating the Researcher

A core assumption of reflexive thematic analysis is that *"knowledge generation is inherently subjective and situated"* [247 p. 8]. Braun and Clarke further advise that researcher subjectivity should be embraced rather than managed, and it is an asset to the research when acknowledged and incorporated into the analysis [247 p. 8]. I came to this research with a comprehensive background working around the NDIS. I was employed by the NDIA, mainly focussed on access for people with psychosocial disabilities and working for the NDIA on their Administrative Appeals Tribunal (AAT) Team. These roles provided extensive exposure to the APTOS [8], how the NDIA staff make decisions against them and the jurisdiction decisions that AAT members make when NDIS applicants or participants appeal decisions made by the NDIA. The AAT conducts independent merit reviews of decisions made by Australian ministers, state and Commonwealth departments, and non-government bodies. Australia's Governor General appoints AAT members with expertise in diverse areas [262].

I later worked in the Compliance Team of the NDIS Quality and Safeguards Commission, the regulatory body that monitors the quality and safety of NDIS supports and other services. This gave me a broader understanding of the problems experienced by NDIS participants and providers. I later worked for an NDIS provider and was also a board member for a different NDIS provider. I worked on the NDIS Ready Project with the Aboriginal Health Council of South Australia, a state peak body for Aboriginal health organisations around the state. My role involved travelling to and working with member organisations throughout South Australia to assist them in understanding NDIS processes, supports and registration. Additionally, I worked for the Flinders University NDIS Transition Project, assisting mental health non-government organisations to understand the NDIS and support people with psychosocial disabilities to access the NDIS. Before working in the NDIS, I worked for a non-government mental health provider that received inreach from state-mental health services; I worked in a tertiary hospital emergency department and was a South Australian police officer. These roles have all added to my understanding of the formal and informal systems that support Australians living with mental illness.

I discovered, through my friend Leani's experience, that, at least for South Australians, there was little to no support that enabled people under 65 to palliate at home. While she received some help from friends, she could not receive formal support in the community. Leani was admitted earlier than she wanted to an acute public hospital bed, later dying in a public hospice, away from her young daughters and pets. Leani had worked with me in the NDIA and wondered. as her experience was so fraught, what it was like for others without her capacity and agency. She asked, "*This has been so hard for me, and I'm a social worker, I know how to get support. What must this be like for people with mental illnesses - for NDIS participants?*".

My personal and professional experience with these systems brought me to this research question and informed the research throughout. I was aware of my expertise and ability to understand the contexts being discussed throughout the research interviews. This knowledge was constructive, particularly in building rapport and guiding interviews, enabling me to explore a topic more deeply with research participants. I was mindful, however, that I let research interviewees share their understanding of systems without imposing my system understanding upon them.

3.6 Methods

In keeping with the researcher's pragmatic worldview of "what works" [263 p. 10], the research design has changed over the life of this study. This research was initially conceived as an exploratory-sequential mixed methods study where qualitative methods explore the phenomenon in detail, and a second quantitative stage follows this to see if these findings can be generalised to a broader population [264 p. 226]. The qualitative interviews commenced on 15th April 2022 and continued through to 12th May 2023. On 18th October 2022, the Minister for the National Disability Insurance Scheme, Bill Shorten, announced the Independent Review of the NDIS; the report was released on 7th December 2023 [52]. The 2023 NDIS Review has caused considerable upheaval and uncertainty in the disability community as it awaits a response from the Commonwealth Government. This uncertainty led to a decision to conclude the study after the qualitative stage.

3.6.1 Bounding the System

Coming into the research with the concern about whether PwPDs receive equitable and appropriate support if they develop life-limiting conditions, the scoping review found no existing journal articles, grey literature or other government web publications regarding the phenomenon. The scoping review found that, internationally, people with severe and persistent mental illness do not experience adequate or equitable palliative and end-of-life care. While seamlessness between systems was a key principle when the responsibilities of the NDIS and other service systems [11] were agreed between governments, the scoping review revealed significant gaps between systems, impacting the experiences of PwPDs. It is, therefore, important to understand whether these gaps continue to cause significant issues when PwPDs are diagnosed with life-limiting conditions. Therefore, the problem definition or research question is as follows.

Research question

What are the death, dying and palliative care experiences of National Disability Insurance Scheme (NDIS) participants with primary psychosocial disabilities?

Sub-questions:

1. What support do NDIS participants with primary psychosocial disabilities receive from their formal service systems once diagnosed with a life-limiting condition?

2. Are the death, dying, and palliative care experiences of NDIS participants with primary psychosocial disabilities equitable to the experiences of non-NDIS participants with a severe and persistent mental illness and/or other Australians without a pre-existing severe and persistent mental illness?

3. Is the support received by NDIS Participants with primary psychosocial disabilities seamless between systems, both their existing NDIS and mainstream supports?. Once they receive a life-limiting diagnosis, do participants receive integrated planning and coordinated supports, referrals and transitions between services? If so, what works? If not, what are the gaps and barriers?

Identification of the Levels, Niches, Organisations, and Actors Relevant to the Problem

Using the researcher's experience in the NDIS, health and mental health sectors and additional knowledge gained from the scoping review, the following cohorts were identified as relevant to the problem.

1. **NDIS Participants with primary psychosocial disabilities**. People with disabilities are often excluded from research about them. Without their contributions, it would be unlikely that this research could gain a rich understanding of the gaps, barriers and experiences with the NDIS and other service systems [265].
2. **Informal supports of NDIS Participants with primary psychosocial disabilities**. Informal supports, sometimes called unpaid carers, often assist PwPDs in navigating systems and have a unique perspective of gaps, barriers, and experiences with the NDIS and other service systems.
3. **NDIA Planners and Local Area Coordinators.**NDIS Planners and Local Area Coordinators often make decisions and provide advice to PwPDs and informal supports regarding the APTOS system. Their front-line perspectives, rather than management or engagement teams was considered key in understanding how these decisions are made and the impact those decisions have on the NDIA's workforce was also of interest.
4. **Mainstream Mental Health Providers.** This workforce is usually funded by state governments rather than the Commonwealth Government and often has little understanding or connection with the NDIS. Mental health nurses, social workers, occupational therapists, community mental health workers, and peer workers who are certificate-qualified and are not providing NDIS supports would be the ideal research participants for this cohort.

5. **Palliative Care Providers.** The state health systems usually fund this workforce and offer services from hospitals, district nurses**,** or private providers. They can be medical, nursing, social work and occupational therapists.
6. **NDIS Providers.** The NDIS funds many different kinds of supports for PwPDs, the roles of support coordinator and psychosocial recovery coach help PwPDs navigate the NDIS and other systems. Plan managers must also navigate between the systems and understand the APTOS. PwPDs may live in supported accommodation with independent living supports or receive cleaning, gardening and social support. NDIS Providers can be large or small, registered or unregistered.

3.6.5 Understanding Fundamental System Parts as Potential Root Causes

Through semi-structured interviews with open-ended questions that were similar but slightly tailored to each cohort, see the interview guide in Appendix 9, this research sought to define and understand research interviewees' knowledge and perceptions regarding the following:

1. Palliative care
2. NDIS
3. Psychosocial Disability
4. The formal supports that NDIS Participants with a primary psychosocial disability and life-limiting diagnosis should receive
5. How those formal supports should be funded
6. Processes to obtain formal supports
7. Explore any experience or forecast complexity or barriers to quality palliative and EOL care

3.6.6 Assessing System Interactions

The researcher undertook a thematic analysis of the transcripts using Braun and Clarke's Six Phases of Reflexive Thematic Analysis [3 pp. 35-36], see Table 2 below. Results from each cohort were compared and contrasted to understand similarities and differences, explore gaps between systems, and explore system regulations, norms, resources, and operations. The thematic analysis was written up in the Results Chapters 4 to 8. The results were assessed for system interactions such as reinforcing and balancing interdependencies, system feedback and self-regulation, and the results are discussed in Chapter 9 Discussion.

Table 2: Braun and Clarke's Six Phases of Reflexive Thematic Analysis

Phase	Activity
Phase 1 - Familiarisation with data	The audio recordings and transcripts were reviewed multiple times for clarity to ensure that the intent of the interviewee was clear. Listening and reading occurred throughout each phase of the analysis.
Phase 2 -Coding	The NVivo software tool was used to code and sort the interview transcripts, each transcript was reviewed and coded multiple times. Data was coded to a single or multiple codes as appropriate. Codes were regularly reviewed and merged as similarities between codes became evident.
Phase 3 – Generating Initial Themes	Codes were clustered into themes and sub-themes, this occurred iteratively throughout the coding and review proceses.
Phase 4 – Developing and Reviewing Themes	Themes were regularly reviewed and merged as commonalities became evident.
Phase 5 -Refining, Defining and Naming Themes	Themes were fine-tuned and reviewed against the research question for relevance.
Phase 6 – Writing up	Results were written up in Chapters 4 to 8 and further discussed in Chapter 9.

3.6.7 Identifying Levers for Change

The thematic data and systems analysis results were reviewed to identify potential interactions, patterns, and parts within the systems surrounding PwPDs with life-limiting conditions that could be leveraged or recommended for change. The recommendations are recorded in Chapters 9 – Discussion and Chapter 10 - Conclusion.

3.7 Ethics Approval

The study was approved on 28th March 2022 by the Flinders University Human Research Ethics Committee (Project No. 5134). The study was carried out in accordance with the *National Statement on Ethical Conduct in Human Research (2007)*. Research interviewees signed a consent form appropriate to their cohort and were provided with the contact details for Professor Sharon Lawn and the Executive Officer for the Ethics Committee if they had any complaints or additional questions; (see Appendices 5, 6, and 7).

3.8 Recruitment

The research adopted a purposive sampling approach [266]. Research participants were self-selected for semi-structured qualitative interviews via the following recruitment methods. Nine participants with psychosocial disabilities interviewees (PwPD Interviewees) and seven informal support interviewees (IS Interviewees) were recruited through Lived Experience Australia's e-news and Facebook groups, the Kinora platform, and snowball recruitment. Nine NDIS provider interviewees were recruited through peak body Community Mental Health Australia's bulk email to members, Facebook groups, the LinkedIn website, the Kinora platform, and snowball recruitment. Five palliative care clinicians were recruited through researcher presentations with the Flinders University Research Centre for Palliative Care, Death and Dying lunchtime seminars, Palliative Care Australia's e-newsletter, and snowballing recruitment. Three mental health clinicians were recruited through snowballing, and none responded to advertising on any other platform. These recruitment methods had national reach. The researcher was unable to recruit the NDIA Planners or LACs as the request to interview was denied by the NDIA Research Team.

3.9 Interviews

The recruitment process sought volunteer interviewees from each research cohort. Research interviewees received, signed and returned an information and consent form for their cohort; see Appendices 5, 6, and 7. Page one of the consent forms advised that participation in the research was voluntary and that research interviewees could withdraw within a fortnight of their interview, after which their data may be submerged into the research; although no research interviewees elected to withdraw from the study, the withdrawal form was prepared can be found in Appendix 8. No interviewees identified as belonging to Aboriginal or Torres Strait Islander communities.

A total of 33 semi-structured interviews were conducted via Microsoft Teams if residing outside South Australia. However, those residing in metropolitan Adelaide, South Australia, were offered face-to-face, if interviewees preferred, at their chosen location. Interviews ranged from 40 minutes to 180 minutes long. PwPD Interviewees and IS Interviewees received a $30 Coles Voucher to compensate them for their time.

Interviews were recorded and transcribed using the Otter Ai platform. A total of 12 recorded interviews were also sent to transcription services, Rev and STTP due to clarity issues with the Otter Transcription. The researcher reviewed and corrected the 33 interview transcripts. Research interviewees were offered the opportunity to review their transcripts, and two research interviewees accepted this and altered their transcripts, adding additional details and clarifying their intent in statements made. Three other interviewees requested a copy of their transcript but did not alter the transcript. All interviewees requested a link to any publications that may result from this study.

CHAPTER 4 – NDIS PARTICIPANTS WITH PSYCHOSOCIAL DISABILITIES INTERVIEW RESULTS

4.1 Introduction

Due to the infancy of the National Disability Insurance Scheme (NDIS), there is limited knowledge or public discourse about the death, dying, and palliative care experiences of NDIS participants with psychosocial disabilities (PwPDs). In order to understand their perspectives and opinions, nine PwPDs (PwPD Interviewees) were interviewed. They contacted the research team in response to seeing the research flyer on Facebook psychosocial disability support group pages, through word of mouth, and via the Kinora community platform. Interviewees discussed their informal and formal support networks and the quality of support they receive from mental health, health and the NDIS systems. Further, PwPD Interviewees shared their experiences with the National Disability Insurance Agency (NDIA) and NDIS providers and their views on the NDIS.

PwPD Interviewees used their knowledge and expertise regarding these systems. They discussed the death, dying and palliative care experience and supports likely to be received by PwPDs with life-limiting conditions and advised whether that experience would be equitable and seamless between systems. The PwPD Interviewees' experiences with systems were explored deeply to enable a better understanding of potential feedback loops within and between systems. As direct quotes from interviews will be included in this chapter, any potentially identifying information about PwPD Interviewees was removed, and pseudonyms were assigned.

4.2 PwPD Interviewee Demographics

Twelve PwPDs responded to the research interview flyer. Three PwPDs, one from Perth, Western Australia, one from rural Victoria, and one unknown, decided not to proceed with their interview due to mental ill-health at the time. The remaining nine PwPD Interviewees, three male and six female, resided in Canberra, Melbourne, Brisbane, rural Victoria, and rural New South Wales.

No PwPD Interviewees identified as belonging to CALD, Aboriginal or Torres Strait Islander communities. PwPD Interviewees had been in the NDIS for between one and four years. One PwPD Interviewee was supported by their psychologist, an NDIS provider. One PwPD Interviewee's informal support was also interviewed for this research.

The NDIS Act [7] does not require a participant to have a formal diagnosis; therefore, PwPD Interviewees were not asked to disclose their diagnoses. However, most volunteered that they have the following diagnoses: schizoaffective disorder, complex post-traumatic stress disorder, major depressive disorder, bipolar disorder, borderline personality disorder and/or generalised anxiety disorder. In addition, most PwPD Interviewees lived with co-occurring chronic physical health and pain-related conditions, and one also had a diagnosis of autism spectrum disorder for which they also received NDIS support.

4.3 PwPD Interviewees Discuss Advocacy

It is essential to recognise that by meeting the access requirements of Section 24 of the NDIS Act[7], this cohort lives with substantial and permanent functional impairment in one of the following domains: (i) communication, (ii) social interaction, (iii) learning; (iv) mobility, (v) self-care or (vi) self-management. The NDIS Act [7] does not require NDIS participants to demonstrate substantial functional impairment in all six domains. PwPD Interviewees acknowledged that they could mostly understand and communicate well during their interviews and felt that they were advocating for PwPDs, who did not have this capacity and could not advocate for themselves.

> *"They need someone to go out there is a little bit pushy who knows the system, who can say "look you know, let's set up a program". Most people on NDIS would not be in a position to advocate for themselves."* ***PwPD Interviewee Nigel***

4.4 PwPD Interviewees Answer “What is a Psychosocial Disability?”

Perspectives were varied, from broad "*under the mental health umbrella*" to listing their symptoms, such as disordered thinking or functional impairments, for example, social isolation and impaired social interaction. One PwPD Interviewee provided her multiple diagnoses, another included intellectual disabilities under the term psychosocial disabilities, and another stated that she did not know. Two PwPD Interviewees felt that it was a "*polite*" way to say mental illness.

> *"Psychosocial disability is a buzzword which they think is acceptable in the community and within themselves to meet the brief. And instead of saying mental health. I think it's for them, it's acknowledging in a polite way of saying that you live with a lifelong condition of mental health."* ***PwPD Interviewee John***

One PwPD Interviewee advised that she found the diagnosis very confronting; the government of her state had defunded her previous mental health services, and she was directed to a non-government mental health organisation to assist her in accessing the NDIS.

> "And the brochure said it's for people with severe mental illness, which was extremely confronting to be in writing. So even the word 'psychosocial'; I know I'm not well, I know I've struggled all my life but it's still really hard to hear that. " ***PwPD Interviewee Lucy***

4.5 PwPD Interviewees Discuss Informal Supports

Three PwPD Interviewees indicated that they did not have family or informal support networks or that their relationships were fractured due to their mental illness.

> *"[W]ith psychosocial [disability], often there's rifts in the family, so there's lots of strain. So I just think there needs to be more creative ways to deal with palliative care."* ***PwPD Interviewee Kelsey***

Lucy stated that the mother of her friend, an NDIS Participant with a psychosocial disability and life-limiting condition, is overbearing and tightly controls his plan and supports. For example, his mother is trying to organise cooking and budgeting classes, and if the NDIS Participant objects to these supports, it leads to disagreement, so he complies with her plans. Lucy herself expressed shame at being on the NDIS and had not told her family that she was an NDIS Participant. She stated that her parents expressed disappointment in her inability to maintain employment, and they do not know that she has a severe mental illness nor that she is on the NDIS. Another PwPD Interviewee, Donna, discussed her resentment regarding her husband's part in her gaining access to the NDIS.

> "I didn't want the NDIS to be in my house. I was really angry when it happened." **PwPD Interviewee *Donna***

4.6 PwPD Interviewees Discuss Palliative Care and the Health System

PwPD Interviewees were asked about their awareness, understanding and experience with palliative care systems. All reported having no personal experience within palliative care systems, although two noted that they viewed their mental illness as a life-limiting condition. Most had experience with family or friends who had received palliative care support. Two had been employed in the health system and understood the palliative care system in their states. One PwPD Interviewee, Donna, could not answer the interview question despite having a background in healthcare before the onset of her mental illness. PwPD Interviewees used the following words, phrases and statements to describe their understanding of palliative care:

- "safety"
- "no reasonable hope of surviving the disease"
- "Improving quality of life as far as possible"
- "Make life less painful for someone who is going to die"
- "With palliative care, you're dying, but you're not dead and you're sort of hidden away"
- "able to give palliative care in the nursing home"
- "palliative is sort of end of life"
- "It doesn't mean that they are actually going to die quickly, but it means that they are on the cusp of that, and can't probably receive the correct care at home or with a carer, everything etcetera"
- "You've got the bad diagnosis and saying that it's not curable"
- "You are going into care, which is either in a residence or in your own residence."

Anita described starkly different metropolitan experiences in two different states with dissimilar outcomes. Anita shared her father's negative and pain-filled death experience. He palliated and died in residential aged care in one state. In contrast, her uncle died at home in a different state, well supported by the aged care and palliative care system.

> *"Absolutely amazing care. He was able to pass away at home in his home. They set up a bed in the lounge, in the lounge room and they had a nurse come and administer the medication. And they had carers. They helped redo the bathroom"* ***PwPD Interviewee Anita***

While PwPD Interviewees did not have direct experience with palliative care, some had family members or friends who did, and their overall opinion of palliative care services was positive. However, while reporting a positive care experience, one PwPD Interviewee noted that palliative care is siloed from other systems.

> *"I nursed my mother into and through her palliative phases too. I was really impressed with palliative care people but they were not joined up with the other people at all."* ***PwPD Interviewee Nigel***

Finally, one PwPD Interviewee, when discussing a friend's death and dying experience, stated

> *"….life here is very painful.... so I imagine she thought like I do, pretty well think, "Fuck, I can nearly get out of here." And she probably chose to fast-track it by not having treatment."* ***PwPD Interviewee Lucy***

4.7 PwPD Interviewees Discuss the Mental Health System

Most PwPD Interviewees were not under the care of a psychiatrist, and their general practitioner (GP) managed their medication needs. Some were privately funded patients of psychiatrists. Those who could be supported by private hospitals, psychiatrists and psychologists noted that they were glad not to be admitted to public hospitals.

> *"So I have heard a lot of stories, from people coming from the public health system, on how bad the system's running, and how they get treated, and all that sort of stuff. Yeah. I wouldn't put my dog into some of them."* **PwPD Interviewee Rhonda**

Rhonda advised that her experiences with the mental health system were not always positive and that she felt disempowered, particularly with the use of electroconvulsive therapy, which she felt she was unable to refuse within her treatment plan. Rhonda further advised that she often felt neglected within treatment facilities, even as a private patient.

One PwPD Interviewee, Anita, advised that she was recently discharged from state-funded community mental health services and expressed concern that this would also result in losing her NDIS supports.

> *"My illness progressed to a stage where they said that you're well enough, we haven't seen you for what was it six months that you're doing really well [Anita] and we're going to hand you over to your doctor, so I'm no longer under the care of psychiatrists. I'm expecting my NDIS plan to cease. So because, once that funding once that support, is taken away, you're no longer ill enough to have NDIS even though I am."* **PwPD Interviewee, Anita**

Anita also believed that PwPD needed to exit the NDIS at age 60 and transition to the aged care system. At the time of the interview, Anita had been a participant in the NDIS for two and a half years and had an eligibility conversation, followed by supporting documentation, an initial planning meeting, and two plan reviews with NDIS planners. Anita said that she was well supported by her NDIS providers and that she has a support coordinator. Her rights under Section 29, of the National Disability Insurance Scheme Act (2013), about the circumstances where a person ceases to be a participant had at no stage been communicated to her. The Australian media regularly reports [267, 268] that people will be"*kicked off the scheme*" and this causes distress and confusion within the disability community [269].

Most PwPD Interviewees stated that they had good relationships with their GP but had issues with long waiting times, which reflects trends across the country [270]. In addition, rural PwPD Interviewees advised that there were very few mental health supports in their area, either through the mainstream mental health system or the NDIS. Anita advised that her NDIS workers were not allowed to support her whilst she was admitted to the mental health inpatient unit in a tertiary public hospital. Anita was admitted for an extended period and noted that one of her NDIS Workers supported other clients in the hospital under the aged care funding models. Anita stated that connecting with her regular worker during this time would have been very beneficial to her recovery, particularly once she was at a stage where she was considering a pathway to discharge from hospital. With private facilities, there were mixed responses from the PwPD Interviewees, with NDIS workers being allowed to support in some instances and not others. One PwPD Interviewee, Rhonda, advised that her NDIS worker supported her whilst she was admitted to a private hospital and described an experience where that worker advocated for her, demonstrating the benefit of multi-system oversight.

4.8 PwPD Interviewees Discuss the NDIS

4.8.1 Support from the NDIS

To consider the likely support that PwPDs may continue to receive from the NDIS if they develop a life-limiting condition, PwPD Interviewees were asked to list the support they currently receive from the NDIS. Their responses can be found in Table 3 below. The interviewer provided no further prompts (other than clarification about whether PwPD Interviewees were referring to plan managers or support coordinators. Any comments made whilst listing their supports are included in the table.

Table 3: PwPD Interviewees - Supports Received

NP Supports Received	NP Participants	PwPD Interviewee Comments
Support Workers	9	
Walking	2	“once per week” “walked to the café instead of driving”
Meal preparation	1	“meal preparation support for two hours per week”
Shopping	2	“once per week for an hour and a half”
Community participation	9	
Transport to appointments/community events/gym	5	
Social interaction	3	“They just sit on my couch and stare at me”
Break for carers	1	
Medication Prompts	1	
Support Coordination	5	Support coordinator provider also provides other supports x 2
Plan Manager	1	

NP Supports Received	NP Participants	PwPD Interviewee Comments
Cleaning	6	The recovery coach blocked cleaning support due to the cleanliness of the house.
Gardening	6	
Psychologist Counselling EMDR	5	“my main motive for joining the NDIS was to find psychology services, because they would not be affordable. The out-of-pocket costs would not be affordable. I have seen psychologist bloke [Name] some, one in particular, was so so and charged a lot and it just wasn’t sustainable. And now I need regular support and to work through various strategies and management sort of stuff”
Occupational Therapy	2	
Physiotherapy	2	
Meals	2	
Yoga	2	trauma-informed yoga therapy
Recovery Coach	1	I'm not able to get a support worker, a recovery coach that is professional and sensitive.
Art psychotherapy	1	Three times per fortnight
Groups social and community	1	Groups not really suited to MH – parking like they did in DES.
Bicycle Hand rails	1	
Chinese Acupuncturist	1	Pushed into it by support coordinator.
Exercise physiology	1	Twice per week one week, and once on the other week. “Takes a lot of money and I'm really considering getting rid of it.“
Gym Membership	1	That was approved but there are problems with it. So I think I'm gonna lose it.

NP Supports Received	NP Participants	PwPD Interviewee Comments
Transport	2	I get this limited most smallest transport budget.
Short-term accommodation	2	This was for Informal support respite, PwPD Interviewee did not want to go. “I needed respite, which was a bull terrier to get on, but I finally got respite. I do use, it does help, because I say, "This is how it helps my mental health.

In addition to his mental illness, Sam advised that he has many physical disabilities and health issues that the NDIS does not support. He stated that it had been challenging to decide what condition to use in his application to gain access to the NDIS. His team agreed that his physical disabilities were likely to be considered health issues by the NDIA, so he applied and got support for his mental health condition. The dichotomous and arbitrary decision-making process around mental and physical disabilities caused him distress.

> *“I didn’t understand that, but for me, it’s a vicious circle, the whole thing it feeds itself. And what I wanted at first was more to do with, I wanted a physio and get into a pool, because I knew that that would improve my mental health. And that’s I just found it was hard they couldn’t write it down,”* ***PwPD Interviewee Sam***

Whilst some PwPD Interviewees were happy with their supports, others felt that the NDIS is limited in what types of support it will fund, such as cleaning, gardening or walking, and did not provide meaningful help with their psychosocial disability.

> *“It’s it’s very, very taxing when they’re supposed to be helping you overcome these hurdles, and I’ve actually specified very doable low challenge tasks and they just walk away from it. LACs walk away from it. They turn the initial specific requests into something vague. Then the support coordinators listen, but I haven’t seen any follow through so far.”* ***PwPD Interviewee Nigel***

4.8.2 PwPD Interviewees Discuss the NDIS as a System

Most PwPD Interviewees reported both positive and negative experiences; however, the overall opinion of PwPD Interviewees of the NDIS as a system was primarily negative. PwPDs’s opinions and comments regarding the NDIS were analysed in context and assigned either a positive or negative value. These analysed comments can be found in Appendix 1 Section 1.1.

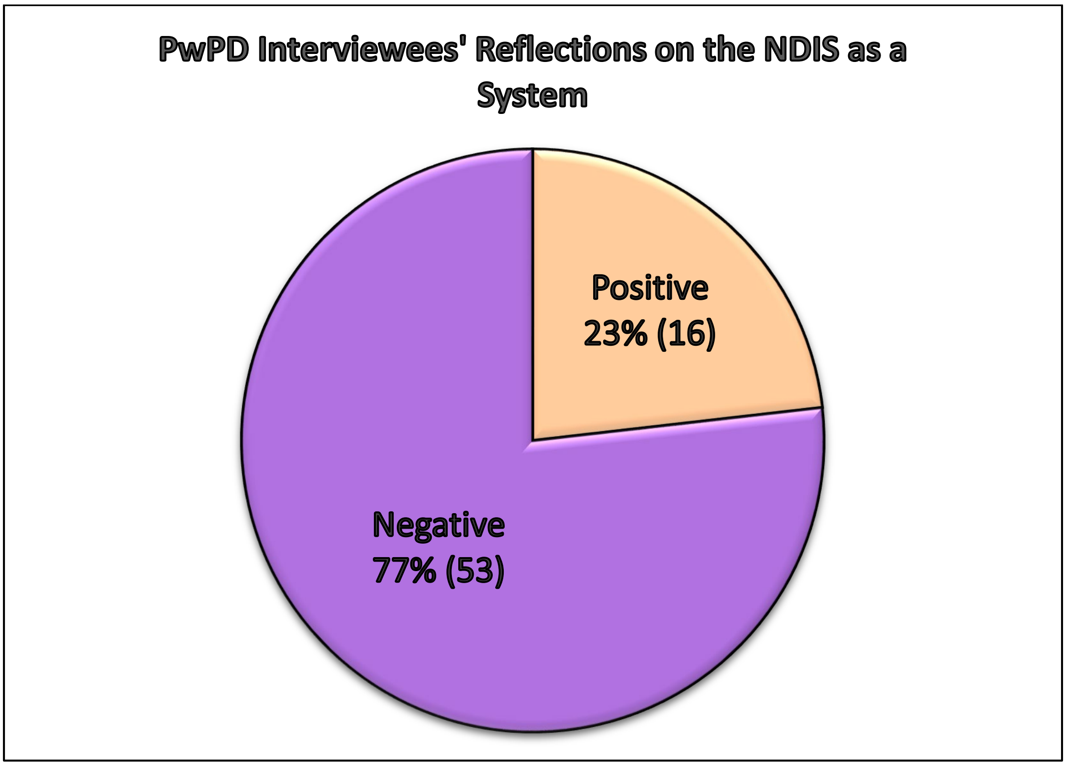

Figure 10: PwPD Interviewees' Reflections on the NDIS as a System

Some PwPDs described experiences that were extremely negative for them. Sam described his experience "*from day one, it's been a nightmare for me, a nightmare*". Lucy stated that her recovery coach, a former psychiatric nurse, had decided that her home was "*disgusting*" and refused to allow support workers to support her in her home. Lucy has had multiple negative experiences with the NDIS and described issues with continuity of support with constantly changing NDIS Workers being a particular concern for her "*I feel I have no control over my life, and I feel I'm just tossed around*."

While advising that her overall experience with the NDIS had been very positive, Kelsy expressed concern about the deficits-based access, planning, and review process.

> *"I think this is wrong about the NDIS when you are doing a review or a plan. You can't say anything positive about how you're going," **PwPD Interviewee Kelsy***

Kelsy also raised concerns about the consent that she and other NDIS participants provide to support coordinators who step in and make decisions when she is unwell. "*Where's the point of being independent and then someone's stepping in?*"

Issues with processes and how the funding is explained and managed were a significant source of frustration for Nigel, who advised that he found it difficult to control his plan with his team despite multiple requests for support and complaints.

> *"Because it's all in code and unclear the you can't follow the chain of funding here. Processing through the plan manager, including support coordination through to what you get. It's impenetrable. And it's not supposed to be"* ***PwPD Interviewee Nigel***

The process of gaining access to the NDIS caused significant distress for most PwPD Interviewees. They described feeling rejected and the access process as slow, confusing, demoralising and depressing.

> *"I was quite pushed into going into it, and I did go into it after almost committing suicide because of it." NP Interview"* ***PwPD Interviewee John***

After this initial difficult period, John now feels he has much more choice and control over the NDIS process.

> *"I make sure I get what I need. They don't like me talking to them because I'm very matter of fact. I don't trust them, and I say to them, "These are my needs." And I say, "Don't piss in my pocket, I won't piss in yours." And I give them the why of what I need"* ***PwPD Interviewee John***

Regarding the flexibility of the NDIS, Kym described how she found her current support team, deciding that a large NDIS provider was no longer a good fit for her as the workers became much more random and support times kept being changed with limited notice or consultation with her. Kym then used Mabel, an online platform where NDIS participants can source independent support workers, and found three workers. She is very happy with her current team and the flexibility that the NDIS as a system provides her. However, other PwPD Interviewees felt that the NDIS was not flexible, with one stating that she she did not know how to ask for a plan review for a change of circumstances. PwPD Interviewee Anita advised that the inflexibility of NDIS payment options and the inability to pay for services in advance resulted in a loss of her supports.

> *“I had paid for ten months, and then they said "no you can't do that with NDIS". You have to do it retrospectively each month. So once you've used that month of exercise, then they can bill the NDIS and get paid for it. So it's not going to work.”* ***PwPD Interviewee Anita***

However, it appears for some NDIS participants that if they understand how the system works, they can obtain the supports they feel they need without explicitly declaring how they spend their NDIS funds.

> *“Yeah, this is going to sound funny. With NDIS, once you have a plan, no one really knows what you do with the plan.”* ***PwPD Interviewee Kelsey***

Three PwPD Interviewees described the review and appeals process as confusing, sometimes resulting in a quick turnaround and other times involving a complete plan rewrite. One PwPD Interviewee, Rhonda, stated that she would never request an Administrative Appeals Tribunal review, even though she had lost $10,000 worth of funding in one year.

> *“There's too many cases, and there's not enough people in the AAT. Also, from what you hear, a lot of people are going through AAT for genuine things, and they actually come out of their review, with less than what they started with. [Intervieweer Okay. And are you hearing that on the Facebook sites?] Yeah, and there's a few of them too.”* ***PwPD Interviewee Rhonda***

Finally, Kelsy described how being on the NDIS had negatively impacted her abilities.

> *"…the weird thing is being on NDIS has actually made me a bit more disabled….Yeah. So you lose motivation. You have all the supports and then you don't need to do as much."* ***PwPD Interviewee Kelsy***

Kelsy also shared an anecdote about another NDIS Participant with whom her support worker works.

> *“They got him off the street. They put him into housing. He's on NDIS. So they've got him into housing, he's getting fed, he's got all the care he needs. Everything's done for him, and he sits there and just plays games all day. And he turned to her one day and he says, "You know, I wish I was homeless again." And she said, "What?" She says, "You have a roof over your head. You have food. You have shelter. You have safety." He said, "Yes, but I have no motivation or willingness to live anymore."* ***PwPD Interviewee Kelsy***

4.8.3 NDIS Quality and Safeguards Commission and Fraud Team

Two PwPD Interviewees raised concerns about providers with the NDIS Quality and Safeguards Commission and NDIA Fraud team. John had a good outcome with the NDIS Fraud Team.

> *“I started up a bit of an action within the NDIA. They came out and audited them, and they said they'd breached about nine conditions. And they didn't rectify it, they was stealing money. It was confirmed they were stealing money out of my plan. NDIA apologised. And then within two months they closed the centre, the owner was taken away. So I'm quite proud of that, because they were stealing money off like 50, 60 people.”* ***PwPD Interviewee John***

However, Nigel experienced significant frustration trying to get support from the NDIA and the NDIS Quality and Safeguards Commission for fraud and quality of support issues.

> *"I made it very clear to both Fraud and Commission, who I've never heard back from. They referred me to Complaints or the Commission, the three different bodies that you can go to. The only other ones left are the media and your federal minister and they're there on the list too."* ***PwPD Interviewee Nigel***

4.8.4 PwPD Interviewees Discuss the NDIA

The overall opinion of PwPD Interviewees of the NDIA was overwhelmingly negative. Comments were analysed in context and assigned as either positive or negative. These analysed comments can be found in Appendix 1 Section 1.2.

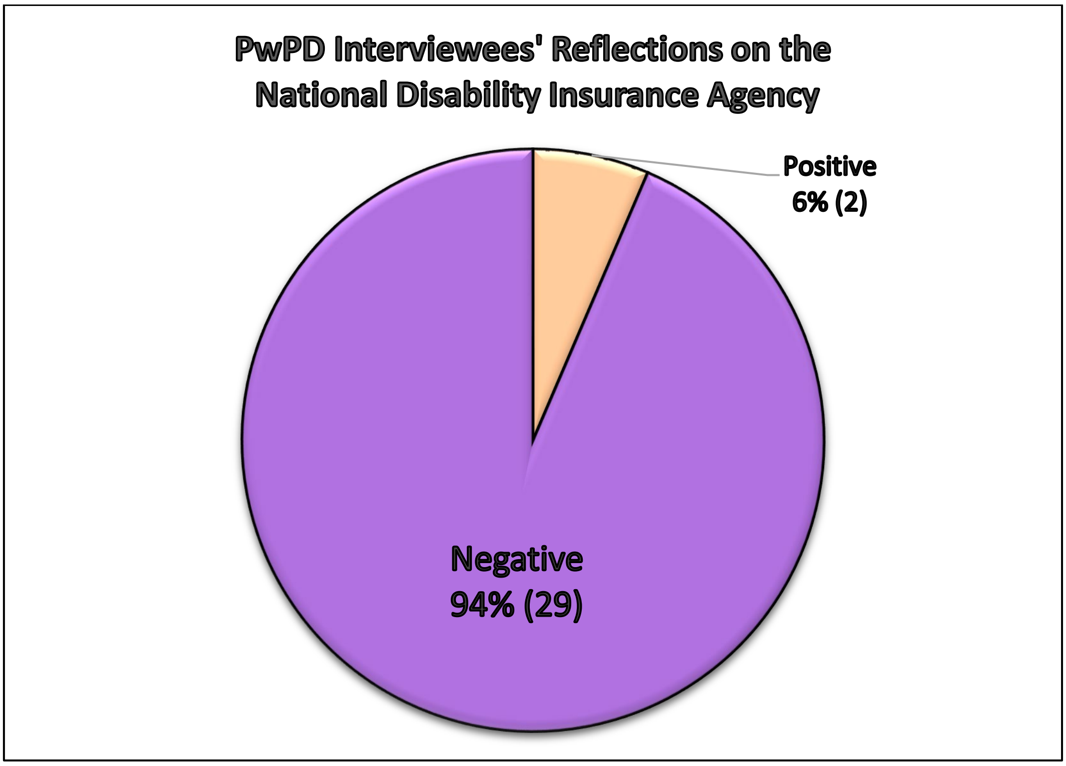

Figure 11: PwPD Interviewees' Reflections on the NDIA

There was often confusion about the NDIA's planning processes and how budgets are set up and explained. Nigel advised that plans are written in "code" and are unclear and that he finds it difficult to follow the funding chain.

> *"The plan is sometimes explained verbally, but it is not articulated in writing so it can be difficult to keep track of what funding has been allocated."* ***PwPD Interviewee Nigel***

PwPD Interviewees felt that the NDIA planners do not take a participant-centred approach to decision-making.

> *"They do not provide funding for the support that you actually need, they provide support for what they think you need."* ***PwPD Interviewee Kelsy***

Nigel described needing to be patient with the process and felt that if you became distressed, this annoyed the NDIA staff and that they would then intentionally slow down the planning process. Rather than feeling that his choice and control were being respected and incorporated into his NDIS plan, Nigel felt his goals and support requests were ignored, resulting in wasted money in the wrong area.

> *"The plan, the one person who wrote the first plan ignored most of what I said and put in some cut and paste general, vague statements, and many of them. How will this be accomplished? "* ***PwPD Interviewee Nigel***

PwPD Interviewees expressed frustration with the inconsistencies in planning decisions and questioned the planners and LACs capacity and skill in planning. Kelsy highlighted a lack of transparency and specific guidelines as to what supports are accepted and what are not.

> *"But they log you all into the same system, like the same diagnosis, the same experience or diagnosis. And they're making decisions on that without actually talking to the health professionals. And I'd like to know who's making these decisions because... Where in that does it say that art therapy may not be as good as CBT, in a mainstream system?"* ***PwPD Interviewee Kelsy***

Whilst some PwPD Interviewees had therapeutic mental health supports approved within their plans, others had requests for mental health therapeutic supports declined or reduced. Kelsy stated that she felt that NDIA planners make decisions without the appropriate consultation with health professionals. John felt that the planning process is deceptive.

> *They're very deceptive in terms of they say that they're there to help you and that they'll listen to you. I don't want any more than what I need. But in the past that they've said, "This is what you are going to get, regardless of your need."* ***PwPD Interviewee John***

Some PwPD Interviewees were uncertain about how to ask for a mid-plan review and had received conflicting advice and outcomes about the "best" way forward. One PwPD Interviewee was told, by their support coordinator that it was better to have a one-year plan than a three-year one, as yearly reviews can be more responsive to a change of circumstances. Alternatively, another PwPD Interviewee described themselves as "fortunate" to get a three-year plan. Nigel described a tension between support coordinators, an NDIS-funded support, and LACs, the government-subcontracted NDIA partners.

> *"So there's this antipathy between support coordinators at local level and LACs where they say that they should be doing this but they're not doing that. And LACs I'm sure, they have said to me that often support coordinators don't, you know, don't fulfil their role. So there is a huge blurring in practice between who does what."* **PwPD Interviewee Nigel**

Rural areas with small overall populations and limited providers can have conflict of interest issues. For example, one PwPD Interviewee, Sam, described a situation where their local area coordinator referred them to a support coordinator who was a relative. This support coordinator subsequently referred him to a range of NDIS sole providers who were also relatives of the support coordinator.

Sam's plan review was part of the NDIA's independent assessment trial (assessment by a clinician who has no prior knowledge or clinical relationship with the participant [271]) and advised that it was a very cold, "*tick-a-box*" process, where they interrupted when speaking about their goals and the independent assessor raised the notion of reducing supports and exiting Sam out of the NDIS. The experience was so demoralising and distressing that he had to withdraw from the assessment before completion.

> *"They left me having to pull out halfway through, I just couldn't take the abuse anymore because of the tone and the accusations she was making towards the coordinator… She was new to her job. She had these rules in front of her. She had a boss that told her she had to do this. And she was going to do it. And anytime you try to say something she'd cut you off. And it was terrible, it left me feeling like I was a piece of shit."* **PwPD Interviewee Sam**

Nigel tried to raise his concern about provider issues with fraud and quality of supports with the LAC reviewing his plan. He advised that neither the LAC or the NDIA staff assisted or referred the Provider to the Fraud Team or the NDIS Quality and Safeguards Commission. They eventually became non-responsive to telephone calls and email requests for meetings. One LAC did make an appointment to discuss the issues but did not attend at the scheduled time.

> *"There's been blocks every step of the way. I can't imagine how it is for anyone who is intellectually incapacitated. My cognitive function is impaired, my stamina or energy and stress levels are very impaired and it takes a huge toll"* **PwPD Interviewee Nigel**

Three PwPD Interviewees were concerned that the NDIA would cut the funding in their NDIS plans, and one worried that she would be exited from the scheme given she had previously been exited from mental health services. Rhonda was frightened that she would lose her cleaning and psychological support as she attempted to become more involved in her community. Rhonda felt that the NDIA would think that she had recovered from her psychosocial disability and would, therefore, exit her from the NDIS.

> *"Because I have a bit of a problem because I am trying to get involved with the community, but to get the supports I need, I have to be sick enough to get the supports I need... but once you get out in the community, they want to stop them."* ***PwPD Interviewee Rhonda.***

4.8.5 NDIS Providers

PwPD Interviewees had mixed opinions regarding their NDIS providers. Two PwPD Interviewees were happy with all of their NDIS providers with one receiving all of her supports from one provider, a local government council that had registered as a provider. The other had struggled significantly with rotating support workers from a large provider before building a support team from the Mable platform, which enables independent contractors or "*gig workers*" to advertise their availability. Two PwPD Interviewees described issues with using small providers or sole providers over large providers, as supports could become unreliable. If a sole provider was unwell, there were no options to replace the support, and both are considering returning to a larger provider rather than relying on sole providers. Other PwPD Interviewees described being happy with some providers and not others.

> *"So the plan manager is excellent, the psychologist who I had before NDIS is excellent, and the employment disability employment provider which is separate to the NDIS, they are excellent. Everything else is really shit pretty much."* ***PwPD Interviewee Lucy***

Sam described NDIS providers as "*body hire companies*" whose only concern was putting bodies, or labour, in place to ensure that they receive the NDIS funds rather than other providers such as allied health.

> *"So their priority, I've worked out their priority is, put their body hire in, I call them, their labourers, their workers. So they're benefiting and that's their priority."* ***PwPD Interviewee Sam***

Nigel advised that there are very few NDIS providers in rural and remote areas. He has even found it challenging to locate any workers via online platforms for sole providers.

> *"There aren't many options in a fairly small community. The databases that have been put up, I have forgotten what they're called, about accessing to make it easy to access support. There's none. There's none in this whole region. I think the NDIS system seems to assume*

> *that you're probably, very replete with options.[Interviewer: And your choice and control is there, yeah?] Oh yeah. Choice and control, choice and control, choice and control."* ***PwPD Interviewee Nigel***

John advised that most NDIS providers cannot support NDIS participants with mental illnesses.

> *"Because more agencies are disability-focused because it took so long to get mental health in the system. So that is still a problem. I'm working, I'm trying to educate people like [Name of Provider] to get maybe someone with a little bit of experience on the board, which they don't have."* ***PwPD Interviewee John***

The "*unscrupulous behaviour*" of their NDIS providers negatively impacted the mental and physical health of two PwPD Interviewees. Nigel stated that *"it was so stressful they took away from my health and well-being"*. Describing his experience, Nigel said:

> *"What is appalling is that these shonky sharp operators are absolutely not safe, and seem to be absolutely untouchable…. It is absolutely ripe for profiteers and mongrels. And there seems to be very, very little political will, even if the mechanisms are there, that you are blocked and ignored and dismissed at every challenge."* ***PwPD Interviewee Nigel***

Sam stated that he "*did his homework*" for the research interview and reflected that his NDIS provider had breached his confidentiality in a small community and only referred him to their family members, who billed his plan for little to no service and were very hostile when he tried to query what was happening.

> *"..that should have put me in the black, hospital as it is. Interviewer: did you go into hospital as a result of that experience?] I've got a comfort zone in me bed, and I just dove. I put on 40 kilos, 30-40 kilos since this all started.* ***PwPD Interviewee Sam***

Two PwPD Interviewees, Lucy and Sam, advised that their NDIS providers were dictating the types of support they could receive. Lucy had previously had workers come into her home to help her clean; despite this, her new personal recovery coach had stated that workers should not be coming into the home.

> *"Help with cleaning would be nice, but again, can't do that, and yoga, I've got to start again in trying to find a new person. [Interviewer Right. And you say you can't get the cleaning. Is that because the NDIS has said that or because you personally can't have someone in your house at the moment?] Because the recovery coach has deemed that my house is not in a state that a support worker will be willing to come inside for."* ***PwPD Interviewee Lucy***

> *"I relied on these coordinators, a local area person as a guide for me, mostly in the initial meetings I just sat there. I believe what everyone was telling me, the providers, the workers, the whole lot, box and dice. I was just, I was getting dragged along, I think, without being able to put too much input in."* ***PwPD Interviewee Sam***

Finally, Sam was, at his request, supported during the interview by his psychologist of many years. With Sam's consent, she summarised his experience and thoughts about NDIS providers as finance-driven rather than person-centred.

> *"Many good services have become bad businesses. That the NDIS is a privatised model, there's no core funding for administration. So the services, that used to be good, you were at that first service and had some good help. But it's actually it's this business model, that has made good services become bad businesses."* ***PwPD Interviewee Sam's support person***

4.8.6 NDIS Participants Discuss the NDIS Workforce

PwPD Interviewees reported both positive and negative experiences with the NDIS Workforce. Often, they acknowledged that their NDIS experience was entirely dependent on the individual attributes of the worker. Analysis of PwPD Interviewees' comments about the NDIS Workforce was conducted, and each was assigned a positive or negative value, as depicted in the chart in Figure 12 below. Analysed comments are included in Appendix 1 Section 1.2.

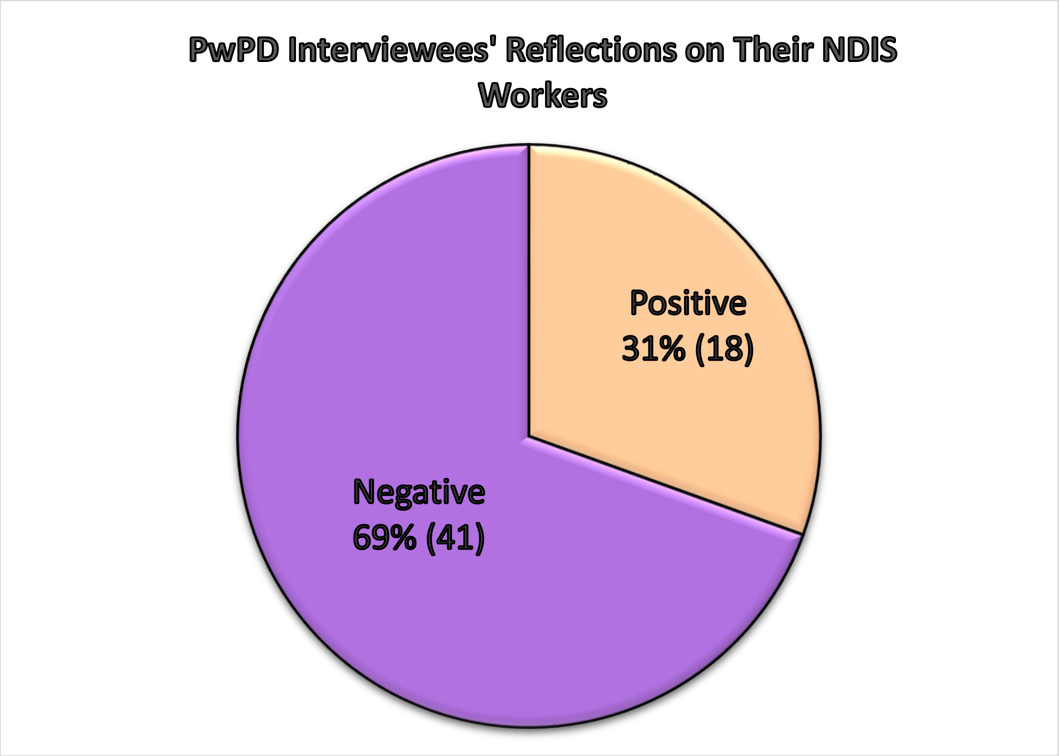

Figure 12: NDIS Participants Discuss the NDIS Workforce

Four PwPD Interviewees felt that the NDIS Workforce is not appropriately trained to work with people with psychosocial disabilities. Kym advised that her support worker, who was completing her Certificate III in Individual Support Work, told her that there was no mental health training in that course. Nigel questioned the value of Psychosocial Recovery Coaches.

> *"I don't see how they could employ people with reasonable training and insight within the system they've got. I believe that they are supposed to operate at a level below support coordination therefore cost less. It sounds nice, but it's a one size fits all assumption and the competence training capacity of these people to do what they're supposed to do. I can't see it flowing through to outcomes for people like me."* ***PwPD Interviewee Nigel***

Two PwPD Interviewees raised issues with the casualisation of the workforce and stated that they believed that it was leading to skills erosion and staff retention issues. Three PwPD Interviewees advised that the NDIS workforce's skills and dedication were inferior to those they had experienced under the previous block-funded mental health programs they had received before being on an NDIS plan. Five PwPD Interviewees raised the issue that their NDIS workers do not have sufficient experience to work with PwPDs.

> *"It seems like the ones before were really dedicated to being a support worker, like that was their life mission. It seems a lot of the support workers on Mable and maybe coming into the*

> *organisations, they're just seeing like, oh, maybe their friends have been support workers and getting good money and sometimes making easy money, so they hop on board.”* **PwPD Interviewee Kym**

4.9 PwPD Interviewees Discuss Silos

Eight PwPD Intervieweesstated there was significant siloing between the mental health, health and NDIS systems, either throughout their interview or in response to the question regarding their perspectives on seamlessness between systems for NDIS participants.

> *“I’ve been listening to politicians and policymakers talk about seamless this and that for decades? It’s rhetoric. And if something was to be done, there would need to be some very long term commitments and bipartisan investment into workforce, pre-service and in service training.”* **PwPD Interviewee Nigel**

Several PwPD Interviewees noted that private and public psychiatrists seldom interacted with NDIS providers but had often contributed to the PwPD Interviewees' reports to access the NDIS. However, the siloing continued between systems afterwards. For example, one PwPD Interviewee, Anita, was prescribed a community mental-health-funded program but required NDIS support to attend and could not have this support funded in her NDIS plan. Rhonda stated, *“The doctor doesn't talk to the psychologist, and my psychiatrist doesn't talk to my psychologist”.* Most PwPD Interviewees identified the silos between mental health and physical health conditions, with Kym noting that support coordination funding and jurisdiction is often quite limited:

> *“It's almost like there needs to be an in-between person who works with the support coordinator but also with support workers and community.”* **PwPD Interviewee Kym**

Most PwPD Interviewees had co-occurring medical conditions, and the NDIA had declined support requests for these. However, two PwPD Interviewees advised that they only had their psychosocial disability recognised by the NDIS but listed multiple funded supports, such as chairs, ramps and other house modifications that the NDIS had funded. Those PwPD Interviewees who had periods of hospitalisation had very different experiences with NDIS supports continuing or discontinuing during their hospitalisation. Some, like Anita, understood that things were and were not “allowed” by the NDIS and had clear ideas about what the NDIS would fund and that her NDIS support would not continue during her admissions. Others spoke of their NDIS workers supporting them during admissions in private and public hospitals. This support, advised Rhonda, was not well received by the hospital, and she presumed they were annoyed at the “double-dipping”.

When explicitly asked about the Council of Australian Government's agreed principle envisioning a no-wrong door and seamless experience across systems, the PwPD Interviewees stated that the systems do not assist each other, that people on the NDIS do not experience seamlessness between systems. John called Principle 6 a "*crock of shit*" and "*The problem is, is you've got to tell your fucking story 155,000 times, which causes distress, it elevates PTSD".* Kelsy noted that everyone navigates the NDIS differently and that health professionals do not understand it. Nigel noted that:

> *"They seem very, very disparate and fragmented and uncoordinated, and the NDIS seems to be populated by both people and ideas that do not want to engage with or interfere with the traditional health system providers."* ***PwPD Interviewee Nigel***

4.10 What Support Would the NDIS Provide for PwPDs with Life-Limiting Conditions?

PwPD Interviewees used their experiences with the NDIS and other systems to consider whether they would like support and how much support the NDIS would provide if they or other PwPDs developed a life-limiting condition. Responses were analysed and are represented in the charts found in Figures 13 and 14 below.

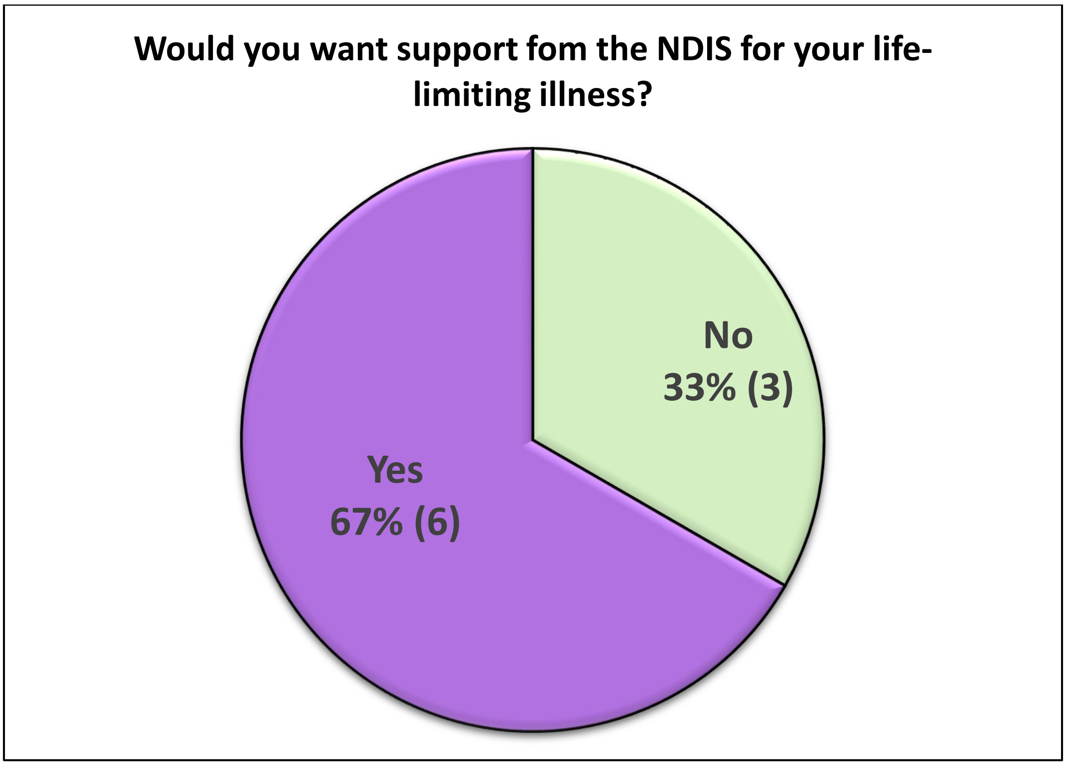

Figure 13: PwPD Interviewees Advise Whether They Want Support from the NDIS for Life-limiting Condition

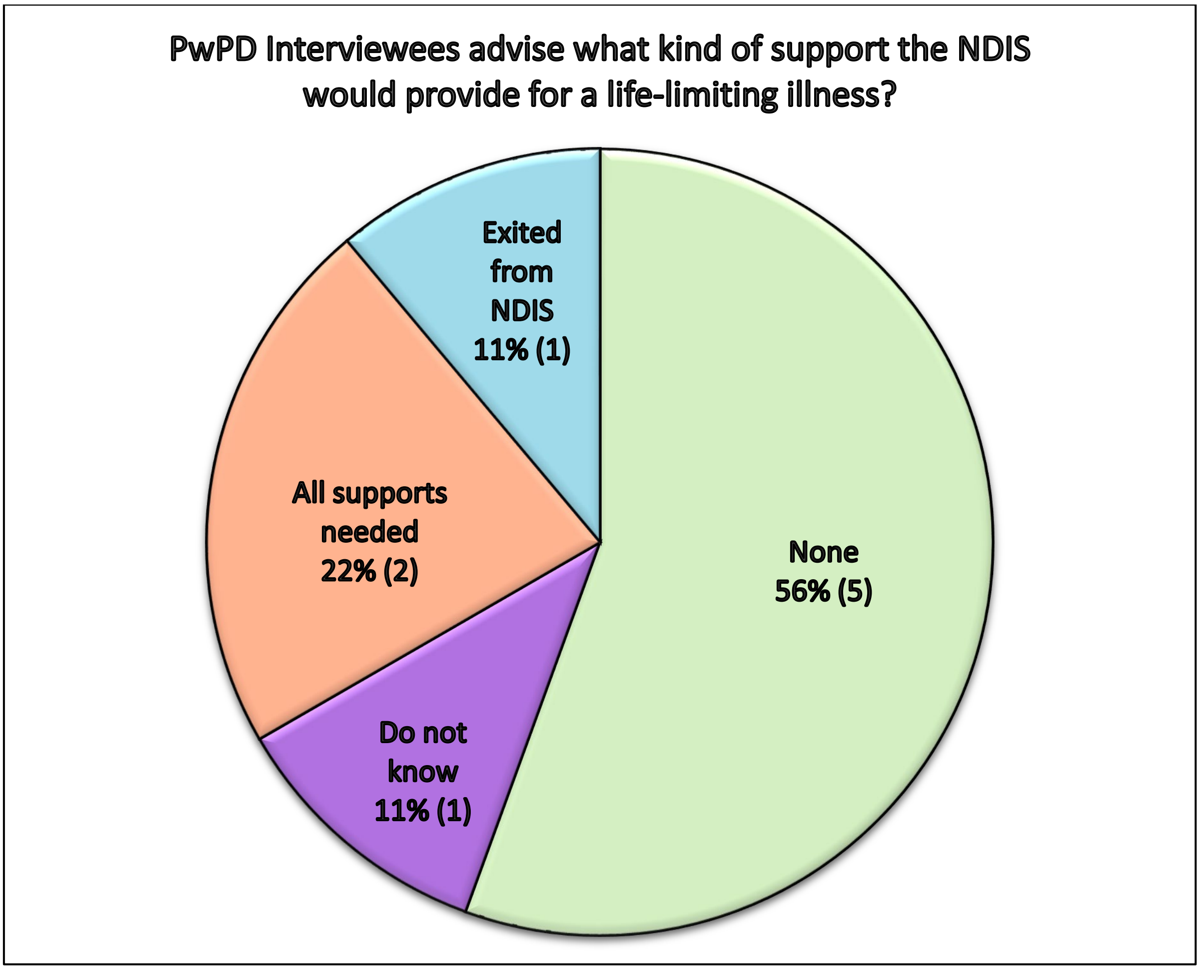

Figure 14: PwPD Interviewees Advise What Kind of Support the NDIS Would Provide for a Life-Limiting Condition

PwPD Interviewees had wide-ranging responses when asked what kind of support they expected from the NDIS if they developed life-limiting conditions. Four PwPD Interviewees initially stated they did not know, although three later shared some of their ideas. Rhonda responded that she did not know and queried whether the NDIA would consider and define dying as a medical condition.

4.10.1 The NDIS Would Not Provide Support for Life-Limiting Conditions

Whilst PwPD Interviewee Sam stated that the NDIS should support participants with life-limiting conditions, three other PwPD Interviewees felt that participants would be exited from the NDIS to a nursing home, hospice, or hospital care. John very confidently confirmed that participants would "*Go to palliative care in a nursing home to die*", and similarly, Lucy advised that the NDIS would inform participants that they need to "*go to a public palliative care*" and that participants could not choose the hospital that they would die in. Anita felt that the NDIS would not consider increasing support unless there was a significant impact on a participant's mental health.

> *"In my personal experiences, no they won't. They won't consider it, unless it impacted by mental health, in a dramatic way. Which, of course, I would, I would become very unwell. If something like that happened, I'd have a breakdown. There'd be a very unwell person here, physically and mentally."* ***PwPD Interviewee Anita***

Anita advised that she would need to be admitted to inpatient mental health if she had a life-limiting condition. Anita noted that her supports were usually suspended when she entered the hospital for any condition, and she believes that her NDIS supports would reduce or cease if she developed a life-limiting condition.

Kym stated that her friend, also an NDIS participant, has a life-limiting liver disease. He struggles to ask for help, his informal supports control his NDIS funding, and he is experiencing issues with system silos. This NDIS participant does not receive any support from the NDIS for his liver condition. The health system has advised him that his liver disease is due to his mental health issue and is best managed by the NDIS or the mental health system.

> *"So he's like just kind of pushed around into little compartments and he just throws his arms up and he's going to die one day, he reckons, so yeah."* ***PwPD Interviewee Kym***

Kelsy advised that the lack of a holistic approach to care and silos between systems would leave NDIS participants without the psychosocial supports they need as they are dying.

> *I think the difficulty with NDIS is that the whole setup between the physical and the psychosocial, it's not a holistic approach. If I was just disabled, physically disabled, or had an autoimmune disease or palliative care, I probably wouldn't have psychosocial support. Now that's crazy. I'm sorry. That's absolutely ludicrous. How can you not have psychosocial issues if you're dying?* ***PwPD Interviewee Kelsey***

4.10.2 Support Provided by the NDIS

Two PwPD Interviewees felt that the NDIS would completely support their end-of-life support needs, including increased mental health supports, equipment to assist with their declining health condition, transport, etc.

> *"I think they would help me, but it depends on... I don't really fully understand how the NDIS works."* ***PwPD Interviewee Donna***

4.10.3 Supports That the NDIS May Fund or Increase if a Participant Receives a Life-Limiting Diagnosis

Those PwPD Interviewees who felt that the NDIS would fund all or some supports for an NDIS participant's life-limiting condition suggested the following supports would ideally be part of that process:

- Increased support coordination hours
- Specialised support coordination
- Additional transport
- Increased gardening and cleaning support (continued during admissions)
- Carer support
- Increased support worker hours
- Flexible in-home supports
- Meal preparation
- Respite for carers
- Tailored exercise
- Increased psychological support
- Wheelchair
- Shower chair
- Personal care

4.10.4 The Quality of NDIS Supports Would Negatively Impact the Death and Dying Experience of NDIS Participants

PwPD Interviewee Lucy spoke about the disempowerment that PwPDs and life-limiting conditions may experience, that there would be no guarantee of supports or the quality of those supports.

> *"So I'd say people with the NDIS who have a life-limiting illness, their fate would be completely in the hands of the NDIS supports they got and their quality."* ***PwPD Interviewee Lucy***

Five PwPD Interviewees felt that the quality of NDIS supports currently available to PwPDs would negatively impact their death and dying experience if they developed a life-limiting condition. Rhonda was uncertain but noted a lack of consistency in the quality of her supports. She would be comfortable continuing working with some of her workers if she developed a life-limiting condition. She felt others did not have the capacity or experience to support her in such complex circumstances.

Sam said he would not want the NDIS provider workforce near him or his palliative care team if he had a life-limiting condition. He felt that NDIS providers are predatory and would take funding without providing adequate support. He confirmed that he would steer people with a life-limiting condition away from the NDIS, particularly NDIS providers.

> *"And so like meself, I don't have any family, I've got no friends, my daughters have pissed me off, they don't want to know me. But imagine if you're dying too, but that person, I would say keep the NDIS away from them, let them enjoy what they've got left. They'd be getting injured, they would, with services they would get from these people (NDIS providers) with my experience, you've got to keep them away."* ***PwPD Interviewee Sam***

Finally, John noted that the casualisation of the NDIS workforce and a lack of continuity of care would be a core issue of concern for PwPDs and life-limiting conditions.

> *"It's a casualised workforce. They haven't got enough training… because they're casualised, it's like they hop and jump everywhere. So when it comes to continuity of care…. I think people who are dying, people who are sick, people on psychosocial disability who may be more on a lower scale than me, they need continuity of care, and you can't get it."* ***PwPD Interviewee John***

4.10.5 The NDIS would Contribute to Adverse Outcomes for NDIS Participants with Psychosocial Disabilities and Life-Limiting Conditions

Eight PwPD Interviewees stated the NDIS would contribute to poorer outcomes for PwPDs and life-limiting diagnoses. PwPD Interviewees Kym, Rhonda and Sam expressed fear about the support they would receive from the NDIS. Several PwPD Interviewees advised that the planning process, the knowledge of planners and the slow response to NDIS participants' change of circumstances would create significant stress and uncertainty for NDIS participants who were dying. PwPD Interviewees Kelsey and Anita advised that their plan reviews can take six months, and the NDIA responded very slowly. Anita felt that a lack of support in the community would result in more hospital admissions for NDIS participants.

Nigel stated that engaging with the NDIA planning process was exhausting and that most people cannot advocate for themselves. He noted that advocacy is inadequately funded and would be required to support dying NDIS participants with the planning process. Rhonda advised that the silos between systems would complicate the navigation and ability of both the NDIS and health systems to support dying NDIS participants. Rhonda also raised concerns that the structure of the NDIS meant that PwPDs would need to cancel NDIS supports at short notice due to their life-limiting conditions. Further, she noted that a life-limiting condition would complicate the delivery of NDIS funded supports.

4.11 Would the Death, Dying and Palliative Care Experience of PwPDs be Equitable to Other Australians of the Same Age?

Each of the PwPD Interviewees was asked if they believed that the experiences of PwPDs and life-limiting diagnoses would be the same or different (i.e. be equitable) to the experiences of other Australians the same age as them with life-limiting diagnoses who did not also have psychosocial disabilities or support from the NDIS. Responses were simplified and analysed and are represented in the chart in Figure 15 below.

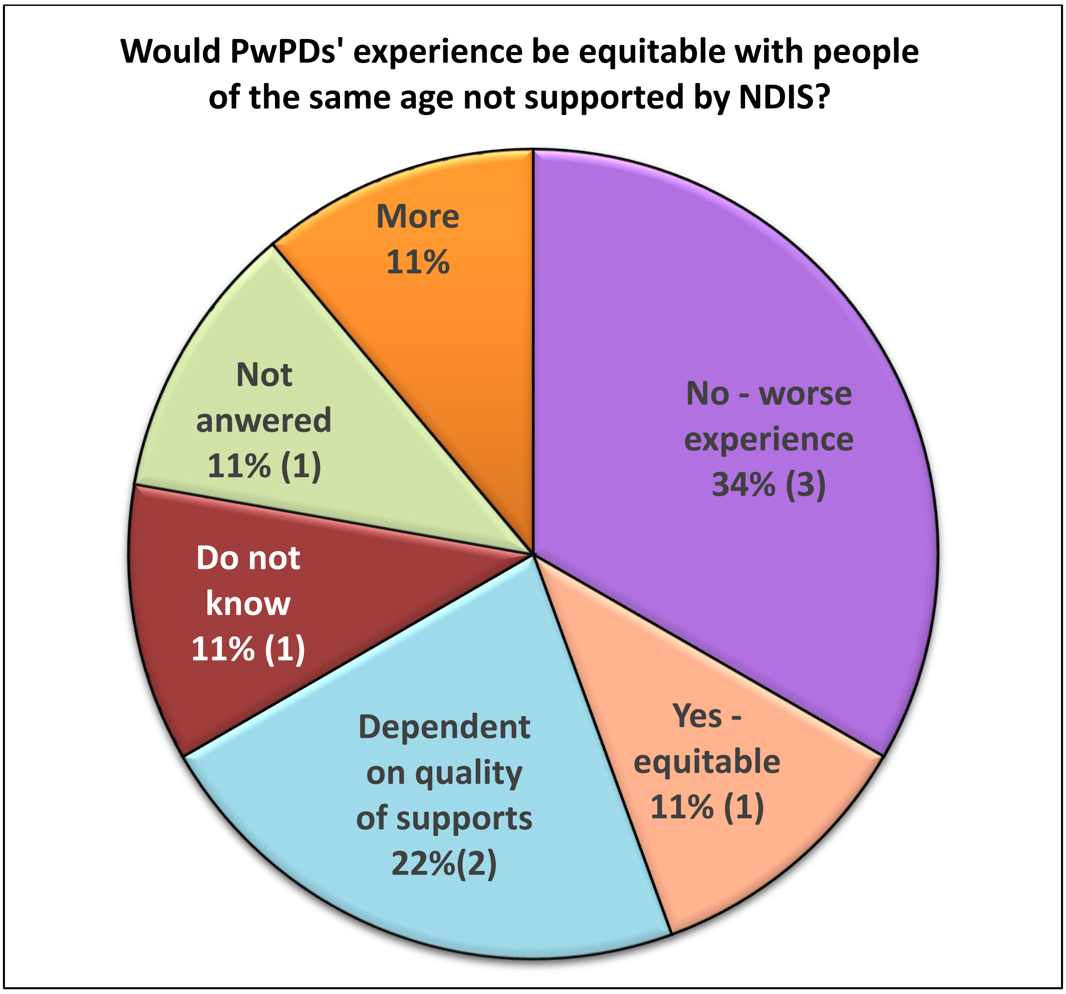

Figure 15: PwPD Interviewees Advise whether the Death, Dying Experience be Equitable

With her prior history of working in the health systems, Lucy advised that she would receive more supports from the NDIS than peers in her age bracket. however she felt that older and younger NDIS participants would not have an equitable palliative experience. Anita felt that the NDIS does not currently support her to live an equitable life, so it would be unlikely that she would be supported to die equitably. Nigel noted:

> *"I doubt it, I think there is some confusion about the role, the roles where they stop and start and where they do need to step across to join up with services and providers that that aren't NDIS." **PwPD Interviewee Nigel***

4.12 The NDIA Would View NDIS Participants' Deaths as a Cost-Saving

Two PwPD Interviewees, Lucy and John, indicated that their interactions with the NDIA have left them feeling like they are viewed as a burden, and that the NDIA would regard their impending death positively. Lucy stated that "*they might want people to die as quickly as possible*".

> *"That's what the NDIA wants. They don't have compassion for this side of thing because you're not going to go into work. You're not going lessen your funding and they don't see value in you. So if you are going to die, happy days, because it's one less person on the NDIS". **PwPD Interviewee John***

4.13 PwPD Interviewee Summary

PwPD Interviewees felt that by participating in this research, they were advocating for PwPDs. They understood that the term psychosocial disability referred to mental illness, but there was no clear or consistent definition beyond this. Half stated they had no or fractured relationships with their families, and three had no informal support at all.

PwPD Interviewees had varying conceptions of palliative care, which was in line with what is understood by all other cohorts involved in this current research, except palliative care clinicians. One PwPD Interviewee highlighted the difference in palliative care in two different states and another noted that palliative care is siloed from other systems. One expressed that they felt that their friend with a mental illness declined palliative care as they wished to escape a painful existence.

Most PwPD Interviewees were not under the care of a psychiatrist, and their GP managed their psychiatric medication needs. Long delays for appointments was raised as an issue for most PwPD Interviewees. Some were privately funded patients of psychiatrists. Those who could be supported by private hospitals, psychiatrists and psychologists noted that they were glad not to be admitted to public hospitals. One PwPD

Interviewee expressed concern that she could be exited from the NDIS as she had been exited from the state-funded community mental health program.

The PwPD Interviewees listed supports that they had received from the NDIS. These were varied; notably, handrails were installed at an PwPD Interviewee's property even though they had no physical disabilities accepted by the NDIS. Additionally, counselling and therapeutic interventions were listed by five PwPD Interviewees despite these being the responsibility of the mental health system[8]. Some PwPD Interviewees reported that they are happy with the supports that they receive, particularly cleaning and gardening, from the NDIS. However, others felt that the NDIS does not provide meaningful help for their psychosocial disability.

Most PwPD Interviewees reported both positive (23%) and negative experiences (77%) with the NDIS. Some described experiences that were extremely negative for them. The focus on deficits in the NDIS was described as "*wrong".* The NDIS process and the NDIA's poor communication about them were cited as frustrating. Gaining access to the NDIS caused significant distress for most PwPD Interviewees. They described feeling rejected and the access process as slow, confusing, demoralising and depressing. The NDIS was described as both flexible and inflexible. However, it appears for some NDIS participants that if they understand how the system works, they can obtain the supports that they feel they need without explicitly declaring what they are spending their NDIS funds. PwPD Interviewees described the review and appeals process as confusing. The NDIS was described as demotivating and impacted their abilities, making them "*more disabled".*

Two interviewees had experiences with the NDIS Quality and Safeguards Commission, one positive and one negative. PwPD Interviewees' responses regarding the NDIA and planning decisions were overwhelmingly negative 94% and 6% of responses were positive. There was often confusion and frustration about the NDIA's planning processes and how budgets are set up and explained. PwPD Interviewees described having to be very patient with the process. They felt ignored and do not trust the NDIA or the LAC partner organisations, with one stating that these individuals acted in ways that are deceptive. However, one PwPD Interviewee stated that she was happy with her plan, and another praised a LAC provider organisation. PwPD Interviewees expressed fear that if they said anything positive about themselves to the NDIA's staff, their plans would be cut. They stated that NDIA staff ignored the assessments and recommendations of the health professionals who know and understand the PwPD Interviewees' needs, are not themselves health professionals, and are making decisions they felt were outside their scope.

The PwPD Interviewees' responses regarding their NDIS providers were varied, with some being very positive (31%) about some or all of their providers and others having very negative experiences (69%). Casualisation, lack of training and poor remuneration were cited as key issues, with most acknowledging that the NDIS workforce, mainly support workers, are not explicitly trained in mental health work. Often, they reported that their NDIS experience was entirely dependent on the individual attributes of the workers. Three had direct experience with nefarious providers who had engaged in fraud, and seven had very negative experiences with workers or providers that led them to become mentally unwell.

Eight PwPD Interviewees noted that in their experience, there is significant siloing between the mental health, health and NDIS systems, either throughout their interview or in response to the question regarding seamlessness between systems for NDIS participants. They identified that they have to repeat their stories to multiple agencies. One PwPD Interviewee identified that their NDIS workers could not support them in hospital settings and explained that this has a negative impact on them.

PwPD Interviewees were asked what kind of support would be provided by the NDIS if they were to develop a life-limiting illness; responses ranged from complete support, including equipment and personal care workers, to no support at all. There was uncertainty about whether PwPD Interviewees would like support from the NDIS if they were to develop a life-limiting illness, with PwPD Interviewees indicating that the quality of NDIS supports currently available to PwPDs would negatively impact their death and dying experience if they developed a life-limiting condition. One PwPD Interviewee stated that the casualisation of the NDIS workforce and a lack of continuity of care would be core issues for PwPDs and life-limiting conditions.

CHAPTER 5 INFORMAL SUPPORT INTERVIEW RESULTS

5.1 Introduction

To understand the perspectives and opinions of informal supports of PwPDs seven informal support interviewees (IS Interviewees) were interviewed. They contacted the research team in response to seeing the research flyer on social media platform Twitter, a Lived Experience Australia newsletter, the Kinora platform, at a community palliative care expo, and hearing about the research via word of mouth. IS Interviewees discussed their family members' experiences, their informal and formal support networks, and the types and quality of support their family members received from mental health, health, and the NDIS systems. Further, IS Interviewees shared their experiences with the National Disability Insurance Agency (NDIA) and NDIS providers and their views on the NDIS.

IS Interviewees used their knowledge and expertise regarding these systems and talked about what it might be like for a PwPD with a life-limiting condition and the formal supports that they may receive. Further, they shared their opinions about whether that experience would be equitable with other Australians and seamless between systems. The IS Interviewees' experiences with systems were explored deeply to enable a better understanding of potential feedback loops within and between systems. As direct quotes from interviews will be included in this chapter, any potentially identifying information about IS Interviewees was removed, and pseudonyms were assigned.

One IS Interviewee, Barbara, had personal experience with the phenomenon as her sister Leoni was, after a protracted period, trying to gain access to the NDIS, a PwPD with a life-limiting condition. This experience is described in section 5.12 A Case Study – Informal Support Barbara and her sister Leoni.

5.2 Informal Support Interviewees' Demographics

Seven IS Interviewees, two male and five female, responded to the research interview flyers and completed the interviews. They resided in Adelaide, Melbourne, and rural New South Wales and were interviewed via Teams or in person. All IS Interviewees were family members of PwPD, mothers, sisters, a husband, and a brother. No IS Interviewees identified as belonging to CALD, Aboriginal or Torres Strait Islander communities. IS Interviewees had been involved with the NDIS for between one and five years. Two IS Interviewees (sister and mother) were interviewed together. One IS Interviewee's wife was also interviewed separately for this research. One IS Interviewee is also a manager for an NDIS Provider, another has worked in the palliative care sector as a social worker, one currently works as a death doula, one is a psychologist, and two are actively involved in mental health advocacy with the NDIS.

IS Interviewees advised that their family members have received the following diagnoses: schizophrenia, borderline personality disorder, depression, anxiety and hyper-manic depression. The NDIS participants that the IS Interviewees support are between 19 and 65. One IS Interviewee, Barbara, advised that her sister Leoni was re-applying to access the NDIS. Her sister had lung cancer and received support from her community palliative care team. Barbara later emailed the research team and advised that her sister gained access to the NDIS a few weeks before she died. Unfortunately, although accepted as an NDIS participant, Leoni had minimal support from the NDIS support before she died. Section 5.12 is a case study of their experience.

5.3 Informal Support Interviewees Discuss Advocacy

All of the IS Interviewees recognised their role as advocates in their family member's life. They stated that, from their experience, PwPDs interactions with all systems, NDIS, health and mental health are fraught. It was emphasised by all that their advocacy was essential for the continued well-being of the NDIS Participants that they support. Further, they expressed concern for Australians with psychosocial disabilities that do not have family or friends to advocate for them.

> *"I worked with – for [State Health Department] for [20+] years, and I thought that was pretty chaotic, and bureaucratic, etcetera. the NDIS is so much worse. It's inexplicable really. So how people with disabilities without advocates, and family members navigate then, and then when their needs change, how do they advocate for that? That's a very scary thought."* ***IS Interviewee Stella***

Those with experience and networks within the disability and mental health sectors actively participated in their family members' interactions with the NDIA and managed their NDIS supports, noting that the workforces of both sectors are very inexperienced in navigating the NDIS.

> *"I made sure that I was there for the initial planning meeting and the implementation meeting because I knew that the people at the SRF would have no idea."* ***IS Interviewee Brad***

Most IS Interviewees advocated for their family members only; however, some advocated for the wider mental health community, other NDIS participants, applicants to the NDIS and carers.

> *"I still, despite my age, stay involved in all these things… getting a little bit old to be the only person representing."* ***IS Interviewee Penny***

Some IS Interviewees said their family members declined or limited their advocacy efforts. Despite having considerable knowledge of the palliative care and mental health sectors, Barbara struggled to support her sister as she often declined her support.

> *"My sister has refused to let me advocate for her, or even just make an anonymous complaint to the palliative care service."* ***IS Interviewee Barbara***

Many IS Interviewees felt that advocacy is vital to ensure positive outcomes for people living with mental illnesses. While IS Interviewees knew of some NDIS participants who could advocate well for themselves, they stated that many could not. Sally stated that without family or advocacy support, PwPDs could have "*horrific outcomes*" and "*end up homeless without advocacy*". Penny realised how lucky her family members have been:

> *"We've been so lucky. But in so many ways, that's also frustrated me because I think it shouldn't all be dependent on luck."* ***IS Interviewee Penny***

5.4 Informal Support Interviewees Answer "What is a Psychosocial Disability?"

While the term psychosocial disability was identified as broad and confusing, IS Interviewees linked the term psychosocial disability to mental illness and the impact that it can have on function. Two IS Interviewees noted that the NDIA had a different interpretation of psychosocial disability.

Table 4: Informal Support Interviewees answer "What is a Psychosocial Disability?"

IS Interviewee	IS Interviewee Quotes
Penny	• It used to be called severe and enduring mental illness. • It is a recognition that mental illness can be disabling.
Sally	The document Unravelling Psychosocial Disability clearly explains it, but it's been forgotten about now.
Simone	• It is a very confusing term. A mental health issue. • Psychosocial disability means that you can seek supports to help with day to day living, but the NDIS does not help with the actual mental health issues
Barbara	• Not depression and anxiety, those diagnoses do not cut it with the NDIA. • A psychosocial mental health condition is really any condition that affects your ability to function socially from a psychological perspective, but let's

IS Interviewee	IS Interviewee Quotes
	face it, that's pretty much any kind of mental health condition is going to affect you socially that way.
Jack	People with mental health issues
Stella	Complex mental health issues that wax and wane, relapse and with periods of personal recovery. NDIS has difficulty with the concept of psychosocial disability and its associated terms.
Brad	• It's very, it's very, very broad. • Psychosocial is very, very similar to autism as in it's such a broad, how can I say disability and there's so many intricate details, you know not two people are alike, for example bipolar. There's not two people with bipolar that are the same because of the chemical imbalances in the brain, because you've got so many working parts in your brain.

5.5 Informal Support Interviewees Discuss Their Role and its Impact

All seven IS Interviewees spend much of their day-to-day lives actively supporting PwPDs. Two of the IS Interviewees were supporting young adults and did not comment on the impact that this had on their lives. However, those with older family members that they were supporting commented on the implications for their own lives, with Penny noting that their family had *"a traumatic 30 years"*. Most reflections on informal support for PwPDs show that they see themselves as advocates (see 5.1). Most informal supports had multiple caring roles, either with more than one family member with disabilities or also caring for children and elderly parents. Stella talked about the importance of PwPDs having family/informal supports in their lives. Most interviewed had paid or unpaid roles in systemic advocacy, the disability, mental health or palliative care sectors.

> *"Well, if my son didn't have me – I coordinate everything in his life from his eating to his finances, his appointments, his medication, everything, I'm the coordinator. He doesn't answer the front door, he doesn't answer his phone, he doesn't eat or drink unless I'm down there prompting him. He would become very unwell very, very quickly."* ***IS Interviewee Stella***

There was an acknowledgement that life is very difficult for people living with mental illnesses who do not have support. Jack said he hoped the NDIS plan management support would be good support for his wife.

> *"…because if something happens to me, then the wheels don't fall off. I was trying to set it up so that I wasn't the critical link in the whole chain."* ***IS Interviewee Jack***

Penny, in her mid-seventies, described "*lying in bed at night*" worrying and becoming "*tearful*" about what would happen to her children, both of whom are supported by the NDIS, when she dies. Penny told us that she always travels separately from her husband so that there would still be someone around to care for her adult children in the event of an accident.

5.6 Informal Support Interviewees Discuss the Mental Health System

The NDIS and the state-funded mental health systems support three NDIS Participants connected to IS Interviewees. Two NDIS Participants, IS Interviewees advised, had been discharged from the public system. Three IS Interviewees funded private psychiatrists for their family members, and one pays for private mental health clinic admissions through their private health fund. Two NDIS participants had psychologists funded through the NDIS, and the NDIS partially funded one participant's psychologists, with the remaining visits funded by their informal support.

Brad advised that his brother's mental health clinical support is managed by his general practitioner and most of his functional supports are funded by the NDIS. His brother lives in a supported residential facility that receives a small stipend from the NDIS and is chiefly financed from residents' pensions or personal incomes. The PwPD with a life-limiting condition, Leoni, who died before receiving any meaningful NDIS-funded supports could not afford a psychologist's support as she was palliating and would not accept assistance from the IS Interviewee.

After experiencing minimal state funding for community mental health for many years, IS Interviewees Sally and Penny described being thrilled that the NDIS was expanded to include psychosocial disabilities as they felt that the mental health system struggled to understand that some people with mental illness live with significant and permanent disabilities.

> *"I've given up now on mental health. I refuse to advocate any longer….. I'm just banging my head against a brick wall. Nothing was ever going to change".* ***IS Interviwee Penny (Sally expressed a similar view)***

However, Penny and Sally expressed frustration with the NDIS and mental health systems, explaining that each system defers responsibilities to the other, they "*keeping pushing to the NDIS, and the NDIA keep pushing back*".

IS Interviewee Stella advised that she did not want her son to be involved with the state/community-funded mental health systems due to previous negative experiences.

> *"He was in the mental health system for a very long time from about the age of 6, until we moved here to [regional coastal town] about 7 or 8 years ago, because he experienced a lot of trauma, and some terrible treatment in the system. So he's had a couple of appointments down here with Community Mental Health, and they were… So I thought, I'm not going to involve Community Mental Health again, I'll just… hopefully the NDIS can help."* ***IS Interviewee Stella***

Further, Stella felt that the mental health system workers needed significant upskilling to support people with mental illnesses and life-limiting diagnoses.

> *"Obviously, it's a very traumatic and confronting for any individual to be given a life-limiting diagnosis. So mental health support should be there from the get go. Whether or not the person takes that offer up. So we should be upskilling all of our mental health professionals, because hey, we all die. And if your mental health consumer develops an illness, then that's going to exacerbate their mental health issues. So we need to be proactive about it, and speak up about it."* ***IS Interviewee Stella***

5.7 Informal Support Interviewees Discuss the NDIS

5.7.1 NDIS Participants

The IS Interviewees stated that PwPDs are highly vulnerable and often die sooner than others due to various factors, including iatrogenic effects of psychiatric medications, lifestyle factors and their inability to manage health concerns. Psychosocial disability was viewed by two IS Interviewees as a life-limiting condition. Brad expressed concern that PwPDs, particularly those in the community not living in supported accommodation, were most at risk from predatory providers as there are few checks in place to ensure quality and safeguarding, particularly as many unregistered providers are offering NDIS supports.

5.7.2 Informal Support Interviewees Discuss Support from the NDIS

IS Interviewees were asked to list the funded supports their family members receive from the NDIS. Their responses included support workers, cleaners, support coordination, plan managers, developmental educators, and psychology and occupational therapists. Four family members received supported independent living funding in their NDIS plan; one had supported disability accommodation funding but could not find a bed, and another was in a supported residential facility (SRF), which is a for-profit facility that is chiefly funded by participants' disability support pensions, they receive a stipend from local councils and, at times, NDIS or aged care funding. These are often referred to as boarding houses and may also have residents who do not have NDIS or aged care funding. Less common responses included diabetes educators, a canine therapy dog, gym memberships and transport. It was noted that support workers do not seem to have appropriate qualifications or experiences. The interviewer provided no further prompts (other than clarification about whether IS Interviewees were referring to plan managers or support coordinators). If any comments were made whilst listing their supports, they have been included in Table 5 below.

Table 5: Informal Support – NDIS Funded Supports Received by Family Member/PwPDs

Support Type	Participants	IS Interviewee Comments
Support Workers	3	• Can I please have trained experienced mental health professionals with my son, rather than 20 year old disability support workers who turn over every six months and have no experience? And every year it's not approved. • 15 hours per week at the moment. • I get the feeling that many of the support workers that we've had thus far aren't really qualified in anything • Community participation, one on one funding
Developmental Educator	3	• We've received this wonderful NDIA planner. And what she did was she gave us a short plan. Yes. With sufficient funding to employ developmental educator to properly assess their needs. • * Then she suggested, because [NDIS Participant] was after a tutor, and you can get a tutor at uni, but you're not getting specifically what you need. And so then this developmental educator, never even heard of them, and it seemed like that would be the right thing to do.
Diabetes Educator	1	• We've just recently had to go to the to the Administrative Appeals Tribunal, because they tried to cut the services of the diabetes educator.
Support Coordination	4	• We have to have a good support coordinator. So please keep the Support Coordinator funding in our budget practice increase it because I'm getting too old to do the support coordination, which I'm really doing.

Support Type	Participants	IS Interviewee Comments
		• The support coordinators to that didn't have any knowledge in particular about psychosocial disability.
Plan Manager	3	• I don't like the idea of the person who manages the money being part of the same organisation because there's a conflict.
Cleaning	1	
Psychologist	3	• For his behaviour support plan. • Initially, it was privately funded and then some of it was funded through the NDIS.
Occupational Therapy	3	• [W] e've gone through an OT driving school, and so now *[NDIS participant]* had 50 sessions
Canine Support	1	• [Sh] e's got core supports, which we are using for the canine support
Recovery Coach	2	• One hour per week for two years. • Referred to as a mentor.
Gym Membership	1	• [J]ust his first year and then not again
Transport	1	
Supported residential facility (SRF)	1	• **The NDIS has improved their service, but not the SRF accommodation.
Specialist Disability Accommodation	1	• Funded but unable to find a vacancy.

Support Type	Participants	IS Interviewee Comments
Supported Independent Living 24/7 1:1 support	3	• In a privately owned home. • Funded but not yet in SDA due to no vacancies. • People with the NDIS now have the opportunity to live in their own place with their own supported independent living options. And some people with mental illness like that. But there's many like [Participant name] who would benefit from having some of their peers close by because they've been marginalised for so long. And they're lonely. And but they don't necessarily want to live in the shed. Definitely don't, like most people, most people don't want to live and if there's a way around it, and I think there is I mean, if you could have two people full time to look after four or five people that'd be so much more beneficial.

***** Educational supports for university, are not considered best funded by the NDIS [8]

****** In South Australia Supported Residential Facilities (SRF's) receive a small stipend from the NDIS, but most supports are funded through local government grants and the NDIS Participant's private income or income support payments through Centrelink.

5.7.3 Informal Supports Discuss the NDIS as a system

Informal supports described feeling "*grateful*" and "*excited*" about the NDIS and felt that there had been an improvement in the support for people with mental health conditions. However, the overall opinion of IS Interviewees of the NDIS as a system was mostly negative. The NDIS was described as "*frustrating*", "*cumbersome*", "*not working well with other systems*", and as an "*unwieldy beast that nobody understands*", causing much distress for themselves and within the disability community. Comments were analysed and assigned as either a positive or negative value. The results are charted below in Figure 16 below. A table containing the analysed comments can be found in Appendix 1, Section 2.1.

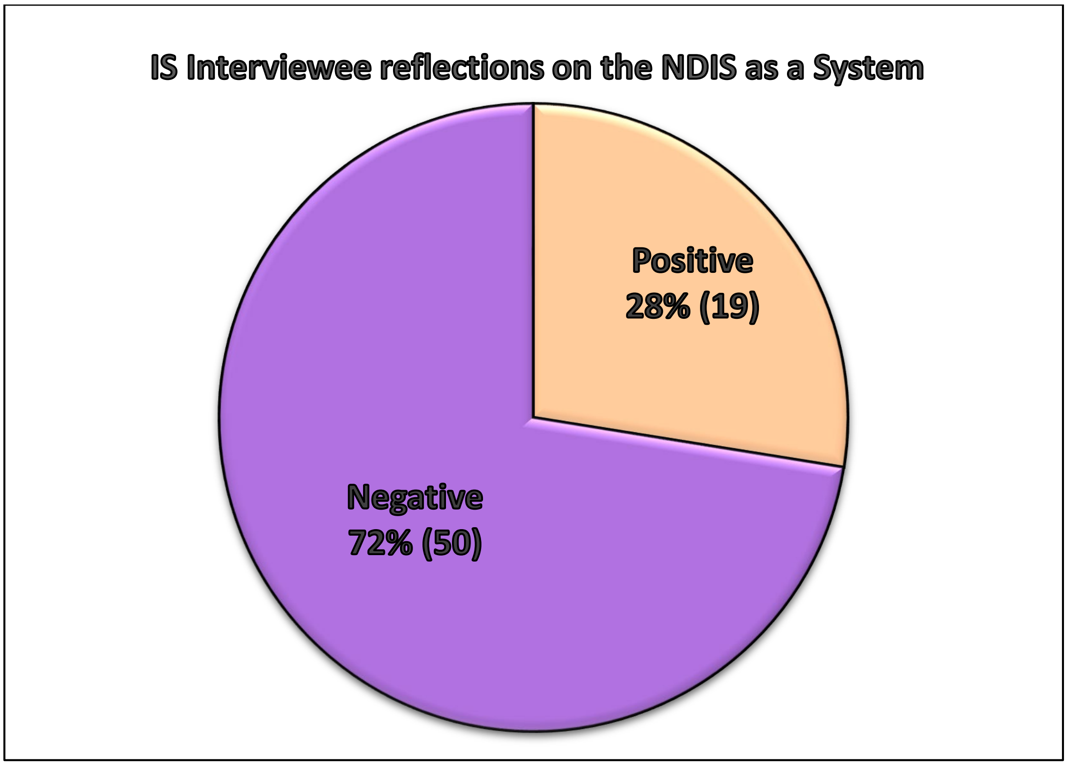

Figure 16: Informal Supports - Reflections on the NDIS as a System

5.7.4 Informal Supports Discuss the NDIA

IS Interviewees reported that they do not trust the NDIA, they feel that it has a "*hidden agenda"* with continual cuts to plans and limited guidance provided by the NDIA staff for PwPDs and informal supports to understand the processes. Further, they state that NDIA staff do not have a good grasp of psychosocial disabilities and do not view PwPDs holistically. IS Interviewees feel that NDIA staff are unqualified, trained and inexperienced. Staff turnover is high and IS Interviewees rarely speak to the same person.

Comments, as listed in Appendix 14 about the NDIA have been categorised as negative or positive and are charted in Figure 17 below. Statements regarding the workforce of the NDIA, including access officers, planners, and partners, also referred to as local area coordinators (LACs), have been included in discussions about the NDIA. Whilst they could also be considered the NDIS workforce, this category has been assigned within this research to employees of NDIS providers.

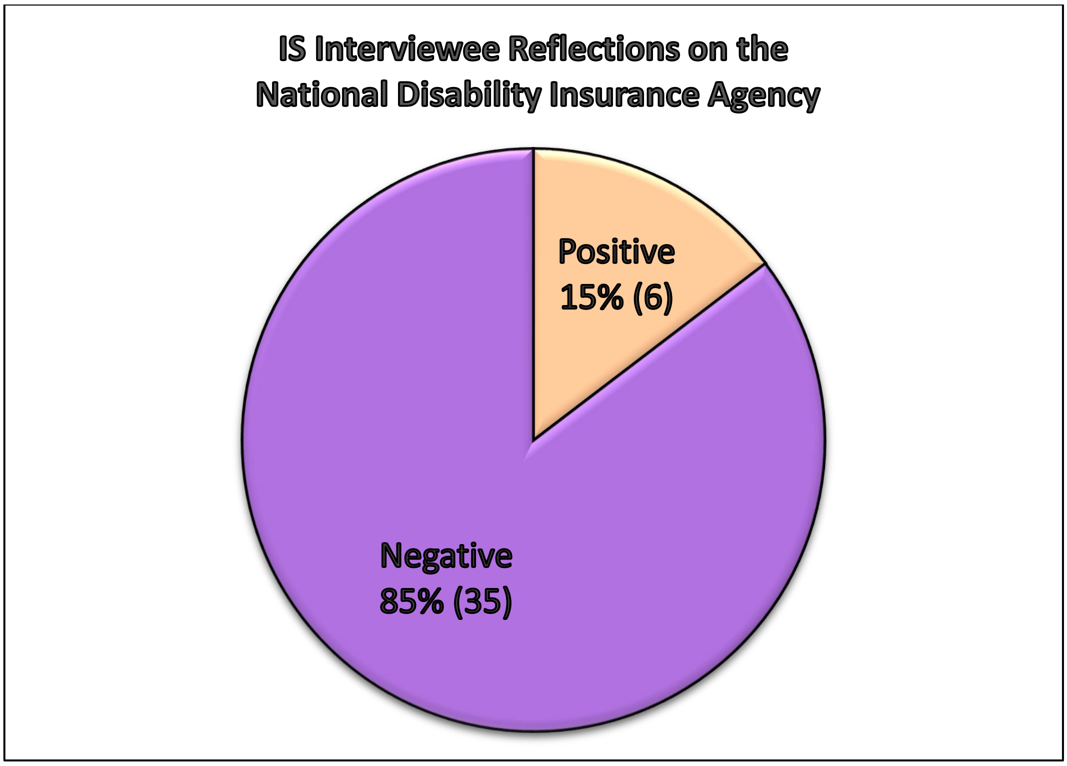

Figure 17: Informal Supports – Reflections on the NDIA

5.7.5 Informal Support Interviewees Discuss NDIS Providers

One of the informal supports interviewed, Brad, works as a middle manager for an NDIS provider; his workplace does not provide NDIS support for his brother. Brad's reflections about providers included his experiences with his brother's providers, references to his workplace and the experiences with other NDIS providers that support participants from his workplace. Brad advised that PwPDs are the most vulnerable people in our communities and are likely to become the victims of predatory providers. Further, he felt that there are "*more people just popping up left, right and centre*" and that the sector currently has no appropriate checks or quality controls in place.

> *"It's those sole traders, those individual people, they're the ones that I'd be concerned for the participants out and about in the community and, in particular, people going through palliative who don't have many family connections left or are not well connected with the community."* ***IS Interviewee Brad***

Brad’s brother does not engage with the NDIS processes; he is aware that he has funding but relies on providers to tell him how he can use the funding. He lives in an SRF that has around 40 residents living there, most with mental illness. They have all meals provided at specific times in shifts.

> *“That’s one thing that I, one reason why I don’t like my brother there is because there’s no choice and control at all. If he chooses “oh I don’t want to eat my dinner at 5 o’clock tonight and I only want it at 6:30” well bad luck.”* ***IS Interviewee Brad***

Brad hopes the SRF will support his brother if he is diagnosed with a life-limiting condition and wants to die at home. He notes that, although their service has improved slightly with the introduction of the NDIS, they are a for-profit provider, so he is uncertain whether they would be comfortable supporting people at the palliative stage. He believes his not-for-profit employer would support NDIS participants with life-limiting diagnoses unless their physical support needs exceed the range of support they are registered to provide. This would include advocating for additional funding in their NDIS plans. Brad agreed when asked if he thought it would be good for providers to be funded to support NDIS Participants if they were dying.

> *“Absolutely, and especially for participants that don’t have many family at all because really that’s all they’ve got in their lives. Like I said, we’re thankful and grateful that we’ve got very, how can I say, understanding staff and staff that have a real passion and heart for people not because they’re getting paid to do the job but because they want to do it.”* ***IS Interviewee Brad***

After several attempts with different providers who were not flexible with their support options, Penny and Sally told of incredibly positive experiences with one NDIS provider. They describe the company owner as dedicated and the workforce as committed and connected. They regularly meet with the participants’ families, which has had highly positive outcomes for the participants and their families.

> *“They really have that collective culture where it’s about, you know, supporting the whole community. And they say, you know, we love [participant name], they do, they say that, and it truly is person-centred.”* ***IS Interviewee Sally***

Penny stated that she felt confident that if a participant were diagnosed with a life-limiting condition, this particular NDIS provider would provide excellent support as they were dying. However, Penny advised that, apart from the current NDIS provider, from whom their family members are receiving support, she had concerns about the quality of NDIS providers: “*if we didn’t have them, I don’t think we would find a good provider*”.

Simone, the mother of a 19-year-old PwPD, finds that NDIS providers “*notoriously are a bit faceless*”. Simone struggled to find NDIS providers that could provide workers with any understanding of psychosocial disabilities.

> *“I actually think what’s happening, is all the companies that provide support coordination in one way or the other have then said, “Ooh, mental health, okay, we’ll be psychosocial disability support people as well,” and put that on there. But nobody’s qualified. Nobody has that mental health support background to be able to do that job properly… we’ve found [NDIS Provider name], which are fairly new. I think they’re only a couple of years old, and they deal with physical disabilities, but they have just started to bring in people that can support the mental health side. Even then, I think they don’t fully know what they’re doing with that, either. So, I think all these companies are getting on this mental health bandwagon without really understanding what it is that a person that has NDIS funding for mental health issues or psychosocial disabilities, needs.”* ***IS Interviewee Simone***

Simone describes the NDIS support her daughter has received to date as “*very average*”.

> *“They're just tick and flick, they just want the money. And they don't make you feel better, they just, it's kind of like, "Yeah, move on, go away."* ***IS Interviewee Simone***

When asked about NDIS providers when considering a family member with a life-limiting condition, Simone stated that, based on her experience with NDIS Providers, "*I wouldn't be going to the NDIS, because I don't think well, that'd be the last place that I'd go."*

Stella had limited interaction with NDIS providers providing support workers. Her son had been too unwell for his NDIS support workers to work with him. She noted that few providers seemed to have staff that could work with NDIS participants with significant psychosocial disabilities. Conversely, Stella stated that her son's support coordinator was very proactive, and his NDIS behaviour support plan, completed with an NDIS occupational therapist and psychologist, was comprehensive.

Barbara expressed concern as the provider of NDIS support coordinators seemed unable to retain or educate staff.

> *"Then lo and behold, he'd left, you know, he only lasted a few months at the most, and then I've had two other coordinators since then. No one's even told me when they've left. There were months there where I've had no one and I couldn't – I tried to get in touch with them, and I couldn't get in touch with them. They kept on referring me back to him,*

> *but he had gone from the organisation and his supervisor wasn't communicating with me."* ***IS Interviewee Barbara***

5.7.6 Informal Support Interviewees Discuss the NDIS Workforce

With his perspective as an informal support and a middle manager in an NDIS provider organisation, Brad brought a unique IS Interviewee perspective on the NDIS workforce. He spoke of his workers taking their own time, unpaid, to support NDIS participants on Christmas day.

> *"Now this participant three years ago Christmas Day had no funding for NDIS for Christmas Day from 10 am until 5 pm and, like I said no. family or anything. Staff members volunteered knowing that they can't get paid, but picked him up from his home, took him to their family lunch for Christmas Day and then dropped him off home at 5 o'clock in the afternoon when the actually paid staff could start."* ***IS Interviewee Brad.***

Brad shared his experience with one of their PwPDs and a life-limiting condition, who had no contact with his family or any friends at the time of his death. The staff at Brad's workplace visited the participant in the hospital and arranged his funeral. Brad said they did this "*out of love for that participant*".

> *"They did it themselves. They did it, they just walked in because lots, lots of their employees will go above and beyond unpaid for any of our participants."* ***IS Interviewee Brad.***

In his organisation, Brad stated

> *"We're thankful and grateful that we've got very, how can I say, understanding staff, and staff that have a real passion and heart for people. not because they're getting paid to do the job because they want to do it."* ***IS Interviewee Brad***

Brad spoke less positively about NDIS workers outside of his employer. He noted a considerable variety in the quality of the workers from NDIS Provider to NDIS Provider. He also stated that rather than being qualities that sat with providers, good work and the passion to support NDIS participants often sat with the individual workers.

> *"Support coordinators, they've got no idea what they're doing at all, or they're non-responsive. To get them to assist it's like banging your head against a brick wall and it's like, well it needs to be done."* ***IS Interviewee Brad***

Penny stated that support coordinators are vital, particularly for NDIS Participants with aging parents; however, she expressed similar concerns regarding their understanding of psychosocial disability and their scope of practice.

> *"The support coordinators didn't have any knowledge in particular about psychosocial disability. You've got to be able to, to give good instruction about what you're needing, what you've been dissatisfied with and what they've been doing as well not doing or not doing."* ***IS Interviewee Penny***

Penny also feels that a return to the case management model would benefit NDIS Participants with complex needs, as support coordinators only offer support around a participant's NDIS funding, not their holistic psychosocial disability, mental health and physical health needs. Penny expressed significant concern that there is no support for an NDIS participant across the various systems around them. When asked about the NDIS workforce's capacity to balance duty of care against choice and control, Penny expressed:

> *"I'm just not confident about anything at all. Honestly, it's just a lie at night worrying about the future. And I don't just like worrying about my sons; I just think about all the poor people in Australia and probably the world who develop mental illnesses.* ***IS Interviewee Penny***

Continuity of support workers was flagged as an issue by most IS Interviewees, with Stella stating, "*They seem to rotate every six months, so I don't get too attached or have high expectations*".

5.7.7 NDIS Workforce Skillset Deficits

Deficits in skills and training were identified as a significant issue by all of the IS Interviewees. Simone had struggled to find support coordinators who are "*not NDIS tick-a-box support coordinators*" and felt that "*nobody's qualified*" or "*has that mental health support background to be able to do that job properly*".

> *"And looking for [NDIS Participant], it was very difficult to find anybody. And I still question whether our support coordinator fully understands [NDIS Participant]'s needs, because I've had to, I don't know, correct her, not really the right term, but steer her back into a different direction, because she's gone off track. Still very caring. But yeah, I don't think the skill levels are there for that."* ***IS Interviewee Simone***

This view was echoed by Jack who stated, "there's very much a training and skills gap" and that there are "different skills needed for different disability types".

> *"This is where it gets tricky. If I've got someone who's got a physical disability and they've got a mind that's intact, then the skill set's different. If I've got someone with a mental health issue, which is what [PwPD's name] 's got, that's entirely different, the skill set that we need."* ***IS Interviewee Jack***

Jack also expressed concerns regarding the quality of the NDIS support workers that are supporting his wife.

> *"Doesn't have initiative. Constantly asks [PwPDs name] 'what would you like us to do?' and 'how will we do it?'. Doesn't lead the conversation. Doesn't lead the care program. Now, [Participant name] had had enough of her and went out and was walking in the garden. [Worker name] 's response was 'I'll sit here and play on my phone'."* ***IS Interviewee Jack.***

Barbara emphasised how difficult it is when NDIS workers do not know what they are doing particularly when you, as informal support to a PwPD, do not understand the NDIS well.

> *"He was a lovely guy, but he had no idea what he was doing, and I had no idea what I was doing, so I couldn't even kind of, I could only do so much to manage him, because I hadn't been in the NDIS system before."* ***IS Interviewee Barbara***

Stella has tried to advocate for more skilled workers with the NDIA, for workers that are mental health trained professionals, but states her son receives enough funding for disability support workers who do not possess the "*qualifications or experiences in complex psychosocial disability*" that he needs.

> *"So I've had workers who've come in for a shift, and he's totally disengaged, down in a foetal position, or he's starting to escalate, and I've had a couple of workers just say, 'I need to leave, because it's a safety issue'. Again, it gets back to me asking the NDIA 'can we, can I please have trained experienced mental health professionals with my son, rather than 20-year-old disability support workers who turn over every 6 months and have no experience?' And every year it's not approved."* ***IS Interviewee Stella***

Four IS Interviewees, Sally, Penny, Stella, and Jack, advised that the NDIS workforce currently does not have the skills or ability to support PwPDs and life-limiting conditions. Stella stated that NDIS workers still struggle to speak about death and dying.

> *"Isn't it interesting, it's like there's something wrong with you if talk about such a morbid subject, that you're being pessimistic, that no let's remain hopeful. Never, nobody speaks*

> *about death. Even though my son has a history of suicide attempts."* ***IS Interviewee Stella***

5.8 Informal Support Interviewees Discuss Palliative Care and the Health System

IS Interviewees shared their experiences interacting with the palliative care and health systems and shared their thoughts on PwPD and life-limiting conditions.

NDIS participant Leoni had a psychosocial disability and a life-limiting condition; Leoni's experience with the palliative care team and her NDIS experience (included in Section 6.2.11 – A Case Study) was shared by her sister, Barbara. Therefore, it will not be reiterated here.

5.8.1 What is Palliative Care?

Palliative care was described in various ways by the informal supports interviewed, Brad had recent personal experience, having moved his father into his family home and supporting him to die at home. Rather than the aged care system, Brad paid for home modifications and assistive technology. Community palliative care provided in-home clinical support. Simone described it as when

> *"Somebody's not going to survive and they need extra support to help them be comfortable to the end. And feel that they're cared for, I guess, and not suffer."* ***IS Interviewee Simone***

IS Interviewees Barbara and Stella had direct experience working in the palliative care sector and had, therefore, a much more comprehensive understanding of palliative care.

> *"Palliative care, yes I know a little bit about it. To me it should be person-centred, holistic care for an individual who's facing the end of life. And it doesn't need to be – it used to be a very scary, well this is the end, and we're going to over medicate you, and lock you up in a hospital room. Now I think it's much more – it's broader than that. And it's caring, and it's softer, and more based on what the individual wants and needs. And it's about quality of life, that's how I see it."* ***IS Interviewee Stella***

> *"I've seen people who have had palliative care services when they're very close to the end of life, and I've seen them doing fantastic work, and so, that's why I guess it's been really disappointing with my sister, and I guess I can understand part of the reason is*

> *that there's just a lack of resources, you know, but – and because she is not as close to the end of life as the really good experiences I've seen."* ***IS Interviewee Barbara***

Jack has been attending courses with a carers' organisation in order to prepare for his and his wife's future, learning about aged care and the palliative care system in his state.

5.8.2 Issues with the Palliative Care/Health Systems

The healthcare system often delivers Palliative or end-of-life care in hospitals, community support services, or residential care. Brad advises that many health workers do not understand disabilities and that navigating the health system is his most significant issue.

> *"So the biggest issue that I have, here's an example for you. I rang and spoke to a person in the ED at the [hospital name] about 2 years ago because I had a participant in there and he straight out asked me what medication is this person on for autism. I had to explain to this senior doctor in [hospital name] about a basic disability of autism that this person doesn't have medication for autism. So that, to me that's the – the biggest issue I have working in the disability sector is health yeah. So it doesn't matter what hospital you go to, this that and the other, don't get me wrong. There's some fantastic people out there, but the lack of understanding of the disability sector in general is huge."* ***IS Interviewee Brad***

Stella had experience with a family member with a severe pre-existing mental illness. Stella felt that, except for communication with the family, her family member was well supported as his mental health team was in the same hospital as his hospice. However, Stella suggested a specialised workforce would be better than current palliative care support options.

> *"Palliative care staff are highly trained, highly specialised in their area. So they have a particular lens. And then you bring in mental health staff, they're speaking two different languages, again it's not integrated. What we need – and I'm – I think this is changing. We need specialised mental health and palliative care workers**." IS Interviewee Stella***

When asked to reflect on whether palliative care and health systems would work well with the NDIS, Stella felt that without advocacy from families, PwPDs would likely be discharged to homelessness, poor-quality boarding houses, or to die in aged care homes.

> *I don't think there's enough awareness. It – it's not uniform. There's no standardised baseline of knowledge between all of these different services. And for some reason the*

> *NDIS is like this big mountain over here, and nobody really understands, or touches, or – okay they're doing something, we know they're doing great work. But how – how we approach them, or who they are it's – it's really quite bizarre. I think it's just too … and too complex for people.* **." IS Interviewee Stella**

Barbara's sister Leoni had a negative experience with palliative care. They struggled to support her complex needs. Barbara and Leoni's experiences with palliative care are detailed in the case study at 5.12.

> *And all of this is just completely different to my sister's experience. She just has to keep chasing up things and asking about things, and if she doesn't ask, they don't tell her, and even if they do tell her, it's different than what they will tell her the next time, and there's no continuity of staff, you know.* **." IS Interviewee Barbara**

5.9 Informal Support Interviewees Discuss Silos

All seven IS Interviewees advised that there were significant issues with siloing between the NDIS and other systems. Penny and Sally want to see care coordination funded by the NDIS or a return to the Partners in Recovery model. They believe that both the Local Area Coordinator and the Support Coordination models are only concerned with NDIS support, which has exacerbated the siloing between systems. . Barbara stated that workers "*only know the bit they need to know"* even within systems, there are silos, and it depends on who you speak with on the day.

> *"[Y]eah, no, not at all. I just can't see that from my … - my son and with my sister, you know, it's so piecemeal. I mean even within the NDIS it is – it's not seamless within the NDIS, you know, it's all down to who you talk to on the day. And then every person you deal with, so whether it's a private person giving a NDIS – as a service provider, or whether it is a bigger health system, like [name of health system] or something, because they all have a different interpretation or a different level of experience as well. And so, then that's influencing whatever you're getting from them, rather than how it should be or how the legislation has been written, or the policy, it's all just so piecemeal and ad hoc, and down to the interpretation of people, you know."* **IS Interviewee Barbara**

Jack described seamlessness between systems as "*a great goal*", but that support is "*quite the opposite*" of seamlessness between systems. He advised that his wife's medical professionals have no idea how the NDIS works "*It's just plain obvious. There's a gap. Just this gaping chasm that there's no bridge between the two*". Brad stated that the experience is

> *"Not any where near seamless at all, , NDIS is very much we're NDIS that's healthcare. There's no cross over".* ***IS Interviewee Brad***

Stella has significant experience with mental health, health, palliative care and NDIS systems and had a unique perspective on the siloing between systems from the hospital:

> *"They wouldn't communicate with the NDIS. But there's no links there, they wouldn't think, 'oh maybe he's participant … what service providers are involved?' That wouldn't occur to the hospital"* ***IS Interviewee Stella***

Stella highlighted the issues are about lack of knowledge across systems.

> *"I don't think there's enough awareness. It – it's not uniform. There's no standardised baseline of knowledge between all of these different services. And for some reason the NDIS is like this big mountain over here, and nobody really understands, or touches, or – okay they're doing something, we know they're doing great work. But how – how we approach them, or who they are it's – it's really quite bizarre. I think it's just too … and too complex for people."* ***IS Interviewee Stella***

IS Interviewees advised that siloing adversely impacts NDIS participants and themselves. Trying to advocate across complex systems that do not work together and have different requirements and rules makes it incredibly difficult to navigate positive outcomes. Stella indicated that the siloing between systems harms her son and his sense of identity.

> *"I think professionals see the NDIS as being totally separate to everything, that they look after all things disability. So there's no nuance kind of understanding of the roles, and the structure, or how they communicate and collaborate. None of [son's name] psychologists, or psychiatrists have communicated with the NDIS, or any of his support providers. So everybody works separately assuming that the other entity is doing their part. And it's quite bizarre, because as I said, my son is literally diced up. So how can you have a – a – and he is 19, how can you develop a healthy sense of identity, and direction in life when you're compartmentalised? It's very strange to me. There's no one person leading this*" ***IS Interviewee Stella***

5.10 What Support Would the NDIS Provide for PwPD with Life-Limiting Conditions?

IS Interviewees used their experiences with the NDIS and other systems to consider how much support the NDIS would provide if PwPDs developed life-limiting conditions. Responses were analysed and are represented in Table 6 below.

Table 6: Informal Supports – What Supports Would NDIS Fund for PwPDs and Life-limiting Conditions

IS Interviewee	What Supports Would NDIS Fund for PwPDs and Life-Limiting Conditions
Penny	• I don't even know how to answer that. • We would push them to give us more funding because it's not fair that they're having to do all these hours, extra hours and care and things like that.
Sally	• they've got the up-top principles, which talks about what the NDIS provide and what do the mainstream state based services provided. So a life limiting diagnosis is usually a health diagnosis. Yet, NDIS sometimes funds health related disability supports. • Taking them to appointments.
Simone	• The function of the NDIS would be to, to support the carer in their role, that sits around a person who is in palliative care. • My understanding of NDIS is to help people to access things. I guess if you are looking at helping someone to live their best life, despite the fact that it will be short, or however long that palliative care runs for that, if their best life is at home
Stella	• I think they would say palliative care is a health issue. Just like they divide off neurology and psychiatry, that's a health issue. So they've cut my son up into pieces – because he has neurological issues as well. So he's diced up • So they probably would make sure that we had enough support workers coming in to help with house work, and cleaning, and transport, and food preparation, etcetera. Which is what he gets funded for now. So that might be ramped up. But I'm thinking if he needed nursing care, or emotional support, that they might try and farm that off to the health system, and that's not funded.
Barbara	• Cleaning support, the transport, the cooking support, and I was – I kept on saying, and some mental health support would be good
Jack	• I don't think in the real world, the person would actually get the supports they need in a timely manner that they need them. They would probably get, like if I

IS Interviewee	What Supports Would NDIS Fund for PwPDs and Life-Limiting Conditions
	had a severe illness like cancer and I had six months to live, they'd probably manage to get the supports at the moment they die. If my life expectancy was six months, I'd be getting my supports around about the six-month mark. I probably wouldn't need them anymore at that point.
Brad	• Depends on the level of support for the client • It depends on the individual. • I do know that NDIS if it's something health related as in cancer or something like that they'd much prefer to see participants use the public health system or their private health rather than NDIS funding • Absolutely our organisation would support someone palliative up to the point where it was safe to do so for the staffing and also for the participant as well. As long as the participant felt comfortable.

5.11 Would The Death, Dying And Palliative Care Experience of PwPDs be Equitable to Other Australians of the Same Age?

Each of the IS Interviewees was asked if they believed that the experiences of PwPDs and life-limiting diagnoses would be equitable to other Australians of the same age. Responses were analysed and represented in the chart in Figure 18 below.

Despite reporting a very positive NDIS experience for their family members, IS Interviewees Penny and Sally were emphatic that support from the NDIS would not result in a participant having an equitable end-of-life experience to peers of the same age.

> *"I think they would die very early. I do honestly I just haven't got confidence that they will get good support the way things are now, and this is a great improvement."* ***IS Interviewee Penny***

Brad felt that having a disability often leads to other health conditions, and this will result in inequitable end-of-life experiences.

> *"I would say it'd be worse because of the underlying conditions they have themselves, I mean not that that's an issue with NDIS, but at the end of the day anyone that has underlying disabilities whether it's psychosocial, intellectual, doesn't matter, is not going*

> *to have, how can I say equitable towards end of life because of their underlying health conditions."* ***IS Interviewee Brad***

Stella, who had previously worked in the palliative care sector, felt that people without advocacy and families would struggle to have equitable death and dying experiences.

> *"People that are homeless, or don't have family to help them, so they would be discharged into nursing homes at very young ages, or terrible boarding houses, or refuges. And then you'd make a referral to community mental health, and hope that there would be enough follow up."* ***IS Interviewee Stella***

IS Interviewees Simone and Barbara felt that the NDIS intends to create equity, however, the current execution of the NDIS may interfere with their ideals to provide equitable access to care…..

> *"I think there's an element to the yes in there, because I think the ideas that they set to to achieve for people in general, it doesn't matter whether it's physical or mental, I think they want to be able to provide this equitable platform for people in life… But I think where NDIS falls down in terms of being able to deliver it, is in their accessibility."* ***IS Interviewee Simone***

> *"I think within their own agencies then maybe it's a bit coming down to interpretation and not having a good model of practice and all that kind of stuff, and then not having the resources and everything else….. it's not equitable at all, because for some people where they're depending on who their service provider is or what services they get."* ***IS Interviewee Barbara***

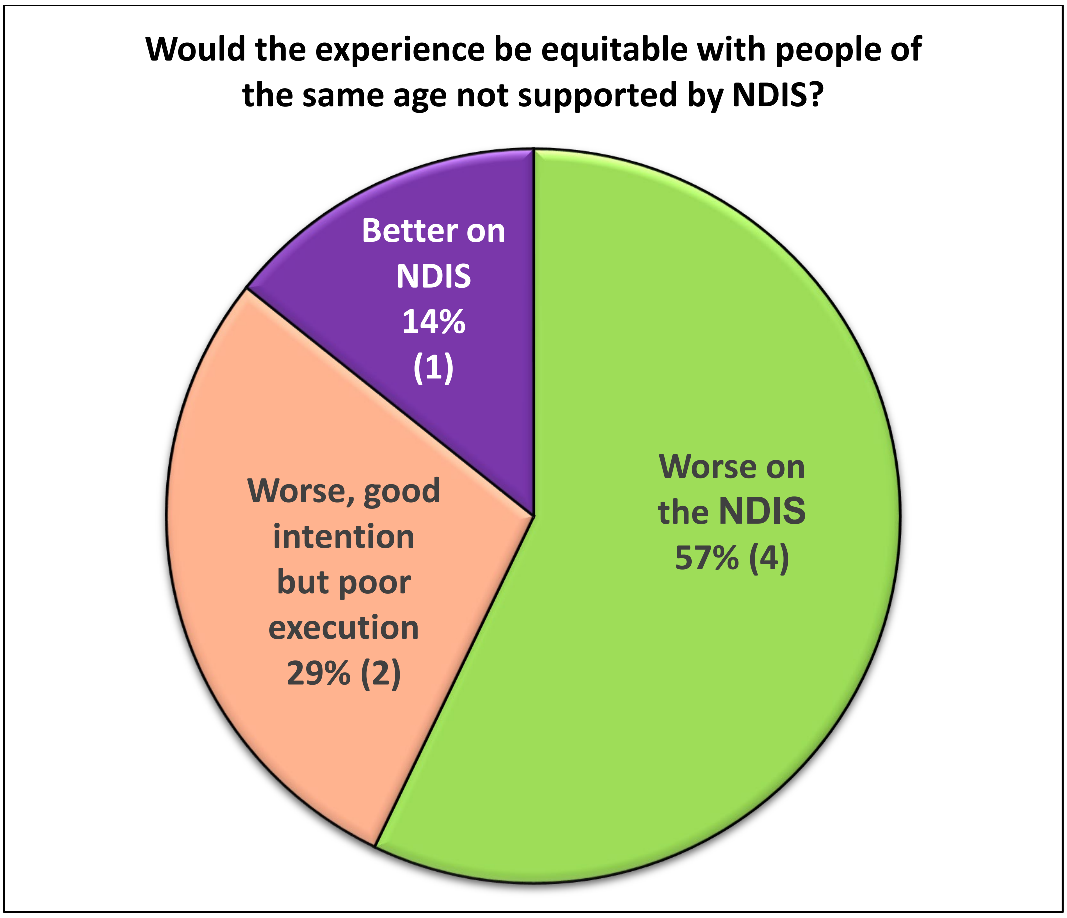

Figure 18: Informal Supports – Would the Death and Dying Experience Be Equitable?

5.12 A Case Study – Informal Support *Barbara and her Sister *Leoni

Barbara had lived experience supporting her sister, Leoni, who was in her 40s and had both a psychosocial disability and a life-limiting condition of primary lung cancer. Throughout the interview, it became evident that their experience with the health and NDIS systems, the lack of understanding between systems and the impact that this has on a person with a psychosocial disability and life-limiting illness should be presented as a case study.

Barbara also works in the end-of-life care and grief and bereavement sector and has previously worked in the disability sector. Barbara has other caring duties, supporting her elderly father and her son, an NDIS Participant. Leoni had a significant mental illness for many years; however, she had never attempted to access the NDIS before being diagnosed with lung cancer.

> *"The whole other side of this is that she's had mental health issues for a long time, and really, that's really continued to be the thing that really dominates her, well it impacts on her quality of life more so than the cancer situation, you know, that the mental health*

> *stuff doesn't stop just because you have a diagnosis, and it's just an added thing to be worrying about when you have mental health conditions***." IS Interviewee Barbara.***

Leoni had also struggled with insight into her life-limiting diagnosis. Her oncologist was "*unable to talk about death and dying in any way*", and that had a significant impact on her mental health. Her oncologist was also not open to discussing Leoni's pre-existing mental illness.

> *"That's been pretty hard because she's – her level of acceptance has not been there really, and you know, up until very recently she really – yeah, I guess she was really lacking a bit of insight into her situation. She still believed that she just needed to find the right treatment, and once she found the right treatment she would be cured."* ***IS Interviewee Barbara***

With her background in end-of-life care, Barbara was keen to support her sister in preparing for end-of-life, but it was challenging due to her pre-existing mental illness.

> *"[I provided] a lot of counselling, a lot of reassurance, not even really, hardly getting into kind of any grief, loss, preparing for death and dying, or any of that kind of stuff, like she just very much consumed by, in the moment, by all of the mental health stuff that was coming before, and maybe the things that are affecting her now."* ***IS Interviewee Barbara.***

Leoni struggled with self-care and managing her medications and needed to be admitted to the hospital several times to bring her symptoms under control. COVID-19 and a phobia of germs significantly impacted her mental health and ability to cope with treatments and end-of-life experiences.

> *"A few weeks ago she was in such a bad way that she actually went into the palliative care ward and got – purely for respite. They wanted to keep her in there, but she wouldn't stay longer than a week.* ***" IS Interviewee Barbara.***

Leoni wanted Barbara's help and support but regularly lashed out at her when she became overwhelmed. At the time of the interview, Lenoi was more accepting that her death was imminent. This acceptance created additional stress for them as they worked on Leoni's end-of-life goals. However, providing other practical support throughout her cancer trajectory has been challenging as Barbara does not live close and has her other caring duties. Leoni had been admitted to the community palliative care service for about 18 months in an attempt to obtain practical support, such as house cleaning, shopping, cooking, transport etc.

> *"She started with them about, oh probably close to 18 months ago now, but that hasn't translated to a lot of service, and particularly in regards to NDIS it's just been, just a major balls-up."* **IS Interviewee Barbara**

Unfortunately, these kinds of supports through the palliative care service were limited, and there was an extensive assessment process to qualify for them.

> *"So, she said – "look", at that time Leoni said, "look I'm not really willing to go through assessments and things if all I'm getting is one session of cleaning, like I'm looking – I need something regular, I'll just kind of muddle through.""* **IS Interviewee Barbara**

Barbara observed that the palliative care team "*don't even want to talk about mental health issues either".* Barbara shared an incident to demonstrate her concerns with the palliative care team's understanding of mental illnesses and how to support someone with psychosocial disabilities adequately.

> *"She actually said, "well I'm going to kill myself if I can't get this pain under control, I'm going to kill myself". So, I had tried to call them to tell them what was going on. They wouldn't talk to me. But I did end up telling them. So, when she was then on the ward and I was talking to them about she'd given permission for me to talk to them, and I disclosed to them then that she had threatened suicide, and still, all they gave her was this one session with the art therapist, who hasn't followed up with her since then. They sent her home with more than two weeks' worth of really strong pain meds. Despite the fact that they knew that she had threatened suicide, and they didn't even really do very good follow-up and stuff with her."* **IS Interviewee Barbara**

Further, Barabara advised that despite presenting with extreme psychological distress on multiple occasions, Leoni received no referrals for Medicare-funded psychological sessions from the palliative care team, her oncologist or her GP. Additionally, Barbara reports no discussions with Leoni regarding possible interactions with pain and psychiatric medications.

Eventually, after a year of receiving clinical supports with community palliative care, a social worker with the community palliative care team visited her home and recognised that Leoni needed significant support.

> *"They came out and they saw her, and they said, well we can see you really need services. I mean her mental health has been really bad, and she kept on saying she needed this support, but they kept – and after they finally said, yes we can see you really need support, we're going to do all this stuff" – this was a physio and a social worker – then they just didn't get back in touch with her for a month, and then she had to keep chasing them. So, eventually the social worker said, "yeah, we can access NDIS", but*

> *then my sister was thinking, "well why didn't they suggest this a year ago when I could have – when I came to you saying this is what I need help with?"* **IS Interviewee Barbara**

Barbara reported a chaotic application process where the application took months to complete, and her reluctant GP was tasked with completing the forms.

> *"I only saw the application after it got rejected, and then like I said, well no wonder you got rejected, because this is a pathetic application"* **IS Interviewee Barbara**

Barbara's observations were that the palliative care team's access request was not to the standard acceptable to the NDIA for access.

> *"And coming from both disability and having a son on NDIS, I know what an application needs to look like to get past, and it just, it didn't get past, and the reason that it didn't get past was they said that it didn't present that her condition was permanent and that there was no other treatment options available. Now it did say that, but I know that the people looking at the NDIS form are not always medical or disability people, so they might not have even understood everything that was on the form, and I know they kind of score it or whatever, and so, I can see there wasn't a compelling enough argument in this application, like it was just bare bones, and it was kind of like, oh well, let's just put it in and see if they give it to us."* **IS Interviewee Barbara**

Again, Barbara worked with her sister and the palliative care team to help her sister gain access to the NDIS.

> *"So, we pushed back, and they are now re-doing the application and they're organising an assessment for her with an OT, and they're getting one of their doctors to fill it in, rather than the GP. But now it's November, so this was brought up in June or July, and it's taken this … - this new application still hasn't gone in, and they've gone from the palliative care people being like, 'oh yeah, I think you've got a good shot', to 'no, I don't think you've got a good shot', to 'mm, now we're not sure'. And actually, to be honest, now I don't even know where the NDIS form stands, because they've now turned around and said, 'well we can give you a 12-week program with [Community Nursing Organisation]'".* **IS Interviewee Barbara**

Barbara was unsure whether the community nursing organisation was aware that another NDIS application was being completed for her sister and was still determining what impact that would have.

Throughout her cancer treatment and admission to palliative care, Leoni received substantial pressure from Centrelink to continue job-seeking. Barbara had to advocate strongly to have Leoni's disability support pension application completed by her oncologist, general practitioner and the palliative care team, all of whom were resistant.

Some months after our interview, Barbara emailed the research team and provided the following update.

> *"Leoni finally got approved for NDIS on her second application just before Christmas - by then she had a prognosis of 1-2 months, and with all the Christmas delays, she barely got to use her funding. It was a relief for her and myself when she died at the start of [month]. [She decided to] take up Voluntary Assisted Dying."* ***IS Interviewee Barbara***

5.13 Informal Support Interviewee Summary

All of the IS Interviewees recognised their role as advocates in their family member's life. It was emphasised by all that their advocacy was essential for the continued well-being of the NDIS Participants that they support. Those with experience and networks within the disability and mental health sectors actively participated in their family members' interactions with the NDIA, and managed their NDIS supports, noting that the workforce is very inexperienced in navigating the NDIS. Most IS Interviewees advocated for their family members only; however, some were involved in broader advocacy. Many IS Interviewees felt that advocacy is vital to positive outcomes for people living with mental illnesses. Whilst IS Interviewees knew of some NDIS participants who could advocate really well for themselves, they stated that many could not.

IS Interviewees had a varying understanding of the term 'psychosocial disability' but understood it to be a complex and severe mental illness that can be disabling and impact function. Psychosocial disability was viewed by two IS Interviewees as a life-limiting condition.The IS Interviewees spend a great deal of their time and energy supporting and advocating for their family members and recognise that it would be very difficult for PwPDs without family or carers in their lives.

Some IS Interviewees had significant contact with the state-funded mental health system and did not feel that it offers good support for people with severe mental illnesses and psychosocial disabilities. Others had family members whose mental health was treated by their general practitioners, or whose treatments were funded through private health systems. The IS Interviewees advised PwPDs are highly vulnerable and often die sooner than others due to various factors, including medications, lifestyle factors and their inability to manage health concerns. They are at risk from predatory providers as there are few checks in place to ensure quality and safeguarding, particularly as there are many unregistered providers offering NDIS supports.

IS Interviewees provided a comprehensive list of NDIS supports available to the PwPDs in their lives (Section 5.5.6.), and their reflections on the NDIS as a system were mostly negative (72%) and these can be found at Appendix 1, Section 2.1. Their reflections on the NDIA were mostly negative (85%), which can be found in Appendix 1, Section 2.2. IS Interviewees had mostly negative reflections on NDIS providers, describing them as "*faceless", "predatory," "very average"*. When NDIS Providers were described positively, it was felt that they were the exception to the norm.

While some of the NDIS workers were described as very caring and dedicated, all of the IS Interviewees identified deficits in skills and training as a significant issue. NDIS workers are often not trained or skilled in mental health. Most IS Interviewees also flagged the continuity of support workers as a key issue, noting that staff retention is poor. Four IS Interviewees (57%) worried that NDIS workers do not have the skills or ability to support PwPDs and life-limiting conditions.

All IS Interviewees were very positive about palliative care services and clinicians, although it was felt that specialised training to help them support PwPDs would be ideal. One, however, had a negative experience as the clinicians struggled to support a PwPD and a life-limiting condition with her NDIS applications; this is further described in Section 5.12. Advocacy was seen as vital for PwPDs and life-limiting conditions; without it,PwPDs would likely be discharged to homelessness, poor-quality boarding houses, or die in aged care homes.

All seven IS Interviewees advised that there were significant issues with siloing between the NDIS and other systems, and it is "*quite the opposite of seamless*". Workers within each system "*only know the bit they need to know*" and work separately "*assuming that the other system is doing their part*". One noted a "*gaping chasm*" between the NDIS and the health system and the complexity of and the lack of understanding about the NDIS as a barrier to collaborative and seamless care. The "*bizarre*" siloing and compartmentalising of PwPDs was seen as harmful and impacting their "*sense of identity".* Each system works independently, assuming the other systems are doing their part. Funded case conferencing and a return to the Partners in Recovery model were viewed as potential solutions to the gaps between systems.

IS Interviewees opined that the NDIA would view life-limiting conditions as a "*health issue*". They did have varied ideas about what support would be provided by the NDIS for PwPDs and life-limiting conditions. Core supports, including cleaning, gardening, cooking, and transport to appointments, were nominated as potential NDIS supports for PwPDs and life-limiting conditions, but this may not be consistent. Most IS Interviewees felt that the experience of PwPDs and life-limiting conditions would be worse than those of other Australians.

CHAPTER 6 – NDIS PROVIDER INTERVIEWEE RESULTS

6.1 Introduction

To understand the perspectives of NDIS workers, managers and NDIS Provider business owners, nine NDIS Provider Interviewees (PR Interviewees) were interviewed. They contacted the research team in response to the research flyer posted on Facebook provider group pages, LinkedIn, and NDIS provider groups or learned about the research through word of mouth. Six PR Interviewees had experience with NDIS participants who had life-limiting conditions, including cancer, anorexia nervosa, end-stage chronic obstructive pulmonary disease, motor neurone disease, genetic diseases and human immunodeficiency virus. One PR Interviewee advised that they considered a PwPDs they supported, who was bedbound through extreme obesity, as having a life-limiting condition. Not all of these experiences involved NDIS participants who had a primary psychosocial disability. If the PR Interviewee did not have direct experience regarding PwPDs with life-limiting conditions, they were asked to speculate on the experience based on their experiences with informal and formal support networks, including mental health, health and the NDIS systems. PR Interviewees were then asked to use their knowledge and expertise regarding these systems to predict the death, dying and palliative care experience and supports likely to be received by PwPDs with life-limiting conditions and to advise whether that experience would be equitable and seamless between systems. The PR Interviewees' experiences with systems were explored deeply to enable a better understanding of potential feedback loops within and between systems. One PR Interviewee, Heidi, had direct experience as a supported independent living worker supporting a PwPDs with a life-limiting condition. This experience is described in Section 6.12 - A Case Study – PR Interviewee *Heidi, PwPDs, and Life-Limiting Condition *Margaret. As direct quotes from interviews will be included in this chapter, any potentially identifying information about PR Interviewees was removed, and pseudonyms were assigned.

6.2 NDIS Provider Interviewees' Demographics

Nine PR Interviewees responded to the research interview flyers, three male and six female. Three were from metropolitan Adelaide, two were from metropolitan Melbourne, and one each from the following locations: metropolitan Sydney, rural Victoria, rural New South Wales, and rural Queensland.

Four PR Interviewees advised that their NDIS Provider business supported NDIS participants across a large geographical area, and three of the NDIS Providers supported participants outside of the state where the PR Interviewees were located. Four PR Interviewees either worked for or owned and operated a large provider business with over 20 employees, and four worked for or owned businesses with under 20 employees. One PR Interviewee worked for a large provider but also ran their own provider business.

PR Interviewee roles included three NDIS support coordinators, two NDIS psychosocial recovery coaches, four managers, a psychologist, a supported independent living worker, and a social worker (NDIS Specialist Support Coordinator). Three PR Interviewees held dual roles.

6.3 NDIS Providers Discuss Advocacy

Three PR Interviewees talked about advocacy for PwPDs. Due to her experience with a lack of responsiveness from other community services, Sofia stated that there is a need for NDIS providers to advocate for PwPDs and life-limiting conditions. From her experience, she found the NDIS to be more responsive than other community services. Tina advised that NDIS support workers often know the PwPDs better than other providers and health professionals because they have more regular contact and build strong relationships. Tina reported that often, PwPDs and their support workers are excluded from the decision-making processes around the NDIS, and this would make it difficult when trying to advocate for PwPDs with life-limiting conditions. Blake, who works for a large national provider, discussed the importance of advocating for PwPDs and advised that many cannot advocate for themselves. Blake reported that, as his company is very large and has other funding streams besides the NDIS, they can share customer service staff across the funding streams that can help advocate for PwPDs or people with SPMI looking to gain access to the NDIS.

6.4 NDIS Providers Answer “What is a Psychosocial Disability?”

Eight of the PR Interviewees had differing perspectives on psychosocial disability and how they and the NDIS interpret the term, responses are listed in Table 7 below. These perspectives included that the term was unclear and hard to understand, permanent mental health challenges that may be episodic and create a disability that impacts a person’s ability to connect with others or self-manage their affairs.

Table 7: PR Interviewees answer "What is a Psychosocial Disability"?

PR Interviewee	PR Interviewee Quotes
Adam	• I don’t think that the NDIS really does come out with a clear statement as to what it is. • I have another gentleman who’s a new client he has ASD, he has schizophrenia. And he’s been given the label of psychosocial. The lady of our age group [*50’s*] who has been determined that she has a

PR Interviewee	PR Interviewee Quotes
	requirement for it, she has anxiety. The gentleman who’s 39 He has learning difficulties, and I suspect an ABI, but I can’t be sure of that. And that’s about it. So, they’re all quite different. And yet they’ve all been given psychosocial Recovery Coaching. And I don’t know why, and they won’t talk.
Tina	[P]sychosocial disability means that participants who you know have a disability; but have also mental health challenges or diagnosis that limits them from participating in the community. In work in in everyday sort of life activities, whether it’s social, work or relationships or anything like that. So, their diagnosis is or mental health challenges just it’s very limiting to their capacity in everyday life.
Peter	I have not had a lot of conversation with the agency that in any way relates to the disability of the person.
Sofia	• It has a lot to do with mental health illnesses and how that impacts on someone’s ability to engage with others just full stop. It might be others within their home, it might be within the community and, you know, joining some kind of a group or activity. • I’m saying it’s a person that’s very isolated and doesn’t have their own skills or ability to be able to start making that, you know, safe connection with someone to bring them into a bigger sort of community, I suppose.
Michaela	So usually, they would be classed as permanent, lifelong challenges and disabilities, which is really interesting from my point of view, because it’s kind of to make access, you have to satisfy that criteria and then the way that the recovery coaching line item has kind of been unpacked by the NDIS is that it is a recovery model forward thinking that these people will, in their opinion, improve and recover per se, which is a huge challenge that I’ve had with participants and case managers, everybody involved around this title, where we’ve kind of been classed as permanent, lifelong and then expected to kind of recover and progress.
Kelly	• Well, it obviously needs to be a lifelong and permanent condition, have some mental ill health that functionally impacts you on a day-to-day basis.

PR Interviewee	PR Interviewee Quotes
	But it might be episodic in nature, although they have a hard time with that. • It's, you know, psychosocial is harder for people to understand. There's more stigma around it,
Blake	I think it's sort of have created like a create clear delineation between a mental health issue and a psychosocial disability. So, some people may have a diagnosis, but that doesn't necessarily mean they have the psychosocial disability. That's been quite difficult to quantify and the permanency side of it as well. Even though the diagnosis may be permanent, the function may fluctuate or different treatments so that sort of being a bit. It's not a cut and dry as a lot of other disabilities,
Heidi	• Having a psychosocial disability is where clients need support to interact with the world, whether it be medical or on with like Centrelink. • I think they'd be supporting some with chronic mental illness such as schizophrenia. However, I think that on another level people with anxiety may not get support from the NDIS, who need it. Yeah, so I don't think it would be covering everyone with a mental illness.

6.5 NDIS Providers Discuss Informal Supports

PR Interviewees discussed informal supports, including carers, families, friends and neighbours. The issues that they flagged were that, often, PwPDs are socially isolated and do not have these connections in their lives. Additionally, where PwPDs does have informal support, no services are available to assist them or provide respite. Finally, the complex family dynamics that are around PwPDs can have an adverse impact on them, particularly if they have a life-limiting condition.

6.5.1 NDIS Providers Discuss PwPD Having No Informal Support

Four PR Interviewees commented that the PwPDs they worked with had no informal support, family or friends. They acknowledge that their NDIS support workers are often the only people that PwPDs have in their lives, and this can create a lot of pressure on NDIS workers.

> *"I work with 30 clients at the moment. I would say, eight, no, no 10 out of 30 are within the 35 to 55 [year age bracket],. and do not live with anybody to not have family close by or interested in helping."* **PR Interviewee Sofia**

Sofia also reflected on how the staff at the NDIA may perceive claims that a PwPDs or their support workers may be lying about their social isolation or lack of informal support.

> *"It doesn't reflect enough when you're going to NDIA to implement that as because I do ask "Do you have anyone that you live with? Do they help you with anything?" But even when you say no [to the NDIA], they have no one it's almost like secretly, they think you're lying about it and that there is someone there helping."* **PR Interviewee Sofia**

When discussing what it would be like for PwPDs that she supports if they get a life-limiting condition, Kelly noted that often, when people get a life-limiting diagnosis, they have family or neighbours around them to help but that experience may not be available to PwPDs.

> *"you know, there may be some great informal supports around that can smooth a lot of a lot of that for them. But that's not always the experience that people have that they have great families or neighbours or whatever that can."* **PR Interviewee Kelly**

6.5.2 No Support for Families

Tabitha raised that, even though it is written into the legislation, support for families and carers is often dismissed as not the NDIS's responsibility. Sofia and Tabitha noted that when families are involved in PwPDs' lives, their lives are tightly connected. Sofia notes that they have few practical supports or services for them, particularly grief services that they can access if a PwPD dies. Peter advised that when an NDIS participant dies, if the NDIS-funded equipment is not picked up, or NDIS supports are not immediately cancelled, which sometimes cannot be achieved, the NDIA will commence debt recovery against the family or plan managers. This is exceptionally stressful for providers and families.

6.5.3 Complex Family Dynamics

Complex family dynamics were raised by PR Interviewees, discussions of financial coercion, and control over PwPDs's NDIS supports and plans. Family members may also live with their mental illnesses.

> *"They often have complex family pictures, as well. And that doesn't just add to it doubles or triples the experience of disadvantage that they face and their difficulty in finding time to advocate for their own needs."* ***PR Interviewee Tabitha***

When discussing PwPDs and life-limiting conditions, Heidi talked about an incident where both the NDIS provider and the community mental health clinician were trying to force the PwPDs to reconcile with her son.

> *"I just didn't like what they were saying that she was incapable of making decisions about [her life] She didn't want contact with her son. And they didn't get that. And I don't understand why they didn't get that, she just didn't want contact with her son, who knows what went on."* ***PR Interviewee Heidi***

6.6 NDIS Providers Discuss the Mental Health System

Most of the PR Interviewees commented on the scarcity of mental health system support for PwPDs, particularly outside of metropolitan areas. General practitioners create mental health plans that avail their patients to ten Medicare-funded psychology appointments; however, there are long wait lists to see a psychologist, or no appointments are available. The gap fees charged are prohibitive for PwPDs with low incomes.

Kelly reported that PwPDs in regional towns struggle with support, being referred to community mental health services in other towns and being evacuated to major capital cities when there are significant risks and are discharged into the community without appropriate support to get home. PR Interviewees reported that the state-funded community mental health services are very disconnected from the PwPDs and are only available for crisis or emergency support. PwPDs are discharged when deemed to no longer be an immediate risk to themselves or others. Further, PR Interviewees advised that the only time that PwPDs remain under the long-term care of the community mental health team is when they are on community treatment orders (legally enforced treatment under the Mental Health Act) and depot medications (long-acting injectable medications).

> *"They get, you know, so many new referrals every single day. And, you know, how do they possibly keep up but where does the person get their mental health support? Community Mental Health exit them because they're not suicidal."* ***PR Interviewee Kelly***

Community mental health teams are struggling to write reports that PwPDs get the NDIS supports that they need, often as they will report on their presentation while they are receiving active treatment and support from the mental health system. Tabitha noted that many of the clinicians do not have the experience or skill set to write NDIS reports. PR Interviewees were not confident that PwPDs would get support from the mental health system if they developed a life-limiting condition. Sofia advised that once a person with a psychosocial disability becomes an NDIS participant, workers from the mental health system expect all support to be funded by the NDIS.

> *"We were offered nothing. It was just passed the buck or "he's got NDIS get them to fix it."* ***PR Interviewee Sofia***

Heidi, a supported independent living worker, witnessed her employer's management and a community mental health case manager conspire, using capacity grounds, to force a PwPDs and a life-limiting condition into treatment and reconcile with her adult children. Heidi found this pressure to be unacceptable as she felt that the PwPDs had the capacity and right to make decisions about her treatment and end-of-life goals. More information about this experience can be found in section 6.12.

6.7 NDIS Providers Discuss the NDIS

NDIS providers discussed their experiences and opinions about the NDIS. They shared their experiences with PwPDs and Participants with other disabilities, the NDIA and other providers and the kinds of supports that PwPDs were likely to receive from the NDIS.

6.7.1 NDIS Participants

> *"Those who've always lost continue losing out."* ***PR Interviewee Tabitha***

PR Interviewees reflected on the PwPDs they support and advised that most have co-occurring health conditions or disabilities. They stated while often highly intelligent, PwPDs are often socially isolated. When they are connected with others, they can be exploited. PR Interviewees advised that they know of PwPDs who are being financially exploited by their guardians or plan nominees but feel that there are few avenues to protect them. Sofia advises that it often takes a long time for PwPDs to trust their NDIS support workers and clinicians. Tabitha declared that workers from all systems have such low expectations of the quality of life that PwPDs can have that it impacts the kinds of supports offered by every system.

Furthermore, as the mental health of PwPDs often fluctuates, it can be difficult to have clinicians from other systems, such as health or mental health, write reports, resulting in insufficient funding and support. Tina noted that it requires the whole team from the different systems around the PwPDs to collaborate to achieve good outcomes for them. Tabitha discussed having to combat misinformation or incorrect beliefs about the NDIS by clinicians in the mental health systems.

> *“I'm liaising with junior OTS in this environment, who think that the funded housing through NDIS wouldn't be suitable for him because of advice given to them from people within the hospital that we don't usually see people with psychosocial disability, getting housing and NDIS"* ***PR Interviewee Tabitha***

The goal-setting requirements of an NDIS plan can be a struggle for PwPDs because they may find it difficult to understand what they need, how to address that need, and what they need to ask for from the NDIS that would help.

> *"[T]hey don't really know what to ask for as well which kind of puts everything out of whack. So they're just going to either repeat what they've been told is the best option to say or not really understand what their goal is involved with and how it impacted on their final plan"* ***PR Interviewee Sofia***

> *"You know, she's basically existing until she dies. I talked to her about goals, and goal setting. And breaking those goals down. She said, "I can't get out of bed. What goals am I going to have?"* ***PR Interviewee Adam***

Most PR Interviewees stated that PwPDs do not get the support they need and feel that the NDIA may have a strict mandate about what they will approve for psychosocial disabilities. Tabitha advised that PwPDs can only get the support they need from the NDIS if they are described as problematic.

> *"And so, if we describe a person as being problematic, which is against the human rights and against the recovery model, then that being problematic then allows more resources to come. And I think it should be, we all know it should be, you know, far more recovery-oriented than this. But it's harder to substantiate when a person internalises the difficulties on themselves and they are no less suffering, but they're suffering"* ***PR Interviewee Tabitha***

Kelly advised that many PwPDs do not understand the concept of "reasonable and necessary" and what the NDIS should fund and ask for everyday items such as toothbrushes and larger items such as project cars and pianos. Kelly was once fired by a PwPDs when she queried why the NDIS Plan Manager approved a holiday using NDIS funding. Conversely, Kelly has PwPDs who do not use their funds for supports that they are entitled to use them for and self-fund when they have the means to do so. Peter also described how PwPDs often try to organise the release of NDIS funds to pay for crises or emergencies. However, the NDIS is not designed for crisis support and can result in a debt being raised against the PwPDs. These consequences have seriously impacted the safety or living situations of PwPDs.

On a positive note, Heidi advised that the NDIS had significantly improved the lives of PwPDs in supported independent living.

> *I think things have changed. And I think it's huge, hugely improved. And I think it will continue to improve. Because I think it's getting better, but great. think it's been much improvement, like 400% In my opinion, it could be better, but I mean, what their life was before. What is now Yeah, I mean, they were so oppressed before. They wouldn't speak out. They never went on a holiday. They, you know, ask for what they want. Is just hugely improved. Hugely.* ***PR Interviewee Heidi***

When discussing support from PwPDs and life-limiting conditions, PR Interviewees advised that there may be declines in mental health and function. PwPDs would need increased support to help them cope with the new diagnoses and manage all of their hospital appointments. PR Interviewees felt that PwPDs with life-limiting conditions are at greater risk of being exploited due to their increased vulnerability and would not have the energy to make complaints to the statutory bodies that handle complaints or issues within each system.

> *"It's quite scary, to be honest. Because I have seen quite a few people slip through the gaps. Quite a few people get stuck in hospital for months and months and months because there is just no not enough support when they are coming out. And I would say the risk for exploitation, especially as someone is declining, gets greater and greater because they become more and more vulnerable. Yeah. It is. It is scary to think about a declining person and whether or not there would be someone in that circle that would be mindful enough to pick up on it. And they will care enough?"* ***PR Interviewee Michaela***

Tabitha noted that PwPDs often have complex pictures and that a life-limiting condition "would not just add to their burden, but may double or triple the experience of disadvantage that they face".

Heidi reported that a PwPD and a life-limiting condition in a SIL/SDA setting did not discuss her pain or ask for help. Blake discussed how a SIL facility in his organisation needed to support PwPDs distressed by the loss of their housemate, a PwPD and a life-limiting condition who had palliated at home. However, there was a very different reaction from housemates in Heidi's SIL setting.

> *"Oh fine, they weren't aware. They're so drugged up, all they are worried about is, really, themselves, their smokes, what they're eating. So they're always friendly and lovely to whoever goes there. I think that they became aware that she was experiencing some difficulty. But they weren't, weren't that concerned really."* ***PR Interviewee Heidi***

6.7.2 Support From the NDIS

PR Interviewees volunteered the kinds of supports that PwPDs that they work with are currently receiving; these are listed below in Table 8. The list was comprehensive as they often supported multiple PwPDs. It was noted that there was confusion about psychosocial recovery coaching and that there are limitations to the types of support offered in rural and remote areas.

Table 8: PR Interviewees Discuss Support that PwPDs Receive From the NDIS

11	Participants	PR Interviewee Comments
Support Workers Meal Preparation Community Participation Personal Care Medication Prompts Transport Shopping	9	• biggest complaint is community access, where people just go where the support worker wants to go. • whilst a lot of them are well-meaning, they don't have any education, they don't have any skills necessarily in in how to help someone meet their goals. • 95% doing a half-arsed job
Psychosocial Recovery Coach	6	• It is a cheap form of support coordination • There's a lot of confusion about what it is.
Support Coordination	9	
Plan Manager	4	
Cleaning	6	
Psychologist	1	
Capacity building	2	

11	Participants	PR Interviewee Comments
Gardening	2	
Groups – Community Engagement	3	
Supported Independent Living 24/7 1:1 support	3	He was basically turned out and put on the street for his drinking and smoking within the property.
Behaviour Support Practioner	1	[W]e're relying on the behavior support practitioner to provide us advice or strategies to work with the participant. But we don't hear anything.
Short-Term Accommodation	1	
Occupational Therapy	2	• At least a 12-month waitlist • specialist mental health OTs, but they're pretty thin on the ground. Yeah, absolutely. In rural areas
Group Pilates	1	
Physiotherapy	1	

PR Interviewees advise that the quality of NDIS supports available to PwPDs is often poor, noting that this can lead to poor outcomes, stating that they do not build capacity and are inflexible. Additionally, they advised that supports funded in NDIS Plans are insufficient to realise the aspirations of the NDIS for PwPDs. Sofia reports a significant gap in understanding between PwPDs and providers about what the NDIS can offer them. The scarcity of providers who can offer the NDIS support types that PwPDs wish to receive was flagged by most PR Interviewees.

There was confusion about what supports the NDIS will fund for PwPDs, mainly whether NDIS will fund therapeutic supports or whether therapeutic supports will improve function. Heidi felt that more intensive one-to-one support to build PwPDs capacity would have better outcomes in the long term.

Choice and control, a core principle of the NDIS, was poorly explained by PR Interviewees and can cause issues for PwPDs when managing their supports. Tabitha discusses some of the problems around choice and control.

"Many people don't know they can ask for a level two or level three worker and it is coincidental whether there is sufficient support coordination in a plan or whether people know that they can change agencies they're so accustomed to, having had a fixed system under block funding, where they didn't have a choice, that they feel apologetic to have a need to change. So, we're still changing culture around choice and control. And then And, yes, sometimes that swings in the other direction where people change very frequently. It becomes destabilising, but it's generally the other way where people are still apologetic in having a need and feel or express concern around everyone's feelings of them rather than feeling entitled to having things, and so when you've got a grateful participant, they don't ask for very much. I don't know that the feedback is getting to the government around the agency's actions that are quite diminishing of their lifestyle. ***PR Interviewee Tabitha***

6.7.3 NDIS as a System

The overall opinion of IS Interviewees of the NDIS as a system was overwhelmingly negative; it was felt that the system is confusing, under-funded and inequitable, reinforcing stigma and discrimination. The lack of funding for training and development was seen as a significant issue, and the NDIS it has led to a de-professionalisation of services around PwPDs. There were some positive opinions, where PR Interviewees felt that PwPDs lives were improved by the NDIS, particularly for those who could navigate the system or had people around them who could. Comments were analysed and assigned as either positive or negative and are depicted in the chart found in Figure 19; the comments are listed in Appendix 1, Table 3.1.

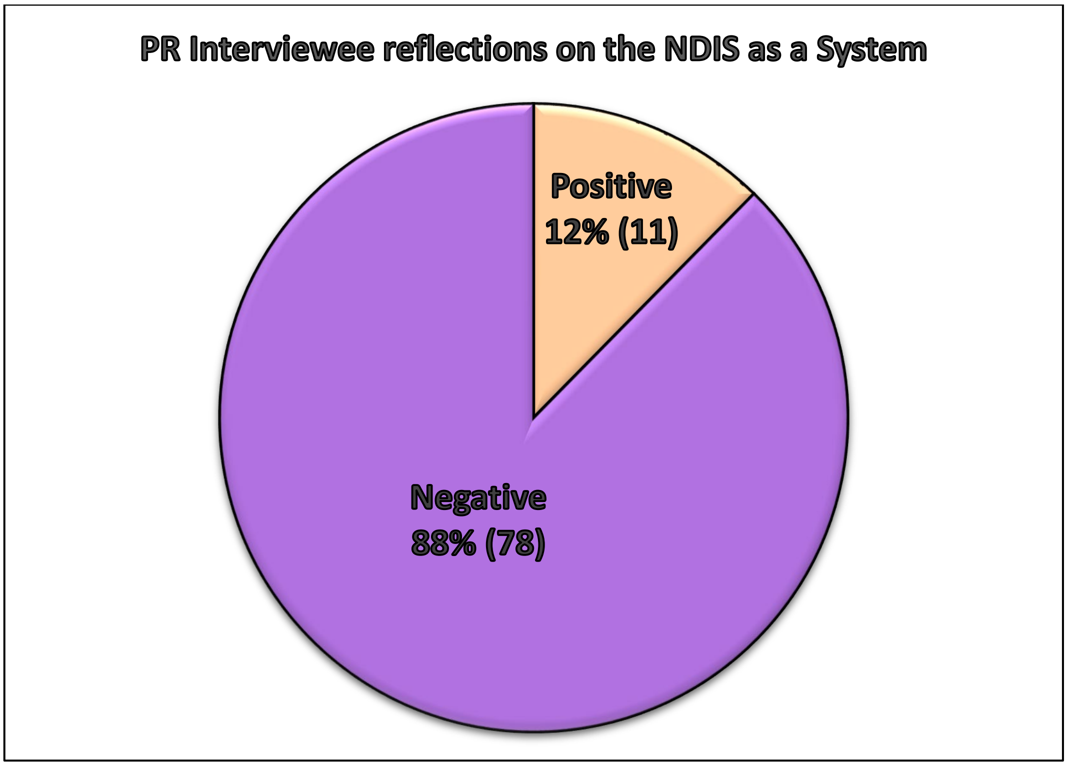

Figure 19: PR Interviewees' reflections on the NDIS as a system

6.7.4 NDIS Providers' Reflections on the National Disability Insurance Agency

Comments about the NDIA have been categorised as either negative or positive. Comments regarding the workforce of the NDIA, including access officers, planners, partners, or local area coordinators, have been included under the NDIA heading. Whilst they could also be considered the NDIS Workforce, this category has been assigned to employees of NDIS Providers. Overwhelmingly, the reflections about the NDIA were negative (89%), where PR Interviewees expressed frustration with the slow processes, lack of transparency, poor communication, understaffing, overworking and a high turnover of NDIA staff. They describe constantly "*fighting*" with the NDIA to support PwPDs. They felt that the NDIA is arbitrary and punitive in its responses to NDIS providers and PwPDs despite being haphazard in their decision-making, which leads to a continuous state of confusion. They felt that there is a lack of empathy and compassion that causes trauma for PwPDs and their families and that NDIA staff do not understand the needs of PwPDs. PR Interviewees described the NDIA staff as "*secretly think that you are lying".* Comments were analysed and assigned as either positive or negative and are displayed in the chart found in Figure 20 below; the comments are listed in Appendix 1, Table 3.2.

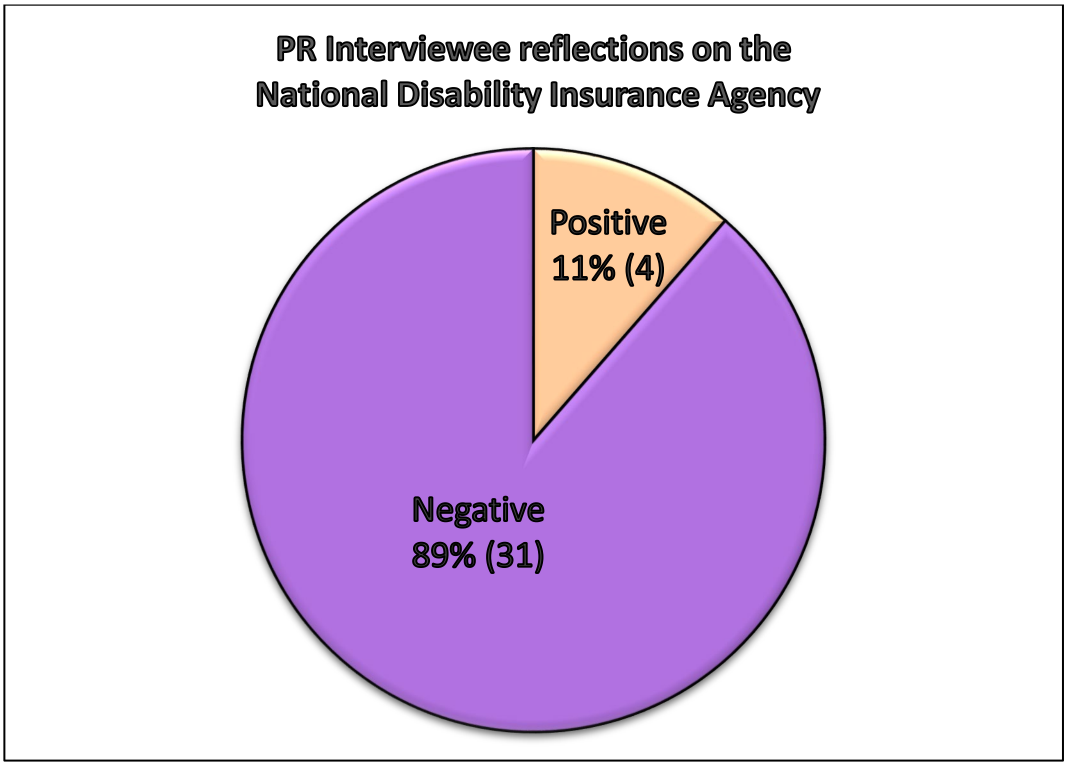

Figure 20: PR Interviewees' Reflections on the National Disability Insurance Agency

6.7.5 NDIS Providers Discuss NDIS Providers

The PR Interviewees talked about their experiences as NDIS provider business owners, workers or managers within a larger NDIS provider organisation and their experiences with other providers.

6.7.5.1 NDIS Providers Share Their Personal Experiences

PR Interviewees advised that there are significant issues for providers using the NDIS funding model. There are insufficient hours funded by the NDIS to attend to risk management, reportable incidents, and staff training and development. Further, protections that registration may offer PwPDs can often not be realised due to the prohibitive costs involved with the NDIS registration process. All PR Interviewees talked about doing unpaid work that is unbillable. Retaining workers is a significant issue and results in adverse outcomes for PwPDs. It is difficult to recruit workers who understand the NDIS and PwPDs.

> *"It is hard to retain people, they'll move once trained or they'll be poached. A good worker will if we keep them for eight months, we're very happy. So, the funding affects everything. Yes, everything. So our ability to develop staff around psychosocial disability is is difficult and our ability to retain people. "* ***PR Interviewee Peter***

Information sharing with NDIS providers was reported as poor, making it very difficult to support PwPDs who may not understand the full suite of their services, their NDIS plans, and what their funding should be used for.

> *"I don't think that the NDIS really does come out with a clear statement as to what it [psychosocial recovery coaching] is. So I'll give you a for instance, I have another gentleman who's a new client he has ASD, he has schizophrenia. And he's been given the label of psychosocial. The lady of our age group who has been determined that she has a requirement for it, she has anxiety. The gentleman who's 39 He has learning difficulties, and I suspect an ABI, but I can't be sure of that. And that's about it. So, they're all quite different. And yet they've all been given Psychosocial Recovery Coaching. And I don't know why, and they won't talk".* ***PR Interviewee Adam***

Assisting PwPDs in applying for additional funding to accommodate changes in circumstances can sometimes exhaust their existing NDIS funding, often without successful outcomes. Sofia noted that:

> *"There probably be more work in offering your own justification for needing funding that you use what you what work you needed to make into a presentable document to only be paid for that work anyway."* ***PR Interviewee Sofia***

Peter highlighted the significant oversight and risks for plan management providers, particularly ensuring that NDIS Participants are not coerced, exploited or penalised when errors occur.

> *"The issue that arises tends to be what do we then do with that information? What jurisdiction do we operate in? And what powers do we have? For that that becomes a, as a nuanced canary in the mine. It's actually how we join the groups together. And as part of all of that, we have to be very mindful, we live in a very litigations world at the moment. So providers will take legal action against clients who have spent money or book services for which there's no money. They'll take legal action against the plan manager. So I'm quite familiar now with the small claims court and writs in the county court. Like oh, yeah, likewise, the agency will threaten plan managers with debt recovery. If we've paid for something I pay for it. Don't think it's in accordance with the clients plan in other clients as it is. And then we have the [NDIS] Quality and Safeguards Commission."* ***PR Interviewee Peter***

Peter noted at several points during his interview that the NDIS Quality and Safeguards Commission currently does not have the capacity to monitor and investigate unscrupulous providers, particularly unregistered providers. Most PR Interviewees echoed this. Blake, a manager for a larger provider, confirmed that monitoring the safety of participants is a high priority for his organisation.

> *"So, we've invested a lot in technologies to make it easier for people to provide that information on to flag risk factors in the system, but I know a lot of providers wouldn't necessarily have that."* ***PR Interviewee Blake***

6.7.5.2 NDIS Providers Share Their Experience with Other Providers

PR Interviewees identified that there are long wait lists and limited support options, and the support quality can be poor.

> *"It can be very 50/50 to be honest. I would say a quarter of my work time is dedicated to policing other providers making sure there is no exploitation making sure that they are actually receiving the support that they are said to be receiving that it actually is quality support. So, I would say 50% of the time it is very poor quality, and I wouldn't wish that type of support on any person. And then the other 50% we get brilliant people who are very good at what they do. And I would say the reason why 50% are really good at what they do is because we find those people and then we keep using them."* ***PR Interviewee Michaela***

When there was inadequate support coordination, PR Interviewees described that there were frequent issues with PwPDs running out of NDIS funding before their plan ended, leaving them without any support. Additionally, conflict of interest is not well managed, with providers offering support coordination, plan management and other services and paying themselves. There is coercion of PwPDs by providers, and it can be challenging to act on issues as some providers threaten each other with business loss, as Peter described:

> *"The conflict of interest is very much out there. We have support coordinators, even this week, threatening to remove 50 clients from us, because we wouldn't do what they wanted in relation to one client…I've got to say is it's not paid any attention to it. It's almost the reverse of Section 52 of the Code of Conduct about no inducement for referral. This is an inducement to maintain business under threat. So the code of conduct deals with one perspective, but the market works in other ways."* ***PR Interviewee Peter***

PR Interviewees identified that many providers do not wish to support participants with complex disability profiles. Additionally, they often do not have experience in mental health service provision.

> *"So you've got all these providers sort of trying to get in,get a piece of the pie and may not have that background, the qualifications and the understanding of mental health like they've just sort of comes jumped from one industry to the to the mental health industry without any prior knowledge just for the business purposes of setting up."* ***PR Interviewee Tina***

PR Interviewees also identified that larger providers that used to, or still, work with state block-funded programmes come with existing knowledge. Further, Blake advised that as a large provider, his organisation can share skills and expertise across different programmes, including NDIS, aged care, foster care, and state-funded mental health programmes. Peter advised, though, that many larger providers appear to be coercing PwPDs to remain with them as they transition from state-funded mental health to the NDIS.

PR Interviewees advised that small and large businesses struggle to survive under the NDIS funding models, other NDIS providers are thriving as they are engaged in unscrupulous practices and provide poor services, and profit is prioritised over participant well-being.

> *Where I work right now for that two days a week, my boss updates his BMW every 18 months. Apparently, he's building a mansion and clearly, that's where the money's going. And the organisation itself is running on a smelly rag to a large degree."* ***PR Interviewee Adam***

6.7.6 NDIS Providers Discuss the NDIS Workforce

> *The history of disabilities relies upon people of goodwill and good faith to get around barriers.* ***PR Interviewee Peter***

The PR Interviewees discussed NDIS workers within their own and other NDIS provider organisations, and they advised that their core values, quality of work and skillset were highly variable. Some NDIS Workers go above and beyond, often doing unpaid work because they care about and "*are very tuned into*" PwPDs and wish to help them work towards their goals. The key issues highlighted were staff turnover, workforce skillset and training and development. Notably, PR Interviewees state that NDIS workers often do not have experience and training in working with people with mental illnesses. Kelly stated that workers have come back to her commenting:

> *"Oh, this is too hard. Just if he doesn't want to help himself, then I'm not going to work for them."* ***PR Interviewee Kelly***

PR Interviewees who owned their NDIS businesses tried to ensure that their workforce had qualifications and experience. There was an acknowledgement that, for the most part, many NIDS workers are not highly skilled. They do not have the insight required to work with PwPDs, to understand their perspective or the fluctuating nature of psychosocial disability. Adam shared that "*95% of workers do a half-arsed job*" and do not appear to really care or aim for good outcomes. He shared an anecdote regarding one of his PwPDs, who wants to improve his health and well-being through gym workouts.

> *"The same thing happens in both cases with two different support workers. They sit there playing on their phones, while he's in the gym working out. Equally, the professional exercise physiologist who is supposed to be working with them says I want you to do 10 press-ups, 10 whatever's, instead of whatever it might be, and then he turns around and walks away and expects the guy to do it. Okay. So even at that level, it's kind of like the NDIS is paying for people to do a half-arsed job."* ***PR Interviewee Adam***

When considering PwPDs with complex support needs, Tabitha flagged the lens in which NDIS-funded behaviour support practitioners view participants. She noted that there are some excellent, highly skilled behaviour support practitioners, however:

> *"What we're seeing is a lot of quite young, well paid. Yeah, I'd say some fairly rough operators out there and even some highly skilled people that who see things as counting the problems and naming the problems, rather than observing the skills that we want to continue developing."* ***PR Interviewee Tabitha***

All PR Interviewees recognised that the NDIS workforce has a high turnover rate, attributed to poor pay, conditions, and training.

> *"So it's an industry problem. It's it's the fact that the minimum wage is so low and the minimum qualifications and entry into these roles are very low or if not none. So I think yet making things meant making certain education mandatory and raising the minimum wage with it or stop that the staffing turnover would stop the poor quality. Yeah, absolutely. That's one of the issues."* ***PR Interviewee Michaela***

Adam stated that the turnover rate was impacting the NDIS participants, who are then unable to meet their goals as they cannot build trusting relationships, and there is not enough time allocated for either reading or writing notes, so PwPDs have to start over with each new worker.

> *"The support workers, they need to have a level of income that they can actually survive on. It does come back to that, I'm afraid, so that they can keep doing their job. Because*

> *to a large degree, there are going through a rotating door and they don't hang around, and because of the pay scales they're on. They'll move for five dollars for two, three, four or five dollars now. The participant, at the end of the day has no continuity of support with their workers."* ***PR Interviewee Adam***

The NDIS funding model puts workers at risk, with insufficient time for handover and professional development. Adam advised that few NDIS providers ensured that staff had appropriate inductions at commencement, and very little information was given about the PwPDs. He once supported a PwPD, without being told by his team leaders or via an alert that "*the guy put a knife in a support worker's back*" six weeks earlier. Heidi stated that the NDIS has made workers much busier, and Tina expressed concern about workers burning out. She noted that with some of the more isolated PwPDs, they are that person's only connection, and it is "*a lot of pressure on like one person or one worker to kind of be everything".*

Workers lack the training required to understand and appropriately support PwPDs to "*build on their own skills*" or "*broaden their horizons*" so that they are "*bottom of the barrel*". Nearly all PR Interviewees provided comments about worker capacity in either their organisations or working for other providers. They expressed concern about workers playing on their phones, sitting and watching television, walking away and leaving the PwPDs to engage in tasks and activities alone. When asked if PwPDs knew that their NDIS workers' performance was less than optimal, Adam advised that not always, but many were.

> *They say things like I don't know why they wasted time coming. They don't know what I'm trying to achieve. They don't know what I want. They just do what they want. So, the biggest complaint is community access, where people just go where the support worker wants to go.* ***PR Interviewee Adam***

NP Interviewee Peter advised that while many support coordinators and psychosocial recovery coaches are very skilled, he is aware of some coercing or defrauding of PwPDs. Psychosocial recovery coaching has been creating some confusion with PwPDs and PR Interviewees; with it being seen as a "*cheap form of support coordination*" there is often little explanation about why PwPDs have been allocated this form of support. It has reverted to support work by the NDIA with no explanation to either the PwPDs or the provider. NP Interviewee Tabitha advised that administrative people are filling support coordination and psychosocial recovery roles and are doing what is actually social work without the required training or expertise. Kelly echoed this concern.

> *What good are you to this participant, if you can't even set up a basic budget? So, I think that the proliferation of independent supports is problematic. It's great because it does provide more choice to the participant. And it's great because they get to have a lot of fun. Yeah, you know, Oh, you want to go to [city], whatever. I have one [PwPDs] that*

> *needs help to get a birth certificate. You can't do anything else without that, he can't get a bank account. He can't get a Centrelink he can't get anything. And I'm trying to sort of say [to the NDIS Worker] you know, 'Can you ring them tomorrow and then when I talk to the participant, what do you do? Oh, fishing.'"* ***PR interviewee Kelly***

6.7.7 NDIS Providers Discuss NDIS Workers Working with PwPDs and Life-Limiting Conditions

PR Interviewees felt they would need significantly more training to support PwPDs and life-limiting conditions. Heidi stated that she felt guilty about the level of care that she was able to provide to a PwPD with a life-limiting condition. Heidi said that her employer had not provided any training. Sofia worried that she would not know enough "*about the medical side of things*" and would continuously blame herself for not understanding what was required. Understanding that the NDIA may view supports as a health matter, she felt that she "*would have to to be a little bit of a magician"* to make the supports cohesive and wrap around a PwPDs. Michaela argued that even with extensive expertise in the health and NDIS systems, a participant would need to have all NDIS workers, including plan managers and support coordinators, agree to achieve good outcomes. Michaela also felt that psychosocial recovery coaches have much closer relationships with PwPDs than support coordinators, so they would be better placed to support them if they are dying. Blake advised that his organisation can use its training programmes for aged care workers to upskill NDIS workers and support PwPDs with life-limiting conditions as a large provider. His organisation's workers were able to support PwPDs with life-limiting conditions to stay in their SDA/SIL accommodation until they needed the higher level of medical care offered by a hospice. Heidi advised that none of the staff received any training or additional support when a PwPD and life-limiting condition was living in her employer's SDA/SIL.

> *I think it would be very emotional. And, you know, especially for the workers who have built that rapport and that relationship with the participant because they're spending so many hours per week with these people that you know, they develop a bond or relationship with them. And so actually, you know, when we get into this work, we want to help people so naturally it would affect them, I think, emotionally****. PR Interviewee Tina***

6.8 NDIS Providers Discuss Palliative Care and the Health System

The PR Interviewees did not discuss health-funded palliative care services in great detail and were largely unfamiliar with them. They understood that it had to do with hospitals, death and dying and end of life. Although Sofia stated that in her experience, they were "*ignorant of what NDIS* is". Additionally, Michaela noted that PwPDs may not be accepted into palliative care due to their pre-existing mental health issues, substance abuse issues and behaviours of concern.

"They kind of don't have a space they don't have a pathway" ***PR Interviewee Michaela***

Adam indicated that PwPDs and life-limiting conditions may not wish to enter the palliative care system, particularly hospital or hospice, as it would be "too structured and medically driven". Adam felt that "*a community approach with medical involvement*" would be more successful. Heidi advised that the PwPDs and a life-limiting condition that she supported did not build trusting relationships with the community palliative care team as they were "*sending someone different all the time*". Further, the community palliative care team did not organise any additional equipment, advise the NDIS provider on how to support the PwPD and life-limiting condition better, or notice or help her manage her pain. PR Interviewees responses are listed in Table 9 below:

Table 9: PR Interviewees Describe Palliative Care

PR Interviewee	Responses
Adam	Palliative care, as far as I'm aware, is an end-of-life care. And it's as simplistic as that to me.
Tina	Palliative care, like I when I think of that, I think hospitals and life-threatening sort of you know, incurable sort of illnesses Yes, that's sort of hospital sort of related care. I guess. That sort of thing
Peter	So, we might find a person has moved into a health setting before palliative, but the normal service may have stopped, or we might find that they're unable to be discharged from a health setting. So that there might be an issue or who's paying for what and the health system has its own views.
Sofia	Palliative care and for my understanding, which I'm not as familiar with, is end-of-life type caring. So, there has been every other avenue sort of explored, whether it be medical, whether it be you know, even I suppose to surgery even to you know, long stays in hospital, and there is as harsh as the

PR Interviewee	Responses
	words I'm about to use is going to sound there's not much more that we can offer. We will make your life as you know, safe, happy, comfortable as we possibly can until your time is you know, to leave.
Michaela	To be honest, I haven't worked in palliative care. We don't tend to delve into that type of realm. But my understanding is palliative care is when you've kind of made the assumption or or the choice that this person is no longer kind of going to progress and let's make them as comfortable as we can to the time that they have to have left.
Kelly	I would think that its end-of-life care. So, it's when you've got a diagnosis of a terminal condition that it's a specialist group of healthcare professionals that can manage all of those kinds of affairs, whether it both be physical health, mental health, as well as your affairs, you know, to get your affairs in order. And generally, that's through the health care system.
Blake	I guess. I just be, you know, supporting people to you know, pass away with dignity and comfort and you know, is the end-of-life support, basically.
Tabitha	Not explicitly answered.
Heidi	Support when someone has a terminal illness, when they're dying. [D*o you have any idea when palliative care starts and who provides it?]* No idea whatsoever? No, not really.

6.9 NDIS Providers Discuss Silos

The siloing between systems was an overarching concern with PR Interviewees. Tabitha advised, "*It's next to impossible to deduce whose job it is to do anything*" and that systems do not work together that "*restores human dignity*" but rather "*pass the buck*", making it very difficult to hold any system to account.

> *"There's not really clear guidelines, it's really convoluted political language when you're looking at the legislation around who's responsible for disseminating which resources. Yeah, who is ever going to be able to work out what NDIA should be providing versus*

> *what the health system should be providing at any given moment?"* ***PR Interviewee Tabitha***

PR Interviewees advised that there were significant siloing issues between the NDIS and other systems, particularly the mental health and health systems. The systems do not communicate effectively with each other.

> *"Yeah, it's very, very rare that I will have someone on the end of a phone call or in a meeting in which the level of understanding is high, and it means that we can't unravel a problem other than to quote legislation each other."* ***PR Interviewee Peter***

Further, Peter stated that significant silos between the NDIA and the NDIS Quality, Safeguards Commission, the Australian Practioner Registration Agency, Australian Insurance and Investments Commission, state guardians, state health commissions and state law enforcement make it exceptionally difficult and convoluted to keep NDIS Participants and free harm and exploitation. Tabitha also asked, "*who holds accountability?"* Kelly advised that there are also significant issues for PwPDs who live close to state borders. A PwPD, in these circumstances, may and sometimes must obtain support from different sides of the border, therefore being subjected to siloing between the two states and the NDIS.

Sofia advises that "*red tape, excessive paperwork", and a lack of support* ", *I need to ask 15 people"* hampers her efforts to support PwPDs across systems*.* When PwPDs have multiple conditions, this can be increasingly complex, and this frustrates Sofia, "*Which bit of this is schizophrenia?…. It's still the same person, ultimately".* Tabitha advised that when trying to find the appropriate support for PwPDs across systems, *"you trip over them, you're not guided to them, there's no pathway*". Further, Tabitha noted that when people have multiple conditions, supporting them across systems becomes increasingly complex.

> *"It's that old chestnut. That used to happen when everything was state funded. It's happening again, but as a divide between state and federal funding where no no, that's not our job. That's their job. Let's just argue over who holds responsibility here and cost shift and say that it's someone else's role to play this part. to provide the housing or to you know, oh no no, we aren't going to pay for psychological support that comes out of Medicare. That is such a furphy."* ***PR Interviewee Tabitha***

Adam raised the issue of the multiple silos leading to a significant waste of resources, where each system has administration costs that cut into the overall budget leading to a reduction in services for PwPDs and other Australians. Adam also noted that holistic care across systems is not possible. He stated that the kinds of supports offered by the NDIS often cannot effectively report back to the health and mental health systems which manage medication. Further the health and mental health system clinicians do not understand how NDIS supports work and the nuances of choice and control, for example; this can result in significant harm to PwPDs. Peter noted that scheduled GP checkups are no longer occurring for PwPDs as they previously were under different funding models. The NDIS does not have the "*fundamental basic systems that you put into a disability model as we have done in the past*."

Blake noted that there is no standardised baseline of knowledge about systems, no clear understanding of "*who pays for what?"* or the ability to support PwPDs effectively within each system and across the systems. Sofia surmised that no organisation within each system has the capacity to train its staff to understand other systems. This then impacts PwPDs or applicants to the NDIS.

> *"They might have a pamphlet kicking around that says you have a disability; you can now get funding you can now get care. That is it. That's all that organisation is going to actually have accessible"* ***PR Interviewee Sofia***

Sofia believed that PwPDs' general practitioners should be part of the NDIS planning meetings, as they know their patients, and it would help them understand what support their patients were receiving from the NDIS.

> *[On case management] "I think it is the recognition of that liaising across different services and not having this crap of, you know, it's here or there when you're talking about a human being are going to cross over different sections and having ways to actually make that easier, so it doesn't put the burden on the person who's going through dying basically, all you know, disability in general. So yeah, I think that liaison across those different things is important"* ***PR Interviewee Blake***

With the exception of Heidi, who has limited interaction with other systems, all PR Interviewees did not feel that PwPDs experienced seamless transitions between systems. Responses are listed in Table 10 below:

Table 10: PR Interviewees' Responses Regarding Seamlessness Between Systems

PR Interviewee	Responses
Adam	Hogwash
Tina	To make the experience seamless, you need to communicate effectively between systems and there is not enough funding allocated in plans to adequately communicate between systems
Peter	[Laughs] Sorry that's that's an emotional release. It's unprofessional. The architecture does not allow it to happen… At the moment, it's about being defensive, who's responsible for what.
Sofia	Not even close. It's not even close to seamless

PR Interviewee	Responses
Michaela	No very disjointed… You've got 10 different people doing all their own thing and nobody knows.
Kelly	[Laughs]Yep, it is no. I don't think it is for anybody.
Blake	Nup [laughs] I think sometimes people are restricted from working collaboratively as well.
Tabitha	Oh, that's absolutely not the case. It's traumatic. It's the opposite of that. And it's traumatic for the families it's traumatic for me massive gaps in integrated care? Yeah, massive gaps… it's more gaps than systems.

PR Interviewees felt that the siloed nature of the NDIS and other systems would have a significantly negative impact on PwPDs and life-limiting conditions.

> *"The interface of palliative care, what's funded through the government and what's funded through the NDIS as a disability support and sometimes it seems very odd that we'd have a modern society looking at that, at such a time in anyone's, any family's life but that's the unfortunate reality of, whilst the NDIS aims to make disability mainstream in many ways. It's separation from developing a holistic model. It is, with the government right now, something that you'd never design that no human being would ever design."* ***PR Interviewee Peter***

Each PR Interviewee indicated they would go out of their way to support PwPDs and life-limiting conditions, acknowledging that they would be working unpaid to do so. They recognised that the siloed nature of the systems would make it extremely difficult to support them adequately. Most would aim to get a change of circumstances into the NDIA but felt uncertain about what supports would be funded, with Kelly asserting, "*Yeah, would it be successful? I'd give it my damnedest shot*". Support coordinators and psychosocial recovery coaches advised that it was unlikely that the NDIS would fund it. Still, they would work unpaid to pull together case conferences between the various systems workers to ensure that PwPDs and life-limiting conditions would experience cohesive services as they were dying. With her direct experience with PwPDs and life-limiting conditions in a SIL/SDA setting, Heidi advised that support, even in this kind of setting in the future, would still be lacking. PR Interviewees felt there was a greater likelihood of better outcomes and seamless experience for PwPDs and life-limiting conditions if the NDIS would fund case conferencing. Tabitha commented on the likelihood of a seamless experience for PwPDs and life-limiting conditions under the current NDIS funding model.

> *"To find themselves supports that would actually knit everyone together in a collaborative multidisciplinary approach is more of a happy accident."* ***PR Interviewee Tabitha***

6.10 What Support Would The NDIS Provide For A Participant With A Life-Limiting Condition?

> *"It's really like, you have to be a little bit of a magician to make the to coincide. It's still the same person ultimately, and they still do have, you know, a disability."* ***PR Interviewee Sofia***

Adam advised that a PwPD had significant health concerns and was frequently in hospital, and the NDIS would not fund his regular support workers while he was admitted. He was, therefore, isolated as no one else he knew was coming to see him in the hospital. When asked what impact it would have if regular support workers could not support PwPDs and life-limiting conditions if they entered a hospital or hospice.

> *"Devastating because, in many cases, that's the participants' sole link to society."* ***PR Interviewee Adam***

Most PR Interviewees echoed this; Tina talked about how distressing it would be for PwPDs, *"because you're their support person, and suddenly you're not in the picture"*. She stated that the workers would feel distressed and powerless and "*letting the participants down*".

Most PR Interviewees had direct experience supporting NDIS participants with life-limiting conditions. Some had direct experience with PwPDs and life-limiting conditions, notably Heidi, who had supported a PwPD and life-limiting condition while working for a SIL provider. This experience has been detailed in a case study at 6.12.

Tina, an NDIS provider-owner who employed support workers, did not have any direct experience with PwPDs with life-limiting conditions or NDIS participants with other disabilities with life-limiting diagnoses and was asked what her company would do to support them. Tina advised that her workers would talk to the PwPDs and life-limiting conditions about what kinds of supports could be helpful. She thought of providing support for hospital and specialist appointments and in-reach hospital or hospice support as required or requested. Once established, they would contact their support coordinator and discuss how PwPDs and life-limiting conditions could obtain more support. Part of these discussions would be how they could work collaboratively with workers from other providers and other systems. Further, Tina recognised that this might be very challenging for her workforce, so she would provide extra training, supervision, and support for staff, although she acknowledged there would be no funding in the NDIS funding model to provide that kind of support and training.

Of those PR Interviewees with experience supporting PwPDs and life-limiting conditions, the dignity of risk and training workers about it was flagged as a factor that providers must consider for PwPDs and life-limiting conditions. Michaela advised that she had supported a PwPD and a life-limiting condition. She advised that his SIL/SDA provider "*basically turned him out and put on the street for his drinking and smoking within the property".*

> *"It's a rule of supported living and SDA is that you do not consume drugs and alcohol on the premises and or smoke on the premises, which is quite difficult for my type of participants because it's part of their life."* ***PR Interviewee Michaela***

Heidi felt that her workplace would exit any PwPDs as soon as they "*become a liability".* Heidi also raised that workers often have strong relationships with PwPDs and that it can have a significant and negative on both if the PwPDs are exited from services when they become elderly or develop life-limiting conditions.

> *"She went out into a nursing home, and she was distraught. Really. It was heartbreaking for her, heartbreaking for me. We're not allowed to have any contact with former clients. And when she went there, I said "I'd love to go and visit her. And my boss said to me, "you can, you can" and so I did, and that first Christmas she wasn't there. I went and visited her. I saw her in there about three times, I think. And I told my current boss, and she gave me a written warning."* ***PR Interviewee Heidi***

Several PR Interviewees stated that they would or have used the balance of a PwPD's NDIS Plan to provide additional support towards the end of their lives. They did not describe any repercussions for taking this approach. Sofia felt that the NDIA are more responsive than community palliative care services, so obtaining functional support from the NDIS would be a better option. Most PR Interviewees had an entirely different opinion, stating that the NDIS is much too slow to support dying PwPDs, reciting many occasions where PwPDs endured significant delays for change of circumstance requests for additional funding. Tabitha stated that trying to navigate the systems for PwPDs and life-limiting conditions was challenging, both logistically and spiritually.

> *"It required a whole lot more explicit navigation of which set of challenges is responsible for which set of impacts Yes, and when we are successful in setting up a rubric, and saying, This bit is the chronic depression. This bit is the chronic illness. This bit is the nursing care need aligned to that illness. It takes almost needing an auditor's level of detail to break it down for funders to make sense of. And when we do it in an actuarial*

> *fashion, which is disgusting, because human beings should not be reduced to that process. Only then can we substantiate the reasonableness of supports against each of those phenomena or health experiences and you know, pain management experiences that they face."* ***PR Interviewee Tabitha***

When asked what specific supports the NDIS would provide for PwPDs and life-limiting illnesses, the responses ranged from none to an extensive list of end-of-life supports; answers are listed in Table 11 below.

Table 11: PR Interviewees advise what type of Supports the NDIS would fund for PwPDs and life-limiting diagnoses?

PR Interviewee	Responses
Adam	No NDIS support in hospital or hospice
Tina	• Psychosocial support while in the hospital. • The NDIS would be just one component of their care, they will need to use other services.
Peter	None, they are funded by the health system.
Sofia	Additional personal care, such as showering, would be funded. NDIS would not fund equipment as it doesn't mesh with psychosocial.
Michaela	If I could link it back to their psychosocial disability: • Physiotherapist • Hi-Lo bed • Mobility aids around the home (such as grab rails, ramps) • Mobility aids for access to the community. • Psychology • 24 hour care • Apply for SIL/SDA • Fill the gaps with NDIS "Let's just get it to happen"
Kelly	• Would like to think that they would get what anyone else should be able to get in that time of need – plus. • Shopping • Meal preparation • Changing of sheets • Somebody to read to them

PR Interviewee	Responses
	- Personal care, "But whether the NDIS would consider dying a physical issue when they have a psychosocial disability, I can't answer that question." - Psychosocial support in hospital and hospice "I would expect that regardless of where they're residing,. Whether it's under a bridge or in palliative care or something, that there would be a way to get those supports into them."
Blake	- Core support to keep everything going. - Therapeutic supports - Life-change transition - All supports should be enhanced as their needs will increase. - Should fund personal care, but the NDIS would probably consider it a health thing.
Tabitha	- Respite - Support coordination to leverage other systems - We used under-utilised funds in plan to get the support that they needed for their end-of-life care.
Heidi	- All equipment needs such as shower chairs, beds etc would be funded by NDIS. - Take PwPDs to medical appointments.

> *I've worked in [stated funded], disability, and I know what it's like when the hospital requests for a support worker to be in attendance. And I know what it's like when the person wants someone in attendance. And equally, I can sit back and say, well, are we saying [we will fund] a support worker and the kind of support you get when to go to the footy, but they cannot support you to go to the hospital?* ***PR Interviewee Peter***

6.11. Would the Death, Dying and Palliative Care Experience of PwPDs be Equitable to Other Australians of the Same Age?

Opinions about the equity of the experience of PwPDs with life-limiting conditions were varied, with answers being that the experience would be better, the experience would be worse, they did not know, or that they felt that it could be equitable, but it is too inconsistent.

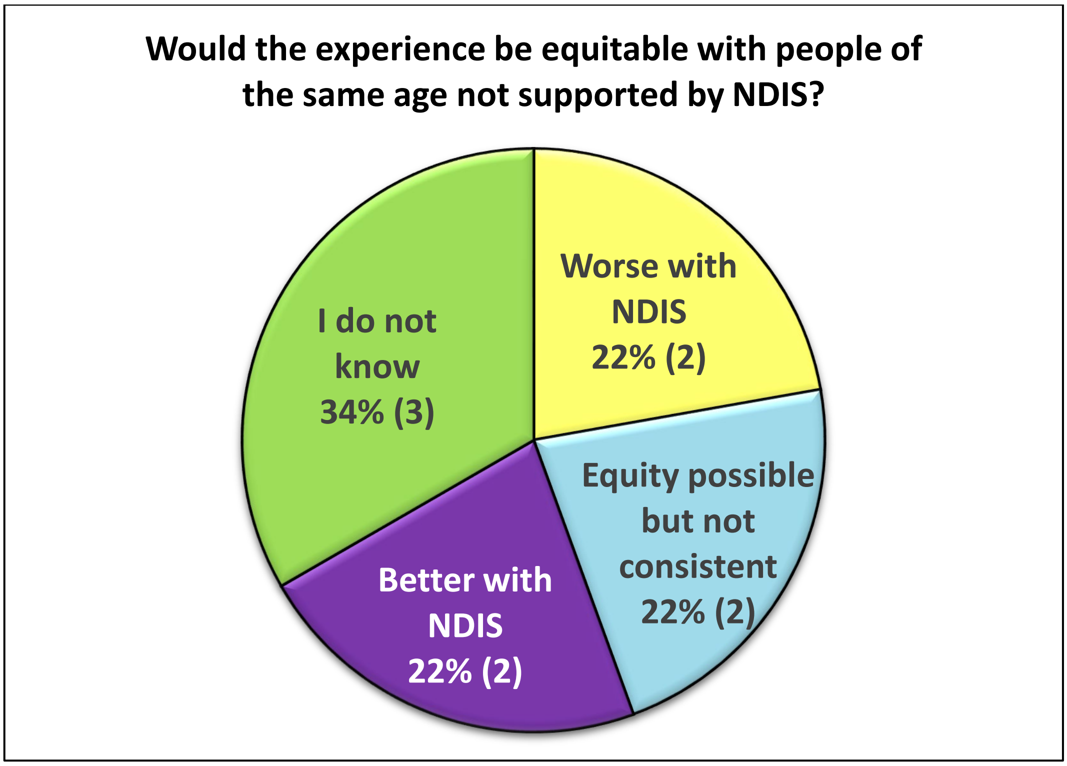

Figure 21: PR Interviewees Advise Whether the Experience be Equitable

PR Interviewees indicated that they would work exceptionally hard to try to get additional supports for them. Those PR Interviewees who felt the experience would be better than their peers of the same age acknowledged that PwPDs could receive functional supports that may not be available to other Australians, such as shopping and transportation. There was, however, concern and confusion about what sort of support the NDIS and other systems fund. PR Interviewees all wondered how successful their applications for additional support would be. Most felt that the NDIS had the potential to ensure an equitable end-of-life experience. However, until the inconsistencies in decision-making by the NDIA and the quality of supports offered by providers could be assured, it is unlikely that they would feel confident this would be a reality. Tabitha felt that society's poor expectation of the kind of life that PwPDs should expect would impact the types of supports that they were likely to receive at the end of their lives. Additionally, Tabitha felt that the "*passing the buck*" that occurs would significantly and negatively impact a PwPDs's end-of-life experience.

> *There's not really clear guidelines, it's really convoluted political language when you're looking at the legislation around who's responsible for disseminating which resources Yeah, who is ever going to be able to work out what NDIA should be providing versus what the health system should be providing at any given moment?* ***PR Interviewee Tabitha***

6.12. A Case Study – PR Interviewee Heidi And PwPDs and Life-Limiting Condition Margaret

Heidi shared her experience supporting Margaret, a PwPD, with a life-limiting condition. Their experience with the health and NDIS systems, the lack of understanding between systems and the impact that this has on a PwPD and life-limiting condition and the NDIS worker became evident, and their experience is therefore presented as a case study. Heidi is a support worker working for a supported independent living (SIL) provider that operates out of specialist disability accommodation (SDA). This facility only supports PwPDs. Margaret had previously been unhoused and had an advanced stage of cancer. Heidi felt that the reason that Margaret was accepted into the facility was because she was so unwell and was an NDIS participant, though Heidi had reservations about her living in the facility.

> *"I'm shocked they allowed her to come in, they spoke about her staying with us. At the time, I didn't question the bosses, but I was just wondering how that would work. Because staff that we have aren't nurses and we don't have any training at all in that."*
> ***PR Interviewee Heidi***

Heidi stated that no staff in the facility had any training to help them to work with PwPDs and life-limiting conditions. As far as Heidi knew, none of the NDIS workers had any experience working with dying people. The staff were also not provided with any psychological support for their well-being.

Margaret had no personal or professional relationships with anyone in the SDA or with this NDIS provider, which also provided other forms of NDIS support. She was estranged from her family and had no informal supports. Heidi was uncertain if Margaret was under the care of a state-funded public guardian. Margaret lived at the facility for six months but made no personal connections with the other PwPDs residing there. When asked if her living in the SDA impacted the other PwPDs living there, Heidi stated.

> *"Oh fine, they weren't aware. They're so drugged up, all they are worried about is, really, themselves, their smokes, what they're eating. So they're always friendly and lovely to whoever goes there. I think that they became aware that she was experiencing some difficulty. But they weren't, weren't that concerned really."* ***PR Interviewee Heidi***

Margaret had no other service providers from other systems attend the premises. Eventually, her case manager from the state-funded mental health system came in to visit her on-site. Workers from the SIL/SDA would transport Margaret to her health appointments. Heidi became concerned about how the health and mental health providers treated Margaret.

> *Mental health who obviously was liaising with the bosses. And with the doctors, and they, I could tell that, they believed her cancer, she was stage three, I think, and they, she'd been offered chemotherapy. However, she denied it. And they were saying that she wasn't able to make that decision. which I felt was not correct. I think she was well aware of the fact that she had cancer, that it was terminal and that she just didn't want treatment and she was happy to allow it to go on. And just um, die, really, because she had a strained relationship with her daughter and her son. That the relationship with them was estranged. She wasn't having any contact with them while she was there. Didn't want to. And I saw people making decisions, sort of trying to make decisions for her. I thought that was wrong. And to say that she didn't have the capacity to make a decision about her medical care. I thought that was wrong. I think she was well aware of that she had cancer and that she was going to die.* ***PR Interviewee Heidi***

Despite their best efforts, Margaret did not enter into any treatment.

> *"No, she stood firm. She said no, no, no. Which was good, which was really good because I think, even if you said to a young child if you say cancer, the word cancer, they know. That, it's a serious illness, and she knew what was going on. She just, yeah, was happy for it just to progress.* ***PR Interviewee Heidi***

Heidi became upset about how other workers and managers spoke about and to Margaret.

> *Sometimes, they just made judgments about her that really got to me. Like one what one thing, one thing that was really important [to them], she had bad breath when she was dying. And they just went on about this. And I thought, she's dying, she's not well."* ***PR Interviewee Heidi***

Heidi also felt uncomfortable that the provider managers and the stated-funded mental health care coordinator were trying to force Margaret to reconcile with her family. T

> *"She didn't want contact with her son. And they didn't get that. And I don't understand why they didn't get that; she just didn't want contact with his son who knows what went on."* ***PR Interviewee Heidi***

As Margaret's condition declined, she was visited by community palliative care to support her with her medications and pain management. Heidi noted that her pain was assumed.

> *In the last stages, they organised a nurse to come in, because it was assumed she was experiencing more pain. And that's the thing with people with mental illness though,*

> *they'll often be in pain, and they won't ask for help or tell people what they're feeling.* ***PR Interviewee Heidi***

Heidi believes that this may be because PwPDs often do not have close relationships with those around them and do not feel comfortable sharing this information. This resulted in Margaret being on minimal pain relief while she was living in the SDA.

> *"And she and what they put her on wasn't much anyway because she kept saying she was, she was sort of like okay."* ***PR Interviewee Heidi***

Heidi advised that the palliative care team kept "*sending random nurses, you know, like different nurses all the time*", and she felt that this impacted Margaret's ability to discuss her pain as she could not build a relationship or trust with any of the team.

> *"But in [Margaret's] situation, not in the time that she needed for them to understand. Because she needed people to be quick, like responding to her quickly. Not not, you know, a couple of weeks later, "oh well, you know, maybe, maybe you actually have more pain than what you're telling us***". PR Interviewee Heidi***

When asked about whether Margaret died at the facility, Heidi responded that her management became concerned about risks and concerns that there may be grounds to be sued.

> *No, so when they, I don't know, it was like when they became really aware that she was actually dying. And someone sort of sat down and thought, "well, there's some risks here". And I don't know if this is a risk of her falling.* ***PR Interviewee Heidi***

Margaret did not receive any shower chairs or a hospital bed from either the NDIS or palliative care service to help her with her comfort and risk as she was dying. Heidi felt that on every personal level, care for Margaret "*was lacking*". She usually does not go into PwPDs's rooms but started to do so as Margaret was declining.

> *"I went into her room, and she had this old crusty old flat pillow that wasn't adequate. And some things in her room, if I can recall, that weren't up to standard, and I remember going and getting her, like, a couple of nice pillows and making sure yeah, that she had some nicer stuff, like a jug, a jug with water and things that you'd need, if you didn't want to get out of bed and explained to her a lot what I can do for her, if she needs anything to just ask. So, I don't even think she was told what we were there for. But I do remember her asking me this when she started to feel a little bit unwell. She said to me, "Can I eat in my room?" and I was really happy to do that. However, there was someone*

> *on site at that time, that was above me, and she said that that was impossible. So, I had to make her come out and have her dinner in the communal area. Which, you know, she was unwell. It was wrong, really, really wrong. And I felt really guilty that, that, that had happened"* ***PR Interviewee Heidi***

When asked whether Margaret understood her rights as an NDIS participant and choice and control, Heidi stated:

> *No, no, no, not at all. She had to come out because there was that this level of uncertainty about what might happen to her in the room."* ***PR Interviewee Heidi***

The management of the SIL/SDA insisted that Margaret come out of her room to eat her meals, even though her illness was progressing, which became very distressing for Heidi.

> *"The way they spoke, just about a spoke about her. You know, "she really needs to get up", "she really needs to get to the shower", "what she really needs is to like, go to this" and I think, you know, she's fucking dying. She's dying, what the fuck?" I'm not trained in it, but what don't youse get? She's, she's not well, who gives a fuck about her, like bad breath and, you know, she's actually dying". And, and they said, like, initially they said to her, "you can stay here. You can stay here." So even though the relationship, it was not really strong, but I mean, she got to know us and even if it wasn't the best place to be, for her. But they shipped her off. And it was two weeks later, she died.* ***PR Interviewee Heidi***

Heidi found out that at some stage during the six months, Margaret had broken her arm, and it was not detected by the palliative care team, any medical practitioners or NDIS workers until after she had exited the SDA.

> *The thing is she didn't mention it initially. So, I'm guessing that she might have knocked herself, yeah probably, the cancer had metastasised. Yeah, I don't know anything about cancer. Well minimal. Yes, I'm guessing that it, that's what's happened. But it was just sad that it wasn't until they did take her out, that they found out that, yeah, she did, she broke her arm. That affected me because I feel quite guilty. But I'm not trained in that area. I don't know.* ***PR Interviewee Heidi***

Heidi felt her employer would not accept someone with the same circumstances as Margaret's again. When asked what the plans were for PwPDs already living in the home if they were to get a life-limiting condition, Heidi responded that she "*was shocked*" there had been no future planning for this type of event. She did not think that this NDIS provider would support them to die at home even though some PwPDs had lived there for over 15 years.

6.13. NDIS Provider Summary

Three PR Interviewees recognised the importance of advocacy for PwPDs and felt that NDIS providers often advocate and should advocate as part of their responsibilities. PR Interviewees had a similar understanding of psychosocial disability, it being a disability that results from mental illness. Some listed symptoms, and others pointed to a lack of clarity and understanding of the term.

PR Interviewees discussed informal supports, including carers, families, friends and neighbours. The issues that they flagged were that often, PwPDs are socially isolated and do not have these connections in their lives. Additionally, where PwPDs have informal supports, no services are available to assist them or provide respite. Finally, the complex family dynamics that are around can have an impact on PwPDs, particularly if they have a life-limiting condition.

Most of the PR Interviewees commented on the scarcity of mental health system support for PwPDs, particularly outside of metropolitan areas. General practitioners create mental health plans that avail their patients of ten Medicare-funded psychology appointments; however, there are long wait lists to see a psychologist, or no appointments are available. The gap fees charged are prohibitive for PwPDs with low incomes.

PR Interviewees reflected on the PwPDs they support and advised that most have co-occurring health conditions or disabilities. They stated that while often highly intelligent, PwPDs are often socially isolated. When they are connected with others, they can be exploited. PR Interviewees advised that they know of PwPDs that are being financially exploited by their guardians or plan nominees but feel that there are few avenues to protect them. PwPDs can take a long time to trust their NDIS support workers and clinicians. The kinds of supports offered to PwPDs by every system are impacted by the low expectations of the quality of life that PwPDs have. The NDIS process and concepts, such as "choice and control", are a struggle for PwPDs, and most PR Interviewees stated that PwPDs do not get the support they need and feel that the NDIA may have a strict mandate about what they will approve for psychosocial disabilities.

The overall opinion of IS Interviewees of the NDIS as a system was overwhelmingly negative (88%). It was felt that the system is confusing, underfunded and inequitable, reinforcing stigma and discrimination. The lack of funding for training and development was seen as a significant issue, and the NDIS it has led to a de-professionalisation of services around PwPDs. There were some positive opinions, where PR Interviewees felt that PwPDs lives were improved by the NDIS, particularly for those who could navigate the system or had people around them who could.

Overwhelmingly, the reflections about the NDIA were negative (89%), where PR Interviewees expressed frustration with the slow processes, lack of transparency, poor communication, understaffing, overworking and a high turnover of NDIA staff. They describe constantly "*fighting*" with the NDIA to support PwPDs. They feel that the NDIA is arbitrary and punitive in its responses to NDIS providers and PwPDs despite being haphazard in their decision-making, which leads to a continuous state of confusion. They feel that there is a lack of empathy and compassion that causes trauma for PwPDs, and their families and the NDIA staff do not understand the needs of PwPDs. PR Interviewees describe the NDIA staff as "*secretly think that you are lying".*

PR Interviewees described the support that PwPDs receive from them and others. Whilst each was passionate about the supports their provider and workforce provide, they described the overall quality of NDIS supports as often poor, leading to adverse outcomes for PwPDs. PR Interviewees identified that there are long wait lists and limited support options, and the support quality can be poor. The workforce was described as unskilled and apathetic, and this was attributed to poor pay and poor working conditions. They stated that the NDIS funding model puts workers at risk. PR Interviewees felt they would need significantly more training to support PwPDs and life-limiting conditions.

PR Interviewees advised that there are significant issues for providers using the NDIS funding model. There are insufficient hours funded by the NDIS to attend to risk management, reportable incidents, and staff training and development. Protections that registration may offer PwPDs can often not be realised due to the prohibitive costs involved with the NDIS registration process. All PR Interviewees talked about doing unpaid work that is unbillable. Retaining workers is a significant issue and results in adverse outcomes for PwPDs. It is difficult to recruit workers who understand the NDIS and PwPDs. Information sharing with NDIS providers is poor, making it very difficult to support PwPDs, who may not understand the full suite of their services, their NDIS plans, and how their funding should be used. PR Interviewees stated that NDIS providers struggle to survive under the NDIS funding model. They noted that conflict of interest and coercive practices cause significant negative consequences for PwPDs.

The PR Interviewees did not discuss health-funded palliative care services in great detail, some uncertain what they are. However, most stated that they provide end-of-life care. One noted that PwPDs may not be accepted into palliative care due to their pre-existing mental health issues, substance abuse issues and behaviours of concern.

The siloing between systems was an overarching concern for PR Interviewees, with a lack of knowledge, training, and guidelines about the supports funded by each system. PR Interviewees advised that there were significant siloing issues between the NDIS and other systems, particularly the mental health and health systems. The siloing impacts their ability to support PwPDs effectively and holistically, particularly those with co-occurring conditions. Further, they advised that the systems that support NDIS participants do not communicate effectively with each other. One PR Interviewee stated that silos between the NDIA and the NDIS Quality, Safeguards Commission, the Australian Practioner Registration Agency, Australian Insurance and Investments Commission, state guardians, state health commissions and state law enforcement make it exceptionally difficult and convoluted to keep NDIS Participants and free harm and exploitation. One PR Interviewee stated that multiple silos lead to a significant waste of resources, where each system has administration costs that cut into the overall budget leading to a reduction in services for PwPDs and other Australians. None of the PR Interviewees advised in the strongest terms that PwPDs do not experience seamlessness between systems.

Some PR Inteviewees listed multiple supports that the NDIS would fund for PwPDs and life-limiting conditions such as personal care, shopping, meal preparation, someone to read to them, 24-hour care, psychology and a full suite of equipment to support them to die at home, transport to appointments. Others stated the NDIS would fund nothing. One PR Interviewee stated that the NDIS could provide support in hospitals or hospices, and another specifically stated that the NDIS would not fund this.

When asked if PwPDs and life-limiting conditions would have an equitable death, dying, and palliative care experience to similarly aged people without support from the NDIS, two PR Interviewees felt that the PwPDs and life-limiting conditions would have a better experience, two felt that equity would be possible, but it would be inconsistent. Two thought the experience would be worse, and three did not know if the experience would be equitable.

CHAPTER 7 - MENTAL HEALTH CLINICIAN RESULTS

7.1 Introduction

Three Mental Health Clinicians (MH Clinicians) contacted the research team via word of mouth after learning about the research. Recruitment flyers were posted on Facebook, in mental health clinical groups, and on LinkedIn, and they were emailed to clinicians and managers in the mental health clinician community. However, there were no responses via these avenues. Two of the MH Clinicians had direct experience with PwPDs and other people living with SPMI with life-limiting conditions. The other two MH clinicians speculated using their knowledge of informal and formal support networks, including mental health, health, and the NDIS systems. One MH Clinician had extensive knowledge of the NDIS and Mental Health systems and lived experience as an informal support of a PwPD, another had significant experience in the mental health, aged care and health systems, and the third had only worked in the mental health sector. MH Clinicians were then asked to use their knowledge and expertise regarding these systems to predict the death, dying and palliative care experience and supports likely to be received by PwPDs with life-limiting conditions and to advise whether that experience would be equitable and seamless between systems. The MH Interviewees' experiences with systems were explored deeply to enable a better understanding of potential feedback loops within and between systems. As direct quotes from interviews will be included in this chapter, any potentially identifying information about PwPD Interviewees was removed, and pseudonyms were assigned.

7.2 Mental Health Clinician Demographics

Three female MH Clinicians, two mental health nurses and one occupational therapist were interviewed for this research. Two were from metropolitan Adelaide, and one was from metropolitan Melbourne.

7.3 Mental Health Clinicians Discuss Advocacy

Two MH Clinicians discussed needing to advocate for PwPDs, with Jordana noting that "*everybody is advocating*". Brenda stated that unless someone advocates for them, they will receive poor-quality supports from NDIS providers and workers.

> *"They're not doing high quality work. They're just babysitting and you have to work very hard. Somebody has to advocate somebody has to be there and say, that's not good*

> *enough. You need to do this, you need to do that and keep an eye on them. Because even when you do that, that they they largely and they're not changing their behavior. Because they say well, it's up to the participant what they want to do. Well, with psychosocial disability, the participant's judgment is impaired."* ***MH Clinician Brenda***

7.4 Mental Health Clinicians' Understanding of "What Is A Psychosocial Disability?"

The MH Clinicians had a different perspective of psychosocial disability and how both they and the NDIS interpret the term.

Table 12 - Mental Health Clinicians' Understanding of "What is a Psychosocial Disability?"

MH Clinician	MH Clinician Quotes
Brenda	• People with what they would consider to be a permanent disability and you have to be able to demonstrate that around their mental illness and the NDIS is very specific. • So extreme functional incapacity is basically what we're looking for, in at least one domain of the six domains. So, if you can prove that they have extreme functional incapacity in one domain then you you will be found eligible for the NDIS. And from there you move to planning, and that's where you really need to demonstrate all the functional disability across domains.
Jordana	• I don't think that they have a clear idea of what it is and so it makes it very difficult as clinicians. So trying to understand and work within a framework that is not clear. It just makes burden on everybody. • I think about a diagnosis is from functional perspective. So, you know, if people have something that significantly impacts their motivation, like, you know, depression or something more variable like bipolar, can be really difficult to work with in the psychosocial framework, because NDIS requires evidence that there is not a recovery and something like bipolar, where it's like yes, this person will be completely immobile, potentially catatonic but also there'll be highly motivated and won't sleep and will do 1,000,001 things that also puts them at different risks. Yes, it's very difficult to say yes, they continuously need this level of

MH Clinician	MH Clinician Quotes
	support, but divided differently based on time and place. Yeah, it's a difficult framework to work with.
Alice	I think it means more of the things in their environment and how do I word it I've just last year I think more it's more about everything that can contribute rather than them themselves. So which includes a lot of their environment and when you look at the social aspects, it's not so much targeted on the individual. Does that sort of make sense?

7.5 Mental Health Clinicians Discuss Informal Supports

MH Clinicians advised that if a PwPD has an engaged informal support network around them, they can have great outcomes from the NDIS. However, Jordana noted that "*often people that don't have an advocate outside of themselves, yeah, they miss out*". This was echoed by Alice:

> *"A lot of people with mental health issues don't have a big support network. So a lot of their social interaction is with support workers. So if we remove that they're often left with nothing."* ***MH Clinician Alice***

7.6 Mental Health Clinicians Discuss The Mental Health System

Brenda stated that the mental health system had previously not validated the disability aspect of mental illness and that the NDIS had brought about a positive change in this regard. However, she reported that the NDIS workforce is usually not optimal and or equipped to manage high levels of complexity. This leads to significant strain on the mental health system as PwPDs "*end up back in hospital costing the system a fortune".* Brenda advised that they are engaged in mental health reforms in her state.

Jordana noted that every service is underfunded, referencing her experience with the mental health system.

> *I've not worked in a fully staffed mental health team in the years that I've worked with in mental health, we're always short, usually at least two FTE if not more, so. Your community team can't do or like all those things that ideally they would do they're*

> *meeting the minimum, yes, but they're not doing everything that you would want. As a student, I remember doing a placement in mental health and as a student, you were able to do all those things. And the outcomes were amazing. Whereas then being a clinician, you still want to do those things, but you're limited by time resources and KPIs.* ***MH Clinician Jordana***

Jordana further described the impact of this under-resourcing in the mental health sector and its significant toll on the workforce.

> *The problem is that the best clinicians I've worked with are the ones that advocate the hardest and they burn out and then move on the fastest because, yes, if you're passionate within a broken system, it breaks you or you leave. So these broken systems just don't work.* ***MH Clinician Jordana***

Alice advised that in the mental health system, there is a "*lack of education and real understanding about what the NDIS can do*" Jordana also said that she does not "*know how it* [the NDIS] *all works*". Further, Alice acknowledged that the mental health system can be overwhelming. A friend had recently engaged with a mental health service, and watching her and her family's experiences with the system has given her a new perspective and opinion on its flaws and the frustration and anxiety that it can cause.

> *"I think sometimes when you're in a profession you you can get so complacent and you forget that for so many people, this is a new experience and you really need to explain it like you're explaining it to someone who has no idea because the doctors do it every day and I think they forget that."* ***MH Clinician Alice***

Jordana commented that the mental health system can cause people with SPMI on certain medications to lose their autonomy.

> *"If you're on Clozapine, you're never going to be released from the mental health system because you are constantly having to be tracked by a mental health team. So you [people lose that autonomy almost like you're telling them you're managed, you can never be outside of our system now. Whereas with other treatments, they can be discharged to GP."* ***MH Clinician Jordana***

Jordana advised that the medication can cause significant health problems, and this is "*not well enough understood as well within the NDIS support networks*".

Jordana reported that obtaining state-based support packages is more straightforward and less confronting than obtaining support from the NDIS.

> *"Often, we put people on [name of programme] first, because it's a less confronting and easier to access service. At the moment, there's a big push to get people off it who have been on it for more than two years. But there's consumers who have built that rapport with their [name of programme] workers. And then NDIS is a whole new framework and now they have to validate all these things. And and so often, they just disengage."* ***MH Clinician Jordana***

7.7 Mental Health Clinicians Discuss the NDIS

7.7.1 Mental Health Clinicians Discuss NDIS Participants

MH Clinicians shared that based on observations of their clients, the disability model of the NDIS is having negative impacts on PwPDs, particularly having to prove lifelong disability as required in Section 24 (1) e)of the NDIS Act. Jordana noted that this can increase the experience of isolation for PwPDs.

> *"There's already that cognitive element of feeling a little bit worthless when you tell somebody they're disabled. And there's a new barrier. Another thing that then they go, Well, I can't do anything you told me I'm disabled. So if I'm disabled, how can I be a value to the community?"* ***MH Clinician Jordana***

Jordana was also concerned that PwPDs are not getting the support they need from the NDIS, even those with high-level supported independent living funds in their NDIS Plans.

7.7.2 Mental Health Clinicians Discuss Support from the NDIS

MH Clinicians were aware that PwPDs were accessing a number of supports. These are listed in Table 13, along with any specific comments that were flagged. Highlighting the disconnect between systems, when asked whether she was aware of what kind of supports the NDIS provides for PwPDs, Alice responded:

> *"Not really. To be honest with you, I think. They might get help in engaging with others, or engaging, you know, in programs or getting out and interacting with like, sort of more so their environment rather than being kept inside. But other than that, no."*

Table 13: Mental Health Clinicians List Supports from the NDIS

Support Type	MH Clinicians	MH Clinician Comments
Support Workers	2	• But when you come to the more complex end of the spectrum, that's where you're really lacking. • They're not doing high quality work.
Support Coordination	2	
Cleaning	1	They are the great things about the NDIS. And, and so we don't want to see people lose that.
Occupational Therapy	1	
Behaviour Support	2	• In the last few years, and we've been very happy to have behavioral support practitioners involved in a person's care. • The NDIS might have endorsed the a bunch of these practitioners, but they're not necessarily endorsing the industry specialists that we've been working with for years, you know, so it's an interesting conundrum. • Yeah, that gets really tricky, at least restrictive practice in the mix. You know, like your person might have PRN diazepam and that's a restrictive practice and you need a behavior support plan if you having any restrict yet, and then you have to articulate why that's been utilised and how, and yeah, so it's become a lot more work for our doctors that I think that's been huge for them and our allied health practitioners. • Behaviour Support Plans are fantastic when they work, but often it's a lot of clinical words, put in jargon terms then provided to somebody that

Support Type	MH Clinicians	MH Clinician Comments
		doesn't understand them. And you know, you'll have support workers say are, you know, they'll be readmitted. And you say, Have you been using their positive behavior support plan? And they're like, Well, I don't understand. Okay, so I don't see how it works, or that just doesn't work in practical sense, • They're just the same thing. Repeated in different words over and over again. It'll be like a 40 page document, but only actually 10 of it is original.
Recovery Coach	1	
Transport Training	1	
Supported residential facility	1	
Specialist Disability Accommodation	2	
Supported Independent Living 24/7 1:1 support	1	I learned last year that support independent living was no longer going to be provided for psychosocial disability.

7.7.3 MH Clinicians Discuss the NDIS as a system

The overall opinion of MH Clinicians of the NDIS as a system was negative (92%). Comments were analysed and assigned as either positive or negative and are depicted in Figure 22.

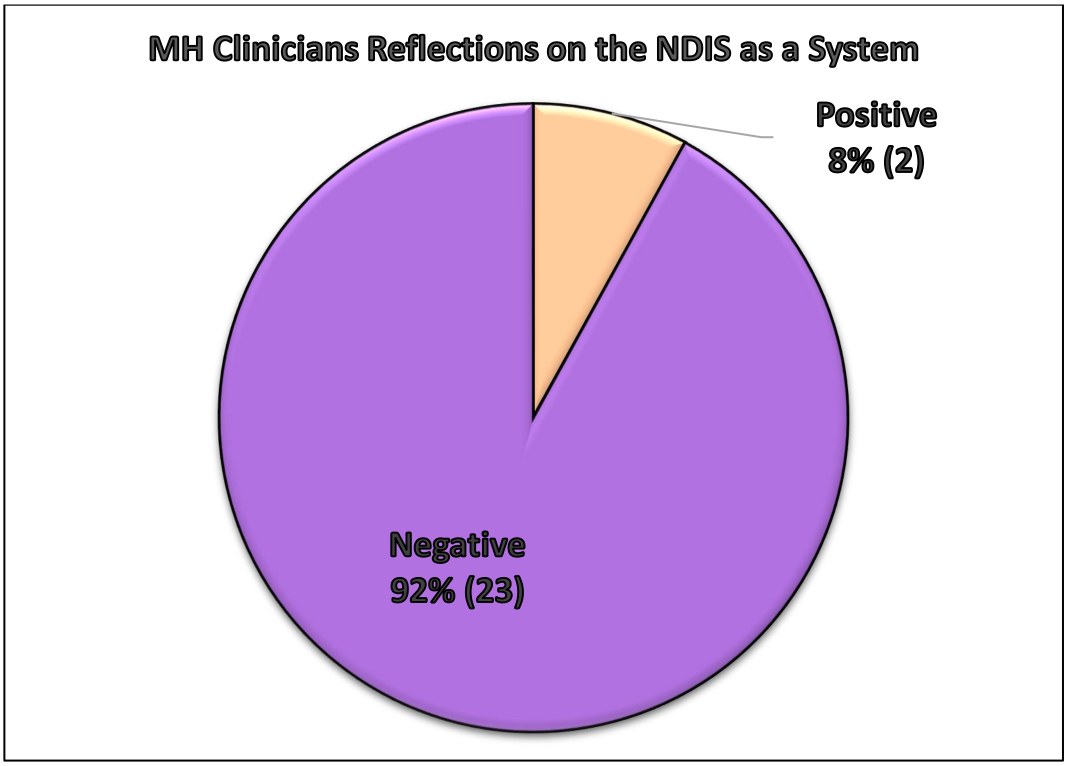

Figure 22: Mental Health Clinicians' Reflections on the NDIS as a System

Jordana discussed the complexity of supporting a PwPD who has a diagnosis of Borderline Personality Disorder. They may have "*huge packages*", and when they receive intensive support during the day and do very well; however, when the support workers leave "*they attempt to take their life".*

> *"They leave them in the person is fine, and a couple of hours later, they're admitted to hospital with significant wounds and, you know, stab wounds hanging cutting.All because the support workers left.That activates that abandonment concern, and then they spiral. Often, those support workers, they take on a level of trauma because they feel responsible for this person's harm. And then NDIS don't fund for risk. So the support workers will be like this is impacting us mentally because when we leave this person is harming themselves. I don't want to come back to work with them because borderline do have attachment issues. So when they do attach to those support workers, they attach hard. And then that can create, you know, issues around boundaries and yeah, that it reinforces some negative traits whilst positively supporting their mental health, but it's just it's its own whole issue within the NDIS".* ***MH Clinician Jordana***

7.7.4 National Disability Insurance Agency

The MH Clinicians advised that the NDIA are not transparent, and Brenda described them as a "*mysterious bureaucracy*", stating that they constantly change the rules but deny doing so. Brenda has read an internal communique within the NDIA that directly contradicts their public-facing communications. These issues are further compounded as each NDIA planner may have their perspective on how the guidelines and internal communique should be interpreted, resulting in haphazard decision-making. Therefore, workers in other systems must try to stay ahead of these changes and guess how best to support PwPDs.

MH Clinician Brenda stated that the NDIA is always trying to cut funding and save money, but their execution is detrimental to PwPDs.

> *"So the solution isn't to cut people's packages, you know, but that's the solution they've seen, you know, from a bureaucratic lens. Oh we'll cut people's package to save us money and then we'll be able to keep funding you know, that's not okay. People need funding. They need packages, they need support."* ***MH Clinician Brenda***

Requesting amendments to existing plans or requesting a review of planning decisions is extremely frustrating and can take months *"it's never a quick solution*". The NDIA consistently demands extensive evidence that can be difficult to source due to a lack of personal or state resources, so you're constantly at an "*impasse*". She felt that "*the review process needs to be examined".* Further, Brenda stated that the Administrative Appeals Tribunal (AAT) is continually being used to adjudicate NDIA decisions, and the AAT process is highly detrimental to PwPDs.

MH Clinician Interviewees advised that the NDIA do not have a good grasp of psychosocial disability or mental illness; Brenda feels this is because it is "*grey*" and is "*never black and white"*. Further, Brenda reported that she has been advised *"point blank"* that under 25's should not apply for the NDIS and that it is "*the responsibility of the treatment services to manage*". Even though there is nothing within the legislation or NDIA operational guidelines regarding this particular age restriction, The fluctuating nature of mental illnesses is not well understood by the NDIA planners and Local Area Coordinators (LACs), and Jordana reported that they struggle to get increased support when PwPDs's mental health declines. This can be particularly challenging when a PwPD has a diagnosis of bipolar disorder, where they can have highly variable support needs, both in type and frequency. The NDIA struggles to understand that mental ill health can cause significant physical disability and poor health and continuously "*separate their head from their body".* When considering NDIS Planners and LACs, Brenda noted that:

> *"We have some excellent ones. I mean, we and I do deal with senior planners more often. LACs can be very variable and can be quite anxious and maybe not make decisions because they know it's going to have to go through to the NDIA. But the NDIA senior*

> *planners tend to be fairly confident. And they Yeah, largely do have some understanding. I have had planners who didn't, but I think they tried to match you up with mental health proficient planners."* ***MH Clinician Brenda***

7.7.5 NDIS Providers

MH Clinicians advised that they have seen some great work by providers happening for PwPDs, although it can be hard to find providers that can support psychosocial disabilities. The basic supports, cleaning, gardening and meal preparation are excellent; however, psychosocial-specific support is limited. Additionally, Brenda raised concerns about the quality of providers, that there are no checks and balances or standards for providers. Consistency in the quality of providers across the sector was indicated as an issue for PwPDs. Brenda also felt that NDIS Providers are poorly equipped to support PwPDs and behaviour support plans. Alice advised that she feels providers are "*rorting the system"* and not doing the right thing by PwPDs and see the "*NDIS as a way to make money".*

> *"I heard this morning on the radio that that they've done an analysis of several providers and they found that they've all run at a loss in the last 12 months. And that's not okay, because that means that people with SIL funding in their packages aren't getting the support they need either, their provider can't afford it. where's it gonna come from? .So there must be cost cutting going on.* ***MH Clinician Brenda***

7.7.6 NDIS Workforce

MH Clinician Jordana talked about the benefits of having an invested, educated formal support network around a PwPD, which leads to excellent outcomes. She expressed concerns about the quality of support that the PwPDs are receiving from NDIS workers, with many of these workers not understanding mental illnesses and psychiatric medications and "*those support workers, they take on a level of trauma because they feel responsible for this person's harm*". Further, Jordana expressed that many workers seem apathetic and disengaged from PwPDs.

> *"We had somebody on the package that was over a million dollars. And the support workers just stayed in a side room and took them to the pub every day. And I feel like there's got to be a better use of funding."* ***MH Clinician Jordana***

Alice echoed these concerns and shared that a PwPD she has worked with has workers who came into a hospital setting with him. Those workers "*played on their phones*" and did not engage with or say goodbye to the PwPDs when they left him in the hospital. The PwPDs said he was enjoying hospital food as he did not like the food these workers were preparing for him.

> *"There was just no relationship, which these people work with him all day, every day. And if you've got people watching you all day, every day that don't talk to you that sit on the phone, they don't even say goodbye. It would be very, very frustrating."* ***MH Clinician Alice***

Brenda had a similar reflection about workers who "*sit on their phones*" and do not appear to understand how to engage with PwPDs effectively. She noted that there seems to be a misunderstanding about choice and control, and NDIS Workers do not have the skill set around supported decision-making and are simply "*paid friends".* Brenda stated that there were some "*amazing workers*", but many cannot support PwPDs whose support needs are more complex, and this is resulting in a high number of them being admitted to hospitals, *"costing the* [health] *system a fortune".* Brenda advised that support coordinators and psychosocial recovery coaches sometimes attend case management meetings. However, the core support workers are those she believed should be involved in these meetings and are not included. Jordana highlighted the poor remuneration of support workers as a critical issue for the NDIS workforce.

> *"I've always said that the people that have the most contact are the least remunerated. And so then you you're more likely statistically to have lower education, greater issues around people with racial conflicts and language barriers. And how do you manage that if people can't get the finances to make that a viable job for them? So it's like, okay, we'll pay the people like the further away you go from human contact, the more we'll pay you but then that doesn't fix this issue at the ground level."* ***MH Clinician Jordana***

Indeed, Alice felt that, despite there being some excellent NDIS workers, many are not committed to the work in the long term and see it as a "*stepping stone"* until they get into other types of work or finish degrees, leading to ongoing issues with quality and continuity for PwPDs.

Jordana advised that the NDIS model of disability support is having a significant and negative impact on occupational therapists.

> *"A lot of friends that I have that are OTs, that previously have worked with NDIS have left the field, not because they didn't enjoy it, but just over the years, the expectations and requirements of reports have just become so ridiculous that, you know, they're spending 15 to 20 hours on a report and it's just not sustainable for them. So trying to understand and work within a framework that is not clear. It just makes burden on everybody."* ***MH Clinician Jordana***

7.8 Mental Health Clinicians Discuss Palliative Care And The Health System

7.8.1 What is palliative care?

MH Clinician Brenda indicated that she had no working knowledge of palliative care systems but shared her understanding.

> *"My understanding of palliative care is that its end of life care that it's really helping people to transition comfortably and safely and respecting their wishes."* ***MH Clinician Brenda***

Jordana had previously worked in the aged care system. She indicated that under a former funding model, it meant that people could get the highest level of care and support, but they had to be proven within six months of death, so "*it was a bit of a double-edged sword"*. Alice had recently witnessed a family friend be supported by palliative care services and provided this summary of that experience, noting that this person did not have a pre-existing SPMI.

> *"It's actually more about making sure that those final stages that patients comfortable and that they're happy and that they keep their dignity. There's a lot more to it than it just being caring for someone because they're dying. And it completely flipped my whole perspective on it to thinking Oh, that would actually be quite a nice role because the care that you give to the family in such a more and the patient as more of a holistic approach. It's so much more than just getting someone through those final stages. So think it's about keeping someone comfortable keeping their dignity, keeping their rights and acting in a very respectful manner that makes those final stages as comfortable as they can be.* ***MH Clinician Alice***

7.8.2 Issues with the palliative care/health systems

Jordana described the complexity of supporting a person with a SPMI and life-limiting condition. They were initially admitted to the mental health unit; however, *"physical health teams got sick of having to come across to the mental health ward*". Once moved to a general hospital ward, he faced difficulties, even though adjustments around Met (Medical Emergency Team) calls were made, where he could be taken outside for a cigarette afterwards. It was difficult to obtain support from palliative care services.

> *"But he also didn't accept the palliative approach. 'The ghosts that visit me in my sleep. Tell me that you're lying to me. So the medications you are giving me what are killing me not myself.' And again, you know, lack of, insight, lack of education understanding. So,*

> *you know, it's hard to get support for palliative services if you aren't willing to accept you're palliative."* ***MH Clinician Jordana***

Jordana concluded overall that PwPDs and other people with SPMI, with life-limiting conditions, find admissions to the hospital challenging.

> *"So it makes it really difficult because the people are like, No, I'm not dying. You're lying to me. Yeah. No, I don't want these supports. Why do I keep coming to when there's somebody aggressively rubbing my chest? I don't want you to take my oxygen stats, because then you just keep bringing in these random strangers that want to poke and prod me and they don't even know who I am."* ***MH Clinician Jordana***

Alice reflected that if a PwPD's regular workers could not visit or support them in the hospital or hospice, it would be challenging for both the PwPDs and the hospital and hospice nursing staff.

> *"Well, there's that emptiness and feeling of loneliness. You know, which it it's hard for nurses to witness that. Almost puts the obligation on them to, you know, spend half an hour talking with the person or, you know, sometimes the person don't need an all day visit, but an hour gives them something to look forward to, or some change of, change of scene or change of conversation, which is is important people. MH Clinician Alice. "*

MH Clinician Alice found that it becomes challenging for PwPDs and other people with SPMI and life-limiting conditions as "*they don't want to engage with treatment because for them, that means they're at the final stage."* MH Clinician Brenda indicated that she had not previously thought much about palliative care and PwPDs and other people with SPMI, but reflected that community palliative care cannot be provided if they are not securely housed.

7.9 Mental Health Clinicians Discuss System Silos

The three mental health clinicians agreed that support for PwPDs was not seamless between systems. Brenda acknowledged that workers in each system are "*doing their bit in the trenches*", but advised that there is often mistrust between the mental health sector and NDIS providers. Alice reported that the systems have "*come to run individually"* and that workers do not know what is happening in other systems, and "*things get missed*". Brenda talked about the "*revolving door"* that PwPDs experience between NDIS, health, mental health and housing and how difficult it is to find options for them to suit their disability needs. Jordana and Brenda advised that these systems lenses result in PwPDs being compartmentalised "y*ou've got this disorder and this disorder*" and that we are labelling people.

> *"Instead of labelling people, we should be just looking at what we're dealing with. And the NDIS said at the beginning oh, it's not about diagnostics, but it is absolutely about diagnostics at every turn."* ***MH Clinician Brenda***

Jordana noted that every service is underfunded and that seamlessness "*is dictated by the understanding"* that workers from each system have of other systems. Alice highlighted training as one of the key issues with the gaps between systems.

> *"I think there's a real lack of education and a real lack of understanding about what NDIS can do, what it does, how you do it, who's eligible. I really think it fails this, it fails to run seamlessly because there is that those gaps in knowledge and you know, you don't, we don't tend to have in services, for example, on NDIS and what we do and what we offer, which is a shame because it does affect a lot of people with mental health, but that people who work in mental health have it tends to operate as a completely separate system."* ***Mental Health Clinician Alice***

Interestingly, despite the NDIS not funding case conferencing, the mental health clinicians were aware that case conferencing that includes NDIS providers is occurring, mainly with support coordinators and psychosocial recovery coaches. Brenda advised that the health system in her state has been funding additional intensive support officers to assist NDIS participants "*unstick things*". These roles are over and above the health liaison officers funded by the NDIA.

Finally, Jordana asserted that supports and services are duplicated within each system and that every service shifts responsibility.

> *"Oh, we don't provide that you need to contact that service or you know that service does that, so we won't cover that or, you know, and so you can't have two pieces of the same cake, but somehow nobody's got a cake at all."* ***MH Clinician Jordana***

7.10 Mental Health Clinicians Discuss What Supports the NDIS Would Provide for PwPDs and Life-Limiting Conditions

MH Clinicians used their experiences with the NDIS and other systems to consider how much support the NDIS would provide if the PwPDs developed a life-limiting condition. They felt that the NDIS should support PwPD and life-limiting conditions, it is not responsive enough or equipped to manage. They also felt that NDIS participants with physical disabilities would receive better support. Their responsibilities can be found in Table 14 below.

Table 14: MH Clinicians Advise What Type of Supports the NDIS Would Fund for PwPDs and Life-limiting Conditions

MH Clinician	Responses
Brenda	• I'd hope that they would help them to maintain their environment to have, you know, a comfortable life that they you know, be able to access the community more effectively. What they want to do those last months or whatever. The opportunity to maybe go and see family they haven't seen for a long time. • The NDIA would not act quickly enough to support a dying participant. • Some PwPDs do not have homes and you cannot provide community palliative care when you have no home. You'd have to die in a hospital ward. • I think the NDIA would fund more support for people with physical disabilities that have an additional life-limiting condition. Like cerebral palsy and cancer, just not for PwPDs.
Jordana	• I don't think the NDIS Workers would be equipped to support them. • Probably not. I haven't seen a situation. We struggle to get increased support when they mentally decline, yes. Whereas palliation is for the majority of physical illness, so then you have to get a whole new diagnosis added to the NDIS because if they're palliation is around a physical health condition, the NDIS won't fund it anyway. Because NDIS is funding for that mental health diagnosis. So they had to adjust the whole package before you can even ask for funding for the physical. • NDIS workers should help the PwPDs to apply for palliative care support in NDIS plans, but it is unlikely that they will do it. • They should fund equipment required so different seating, bedding, pressure care? Physical aids, if they need wheelchairs, things like that. Home modes? Yeah. nursing support if they require for medications, additional social supports because they are going to need additional social.
Alice	• I think they could apply to the NDIS to get assistance but everything takes time. They don't really have any time. • They would provide them with additional supports to help them stay at home for as long as possible.

MH Clinician	Responses
	• The NDIS would not fund equipment or nursing, but they may fund somewhere for PwPDs and life-limiting conditions to go. • Regular support workers could continue to support the PwPDs and life-limiting condition while admitted to hospital or hospice. Many would be left with noone as they often don't have anyone else in their lives.

7.11 Would The Death, Dying and Palliative Care Experience Of PwPDs be Equitable to Other Australians of the Same Age?

Mental Health Clinicians felt that the experiences of PwPDs and life-limiting conditions should be equitable but that they would not be equitable to Australians of the same age. Brenda and Alice stated that this might be achievable if the systems could work together effectively. It would also depend on how much formal or informal advocacy the PwPDs and life-limiting conditions had to support them. It would also depend on what type of support was required and the understanding and proficiency of the NDIA planners.

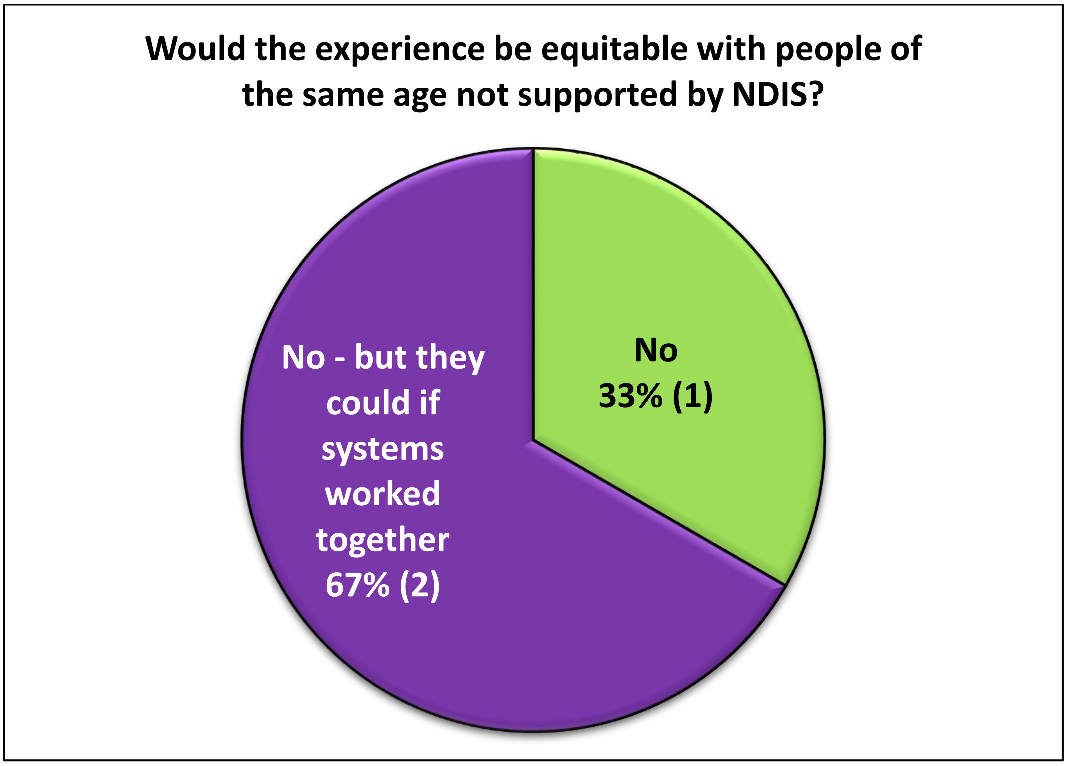

Figure 23: Mental Health Clinicians Advise Whether the Experience Would be Equitable

7.12 Mental Health Clinician Summary

Two of the MH Clinicians discussed needing to advocate for PwPDs, noting that "*everybody is advocating*" and that unless someone advocates for them, they will receive poor-quality supports from NDIS providers and workers. MH Clinicians describe psychosocial disability as extreme functional incapacity that is permanent. However, they stated that it was not clearly defined, so supporting PwPDs alongside the NDIS framework can be challenging. They reported that PwPDs often do not have a "*big support network".*

Whilst the MH Clinicians are concerned about the quality of supports provided to PwPDs, it was acknowledged that the mental health system had not previously validated the disability aspect of mental health conditions. They advised that the mental health system is chronically understaffed and underfunded, and they are not able to provide optimal support for people living with mental illnesses. These issues are causing burnout in the sector. Equally, one MH Clinician advised that allied health professionals are becoming burnt out due to the demands of the NDIS. This can be if they work within the NDIS system or provide reports for the NDIA on behalf of the mental health system. Some of the reporting required for state-funded mental health programs was seen as "*less confronting and easier to access"* than the NDIS. MH Clinicians worry that the entry requirements for the NDIS and the labelling of people as disabled are impacting PwPDs' self-esteem and can leave them feeling that they have no value to their communities.

MH Clinicians' opinions of the NDIS as a system were mostly negative (92%). It was felt that the NDIS is not a good fit for some mental health conditions. Behaviour support plans were viewed as "*fantastic when they work",* but implementation can be difficult, and one MH Clinician noted that some plans usually contain ten pages of original personalised content, and the rest of the 40 pages are the same within every plan. NDIS cleaning, gardening, SIL and SDA supports were viewed positively by MH Clinicians, but one had heard that SIL was no longer going to be provided for psychosocial disability. Cleaning support was viewed as one of the most positive supports for PwPDs, allowing them to focus on managing mental health without having to deal with the mental load of keeping their homes in order. Psychosocial support in the NDIS is very limited, and the MH Clinicians did not feel that support workers were appropriately trained to support PwPDs. They expressed concern that NDIS workers are disengaged from PwPDs and "*sit on their phones"*. It was recognised that poor remuneration of NDIS support workers leads to an unskilled and uneducated workforce. Consistency in the quality of providers across the sector was indicated as an issue for PwPDs and MH Clinicians felt there was a lack of checks and balances or standards for providers. One MH Clinician feels that providers are "*rorting the system"* and not doing the right thing by PwPDs and see the "*NDIS as a way to make money".*

MH Clinicians advise workers in other systems to constantly try to stay ahead of the constant changes to support PwPDs. They stated that there is little understanding of psychosocial disability by the staff within the NDIA, decision-making is haphazard, and each planner has their individual interpretation of the legislation. They feel that NDIA's main objective is to cut funding, which is detrimental to PwPDs, as is their use of the AAT to adjudicate on their behalf.

MH Clinicians reported that PwPDs, and other people with SPMI, with life-limiting conditions, find admissions to the hospital challenging. One MH Clinician advised that the complexity of supporting a person with a SPMI and life-limiting condition can be challenging within the mental health and health systems. Mental health services struggle to support their physical needs, and palliative care struggles to support their mental health needs. One MH Clinician also noted that PwPDs may struggle to engage with treatments and palliative care services as they may not wish to accept "*they're at the final stage"*. Another reported that palliative care may not be available or accessible when PwPDs are not securely housed.

The three mental health clinicians agreed that support for PwPDs was not seamless between systems, all of which are underfunded, and that there is a "*revolving door"* that PwPDs experience. Although workers in each system are all "*doing their bit in the trenches*". They advised there is often mistrust between the mental health sector and NDIS providers. The systems have "*come to run individually",* workers do not know what is happening in other systems, and "*things get missed*". The multiple systems lenses result in PwPDs being compartmentalised "y*ou've got this disorder and this disorder*" To achieve seamlessness, MH Clinicians felt that training in what each system provides would help to minimise the issues and gaps. Case conferencing was also viewed as a key to ensuring seamlessness between systems.

MH Clinicians felt that the NDIS should support PwPDs and life-limiting conditions, but they were uncertain whether it would or what it might provide. They noted that the NDIS was too slow to respond to changing circumstances. It was felt that regular support workers should continue to be funded as PwPDs are dying as they often did not have anyone else in their lives. Mental Health Clinicians felt that the experiences of PwPDs and life-limiting conditions should, but would not be, equitable to Australians of the same age. Two thought that this might be achieved if the systems could find a way to work together.

CHAPTER 8 – PALLIATIVE CARE CLINICIAN RESULTS

8.1 Introduction

Five palliative care clinicians (PC Clinicians) responded to the research flyers posted on LinkedIn, responded to a research presentation or learned of the research through word of mouth. Four PC Clinicians had significant experience with NDIS participants with life-limiting conditions and some knowledge of NDIS participants with psychosocial disabilities (PwPDs)and life-limiting conditions. The fifth PC clinician who worked in senior management was an informal support of an NDIS participant and brought a broad systems-level perspective to these results. Not all of these experiences involved primary PwPDs. If the PC Clinician did not have direct experience working with PwPDs with life-limiting conditions, they were asked to speculate on the experience based on their knowledge of informal and formal support networks, including mental health, health and the NDIS systems. PC Clinicians were asked to use their knowledge and expertise regarding these systems to share and predict the death, dying and palliative care experience and supports likely to be received by PwPDs with life-limiting conditions and to advise whether that experience would be equitable and seamless between systems. The PC Interviewees' experiences with systems were explored deeply to enable a better understanding of potential feedback loops within and between systems. One PC Clinician owns a medium-sized NDIS-funded business that also provides state-funded palliative care supports. As direct quotes from interviews will be included in this chapter, any potentially identifying information about PwPDs Interviewees was removed, and pseudonyms were assigned.

8.2 PC Clinicians' Demographics

Five PC Clinicians, four female and one male, were interviewed for this research, one from rural Queensland, one from Canberra, and three from metropolitan Adelaide. Four PC Clinicians worked in state-funded palliative care services; one worked for a private provider receiving state palliative care and NDIS funding. Their roles included two social workers, an occupational therapist, a nurse practitioner and a medical palliative care consultant.

8.3 PC Clinicians Discuss Advocacy

> *"It seems to me that the majority of resources go to those who advocate best."* ***PC Clinician Stuart***

The PC Clinicians advised that advocacy was vital for all patients with life-limiting conditions, particularly for PwPDs. They and their staff actively advocate for PwPDs and, in some instances, for people with SMPI to help them gain access to the NDIS. They have collaborated with families, public guardians, NDIS support coordinators and formal advocacy services. Where families are involved in a PwPD's life, PC Clinicians advised that the extensive advocacy work they need to do to obtain support profoundly impacts their ability to connect meaningfully during their last months of life. While this is a universal struggle for most carers of palliative patients, they reported that the NDIS places additional burdens on the families of their patients. NDIS providers are advocating for NDIS participants, although the NDIA states that NDIS funds should not be used for this purpose [144]. Amy had seen "*a lovely bit of advocacy"* from an NDIS support coordinator where they managed to have a PwPD and life-limiting condition's case escalated to the National Disability Insurance Agency's (NDIA) Complex Pathways Team. Another PC Clinician who had previously worked as a support coordinator advised that they had advocated for NDIS participants and saw this as part of their role. This PC Clinician worried that PwPDs, particularly those who had grown up in care, would have no one to advocate for them in the future. Advocacy groups and the National Disability Insurance Agency (NDIA) can be at odds with their interpretation of the NDIS legislation. Becky advised that these interpretations can cause delays and issues for NDIS participants, palliative care and NDIS providers. There are reviews requested, and "*time is often not on the side*" of her patients. PC Clinician Stuart advised that access to health and disability services is "*solely dependent"* on disability and health literacy and the strength of an NDIS participant's advocate.

8.4 PC Clinicians Answer "What is a Psychosocial Disability?"

Four PC Clinicians linked the term psychosocial disability to mental illness and the impact that it can have on function, one clinician was not able to define it. One PC clinician identified the complexity of psychosocial disability and the support of the NDIS. Their responses are listed in Table 15 below.

Table 15: PC Clinicians Answer "What is a Psychosocial Disability?"

PC Clinician	PC Clinician Comments
Sylvia	Mental or emotional aspects.
Amy	It's a person living with mental illness that impedes their ability to participate fully in their life in the way that they want to. And that that person has supports, then, that are needed in order for them to fully participate in their lives, or achieve their goals.

PC Clinician	PC Clinician Comments
Jolene	I actually think that there is a lack of understanding about psychosocial disability. And I think if I consider the how the NDIS was originally set up to support people with disability at that time when it was set up, mental health was not considered as part of a disability framework. And so they looked at people with physical disabilities or cognitive disabilities, and then mental health came under disability and whereas previously, that in the medical model with mental health services they brought in psychosocial disabilities under the NDIS and they do not understand it at all. They don't understand the impact that their mental health diagnosis can have on someone's functioning.
Becky	Disability has come that has come around because of for example, mental health issues.
Stuart	Oh, wow. That's a great question. And one that I can't give a meaningful answer to. Sorry, I'm so wrapped up in my world. The question for me around NDIS is around resourcing. And whether we can value add on NDIS and what are the barriers and the blocks that we have in getting resources? I'm so sorry, I'm not even going to try and make something up.

8.5 PC Clinicians Discuss Informal Supports

> *"If you're under 65, you have to have a good family or a good pocket."* ***PC Clinician Becky***

The PC Clinicians discussed the importance of families to their palliative patients and recognise that their role as palliative care clinicians is to support families; however, their resourcing is very limited. They are unable to offer the standard of support for families that they feel is appropriate and required. They highlighted that families support their patients emotionally and financially where they can. Often, family members must advocate extensively for NDIS participants, particularly when navigating the NDIS and communicating with the NDIA. Sylvia reported that this can lead to considerable anguish.

> *"When the [NDIS] participant did pass away, the mother was quite frustrated because she felt like it was such a waste of time because nothing came out of it, and it is a lot for families to deal with that. And also spend time with their loved one and enjoy those moments together. But still trying to take phone calls, organise meetings, think about all*

> *these things, while trying to still be a mother, and advocate for them."* ***PC Clinician Syliva***

Jolene discussed the challenges where families do not understand how slowly the NDIS works and how fast palliative patients can decline. She shared an experience where this lack of understanding led to a PwPD not receiving any NDIS supports before she died, even with extensive advocacy from the palliative care team. "*They just thought they had more time and wanted to wait for a provider that was recommended by the local area coordinator."* PC Clinicians reported that families often contribute financially to buy equipment and pay for carers and cleaners when a patient is under 65. However, when this did not happen, Stuart described how the consequences could be dire, even for those with support from the NDIS:

> *"For the under 65s, on the NDIS and for someone who no longer has the resources to manage a home or the family don't wish the patient to manage at home and provide that support. It has been problematic to try and find a place of care for them. We have found on occasion the misalignment between what the patient and family would desire and what the NDIS feels is appropriate for them."* ***PC Clinician Stuart***

PC Clinicians Interviewees recognised that PwPDs can often be disconnected from families, and they sometimes only have formal support workers in their lives. Stuart advised that without family to help, the palliative care team need assistance from workers with supported decision-making and understanding usual presentation.

> *"We, as a health system, need to determine the correct hierarchy. Who do we need to listen to? Who can advocate for this particular patient client resident? Who knows them best?"* ***PC Clinician Stuart***

8.6 PC Clinicians Discuss the Mental Health System

All PC Clinicians advised that they had limited experience between their unit and the mental health systems.

> *"Mental health is involved, but not, like not very closely, like we're not working that closely together. Usually we work closely with everybody."* ***PC Clinician Becky***

However, Amy described an experience where she had worked collaboratively with a patient's mental health and NDIS teams around symptom management and reducing distress that was related to emergency department presentations.

8.7 PC Clinicians Discuss the NDIS

8.7.1 NDIS Participants

PC Clinicians s reported that they try to obtain NDIS support for people with SPMI and PwPDs and life-limiting conditions. They are either applying to the NDIS and "*hoping for the best"* or trying to get support within their current plans, preparing reports, and sometimes attending NDIS planning meetings. PC Clinicians advised that they are not always aware of why a participant has access to the NDIS as this information may not be shared. Their focus is on trying to find appropriate support for their patient as it pertains to their life-limiting diagnosis for home aids, activities of daily living, pain management, and emotional, social and spiritual support.

> *"I was doing a lot more intensive case management than I would normally do for palliative patients. Because I developed a good rapport with her, better rapport than she had with the agency who's doing the plan [support] coordination. So I sat in with her while she did her NDIS plan review. And it was that it was at that meeting that we told the NDIS planner that this woman has cancer, and she was like 'Well, that's totally news to us. She's registered with the NDIS for psychosocial disability.' Which was news to me, news to the woman. Then she gave consent for that information to be shared with her support coordination agency, and it was news to them."* ***PC Clinician Amy***

Becky advised that she was supporting a PwPD and a life-limiting condition who had complex needs due to multiple disabilities, including those that had resulted from a stroke. The patient's primary disability was her psychosocial disability, and her care became very challenging around advance care planning and capacity. Becky also reported complexities with PwPDs and life-limiting diagnoses who were under guardianship orders with the public guardian over health-related decisions. This could be particularly problematic when there were conflicts between the patient and the guardian about resuscitation at the end of life.

Amy raised that PwPDs may struggle with housing insecurity as they do not meet the thresholds for hospital, hospice or aged care, but they may not, due to the cumulative impact of their psychosocial disability and their life-limiting illness, be able to maintain their home, able to manage their affairs or attend to their self-care needs. Amy reported that some PwPDs and life-limiting conditions assume "*the NDIS just supports you with all of your needs*". In one case, a PwPD and a life-limiting condition refused a public hospital bed in their home through a public loan scheme as they felt that the NDIS should fund a particular bed. The NDIS did not fund this bed. Jolene opined that there are "*more barriers when you've got a mental health condition*", and it makes it "*automatically more difficult to engage with services."* She also noted that it can be complex for stakeholders to support PwPDs and a life-limiting condition due to "*self-sabotaging behaviours*".

8.7.2 Support from the NDIS

PC Clinicians volunteered the kinds of supports that PwPDs that they work with are currently receiving; these are listed below in Table 8.6. It was noted that there are limitations to the types of support offered in rural and remote areas.

Table 16: PCClinicians Describe Support from the NDIS

Support Type	Participants	PC Clinician Comments
Support Workers • Taking to appointments • Shopping • Social participation • Activities of Daily Living	5	The big chunk of her plan was around social support
Equipment	2	• Bed/commode/shower chair – but they want about 10-12 weeks hire, so you have to pay the full amount in advance (also for PwPDs). • Usually, other primary disabilities not PwPDs.
Support Coordination	4	We just burned through the support coordination funding. They did a lot of under-the-grid work.
Plan Manager	3	
Cleaning	4	
Physio	1	
Massage	1	The massage had to be surreptitiously included
Personal hygiene	2	
Gardening	2	
Supported Independent Living (SIL) 24/7 support	4	Participants in SIL usually receive exceptional EOL support from the NDIS provider.

Support Type	Participants	PC Clinician Comments
Podiatry	1	Medical grade shoes (PwPDs)
Behaviour Support	3	
Nursing	1	Generally not PwPDs – other disabilities
Occupational therapy	1	Our occupational therapist is like I'm not spending time reviewing her and doing assessments because she can access that through the NDIS

PC Clinicians advised that they struggle to obtain sufficient support, such as activities of daily living and additional transport and equipment for NDIS Participants. They will request support and try to link the support request back to the participant's psychosocial disability. Often, they will obtain additional functional support and equipment, with the help of plan managers and support coordinators, by utilising any underspend in PwPDs' current NDIS plan. This can be a complex juggling exercise as they do not wish to run out of NDIS funds before the end of the plan or before PwPDs die.

Amy shared an experience where mental health, palliative care, acute care service providers worked collaboratively with a PwPD's NDIS provider support workers and support coordinator to support a PwPD and a life-limiting condition. Whilst initially violent and resisting treatment and care, this collaborative approach, which required significant case conferencing, enabled the PwPDs to stay at home for as long as possible, developing relationships with the palliative care team that helped her to have respite in hospice initially, eventually she was admitted to and died in hospice.

8.7.3 NDIS as a System

The overall opinion of PC Clinicians of the NDIS as a system was negative. The NDIS was described as inconsistent and lacking continuity, that it is "*shocking*", "*tricky*", "*slow*, "*complicated*" and "*controlled from the top-down*". Amy stated that she "*can't see how it's consumer-directed*" and Jolene advised that the NDIS has resulted in funding cuts and a reduced workforce in other systems. Stuart discussed the complexity of having two layers of government, state and federal, which adds to the complexity. It was noted that the NDIS adds to hospital admission times and that the NDIS "*doesn't care*" about what is happening in the hospital system.

> *It’s so, so random at times, you know, and I think in order for it to be successful for someone, so many things have to go well for them.. They have to have a great support coordinator. They have to have a great plan manager. They have to be connected with services that are engaged and wanting to see them, you know, reach their full potential in life. They have to have so much going for them, in order for it to succeed****”. PC Clinician Jolene***

However, it was noted by Becky that you are “*better off*” than your peers if you have NDIS support under the age of 65 if you have a life-limiting condition. Amy commented that the NDIS workers she encountered came from “*an empowerment perspective*” and that choice and control enabled PwPDs to “*get a fresh start and lose baggage”.* However, Jolene has found that confusion about the concepts of choice and control can have detrimental effects on PwPDs. Both Amy and Stuart commented that PwPDs received excellent end-of-life support if they were in SIL settings. Comments were analysed and assigned as either positive or negative and are depicted in Chart 8.1. The comments analysed are listed in Appendix 1, Table 5.1.

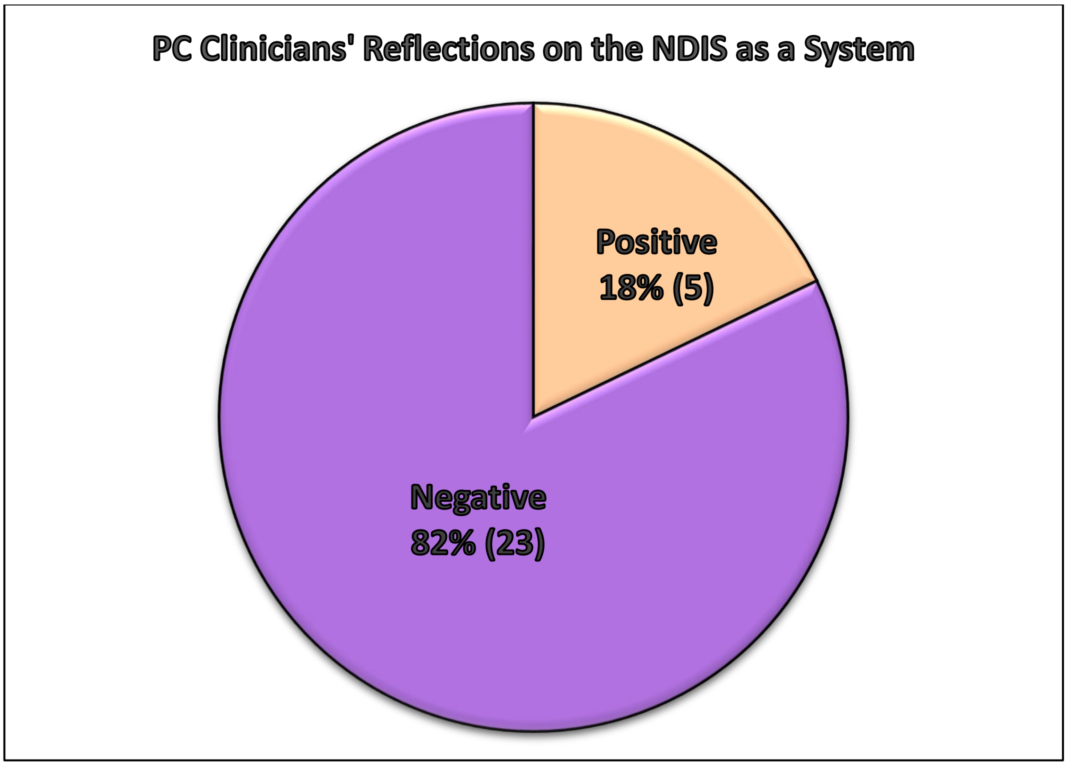

Figure 24: PC Clinicians’ Reflections on the NDIS as a System

8.7.4 PC Clinicians' Reflections on the National Disability Insurance Agency

Comments regarding the workforce of the NDIA, including access officers, planners, partners, or local area coordinators, have been included under the NDIA heading. Whilst they could also be considered the NDIS workforce, that category has been assigned to employees of NDIS providers. All comments about the NDIA by PC Clinicians were negative, and none had positive comments. Long timeframes, lack of guidance, poor communication and poor organisation were critical issues for PC Clinicians. The length of time that it takes, for state health system workers to prepare reports and obtain quotes that are required to receive funding was cited as a key frustration.

> *"We asked for an interpreter, the planner [from the Complex Pathways Team] said, "you sound like you can understand me well enough. It's going to take time to organise a phone interpreter. Should we just muddle on?" And I said, "No, you can't. She has to have an interpreter", so the NDIS planner then went off to get a phone interpreter and the phone interpreter did not speak the same dialect as the woman, the client, and they couldn't understand each other properly, and it was hysterical and very distressing. It was one of the most horrendous things I've I've ever had the displeasure of observing in terms of absolute communication breakdown. And poor process."* ***PC Clinician Amy***

Jolene advised that the NDIA planners do not understand how to engage in supported decision-making, which impacts the quality of NDIS plans and supports.

> *"The [planner was] goal setting within the next five years, where do you see yourself, it broke my heart to have to sit with someone in hospice, we were desperate for him to get home. He and he was looking at me because it was a phone appointment. This woman saying in the next five years, and he just looked at me and said 'Does she not know I'm dying?' On the paperwork, we say a palliative patient."* ***PC Clinician Jolene***

PC Clinicians noted that the NDIA staff do not understand what palliative care is or the kinds of support it provides. Becky advised that NDIA planners are withdrawing NDIS supports for existing participants once they obtain a life-limiting diagnosis under the assumption that the health system will now fund those supports. The health system does not fund disability supports.

> *"Just because someone is dying it doesn't mean they no longer have a disability."* **PC Clinician Becky**

Comments were analysed and assigned as either positive or negative and are depicted in Figure 25. The comments analysed are listed in Appendix 1, Table 5.2.

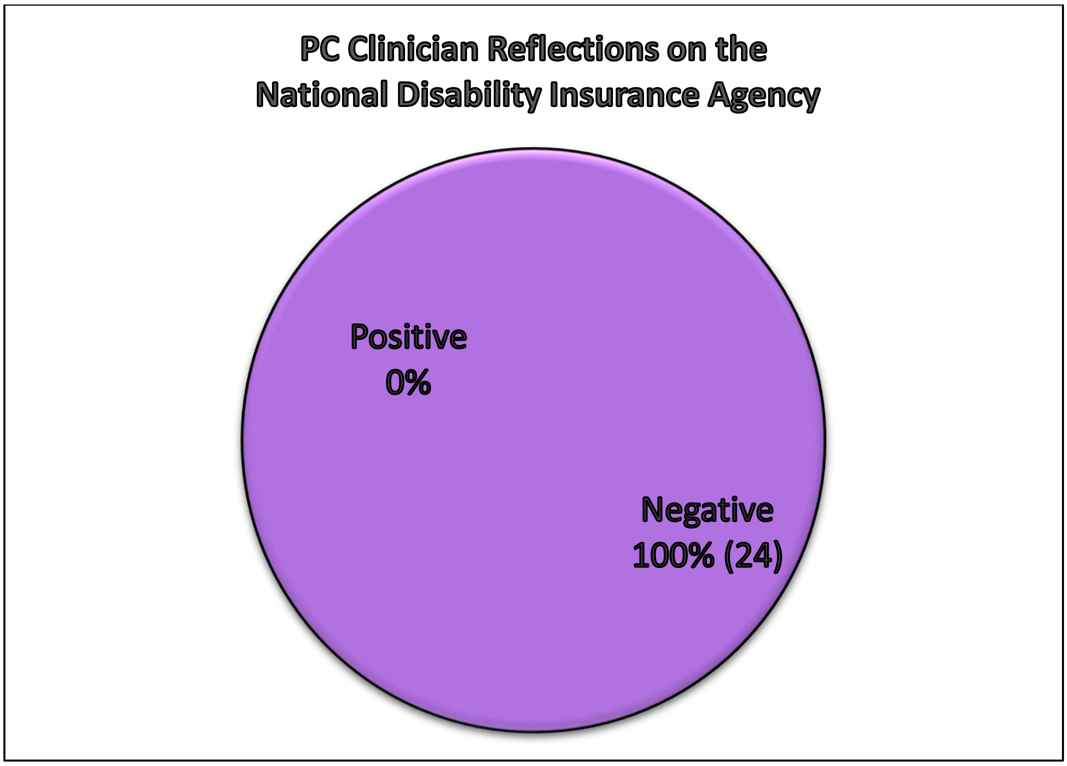

Figure 25: PC Clinicians' Reflections on the National Disability Insurance Agency

8.7.5 PC Clinicians Discuss Palliative Care with NDIS Providers

PC Clinicians advised that they have been able to work with NDIS providers very well and discussed having them, particularly support coordinators, involved in case conferencing. Sylvia expressed concern that once she realised that support coordinators had to bill for each contact, she understood that was "*burning through*" the PwPDs' NDIS funds.

> *I know that we're constantly communicating with support coordinators while they're an inpatient to try and get this participant home. We're chewing up all the support coordination, when we discharged them, they [the provider] really had to step back slash stop because they didn't have any funds left in the NDIS.* ***PC Clinician Sylvia***

Most PC Clinicians understood that NDIS providers and individual workers were doing a lot of unpaid work to support dying NDIS Participants. Amy noted that some providers surreptitiously provide supports, such as complimentary therapies such as massage or equipment for palliative care support that the NDIS does not fund, in order to better support them as they are dying. Jolene, though, commented that outside of end-of-life circumstances, NDIS providers can be predatory.

> *"What happens when someone sees a plan with all that funding, they automatically ding ding, ding, ding, ding, we know how we can spend that money. They're only thinking*

> *about their little pocket. They're not thinking of the individual holistically and all the other supports that are required to support this person to live that throughout their life to the best."* **PC Clinician Jolene**

Stuart and Amy praised the work of NDIS SIL/SDA providers, stating that they provided excellent and collaborative end-of-life care for their patients. Amy's palliative care team also educated NDIS support workers as their employer was happy to support a PwPD who wished to stay in her own home for as long as possible.

> *"The community support agencies, adult services, they pick up a lot for people. I see it in the aged care sector. I see it in the NDIS sector. I see it in the, like CASP [Community Assistance and Support] sector, that the agencies rarely leave someone in a lurch. I feel like they take on so much responsibility for keeping people safe and cared for even if it's not perfect."* **PC Clinician Amy**

Jolene noted that NDIS providers generally struggle to provide positive behaviour support (PBS), which requires a comprehensive understanding of the PwPDs, regular staffing and intense one-to-one support. Hospital staff may not understand PBS, and the PwPDs's behaviour support plan may not be applicable or be a priority in a hospital setting. Jolene noted that state government providers receiving NDIS funding provided a higher standard of care, supporting NDIS participants. She also said that state government NDIS-funded providers make allowances to support NDIS participants when admitted to the hospital or hospice. Stuart observed that this kind of support is beneficial as the hospital and hospice cannot provide the higher-intensity support required by PwPDs.

Amy talked about how inconsistent messaging from providers can be distressing for PwPDs with life-limiting conditions.

> *"If somebody has a moment of weakness, where they use a bit of loose language around that might be possible or 'we can look at that' or whatever she thinks that's been promised. So she feels quite distressed that she's been promised things like paid for holidays, or that other people she knows on the NDIS have gotten TVs and fridges and their bills and rent paid and so she feels quite aggrieved that this agency has not has not agreed to do any of those things."* **PC Clinican Amy**

A model of care currently exists in two states, where providers receive funding from the NDIS for disability support and the health system for palliative care support. These providers understand which supports can be funded by which system and can advocate and provide continuity support for NDIS Participants if they develop life-limiting conditions. This is relatively streamlined if the NDIS participant has physical disabilities such as motor neurone disease or cerebral palsy, primary psychosocial disabilities are more complex to obtain support for. Still, as these providers understand the health and NDIS systems, they can navigate the systems and work towards better outcomes for them without the current confusion that occurs where the services are provided separately.

8.7.6 PC Clinicians Discuss the NDIS Workforce

PC Clinician Joelene advised that many NDIS workers are "*poorly educated*" and "*don't understand bigger concepts"*. She feels that many do not understand the responsibilities of the NDIS and other systems or how to help participants work towards their goals. These factors, she states, can lead to apathy when supporting PwPDs and life-limiting conditions.

> *"If all you've got is someone in your life who is paid to be there. What's their motivation for supporting you? It's only because you're a paycheck to them. You know, at the end of the day, if you've got offered a better job you'd go where does that leave the participant?"* ***PC Clinician Jolene***

Stuart advised that all community members need to be better educated about providing palliative care, which extends to NDIS workers. He has seen some fantastic support by NDIS workers for his palliative patients.

> *"Firstly, the thing I would highlight is at an individual level, the carers are fantastic. And we have a number of patients where the carers come in and spend time with them in hospital, which helps normalise hospital and that works brilliant for some of our individual patients. It's a really good system."* ***PC Clinician Stuart***

Stuart acknowledged that the NDIS does not fund this work and is aware that many workers come in to visit or providers allow this to occur for the participant's benefit. He feels that it is a support that the NDIS should fund. He also noted that, in the absence of informal support, these workers can often assist the palliative care team by advising usual presentation and assisting with supported decision-making. Amy reported that the community palliative care teams rely heavily on the NDIS workforce to monitor changes in NDIS participants.

8.8 PC Clinicians Discuss the Health System

PC Clinicians talked about the health system in general and their speciality area of palliative care. The two themes were intertwined whilst recognising that the palliative care approach can be less of the "*medical model of care*" and a "*more person-centred care*", which they described as a "*privilege*" to work in. Working around capacity issues, supported decision making, consent, and public guardians for PwPDs were raised by the PC Clinicians as critical areas of concern. Stuart acknowledged that in health care and palliative care, there needed to be a better focus on supported decision-making for people with disabilities. He also reported that there can be an unconscious "*bias towards the value and quality of life*" for people with disabilities, and that can work against them in the health system.

Becky advised that health systems are struggling and hospitals can be at 250% capacity. Often the public community palliative care teams cannot offer the face-to-face and continuity of care that they would prefer. Sylvia discussed the state-funded NDIS liaison officers and how helpful they are with supporting NDIS applications. Her hospital also has recognised "*NDIS Leads*" that can assist with applications. PC Clinicians reported that they struggle to get support for NDIS applications and requests from their patients' medical, allied health and nursing professionals within the health system.

> *"I approached her cancer specialist nurse and her oncologist to give me the new evidence for the change of circumstances, and they declined. And they said, basically, that they conscientiously objected and said, I don't feel that the NDIS is for cancer patients. So no, I'm not supporting her change of circumstances."* ***PC Clinician Amy***

8.9 PC Clinicians Discuss Palliative Care

PC Clinicians were asked to describe palliative care; their responses ranged from brief to comprehensive, focusing on holistic care, including psychosocial needs, quality of life, and symptom management. PC Clincian responses are listed below in Table 16.

Table 17: PC Clinicians Describe Palliative Care

PC Clinician	Responses
Sylvia	I feel like it's such broad terminology. It's more supporting people who have a life limiting illness in ensuring that their symptoms are managed, and we're enabling them to have the best quality of life during their shortened time.

PC Clinician	Responses
Amy	Oh, wow. I think for me, in a nutshell, palliative care is about supporting, supporting people to live well with a life-limiting condition. Palliative care is in there for long enough to really help people find their way in the midst of living with this condition that they will die from. So when we get to do really great palliative care, we get to do it for more than just the last few weeks of life
Jolene	I think a lot of people don’t understand palliative care. And for me, I think it is around supporting someone who has received that diagnosis. No one plans for that and I think it can really rock people’s world. So but palliative services for me is that holistic approach. It’s nursing, social work, allied health services, and it’s about supporting people to maintain a quality of life. For the time that they have. And and to ensure that their comfort is maintained as best as possible. Yeah, that you know, their stresses are reduced. But for us, I guess in this in this setting, that’s what palliative care would mean for us.
Becky	It is essentially really within the context of quality of life that it’s it’s all about quality of life in acknowledging that the person is going to deteriorate and die at some point.
Stuart	People when I described palliative care to people that they all gulp because they know that palliative care looks after people when they are dying. We also look after people with a life-limiting illness to live as well as they can for as long as they can, according to what that looks like to them. So palliative care is predominantly focuses on symptom management for people with a life limiting illness and we will work alongside the other specialities. So we will work alongside of respiratory oncology, gastrointestinal etc in neurology and we provide wraparound symptom management for patients and their families. Palliative care, it is biopsychosocial, spiritual. So all of those elements are important. So it’s not just the physical symptoms. It’s a recognition of the emotional and psychological symptoms, which can be you know, 70% of patients who are dying and I suspect pretty close to that in their families. It can be the

PC Clinician	Responses
	social aspects, so isolation, disability, to mention that, financial, carers support all all of those sort of social aspects as well. And part of that is the loss of identity for people in their roles. So you're going from your family role to being a patient or a carer in that family situation. The other aspect, which is often under done is the spiritual aspect and what that means to a patient as well. So it's not about organised religion, it's about connection and what brings meaning to our patients and their families. So to give an example, pennant bowls is a lovely example. Because it is highly ritualised. You go to a weekly meeting, you have to wear the appropriate whites. It's got a very stylised and structured ends and then it's got the community with the beer and the meal at the end. It's actually an extensively spiritual exercise for many patients, as it's football, yes. So, or other sporting activities, but it's around meaning and connection for patients and the families. The aspect that we don't do well, which we espouse to is the grief and bereavement work. And that's not done well by anybody. But there is there's some work being done to try and improve that.

PC Clinician Jolene expressed her concern about the lack of funding to support palliative patients who may need it for years.

> *"Some people are palliative for years, we don't have the funding to support them for years."* ***PC Clinician Jolene***

Stuart noted that 85% of dying patients do not see specialist palliative care professionals. In Australia, palliative care needs are usually supported by generalist care providers such as general practitioners, nursing and allied health professionals, and community, disability, and aged care services for palliative care needs . He advised that, whilst recognising that providing the same services in metro and rural areas is not possible, there should be a minimum standard of care provided in metropolitan, rural and remote areas. He noted that palliative care teams spend "*a lot of time trying to get everyone to that minimum standard acceptable*". Jolene advised that getting even the limited equipment support available can be difficult if you have not been connected to specialist palliative care services. PC Clinicians noted that patients or their families often pay for equipment for their patients so they can stay at home. Amy noted that supporting palliative patients in their homes will always be more cost-effective than in hospitals, hospices or aged care facilities.

PC Clinicians advised that there were limited loan options for beds, wheelchairs, and other equipment, but these were very time-restricted to the last few weeks of life. Jolene advised that when function is impaired, there are few to no supports, such as carers, transport, cleaning, or gardening supports. Becky noted that in the final weeks of life, her local health network could fund one hour of personal hygiene support three times per week, which was a reduction from four hours in previous years. Jolene stated that aged care and the NDIS state that the health services should fund those long-term functional supports, however, "*we don't have the funding to support them for years*" there is no funding or assistance available within the health system.

> *"We can put additional services in but it's literally for six visits. So three times a week for two weeks is what we can do to support someone if it's post hospital discharge or you know, or we know that they're entering end of life, but then we can put in additional services as well, palliative nursing services, but in terms of domestic cleaning, gardening, no."* ***PC Clinician Jolene***

Stuart described how these timeframes place extra pressure on clinicians as they have to try to estimate how close to death their patients are, which can be difficult.

> *"So it's depends how quickly you die because our programs are time-based. And our access, so if you're dying quickly. Yeah, we can throw all the resources at you. That's but it's the long slow protracted those who are not living quite so well, but not quite in a dying phase."* ***PC Clinician Stuart***

The Applied Principles and Tables of Support [8] (APTOS) indicate that the health system should fund palliative care needs; the available supports in most states are minimal and can lead to hospital or nursing home admissions for those who cannot afford to self-fund equipment. There are often attempts to obtain equipment and supports under NDIS plans to enable people to palliative in their home environment if this is their wish. Queensland has a state-funded palliative care equipment program [272], positively impacting NDIS participants who wish to palliate at home. This option was unavailable for patients in the ACT or South Australia.

Stuart noted that people with SPMI are underrepresented in palliative care. He attributes this to people with severe mental illnesses being wary of the health system and that the health system does not recognise, undertreats and dismisses their symptoms.

> *"Severe mental illness, I think we possibly see a little less of in palliative care. I think they're probably underrepresented. And the reason I think that might be or what I wonder is I'm suspicious about delayed diagnosis, delayed treatment, and less the standards of treatment, which lead to more acute deaths in the public hospital system. So that the patients aren't actually referred to specialist palliative care to to delayed and late diagnosis. I think it's not so much an NDIS issue. I think it's a health issue where if you have a significant mental illness, your physical terminal illnesses get under recognised and under treated."* **PC Clinician Stuart**

Further, he reported that supporting palliative patients with psychosocial disability in palliative care units can be challenging. He noted that it is managed on a case-by-case basis, which service holds the care. Generally, in his unit, patients with severe mental illnesses are admitted to palliative care with input from psychiatry.

> *"We're not expert in psychiatry, we don't do it well, but we're good on the physical symptoms, and we sometimes it feels that we can perhaps manage some of the behaviours using some of our skill set than some of the physical needs being met in the psychiatric unit."* **PC Clinician Stuart**

8.10 What Support Would the NDIS Provide For a Participant With a Life-Limiting Condition?

PC Clinicians advised that it can be challenging to get support for NDIS participants with life-limiting conditions. They also struggle to get support for people under 65 who are not yet on the NDIS, either through pre-existing disabilities or disabilities caused by their life-limiting conditions. They spend many hours, sometimes days, completing reports for the NDIA. Several PC Clinicians advised that when their patients have pre-existing disabilities, including those with psychosocial disability, that should meet access criteria for the NDIS, they try not to include too much information regarding their life-limiting condition, as they know this will block access to much-needed support.

PC Clinicians advise that some of their patients under 65 will live for months or years with significant disability caused by their life-limiting condition, and if they do not get their disability support from the NDIA, they will be completely unsupported and can often live in dire circumstances. The NDIA often rejects access requests or requested adjustments to participant plans. They advise palliative care teams that the functional disability supports required by their patients is the responsibility of the health system, which is very frustrating for PC Clinicians. Jolene asked that the NDIA "*tell me what those services are, and I'll connect my patients to it*." They cannot understand how the NDIA determines what support should be funded by the NDIS or the health system, with Joelene noting that the NDIA *"are notoriously difficult to talk to"* and there is *"no continuity and consistency across the planning process"*. Lack of functional disability support in the community results in inappropriate hospital and hospice admissions.

> *"We need the NDIA to understand what services are actually delivered by palliative care teams. Each local health care service in our state looks so different with how they deliver palliative care."* ***PC Clinician Becky***

PC Clinicians advise that the NDIA are too slow with their decisions, and this can negatively impact NDIS participants. Becky advised a situation where the voluntary assisted dying process is faster than the NDIS change of circumstances process for PwPDs and a life-limiting condition.

Table 18: What Type of Supports would NDIS fund for PwPDs and Life-Llimiting Conditions?

PC Clinician	Responses
Sylvia	• Depends on the funding in their NDIS Plan • Depends what the plan manager and support coordinator would approve, sometimes equipment.
Amy	• Would carry on with current supports and try to use NDIS funds creatively to try to provide support for life-limiting conditions. • Have seen massage and orthotic shoes • Physio
Jolene	It would depend on the planner.
Becky	• Personal hygiene • Domestic assistance • Respite • Some wound management if there are funds
Stuart	NDIS workers can support them in the hospital and hospice.

8.11 PC Clinicians Discuss Silos

PC Clinicians advised that the health and NDIS systems work very separately, negatively impacting NDIS participants with life-limiting conditions or people who should meet the access criteria for the NDIS, particularly those with multiple disabilities. They advised that individuals within each system work very hard, often *"unpaid and unacknowledged",* in both systems to overcome the barriers. Case conferencing with NDIS providers, palliative care providers, and other health providers usually results in the best possible outcomes for their patients. They know that these meetings can burn through a participant's NDIS funding, which is a source of distress as they would prefer that NDIS participants get the maximum functional support available through their plans.

There was no clear understanding of what supports each system funds. Becky reported that everyone interprets the legislation differently, and both systems can block support. If a patient is admitted to the palliative care service, the NDIA may refuse to fund disability supports for them. Equally, if a patient is an NDIS participant, they may not be approved for health system support. Becky has found ways to work around these health-system related issues, but there are usually NDIA decision-related delays that impact her ability to provide timely support. Jolene advised that compartmentalising systems' responsibilities negatively affected participants with life-limiting conditions.

> *"We talked about whether it is worth continuing to fight the systems. And the comment was, 'well, I'm dying anyway. So what does it matter?'"* ***PC Clinician Jolene***

Amy found that the health and NDIS systems operate very differently despite both stating that they are patient or person centred, and finding effective ways to share information or understand each other is difficult.

> *"I haven't really kind of got my head around how the NDIS choice and control thing works with a palliative care model."* ***PC Clinician Amy***

Amy had supported a PwPD and a life-limiting condition who would approach every system to get her needs met, and this led to confusion "*she's got both services, both kinds of systems engaged, and we work in very different ways*."

Amy shared an experience with a PwPD and a life-limiting condition who was unable to obtain the necessary supports to enable her to be discharged to home and was "*stuck in an acute ward*" in hospital waiting for a change of circumstances decision by the NDIA. As background, a change of circumstances review of a plan decision should be made within 21 days. However, there can be additional delays if more evidence is required, which can take up to 50 days from the date the NDIA request additional information [273]. If the NDIA initially refuses any additional support requests, NDIS participants can request an internal review of that decision, and the review decision can take up to 60 days [274]. If the NDIA upholds their original decision, the PwPDs and life-limiting conditions can request an external review of the decision by the Administrative Appeals Tribunal (AAT). The AAT process can also be quite lengthy, with reports of NDIS participants waiting up to 120 days [275]. To clear beds during the COVID-19 pandemic, the state governments increased funding and resources to acute hospitals in 2020,2021. The palliative care team could then use those funds to support the PwPD in getting home. The NDIA continuously requested more supporting evidence, and by the time they agreed to her change of circumstances, her functional support needs had declined, and she needed to be readmitted to the hospital. Both the patient and her family wanted the PwPD to then enter into residential aged care so that she could be supported there. The NDIA blocked her entry to the residential aged care facility as they are policy-directed to keep young people out of nursing homes and looked to find her SIL accommodation. This patient then had to be readmitted to a hospital acute ward for three months, waiting for a SIL/SDA home. The hospital strongly advocated for the patient to enable her to be discharged from the acute ward into a nursing home. The patient deteriorated very quickly on arrival and needed to return and subsequently died in the hospital.

> *"When the participant did pass away, the mother was quite frustrated because she felt like it was such a waste of time because nothing came out of it, and it is a lot for families to deal with that. And also spend time with their loved one and enjoy those moments together. But still trying to take phone calls, organise meetings, think about all these things, while trying to still be a mother, and advocate for them."* ***PC Clinician Amy***

PC Clinicians did not feel that PwPDs experienced seamless transitions between systems; two felt that it could sometimes appear that way as individuals in each system work outside of scope to support people who are dying. Responses are listed in Table 18 below:

Table 19: PC Clinicians' Responses Regarding Seamlessness Between Systems

PC Clinician	Responses
Sylvia	No
Amy	Only because agencies will rarely leave someone in the lurch.
Jolene	No, no, no way. I in no way shape or form.
Becky	No, it's It's not seamless. Yeah, it's not. It's it, sadly, is so dependent on individuals who are working within those systems.
Stuart	No it's not seamless.

8.12 Would the Death, Dying and Palliative Care Experience of NDIS Participants With Psychosocial Disabilities Be Equitable to Australians of the Same Age?

Opinions about the equity of the experience of PwPDs with life-limiting conditions were varied, with answers being that the experience would be better, the experience would depend on the NDIA planner, they did not know, or they felt that it could be equitable, but it would depend on their location.

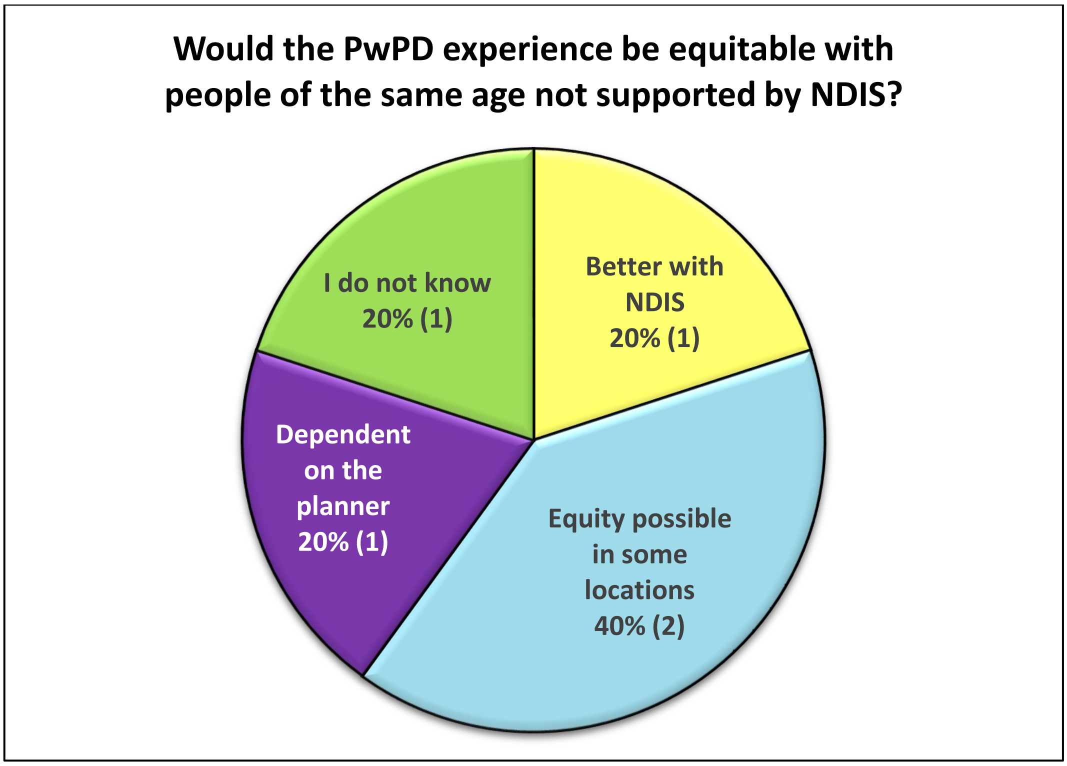

Figure 26: Palliative Care Clinicians - Would the Experience be Equitable?

> *"So if you're under 65, and you've got an NDIS package, as much as there are a lot of challenges, you're still you're still better off because you can maintain your NDIS supports."* ***PC Clinician Becky***

8.13 PC Clinician Summary

PC Clinicians talked about the health system in general and their speciality area of palliative care, which they feel privileged to work in. The two themes were intertwined whilst recognising that the palliative care approach strives to take a person-centred approach rather than medical model of care. Working around capacity issues, supported decision making, consent, and public guardians for PwPDs were raised by the PC Clinicians as critical areas of concern. It was reported that there can be an unconscious "*bias towards the value and quality of life*" for people with disabilities, and that can work against them in the health system, which is struggling with limited resources. Palliative care services are at "*250% capacity*", and clinicians feel they are unable to offer the standard of support to dying patients that they feel is appropriate.

PC Clinicians advised that it can be challenging to get support for NDIS participants with life-limiting conditions. It was reported that there are more barriers when you have a pre-existing mental health condition, as it can be difficult to engage with services and sometimes there can be "*self-sabotaging* *behaviours*". They also struggle to get support for people under 65 who are not yet on the NDIS, either through pre-existing disabilities or disabilities caused by their life-limiting conditions. They spend many hours, sometimes days, completing reports for the NDIA. PC Clinicians reported that they struggle to get support for NDIS applications and requests from patients' usual medical, allied health, and nursing professionals within the health system. PC Clinicians advised that there is limited contact between their unit and the mental health systems and that people with SPMI are underrepresented in palliative care. This was attributed distrust of the health system and the fact that the health system does not recognise, undertreats, and dismisses symptoms.

PC Clinicians advised that advocacy was vital for all patients with life-limiting conditions, particularly for PwPDs. They and their staff actively advocate for PwPDs and, in some instances, for people with SMPI to help them gain access to the NDIS. They have collaborated with families, public guardians, NDIS support coordinators, and formal advocacy services. Where families are involved in PwPDs' lives, PC Clinicians reported that they support their dying family members, emotionally and financially, where they can. Often, they must advocate extensively for their family members, particularly regarding the NDIS. The extensive advocacy work they must do to obtain support profoundly impacts their ability to connect meaningfully during the PwPD's last months. PC Clinicians advised that they have also seen outstanding advocacy from their NDIS workers to support dying participants. It was emphasised that access to health and disability services is "*solely dependent"* on disability and health literacy and the strength of an NDIS participant's advocates.

PC Clinicians acknowledged the importance of families to their palliative patients and recognised that their role in palliative care is to support families. However, funding is very tight, and they are unable to offer the standard of support for families they believe is acceptable. PC Clinicians recognise that PwPDs can often be disconnected from families, and they sometimes only have formal support workers in their lives. Without family to help, palliative care teams need assistance from regular workers with supported decision-making and understanding of their patients' usual presentation. End-of-life decision-making can be particularly complex when a PwPD is under guardianship orders with public guardians. PC Clinicians report substantial difficulties trying to obtain NDIS support for people with SPMI and PwPDs and life-limiting conditions. They are often unaware of how the NDIS supports PwPDs and spend a disproportionate and excessive amount of time wrangling with the NDIA for uncertain, usually disappointing results.

The overall opinion of PC Clinicians of the NDIS as a system was negative. The NDIS was described as inconsistent and lacking continuity, that it is "*shocking*", "*tricky*", "*slow*, "*complicated*", "*controlled from the top-down*", and "*not consumer-directed*". Funding cuts in other systems were blamed on the reallocation of resources to the NDIS. Additionally, it was noted that having two layers of government involved in the care of PwPDs with life-limiting conditions, state and federal, added confusion and complexity. Further, they felt the NDIS increases the length of hospital admissions, and the NDIS “*doesn’t care*” about what is happening in the hospital system. All comments about the NDIA by PC Clinicians were negative due to long timeframes, lack of guidance, poor communication, and poor organisation. The length of time that it takes for state health system workers to prepare reports and obtain quotes was cited as a key frustration. An additional concern was the lack of education and skills of the NDIA and partner workforces. Key concerns were their lack of capability around supported decision-making, the services that are provided in other systems, and, most importantly, that the health system does not fund disability support.

PC Clinicians were more optimistic about NDIS providers having worked collaboratively with them for PwPDs and life-limiting conditions. While it was stated that some NDIS providers are predatory, most PC Clinicians understood that NDIS providers and individual workers were doing the best that they could and that a great deal of unpaid work was being done to support dying NDIS participants. It was noted that some providers surreptitiously provide supports related to life-limiting conditions under NDIS plans. There were mixed opinions about the NDIS workers, some being described as “*fantastic*” and others as poorly educated, apathetic and unable to understand the bigger concepts.

PC Clinicians advised that the health and NDIS systems are very siloed, and there is no seamlessness between systems. This negatively impacts NDIS participants with life-limiting conditions or people who should meet the access criteria for the NDIS, particularly those with multiple disabilities. They advised that individuals within each system work very hard, often “*unpaid and unacknowledged”,* in multiple systems to overcome the barriers for palliative patients. Case conferencing with NDIS providers, palliative care providers, and other key stakeholders usually results in the best possible outcomes for palliative patients.

CHAPTER 9 – DISCUSSION

9.1 Introduction

This discussion chapter will report this research's significant and original contribution to knowledge and explore the research question and subquestion findings. It will deeply interrogate the Applied Principles and Tables of Support (APTOS) and contrast the expectations of the NDIS held by all of the research cohorts, highlighting issues and concerns. This chapter will discuss psychosocial disability and the NDIS, the mental health systems, issues with short notice cancellations and the confusion about what palliative care is and what supports it funds. Finally, the chapter will revisit the elements of systems theory and apply the transformative systems change framework to the research findings.

The National Disability Insurance Scheme (NDIS) has been supporting Australians with disabilities for almost a decade, ample time to see and understand some of the development issues. However, this research has found that there has been no consideration or action on the intersection of NDIS and the health systems' palliative care services. To demonstrate this concern, through comprehensive database searches of the existing evidence in April 2022 and January 2024, the researcher found that there has been no prior research into the formal supports of NDIS participants with psychosocial disabilities (PwPDs) and life-limiting conditions. Therefore, the research question and subquestions were devised to explore these phenomena and understand and examine potential ways forward.

Research Question

What are the death, dying and palliative care experiences of National Disability Insurance Scheme (NDIS) participants with primary psychosocial disabilities?

Sub-questions:

1. What support do NDIS participants with primary psychosocial disabilities receive from their formal service systems once diagnosed with a life-limiting condition?
2. Are the death, dying, and palliative care experiences of NDIS participants with primary psychosocial disabilities equitable to the experience of non-NDIS participants with a severe and persistent mental illness and/or other Australians without a pre-existing severe and persistent mental illness?
3. Is the support received by NDIS Participants with primary psychosocial disabilities seamless between systems, both their existing NDIS and mainstream supports? Once they receive a life-limiting diagnosis, do participants receive integrated planning and coordinated supports, referrals and transitions between services? If so, what works? If not, what are the gaps and barriers?

Initially, a mixed-methods research approach was designed and commenced. However, with the change of national government in 2022 and the announcement of the NDIS Review, there was significant confusion within the disability community about the changes this review and its outcomes and recommendations may bring to the NDIS. It was decided, therefore, to conclude the research at the qualitative stage. A qualitative systems dynamics approach was adopted where in-depth qualitative interviews inform and enable preliminary systems modelling across systems. This included the dynamic systems theory or systems thinking as outlined by Meadows and Wright [244], the qualitative data collection methodology of qualitative description outlined by Sandelwoski [245, 246], and reflexive thematic analysis as described by Braun and Clarke [247]. Foster-Fishman et al.'s [248] systems change framework was applied in Section 9.4.

Thirty-three people from five cohorts were interviewed: nine participants with psychosocial disabilities (PwPDs Interviewees), seven informal supports with psychosocial disabilities (IS Interviewees), nine workers, owners or managers of NDIS provider organisations (PR Interviewees), three mental health clinicians (MH Clinicians) and five palliative care clinicians (PC Clinicians). Interviewees were from Queensland, New South Wales, Victoria, and South Australia, 25 of whom were in metropolitan areas and eight from rural areas. There were some direct experiences within the cohorts, and all five PC Clinicians had experience with PwPDs and other NDIS participants with life-limiting conditions. Research interviewees were asked to describe and use their systems knowledge and experience across the NDIS mental health and health sectors to predict the likely supports and experiences of PwPDs and life-limiting conditions.

Research interviewees from all cohorts described experiences with the NDIS and other systems that were chaotic and ill-defined, which led to poor outcomes for PwPDs. They described multiple gaps and failures, concerns about training and skills and multiple gaps and failures. They stressed the importance of trusted and continuing relationships with formal support workers in the lives of PwPDs. While some positive experiences with the NDIS workforce were described, the overall responses were negative. Most research interviewees within all cohorts reported a lack of understanding about the NDIS, poor choice and control, and an untrained, inexperienced, and constantly changing workforce. Positive and negative experiences with NDIS providers were described, and it was felt that the end-of-life experiences of PwPDs would be contingent on the experience, skills, and quality of the NDIS providers and their workers. However, all five cohorts described poor experiences with the National Disability Insurance Agency (NDIA), citing poor communication and a lack of transparency, capability and consistency around decision-making as the key issues. Research interviewees felt that the lack of understanding about psychosocial disabilities and life-limiting conditions, the inconsistency around decision-making, and the NDIA's time-consuming bureaucratic processes and delays will have a detrimental impact on Australians with SPMI and PwPDs and life-limiting conditions. All five cohorts did not consistently understand the terms psychosocial disability and palliative care nor the types of supports that were available within the NDIS, mental health and health systems.

9.2 Significant and Original Contribution to Knowledge

Using the initial and supplementary scoping reviews (scoping review), qualitative interviews, and the two case studies, this research's significant and original contribution to knowledge is its detailed analyses of:

1. The types of support that formal systems currently provide NDIS participants with psychosocial disabilities and life-limiting conditions.
2. Whether the formal support ensures equity for PwPDs and life-limiting conditions
3. Whether the support is seamless between systems and whether there are gaps and barriers.
4. The specific supports that will be required to improve their experiences and end-of-life outcomes.
5. Finally, this research exposes the confusion about the responsibilities of the NDIS and other systems.

These findings are detailed below.

9.2.1 Subquestion One

What support do NDIS participants with primary psychosocial disabilities receive from their formal service systems once diagnosed with a life-limiting condition?

The fundamental issue highlighted by this research is the ambiguity of how the NDIS and other systems will support PwPDs and other NDIS participants with life-limiting conditions. There is significant confusion about the functional supports the NDIS and other systems provide for PwPDs and life-limiting conditions. The APTOS is not clearly articulated and rarely understood or applied effectively across systems. The agreements, as outlined in the ATPOS [8], between the Australian State, Territory and Commonwealth Governments, dictate that PwPDs should continue to receive their existing NDIS supports if they acquire life-limiting conditions.

> *"In relation to palliative care, functional supports as part of an NDIS participant's plan may continue to be provided at the same time as palliative care services"[8 p.5]*

The health systems should fund any in-patient and out-patient services that support PwPDs' life-limiting conditions through palliative care programmes.

> *"Sub-acute services (palliative care, geriatric evaluation and management and psychogeriatric care) including in-patient and out-patient services delivered in the person's home or clinical settings." [8 p. 4]*

If PwPDs and life-limiting conditions, their informal and formal supports are even aware that the APTOS exists, these statements do not provide the necessary clarity for understanding eligibility requirements and how and if supports will be delivered. The APTOS, as found in the NDIS Review [52], "*has failed"* and is extremely difficult to understand and is open to interpretation, which creates further confusion and ambiguity for the sector. In an effort to obtain clarity regarding the definitions and responsibilities of subacute services, other Commonwealth definitions were reviewed. The Australian Institute of Health and Welfare (AIHW) glossary describes an in-patient (or admitted patient), hospital in the home and out-patient services as:

> ***"Admitted patient:*** *A patient who undergoes a hospital's formal admission process to receive treatment and/or care. This treatment and/or care is provided over a period of time and can occur in hospital and/or in the person's home (for hospital-in-the-home patients)."[276]*
>
> ***"Hospital-in-the-home care (HITH)****: Provision of care to hospital admitted patients in their place of residence as a substitute for hospital accommodation. Place of residence may be permanent or temporary."[276]*
>
> ***"Out-patient service:*** *A hospital service in which patients receive* ***<u>treatment</u>*** *[emphasis added] without being admitted. Classification of certain services as 'out-patient' varies between hospitals as similar treatments may require admission in some hospitals but not others." [276]*

Interestingly, the AIHW also states that palliative care can be provided by "*disability services*" [69]. This could be considered unambiguous if an NDIS participant's primary disability is life-limiting, for example, motor neurone disease. Some life-limiting conditions, such as Patau syndrome and Leigh syndrome, are granted immediate access to the NDIS due to their inclusion on the NDIS List A – Conditions that are likely to meet the disability requirements [161]. Other life-limiting conditions included on List B – Conditions that are likely to result in permanent impairment [277], such as motor neurone disease and Huntington's disease, are granted access to the NDIS once the applicant can demonstrate substantial functional impairment. Other disabling life-limiting conditions, such as brain cancer, have a more complicated and fraught NDIS access experience [10, 278]. Therefore, there is no clear answer concerning the provision of functional supports, such as personal care and equipment, required to ensure that PwPDs and life-limiting conditions can stay out of the hospital for as long as desired and clinically appropriate. Further, there is currently no guidance available regarding the second half of the NDIS' responsibility (below) to palliative NDIS participants:

> *"….. recognising that supports may need to be adjusted in scope or frequency as a result of the need to align with the core palliative care being delivered through sub-acute health services." [8 p. 5]*

When considering therapeutic interventions for PwPDs and life-limiting conditions against the APTOS, the mental health system or the palliative care team should provide therapeutic and counselling mental health supports, whichever provider is most appropriate to meet the individual's needs. However, most research interviewees advised that few PwPDs are aware of or have regular access to therapeutic mental health services unless they are privately funded. The scoping review and research interviews highlighted that specific cross-sector training for mental health, palliative care, and NDIS professionals to support PwPDs and life-limiting conditions is essential for good outcomes, and specialised mental health care is required for people with severe and persistent mental illnesses and life-limiting conditions. However, this research found no evidence that this training is occurring.

For Australians under 65, functional support for the disabilities caused by life-limiting conditions is usually only provided in the last months or weeks of life by the state health systems. However, particularly when NDIS participants are dying, a substantial amount of 'under-the-grid' and unpaid work is being done by individual workers in all systems to manage symptoms, fulfil goals of care and minimise distress. Inconsistent decision-making and laboriously slow bureaucratic processes, mainly the NDIA's, can cause catastrophic delays in care for PwPDs with life-limiting conditions, impacting their quality of life, causing declines in mental health, and increasing existential distress. Research interviewees advised that NDIA and partner organisations' staff are uneducated about psychosocial disabilities and life-limiting conditions, possess poor communication skills, and need significant upskilling when communicating with dying NDIS participants. This is especially poignant when considering PwPDs*Barbara's eventual choice of voluntary assisted dying after a protracted and distressing NDIS application process.

On a positive note, however, PwPDs and life-limiting conditions will, at a minimum, usually already be receiving cleaning, gardening, shopping, and meal preparation support as part of their existing NDIS plans. This support is unlikely to be available to other Australians with life-limiting conditions under the age of 65. Further, PwPDs may also receive minimal transport funding or support from support workers who can transport them to and from doctors' appointments if they cannot transport themselves. Additionally, the research interviewees advised that PwPDs and other NDIS participants with life-limiting conditions who live in supported disability accommodation (SDA) and receive supported independent living (SIL) in their existing NDIS plans have more positive palliative and end-of-life experiences due to the home-like environments and existing relationships between workers and NDIS participants.

The scoping review and research interviews did not report positive experiences with the NDIA. Research interviewees from all cohorts consistently expressed concerns, based on their experiences, about the NDIAs' staff's ability to appropriately support PwPDs and life-limiting conditions. Additionally, they reported inconsistent quality of supports from NDIS providers. Where NDIS providers and workers are providing excellent support, research interviewees advised that it would be ideal for these providers and workers to continue to support the PwPDs and life-limiting conditions until they die. However, most research interviewees expressed that the majority of NDIS workers they have encountered are untrained and highly unsuited to working with PwPDs and life-limiting conditions. Several research interviewees advised that they did not feel that NDIS providers could provide appropriate care and were concerned that predatory providers may severely impact the death and dying experiences of PwPDs and life-limiting conditions.

9.2.2 Subquestion Two

Are the death, dying, and palliative care experiences of NDIS participants with primary psychosocial disabilities equitable to the experience of non-NDIS participants with severe and persistent mental illness and/or other Australians without a pre-existing severe and persistent mental illness?

Socio-economic factors often impact PwPDs and other Australians with SPMI's ability to privately fund the ideal support environment to help them manage the functional decline associated with life-limiting conditions. Additionally, the research found that people with SPMI consistently experience stigma within health systems and significant barriers to palliative care that are both intrinsic and extrinsic. For example, PC Clinicians advised that there are issues with health autonomy and end-of-life decision-making for PwPDs under guardianship orders, particularly around resuscitation orders. PC Clinicians also advised that they spend many hours, often unpaid, attempting to obtain support from the NDIS for their patients who are under 65 and not already on the NDIS. Their patients may have, prior to the functional impact of their life-limiting condition, fit the criteria for access under Section 24 of the NDIS Act [7] but are not currently on the scheme due to being overlooked, extremely socially isolated, or reticent to become part of the NDIS as they do not identify as being disabled. There can be , unexpected responses or that can make it more challenging to provide support to PwPDs and life-limiting diagnoses.

However, when looking at the types of support that could, at the bare minimum, maintain a reasonable quality of life and help Australians remain out of hospital as long as desired and clinically appropriate, the experience is not equitable. It is challenging to obtain any services and functional supports from formal support systems if you are an Australian under the age of 65 with a life-limiting condition. As PC Clinician Becky stated, "*If you are under 65, you have to have a good family or a good pocket*." However, as discussed in Section 9.2.1, PwPDs and life-limiting conditions are likely to obtain more functional support from formal systems than other Australians under 65 with or without SPMI.

9.2.3 Subquestion Three

Is the support received by NDIS participants with primary psychosocial disabilities seamless between systems, both their existing NDIS and mainstream supports? Once they receive a life-limiting diagnosis, do participants receive integrated planning and coordinated supports, referrals, and transitions between services? If so, what works? If not, what are the gaps and barriers?

Australia's governments agreed within APTOS [8] that:

> *"The interactions of people with disability with the NDIS and other service systems should be as seamless as possible, where integrated planning and coordinated supports, referrals and transitions are promoted, supported by a no wrong door approach." [8 p.1]*

Every research Interviewee emphatically denied that PwPDs receive seamless support, integrated planning, and coordinated supports, referrals, and transitions between systems. They advised that this lack of seamlessness and clarity regarding each system's responsibilities has led to poor outcomes for PwPDs, all other NDIS Participants, and other Australians under 65 if they have life-limiting conditions.

A lack of funding within the NDIS framework for non-face-to-face funded support, competition for limited funding, unscrupulous actors, reduced collaboration between NDIS providers, and a lack of direction, education, and knowledge about other systems' responsibilities were the critical factors identified by research interviewees contributing to the gaps and barriers experienced by PwPDs. The research interviewees had either experienced or predicted that these factors cause significant issues for PwPDsand life-limiting conditions.

The scoping review found that mental health workers struggle to support dying participants [15, 25, 28, 37, 84, 93, 97, 151-154], and this can prove challenging when attempting to provide holistic care. In keeping with APTOS and the National Palliative Care Strategy, the role of palliative care services is to assist with spiritual and emotional care. However, palliative care teams may need additional assistance from a patient's mental health team if they have an enduring pre-existing mental illness that could be exacerbated by the stress of managing the physical symptoms and existential distress associated with their life-limiting conditions. Research interviewees advised that many PwPDs are discharged from the state-funded mental health systems and support once they become NDIS participants, so they may be left unsupported, newly referred, or re-referred to mental health services. PwPDs and life-limiting conditions may not have the time or capacity to build the effective, trusting therapeutic relationships necessary to support them effectively when they are dying. No explanations were provided as to why these discharges were occurring; however, as MH Clinicians advised that their systems are overwhelmed, there may be pressure to reduce client load. There may be assumptions made about the kinds of mental health supports funded by the NDIS that go unchallenged due to these workload pressures.

An additional complication disclosed was that palliative care clinicians, NDIS providers, and mental health clinicians are not always aware of which disability is being supported by the NDIS. An NDIS participant may have multiple disabilities, and not all will be supported by the NDIS. For example, PwPD Interviewee Sam lives with chronic pain and restricted mobility from osteoarthritis but only receives support from the NDIS for his mental health condition but not his arthritis or chronic pain

. There is no obligation for PwPDs or other NDIS participants to share this information, so care teams may spend many hours advocating for their patients to have certain functional supports from the NDIS for a condition that is not eligible to receive them.

Strong advocacy and planned case management between key stakeholders were considered vital for PwPDs and life-limiting conditions to overcome the gaps between systems and create a seamless support experience for them as they navigate their life-limiting conditions.

9.2.4 Key Concerns for PwPD and Life-Limiting Conditions

This research found that systems do not communicate well with each other, and support is not consistent across the country within the NDIS and state health and mental health systems. A life-limiting condition is likely to exponentially exacerbate the current issues and barriers experienced by PwPDs when navigating the NDIS and other systems. There is little clarity about definitions, particularly psychosocial disability and palliative care. There needs to be more clarity regarding the eligibility criteria and likely support that can be received from each system or what actions need to be taken to obtain support. Additionally, the current practices regarding short notice cancellations are likely to impact PwPDs and providers, and the intersection with the aged care system concerning palliative care support is not well defined.

9.2.4.1 The Applied Principles and Tables of Support

Very few of the research interviewees were aware of the Applied Principles and Tables of Support (APTOS) [8], and those who were aware noted that they were challenging to interpret. The emphasis on choice, control, and innovative supports by the NDIS can make it difficult to understand and find practical and detailed information about what supports the NDIS is likely to fund for PwPDs with or without a life-limiting condition. If psychosocial disability is the participant’s primary or only disability supported by the NDIS, APTOS [8] provides only general guidance on which system should fund supports. Notably, the disabilities caused by the leading life-limiting conditions in Australia, such as most cancers, coronary heart disease, liver disease, and chronic obstructive pulmonary disease [279], are usually not supported by the NDIS.

However, other life-limiting conditions, such as motor neurone disease, and some cancers, such as brain tumours or spinal tumours, can obtain support from the NDIS, although this is variable [10].

Research interviewees from all cohorts stated that PwPDs would need specific supports to ensure holistic care after they develop a life-limiting condition. It was expected by most that these supports would or should be funded by the NDIS. When considering the responsibilities as they are listed within APTOS and the interpretation provided in the introduction of this thesis (Section 1.2.5 The Applied Principles and Tables of Support), it could be interpreted that many of those supports are the jurisdiction of other service systems. It is essential also to understand that support is not necessarily funded or guaranteed by service systems despite the APTOS agreements. Further, the NDIS is unlikely to fund any additional supports required due to a PwPD's life-limiting condition, only supports related to the disability caused by their mental health condition. How that is and may be interpreted by stakeholders is unclear. Appendix 20 contains a list of the supports that research interviewees stated that the NDIS would or should fund for PwPD, alongside the APTOS responsibilities as interpreted in Section 1.2.5, with additional information about time-frames and potential barriers.

9.2.5 Psychosocial Disability and the NDIS

The Reimagine website, a project run by the Mental Health Coordinating Council (a peak body for psychosocial support provider organisations in NSW) and funded by the NDIS, describes psychosocial disability as being based on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and is:

> *"…the social and economic impacts of living with a mental health condition*…. the challenges a person experiences that are related to their mental health condition, that affect their ability to participate in life." r**eimagine Website** *[280]*

Research interviewees had varying descriptions, but most understood the term psychosocial disability to mean that it is a disability resulting from a mental illness. It was acknowledged by some that the NDIS has, for the first time, validated that disabilities arise from mental health conditions, with a MH Clinician and IS Interviewees noting that this is a positive change. However, the scoping review and research interviews demonstrated that there are still significant concerns about the appropriateness of the NDIS for Australians with psychosocial disabilities. There are concerns that the model itself does not suit the recovery model, the NDIA does not sufficiently understand the fluctuating nature of psychosocial disabilities, and that the NDIS workforce is not appropriately qualified nor experienced to work effectively with PwPDs. Whilst there were undoubtedly positive experiences shared about the NDIS, the majority of experiences reported were negative, and these issues, research interviewees advised, have a detrimental impact on the mental health of PwPDs. Further, these complications then create additional strain on the health and mental health systems as PwPDs become acutely unwell and require the intervention of the mental health and health systems. Importantly, Research interviewees advised that the existing problems with the NDIS and PwPDs will likely cause significant complexity and distress if they develop a life-limiting condition.

9.2.6 The Mental Health System

Research interviewees reported that mental health systems are currently understaffed and underfunded. Community mental health clinicians cannot offer the therapeutic supports they want to deliver and know what their clients need. Few PwPDs, as discussed by research interviewees, received ongoing therapeutic treatments unless they were privately funded. There is a chronic shortage of psychiatrists, leading to long wait times or only being able to attend emergency departments for support [281]. Few psychiatrists bulk bill (accept only the Medicare rebate). The gap payment above the Medicare rebate can range between $174.20 and $222.75 [282] and higher. There are also very long waiting lists to see a psychologist, and the Australian Psychological Society reported that one in three psychologists cannot see new clients [283]. Medicare will only partially fund ten individual therapy sessions and ten group sessions with a psychologist per year. The gaps between the Medicare rebate and the fee charged per appointment can often be between $100 and $200 [284]. Making even subsidised mental health treatments out of reach as many PwPDs are unemployed [285] and, therefore, must live on income support. The current government income support rates fall under the poverty line he March Quarter 2024 poverty line figure of $1,145.61 [286], with Newstart (if single) being $762.70 per fortnight [287]) or Disability Support Pension (if single) $1,116.30 per fortnight [288]). With therapeutic supports out of reach for many PwPDs, it is unsurprising that funding creep was reported by research interviewees, who advised that PwPDs are receiving therapeutic psychological treatments that are funded by their NDIS plans. When asked about supports for PwPDs and life-limiting conditions, it was expected that NDIS would fund therapeutic supports to manage any acute psychological symptoms and and existential distress brought about by their life-limiting conditions. This expectation does not align with the APTOS agreements between governments [8]. Noteably, the NDIS Guidelines state that the mental health system should provide psychology, counselling and social work for mental health treatment, clinical mental health supports to help you transition to a new life stage [289].

The mental health system was described as being very disconnected from other systems, and MH Clinicians have been struggling to obtain adequate support from the NDIS for their clients. MH Clinicians advised that the mental health systems they work within are understaffed and underfunded, and clinicians are leaving the sector due to burnout. Most PwPDs and their informal supports did not share positive reflections about the mental health system, particularly those interactions with the publically funded systems. Those with the financial capacity to fund private mental health services, such as psychiatry, psychology, and private in-patient admissions, describe a more positive relationship. Most PwPD, IS, and PR Interviewees advised that PwPDs are often discharged from the state-funded mental health system when they become NDIS participants. Finally, the research found that mental health system workers needed additional training and upskilling to support PwPDs and life-limiting conditions.

9.2.7 What is Palliative Care?

Interviewees with no experience with the palliative care system had varied interpretations of palliative care, with many equating it with end-of-life care. Additionally, with the obvious exception of the PC Clinicians, the interviewees' knowledge of support provided by the health-system-funded palliative care services was limited. Those with knowledge of palliative care services describe it as disconnected from other systems, and clinicians working in palliative care advise that they and their teams are often working unpaid and under the grid to obtain support for PwPDs and life-limiting conditions and other patients under the age of 65. Finding specific information regarding what functional support patients are likely to receive in their homes can be challenging for those not directly connected with palliative care. The Commonwealth and State Governments' health information website healthdirect advises that end-of-life care is provided in the last few weeks of life, whereas palliative care can be provided throughout a person's illness [68]. This website also states that palliative care "*may*" include aids, activities of daily living, home help, and treatments to relieve pain and other symptoms. The information, however, on the website is not specific and does not detail how these supports will be funded or obtained.

It should be noted that a clear definition of palliative care has not been provided within the APTOS document, and no accompanying explanatory memorandum exists on the Department of Social Services website. Therefore, other government definitions were sought, as shown below.

The definition of palliative care contained within Australia's National Palliative Care Strategy [14] cited the World Health Organization's definition and states:

> *"[P]alliative care is **<u>an approach</u>** (emphasis added) that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual." [14 p.4]*

The glossary of the National Palliative Care Strategy [14 p. 29] contains some additional definitions that include "*offers a support system to help patients live as actively as possible until death*" and "*will enhance quality of life*".

The Australian Department of Health and Aged Care describe palliative care as:

> *"Palliative care is person and family-centred treatment, care and* ***<u>support</u>*** *(emphasis added) for people living with a life-limiting illness. A life-limiting illness is an active, progressive, or advanced disease, that has little or no prospect of cure and that you're likely to die from at some point in the future. If you have been diagnosed with a life limiting illness you may continue to live an active life for many years to come." [290]*

The website does not offer specific information about practical, functional support other than "*referrals to respite services*", "*support you need to live well*", and "*emotional, psychological and spiritual support*" which could also be loosely interpreted as functional support. The website advises that palliative care is provided by:

> *"…a team of medical, nursing and allied health professionals. This team can also work with your doctor to provide services that will help you and your family and carers throughout your illness." [291]*

Each state-funded health system may offer different supports, and even within the state, local health networks may offer different support for palliative patients; for example, Queensland Health loans equipment to palliative patients for up to one year (an initial six months, then a further six-month extension if required) [292]. However, PC Clinicians interviewed for this study indicated that equipment loans may only be for the final weeks or months in other states.

9.2.8 Short Notice Cancellations

For PwPDs and life-limiting conditions, there may be many instances where they may need to cancel regular NDIS supports due to ill health or conflicting appointments. Due to their disrupted lives, they may not be aware that they need to cancel supports or may be too ill to contact their providers and reschedule.. PwPDs and life-limiting conditions must feel comfortable enough to trust their providers with their health information, and they are under no obligation to share their private medical details with either the NDIA, NDIS providers, or workers who support them. For example, one PR Interviewee advised that he, by chance, discovered that a PwPD he worked with lives with HIV/AIDS, and the PwPD does not disclose this information to his NDIS providers or workers.

PwPDs must provide at least seven days' notice to cancel support. If the NDIS provider cannot find other billable work for the worker, the PwPDs' funding will be drawn down from their NDIS plans. This "*short notice cancellation*" is to ensure that providers will be paid for their booked time. There is no limit to the number of short notice cancellations that a provider can claim; however, the NDIA Pricing Arrangements and Price Limits 2024-25 [293] states that the NDIA "*may"* contact providers when there is an unusual number of short notice cancellations for a participant. However, the onus is on NDIS providers to change the booking using a "*Cancellation*" option in the Myplace provider portal. This may leave PwPDs and life-limiting conditions unknowingly depleting their NDIS plans and leaving them with no flexibility to adjust their funding around the needs of their life-limiting condition. Further, due to their potentially increased vulnerability, it may leave them open to exploitation by predatory providers The unpredictable nature of palliative and end-of-life care could also impact a PwPD and life-limiting conditions that need to cancel appointments.

9.2.9 Transitioning to the Aged Care System

If PwPDs develop a life-limiting condition after age 65, they must decide whether to remain on the NDIS or transition to funded supports from the aged care system. However, if they enter residential care or require home care (personal care or personal assistance) for the first time after the age of 65, they will, in accordance with Section 29 of the NDIS Act [7], be exited from the scheme and transitioned to the aged care system. As most PwPDs living in the community do not require personal care under their NDIS plans, they are unlikely to have this support approved by NDIS if they develop this need due to a life-limiting condition. If these supports are required, PwPDs with life-limiting conditions who are over 65 will likely be directed to transition to funding provided by the aged care system. This will involve a loss of their current NDIS support workers with whom they may have trusting relationships. Notably, a level four aged care package, which offers the highest levels of support and is usually required for palliative care in the community, currently have a waiting time of nine to 12 months. The availability of aged care providers to implement the package is also limited, particularly in rural areas. [294]. For many participants, transitioning to the aged care system does not provide an advantage in services provided and may result in a reduction in funding due to funding caps, a cessation of familiar services, and a reduction in services as waiting times elapse

9.3 Dynamic Systems Theory or Systems Thinking

Dynamic systems theory or systems thinking can help explain complex public health and human services problems such as those described by this research and discussed briefly in Section 9.2 above [251]. The results of the scoping review and the research interviews were analysed against the key systems' principles that were used to inform this research and are presented below.

9.3.1 Stocks Flows and Dynamic Equilibrium

9.3.1.1. Funding Issues Across Systems

As discussed in Chapter 3 (Research Design and Methodology) stocks are the foundation of any system, and they can include more tangible information or material such as NDIS, mental health and health system funding, support workers and equipment for palliative patients, the number of PwPDs in the NDIS and the number of workers in each system. Other stocks the research discovered were less tangible, such as trust in the NDIS.

A reduction in health and mental health system funding has occurred for many reasons, such as mental health funding being redirected to the NDIS and health funding being exhausted due to increased use due to advances in health care and Australia's ageing population. The qualitative interviews and scoping review found that inadequate funding (inflow) in the health, mental health or other mainstream systems has led to insufficient supports (depleted stocks) for PwPDs and other NDIS participants outside the NDIS. This has resulted in the NDIS becoming "*an oasis in a desert*"[52 p. 25]. These system deficits are causing excessive growth of the NDIS and are impacting the NDIS' sustainability in the long term (depleted stocks).

The lack of funding in the state health systems (inflow) that is directed toward functional supports in the community to support the disability caused by life-limiting conditions in the under 65's results in increasing demands for support from the NDIS (NDIS outflow) or hospital admissions (health system outflow). Admitting a patient to a hospital can cost an average of $2,370 per day [295]. In order that PwPD, other Australians with SPMI and NDIS participants with other disability types do not suffer at home or are not admitted to hospital unnecessarily, palliative care and mental health clinicians and NDIS providers expend extensive effort, both paid and unpaid (outflow), supporting their patients to apply for functional support from the NDIS.

As discussed previously, there are minimal mental health funding supports in the community for PwPDs and life-limiting conditions (poor inflow). This lack of support may result in extreme distress, self-harm, mental health detentions and presentations to the emergency department (ED). Mental health detentions (involuntary psychiatric admissions) usually require the attendance of state-funded emergency services, such as ambulances and police, causing additional system outflow in these services. Often, patients who attend ED for mental health crises wait longer, are less likely to be seen within appropriate timeframes, endure longer times in ED due to the shortage of mental health beds (depleted stocks) and leave before treatment is complete due to the distress caused by the environment [296]. These experiences may also lead to PwPDs and life-limiting conditions utilising their NDIS funding (increasing NDIS outflow) to help them manage their acute mental health crises.

Those who do not meet the requirements for aged care services either must privately fund supports, or their family and friends, if they have good relationships, may need to or provide much-needed functional support, such as personal care, equipment and home care. As found in the scoping review, people with SPMI can die significantly earlier than other members of their community from a variety of causes. Many PwPDs and other Australians with mental illness and life-limiting conditions cannot fund these kinds of support privately. This has led to requests for additional NDIS funding in PwPDs plans, the surreptitious use of existing NDIS funds or new access requests to the NDIS to obtain functional supports to keep PwPDs out of hospital and hospice.

9.3.1.2. Workforce Shortages

The research interviewees and scoping review found various issues with the workforces that support PwPDs and life-limiting conditions. A key issue discussed was insufficient numbers of workers (depleted stocks) to meet demand, particularly trained and experienced workers, high workforce turnover and burnout, particularly in the mental health and NDIS workforces. There were discussions regarding workers leaving the health and mental health workforces due to burnout or joining the NDIS workforce, which also has high staff turnover. Another key concern, likely to impact workforce shortages was pay and conditions. With the exception of allied health workers, NDIS workers were described as poorly remunerated by the NDIS funding model. However, it must be noted that since the interviews occurred, there have been pricing updates for disability support workers, and shortages of NDIS workers have seen providers offering over $40 per hour, far exceeding the 2024 national minimum wage of $24.10 [297]. However, these figures do not include the unpaid hours that many support workers, support coordinators, and psychosocial recovery coaches need to work to ensure good outcomes for PwPDs. NDIS providers state that they often cannot fund professional development and additional training as they are mostly paid for face-to-face hours. Cortis and van Toon [94] found that many NDIS workers wish to leave the sector due to the increased demands of the NDIS and the casualisation of the sector, and they cannot see themselves working in the disability industry in five years. The NDIS Review[52 p. 196] recommended measures to overcome these acute workforce shortages, including attracting and facilitating a migrant NDIS workforce. However, this approach is not a good long-term solution and does not address the core issues causing workers to leave the industry or change employers frequently. Aside from the obvious need to have a sufficient number of workers in systems, research interviewees raised the importance of continuity of care and trusting relationships as being key to ideal outcomes for PwPDs and life-limiting conditions.

9.3.1.3 Trust in the NDIS/NDIA

This research revealed that changing governments' policies, negative media coverage regarding provider rorting and cost blowouts and poor interactions with the NDIA have depleted the stocks of goodwill and trust held by the Australian disability communities and the public. The negative interactions with the NDIA often appeared to be due to poor understanding and inconsistent decision-making about what constitutes a reasonable and necessary support and the APTOS. These findings echo those of the NDIS Review, which recommended alternative participant pathways and, importantly, that the APTOS be abolished and replaced with new agreements and "***detailed working arrangements***" [52 p. 36].

9.3.2 Feedback Loops

Balancing feedback loops keeps systems stable, and reinforcing feedback loops are self-enhancing and can lead to exponential growth or collapse of systems. This is easily demonstrable when considering the growth of the NDIS. As indicated in the NDIS Review, the number of participants and budget of the NDIS is currently exceeding original predictions [52 p. 30].

The NDIS's impact on the disability community and the Australian economy will have produced countless feedback loops, many of which are outside the scope of this research. The scoping review found, notably in the 2023 NDIS Review. that the NDIS is a large-scale social intervention and is not yet stable. Self-enhancing, runaway loops are regularly reported, particularly with the cost of the NDIS and its impact on NDIS Participants, their families and the workforce that supports them. This research has found that a critical factor impacting PwPDs and life-limiting conditions is the lack of clarity about system responsibilities between the NDIS, health systems and the mental health system. Several feedback loops depicted below illustrate some of the difficulties that have been impacting PwPDs and other NDIS participants with life-limiting conditions, as well as formal support systems.

9.3.2.1 PwPDs Unable to Obtain Functional Supports for Their Life-Limiting Conditions

If PwPDs and life-limiting conditions require additional functional supports, such as personal care or equipment, for their life-limiting condition and cannot obtain these supports, they will likely be admitted and readmitted to the hospital, as demonstrated in Feedback Loop 3 below. These kinds of unnecessary admissions, particularly due to PwPDs' histories with the health system, may be against their goals of care. Often, the home is nominated as the preferred place to die [298] and if well supported, this should be achievable so long as they do not require extensive nursing and medical support to manage their symptoms. Further, unwanted admissions of this nature would contribute additional and unnecessary burdens on Australia's already overstretched health systems.

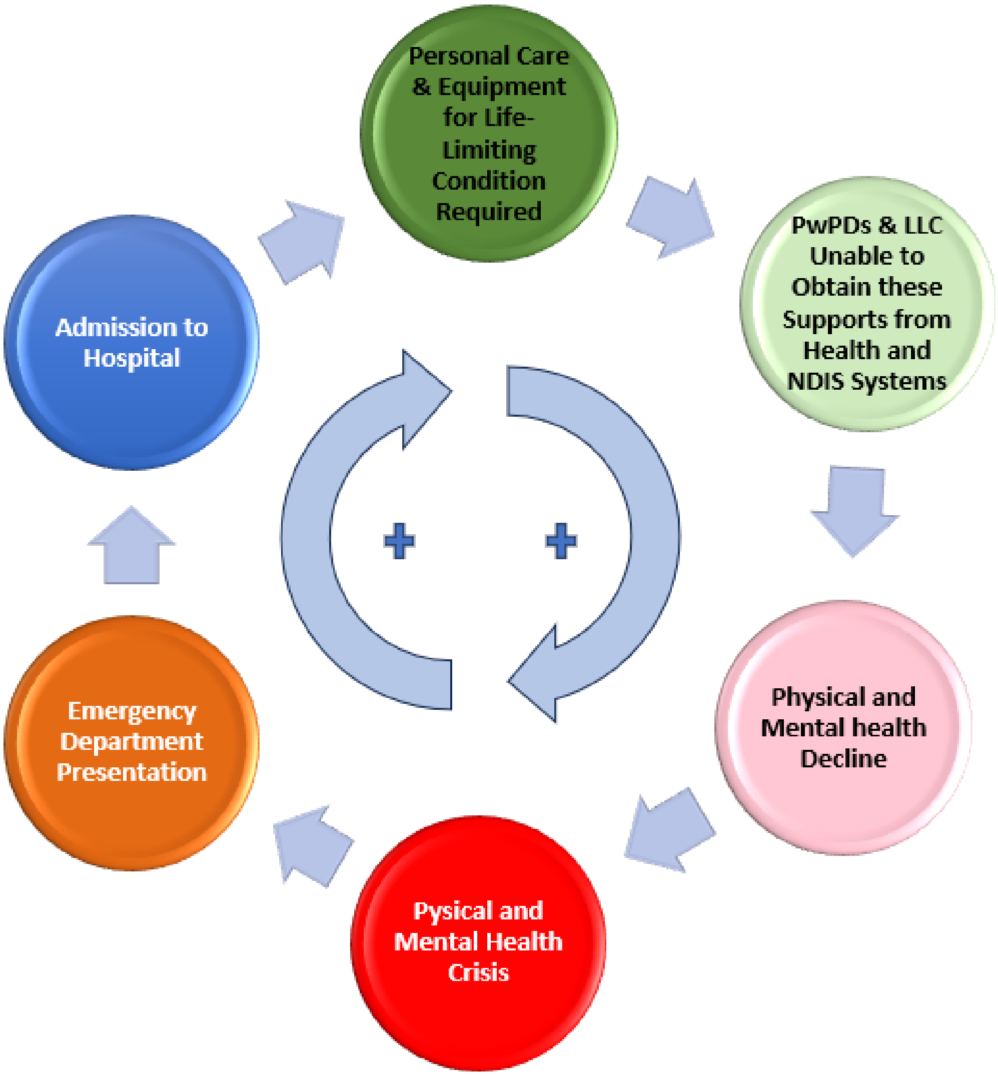

Figure 27: Reinforcing Feedback Loop 1 - PwPDs Unable to Obtain Functional Supports for their Life-Limiting Conditions

9.3.2.2 Mental Health of PwPDs and Life-Limiting Conditions

As discussed in 9.2.6, when the mental health of PwPDs and life-limiting conditions declines, there are limited therapy options available to them. The research indicates that palliative care clinicians do not feel equipped to support patients with pre-existing SPMI. Further, many PwPDs are not connected to mainstream mental health supports, and they are often left without suitable treatment options). This lack of therapeutic mental health treatment may create a feedback loop that would prove highly distressing to PwPDs and life-limiting conditions and their informal and formal support networks.

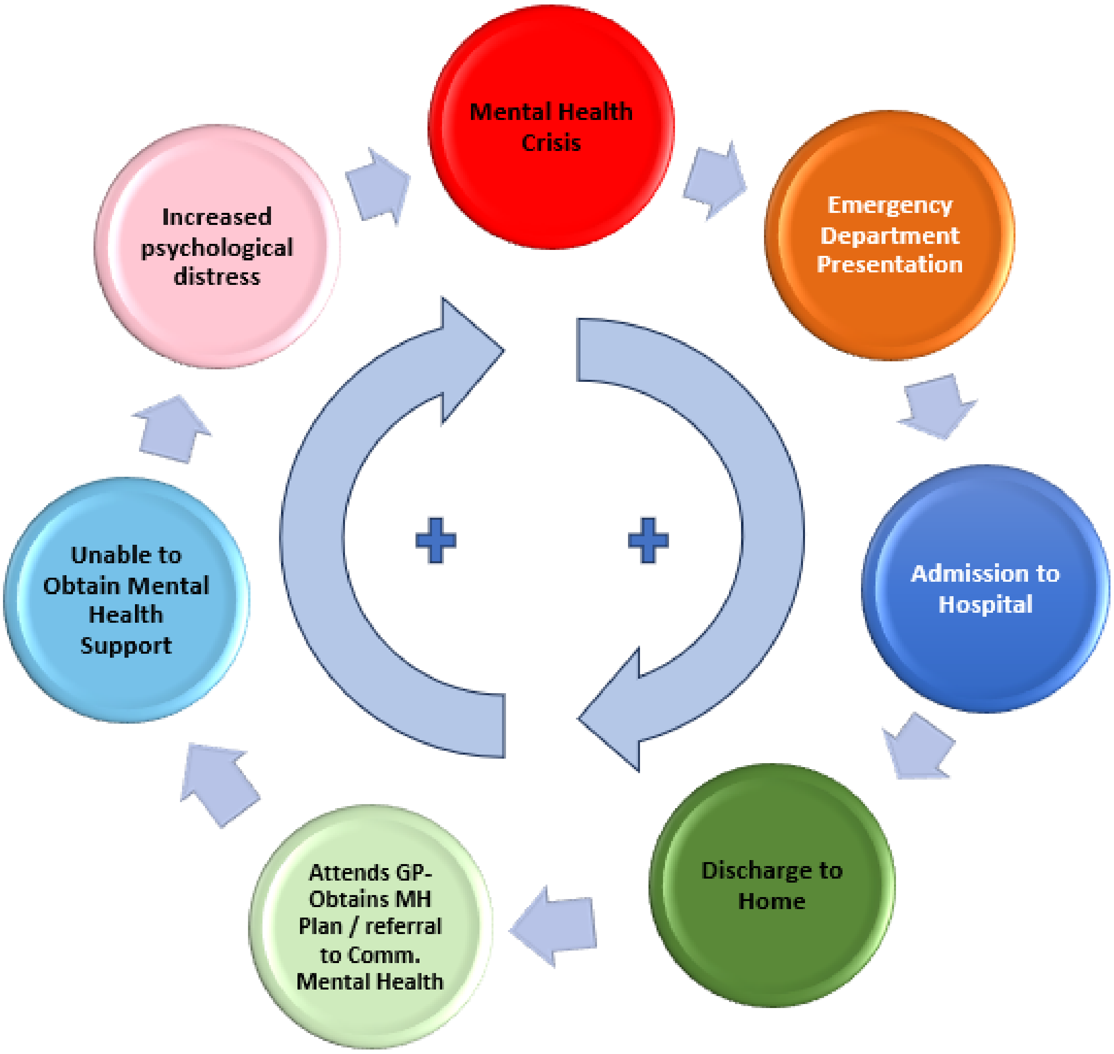

Figure 28: Reinforcing Feedback Loop 2 Mental Health Crisis for PwPDs and Life-Limiting Diagnoses

9.3.2.3 NDIS Psychologist Providing Therapeutic Treatment

An alternative to Reinforcing Feedback Loop 2 would be if PwPDs and life-limiting conditions use their NDIS psychologist to provide therapeutic mental health support to treat their acute distress. This approach has the potential to be a balancing feedback loop for PwPDs and life-limiting conditions, as the psychologist should already have a trusting relationship with the PwPD. However, as the funding is not in line with the APTOS, multiple instances of this kind of funding creep could cause runaway feedback loops for the NDIS budget and mask significant gaps in service delivery in the mental health system.

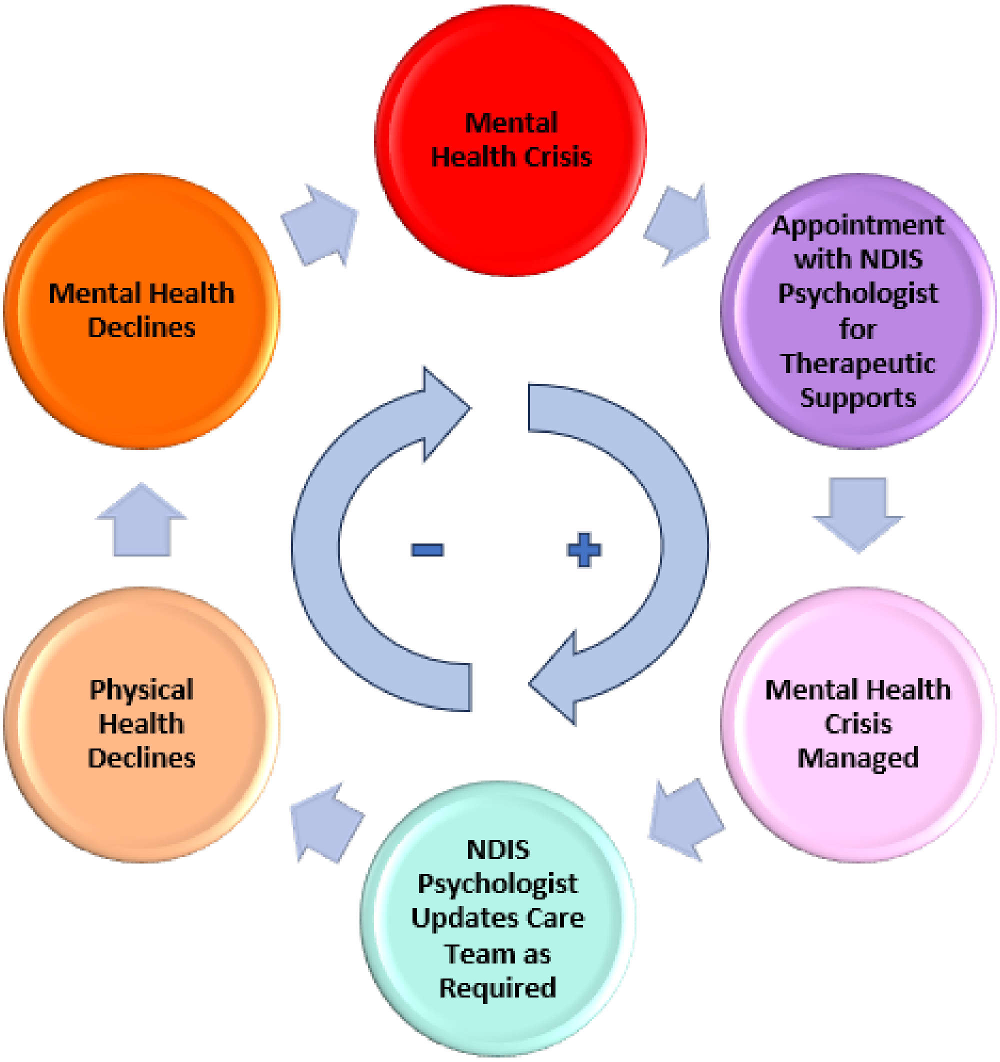

Figure 29: Balancing Feedback Loop 3 Mental Health Crisis for PwPDs and Life-Limiting Diagnoses Using NDIS Funds

9.3.2.4 NDIS Funds Used for Functional Supports for Life-Limiting Conditions

Research interviewees advised that there have been times when they have been able to obtain additional supports using NDIS funds, either unknowingly, surreptitiously, or with the apparent consent of the NDIA planner. The details of how the NDIA planners come to their decisions in plans are generally not clear or consistent. Further, how the NDIS plan is interpreted can be inconsistent and driven by what PwPDs and their care team see as their most pressing need.

If PwPDs and life-limiting conditions utilise their current NDIS funding to obtain equipment and personal care within the NDIS plan, they may expend their funding for all supports, including those usually funded, such as cleaning, gardening and social supports as demonstrated in the Balancing Feedback Loop 4 below.

Reviewing research interviewee responses, the most promising balancing feedback loop was when a PwPD resides in specialist disability accommodation with supported independent living supports. The PwPDs with a life-limiting condition already receive support, with cleaning, meal preparation, behaviour support, transport, and access to support staff 24 hours per day, seven days per week in most cases. Palliative care clinicians actively engage with PwPDs' regular support workers in specialist disability accommodation, and the palliative care service provides in-reach support for clinical support. Although it is important to remember that not all SIL providers are comfortable supporting PwPDs with life-limiting conditions, when we consider Heidi's experience with Margaret, she feels that it is unlikely that her workplace will allow that to happen again in the future and will exit PwPDs from their service if they develop a life-limiting condition.

Figure 30: Reinforcing Feedback Loop 4 Functional Support for PwPDs and Life-Limiting Conditions – NDIS Plan Depleted

9.3.2.5 NDIS Funds Functional Supports for Life-Limiting Conditions

If PwPDs and life-limiting conditions use funds surreptitiously or unknowingly to fund personal care and equipment required for the life-limiting conditions or apply to the NDIA for additional funds and the request is approved, two feedback loops can be created. A balancing loop that improves outcomes is created for PwPDs and life-limiting conditions as per balancing Feedback Loop 5 below, but contributing to the NDIS budget's runaway reinforcing feedback loop.

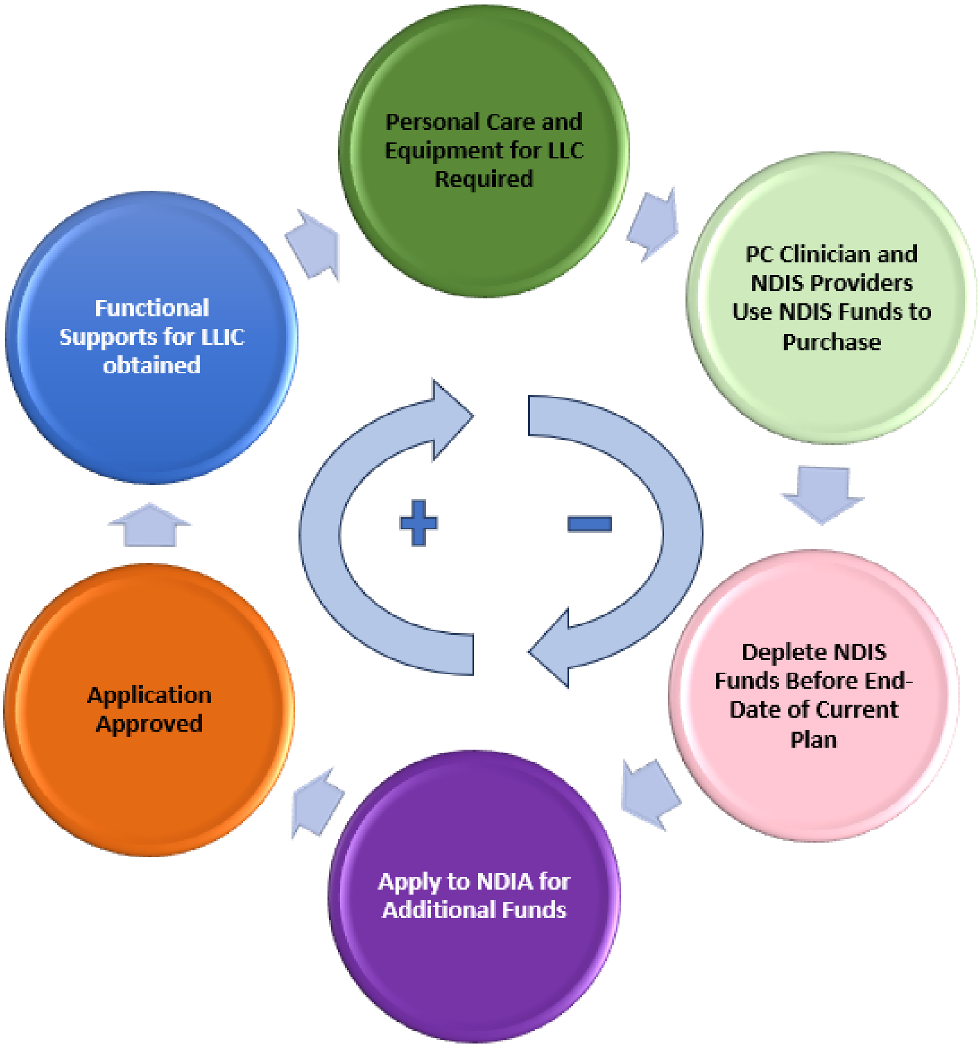

Figure 31: Balancing Feebackack Loop 5 Functional Support for PwPDs and Life-Limiting Diagnoses Funded in Plan

9.3.2.6 Reinforcing Feedback Loops Due to Funding Creep

If NDIS funding is used for supports for a PwPD's life-limiting condition (due to inconsistent decision-making, surreptitious use, or unknowingly), in a manner that is not compliant with the APTOS agreements, other costly and frustrating feedback loops can occur within the health and NDIS systems. Clinicians' time and energy are expended within the health system when preparing reports for the NDIS. Inconsistent decision-making by the NDIA and lack of clarity around APTOS can cause more feedback loops where health system workers increase the time spent trying to understand and obtain support from the NDIS for their patients. Additionally, any funding gaps between systems are not identified, as demonstrated in feedback loop 6. This results in the NDIS paying for supports that are not included in their budget and not part of the APTOS agreements, as shown in feedback loop 7.

Figure 32: Reinforcing Feedback Loop 6 Impact on the NDIS if NDIA Funds Health System Supports for Life-Limiting Conditions

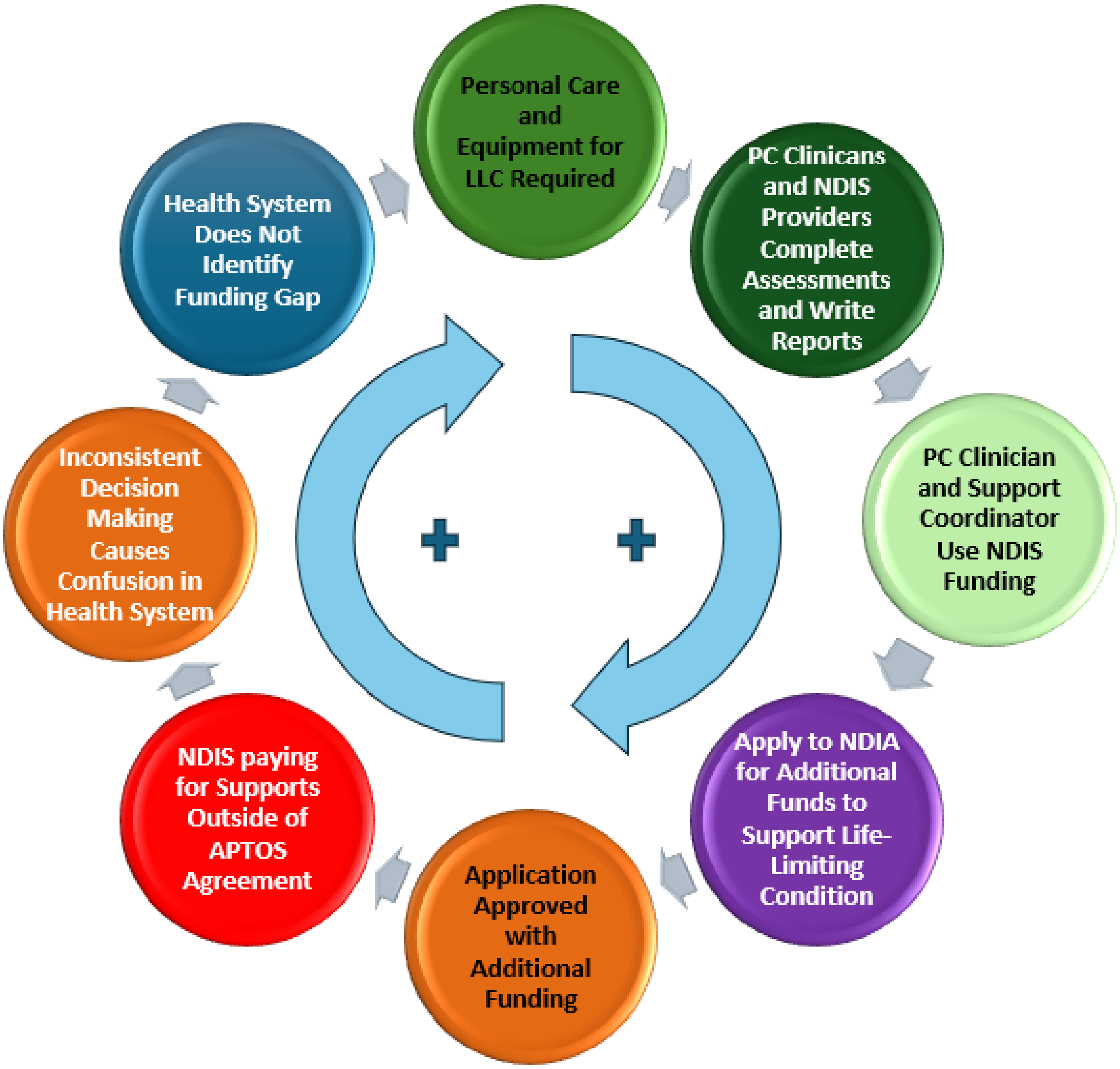

Figure 33: Reinforcing Feedback Loop 7 Impact on Health Systems if NDIA Approves Funding Outside of the APTOS

Case Conferencing

If case conferencing funding for each relevant provider was included as part of the PwPDs plan, a case conference could be arranged between the key stakeholders.

Key Stakeholders:

- PwPDs and Life-Limiting Illness
- Informal Supports, if applicable
- NDIA Planner – Palliative Care Pathway
- Palliative Care Clinician
- A representative from **each** NDIS Provider
- Mental Health Clinician or liaison if not currently connected to mental health services.
- Public Guardian, if applicable

By including these key stakeholders, when appropriate, each stakeholder clearly understands what support can and will be funded by the NDIS and other systems. This will minimise duplication of service delivery, and gaps between systems can be more easily identified and advocated for at an individual or systemic level.

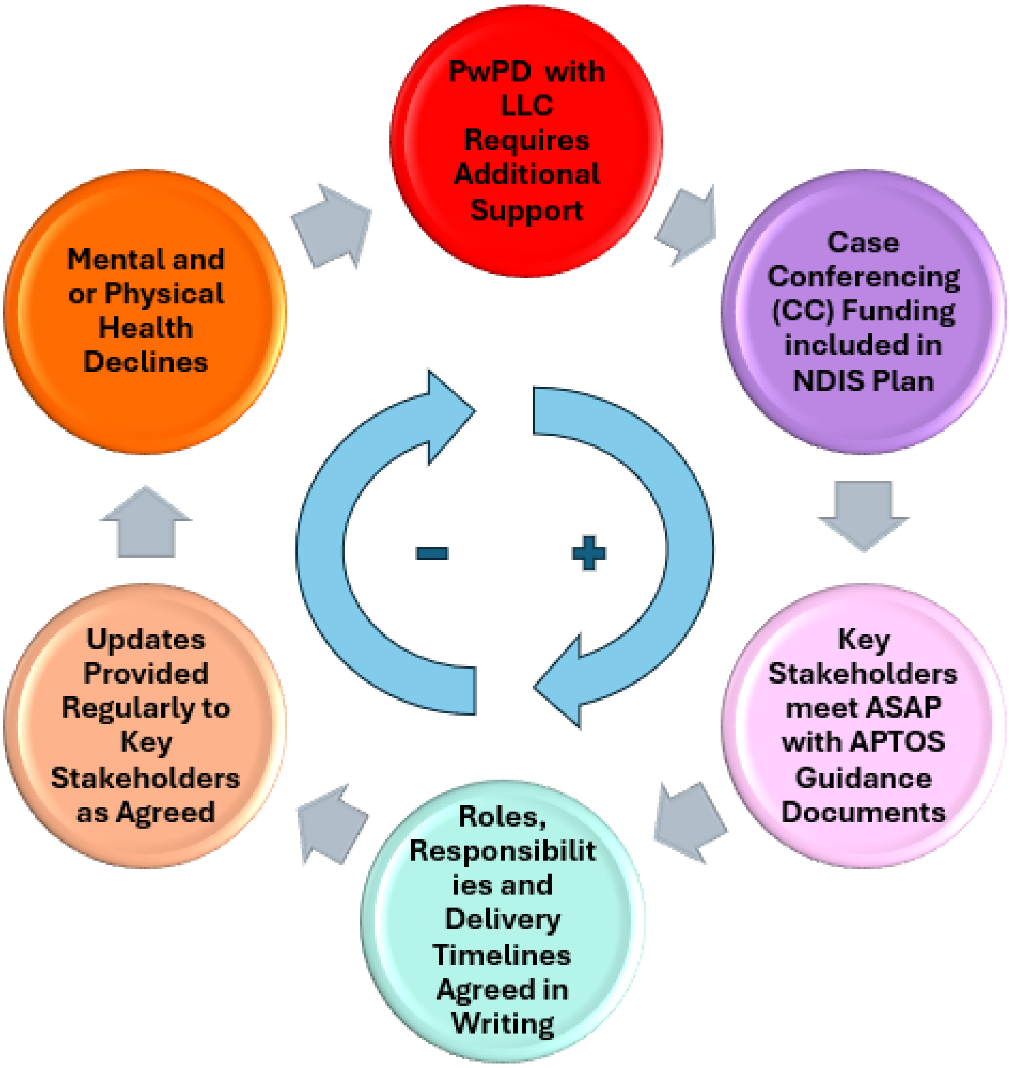

Figure 34: Balancing Feedback Loop 8 – Case Conferencing Funded for PwPDs and Life-limiting Conditions

The simple feedback loops above serve as a crucial tool to illustrate the actual or potential consequences on systems that can arise due to funding creep and insufficient support for mental health treatments, personal care supports, and providing equipment for life-limiting conditions for PwPDs and individuals. Conversely, if systems allocate supports without them being included in their budgets, it can lead to a different set of potential feedback loops. Exploring these potential feedback loops that PwPDs and other people with life-limiting conditions could generate is essential. This exploration will be instrumental in understanding the systems better and guiding future research and interventions to enhance support systems.

9.3.3 Shifting Dominance, Delays and Oscillations

Changes and delays in feedback loops can make a system's behaviour oscillate unpredictably. This research has found that the process and policies change frequently within the NDIA in order to correct perceived or actual issues. The rapid rate and lack of transparency around the policy changes have caused considerable confusion for each of our research cohorts, in the broader research and the wider disability community. Research interviewees described scrambling to adapt to new types of requests for information from the NDIA access and planning officers and partner local area coordinators (LACs). Further, when the NDIA issues unexpected decisions and provides incomprehensible reasoning, PwPDs, informal and formal supports rapidly change their approaches, policies, and practices. When attempting to correct issues, changing policies and processes very quickly or going in the wrong direction can cause oscillations in system behaviour that can make it difficult to interpret how the system is and will respond to further changes. Research interviewees discussed the long delays in the NDIS processes and response times from the NDIA. The length of delays in feedback loops can change system behaviour, making it much more complex and challenging to predict the behaviour or impact.

Additionally, the strength and dominance of multiple feedback loops and their interactions may alter how systems behave [244 p. 45] and contribute to the NDIS' instability. The 2023 NDIS Review advocated for a five-year sequenced and staged implementation of its recommendations [52 p 50], stating this was "*to learn from implementation and make necessary changes and adjustments*" [52 p.215]. The approach recommended by the NDIS Review should assist NDIS policymakers and those within all systems in understanding their respective feedback loops and system behaviour. Ideally, evaluation of the impacts of incremental changes across multiple systems should occur before the NDIS implements its next stage of changes. PwPDs and life-limiting conditions will need to utilise multiple systems, each with internal shifting dominance, delays, and oscillations. The impact of these factors across multiple systems is likely to have an exponential impact on the PwPDs with life-limiting conditions, as each system's reactions may have unpredictable flow-on effects on other systems.

9.3.4 Constraints in Systems

As discussed in Chapter 3 (Research Design and Methodology), systems cannot grow forever, and resources are either flow-limited, such as the hospital beds and equipment to provide supports for life-limiting conditions, or are stock-limited [244 p 190], such as funding for the NDIS, mental health, and health systems. The NDIS Review [52] flagged sustainability issues with the NDIS, and measures are currently being introduced to constrain spending [54]. Systems with reinforcing loops need balancing loops to constrain growth [244], and even within the limited context of personal care and equipment for life-limiting conditions, no balancing loops exist for PwPDs and life-limiting conditions unless provided surreptitiously or unknowingly. If NDIS funding is used, it may resolve the issue of costly, unwanted, and inappropriate hospital admissions for PwPDswith life-limiting conditions. However, funding creep of this nature will lead to runaway feedback loops within the NDIS. As budget allocations will naturally constrain NDIS and other system funding, this may lead to unwanted cuts in other supports for NDIS participants or, if more PwPDs with life-limiting conditions are admitted to hospital due to a lack of equipment, less bed availability for other patients. Without a structured response that considers all of the systems that are likely to impact PwPDs and life-limiting conditions and other Australians that utilise these systems, there will likely be a myriad of reinforcing and runaway loops that will continue to cause substantial functional and budgetary issues, gaps and overlaps in service delivery from those systems.

9.3.5 Resilience and Self-Organisation

Research interviewees described the NDIS funding model as very insecure and that NDIS providers are self-organising, restructuring, and becoming more rigid by limiting the kinds of supports they offer and the types of NDIS participants they support to ensure their businesses remain viable. However, systems theory posits that systems must be flexible, resilient, and withstand variations and oscillations to survive. If they are too rigid and inflexible, they become fragile. Additionally, this research has found that workforce shortages across the sectors have led to even greater system fragility. Workers are leaving or planning to leave the NDIS, mental health and health workforces due to burnout and stress. Unclear system boundaries, moral injury and unpaid hours of work with limited or poor outcomes were indicated as primary concerns for the PR Interviewees and mental health and palliative care clinicians. Even if they choose to remain in the disability workforce, worker turnover with many NDIS providers is very high. This kind of self-organising and rigidity can lead to business and market failure. This may result in a loss of services, or poor continuity of care for PwPDs, leaving many without trusted (or any) NDIS supports, unable to advocate for the support that they need from any system, and falling through gaps between systems.

9.3.6 Bounded Rationality

When interviewing the five cohorts, it was clear that they, their colleagues, and friends were engaging in bounded rationality, making rational decisions that were reasonable to them based on the information they had at the time [244 p. 105]. Little awareness or application of the APTOS was described when discussing supports for PwPDs with or without life-limiting conditions and other NDIS participants. Research interviewees often expressed confusion and anger regarding the decisions made by the NDIA concerning support requests without consideration of the APTOS. Requests that are perfectly rational if looking from their own system's perspective, e.g., the PwPDs has funding for a psychologist within their NDIS plan; therefore, the mental health clinician can feel comfortable discharging them from their care and reducing their excessive caseload. Another example would be that a palliative care clinician has patients with motor neurone disease who have all of their supports, including personal care and equipment for their life-limiting condition by the NDIS. Therefore, the NDIS, from their perspective, should fund all of the disability support needs of a PwPD with a life-limiting condition, including personal care and equipment. They view their patient's support needs holistically and find this sectioning, mostly non-provision, of care shocking.

With limited exceptions, APTOS advises that PwPDs should not receive NDIS supports within health and mental health settings. At first glance, this appears to be a perfectly rational division of funding to ensure no doubling of resources. However, leaving PwPD with life-limiting conditions without access to their usual supports has been described by research interviewees as highly stressful to them and their informal and formal support networks. PC clinicians stated that the support from NDIS workers is welcomed in their facilities and can enable them to care for NDIS participants much more effectively and efficiently. Research interviewees advised that some NDIS providers self-fund their workers to support NDIS participants in health settings without being compensated by the NDIS for the labour. Due to their care for and excellent relationships with NDIS participants, workers also visit them unpaid on their own time. These visits can create issues around business viability for NDIS providers and workers, as with NP Interviewee Heidi's example, where she received a formal warning and risked her employment by visiting a PwPD outside her employer's premises.

Another example of bounded rationality in the NDIS is the support coordination and psychosocial recovery coach model. Support coordinators and recovery coaches are funded to provide capacity-building support to help NDIS participants manage their NDIS supports, maintain relationships, live more independently, and be included in the community. The support must be aligned with the participant's goals. Research interviewees advised that support coordination and psychosocial recovery coach budgets for PwPDs are usually relatively low and insufficient to meet the needs of PwPD. Therefore, the support coordination and psychosocial recovery coaching roles involve helping set up NDIS supports and organising service agreements to be signed by PwPDs and NDIS providers. Once NDIS supports are set up, there is generally minimal funding left, and it is used to check in periodically with PwPDs and providers to ensure that all is going well with their NDIS suppports. In the final stages of each NDIS plan, the support coordinator will gather reports, if appropriate, for the NDIA. Research interviewees, particularly the support coordinators and recovery coaches, advised that any case conferences they attend are generally unfunded. They stated they could not use the NDIS funds for case conferencing for PwPDs and life-limiting conditions. Without appropriate case management to coordinate supports for PwPDs and life-limiting conditions across the NDIS and other systems, they will likely fall into gaps between systems, experiencing service duplication or none at all where assumptions are being made about the services provided within other service systems.

9.3.7 System Traps

9.3.7.1 Policy Resistance

As predicted, this research found substantial policy resistance within each system. For PwPDs and other NDIS participants with life-limiting conditions, this occurs when trying to ensure that they are receiving holistic care. NDIS funding is being utilised either surreptitiously to finance equipment and personal care. Additionally, the NDIS does not fund case conferencing; however, it occurs either with the endorsement of NDIS providers or workers who may participate without their employers' awareness. PR Interviewees advised that these may be paid or unpaid. PC Clinicians and MH Clinicians were uncertain whether these attendances were paid. APTOS indicates that NDIS providers and workers support NDIS participants who are not funded to provide support in health facilities; however, these supports are occurring. Workers may attend either paid or unpaid, and providers may fund this support either at their own expense or they may draw down from participants' plans.

9.3.7.2 Tragedy of the Commons

The tragedy of the commons is when users who benefit from a resource also share the cost of the abuse or overuse of that resource. Evidence that this system trap is occurring was found in this research. Whilst many PwPDs are benefiting from the NDIS, significant abuse and overuse of the NDIS by participants and providers were identified throughout the research interviews and the scoping review. Significant concerns about the sustainability and claims of abuse of the NDIS [52] have caused the government to look at measures to cap and restrain spending on the NDIS. These measures include restricting support categories, increasing information-gathering powers, and introducing an independent needs assessment [299]. This research found that those with limited capacity or support systems to advocate for NDIS supports usually receive lower funding and limited support from the NDIS. Therefore, unless appropriate protective mechanisms, such as increased advocacy and outreach, are introduced alongside these reforms, PwPDs and other vulnerable NDIS participants, particularly if they are also navigating a life-limiting condition, may be excluded or poorly supported by the NDIS.

9.3.7.3 Drift to Low Performance

As discussed in Chapter 3 (Research Design and Methodology), a perception that systems are not performing well can create a reinforcing feedback loop where performance goals are progressively eroded and corrective actions are not implemented, causing the system trap of a *Drift to Low Performance*. The performance of NDIS providers and their workers, the NDIA , and the mental health systems was both praised and criticised by research interviewees. Overall, though, the perception of all three workforces was negative. However, there was insufficient data to understand whether this perception has created a reinforcing feedback loop that has created the drift to a low performance system trap. Further specific studies on the erosion of performance goals and the implementation and success of corrective actions within the NDIS would be warranted.

9.3.7.4 Escalation

As predicted, the scoping review and research interviews found that the lack of understanding of the APTOS and limited support for Australians under 65 with life-limiting conditions has escalated access and planning requests to obtain personal care, transport, cleaning, gardening, shopping, and equipment support from the NDIS. PwPDs who may already receive transport, cleaning, gardening, and shopping support as part of their package of supports from the NDIS are utilising their funding for personal care and equipment. The lack of clarity about why some life-limiting conditions are supported by the NDIS and Inconsistent decisions made by the NDIA planners about NDIS-funded support for life-limiting conditions are causing further escalations in other systems.

Further, throughout the research interviews, it became apparent that, as predicted, increasing support requests from PwPDs are occurring within the NDIS, regardless of need. The reasons for these requests were comparison and information sharing between PwPDs and NDIS providers aggressively or persistently recommending supports that PwPDs are not requesting but accepted as they do not want to upset their workers or providers. The cost escalation reinforcing loop is one of the critical system traps that the NDIS is falling into, and the government is attempting to reign in the exponential growth and prevent the system's eventual collapse [52, 299].

9.4.7.5 Success to the Successful

As expected, this research has revealed that the NDIS contains success to the successful system traps. Large providers can minimise administration costs, such as registration, across multiple services. However, many smaller providers are increasingly electing not to register due to the cost [300]. PwPDs cannot use unregistered providers if the NDIA manages their plans or if they require behaviour support and regulated restricted practices. Additionally, many NDIS participants prefer the increased legislative protections and quality standards that NDIS auditing and registration purports to assure. This reduces the number of supports that small providers can provide, the workers they can attract, and their business viability [300]. These factors help to generate reinforcing feedback loops that reward the already successful and larger NDIS providers. Additionally, the scoping review found that socioeconomic status induced the success to the successful system trap. The NDIS is built on middle-class norms and works best for white, middle-class people. The successful outcomes of this cohort create other feedback loops that reinforce the status quo with the NDIS and further lockout NDIS participants from lower socio-economic groups.

9.4.7.6 Shifting the Burden to the Intervenor

The scoping review and research interviews support the findings of the NDIS Review [52 pp. 24-25], where the intervention of the NDIS has eroded the capacity of other systems to support Australians with disabilities. The system trap/reinforcing feedback of *Shifting the Burden* to the Intervenor is where "*the intervention designed to correct a problem causes the self-maintaining capacity of the original system to atrophy or erode*" [244 p. 135]. The health and mental health systems are struggling to support PwPDs and life-limiting conditions despite the best intentions and 'under-the-grid' work performed by their workforces due to under-resourcing.

9.4.7.7 Rule Beating

Rule beating is where the rules that govern systems can lead to situations where actors appear compliant but act in ways that distort the system. The research interviewees described consistent rule beating across the NDIS, mental health, and health systems. Fraudulent providers may take advantage of participants who have cognitive or memory issues and bill for more services than are provided down funds from plans for services not delivered. Service agreements are drawn up, relationships are developed, and some services are delivered, but without deep investigation or insider whistleblowing, these actions can distort the system by not delivering services as intended and inflating the NDIS's costs. Aside from the actions of predatory providers, this rule-beating occurs knowingly and unknowingly but seldom occurs for the personal gain of the rule breaker. There were examples provided that the NDIS was funding hospital beds and mobility equipment for PwPDs and other NDIS participants who did not have pre-existing physical disabilities but had life-limiting conditions. The actions described were usually to benefit PwPDs with and without life-limiting conditions and could be seen to align with Australia's obligations as a signatory to the UNCRPD [41].

9.4.7.8 Seeking the Wrong Goal

A lack of clarity and consensus about the definition of palliative care and which life-limiting conditions are considered disabilities, along with the lack of awareness, understanding, and clarity around the APTOS has been demonstrated throughout the research. These issues have led to the system trap of seeking the wrong goal, where inaccurate or incomplete goal definitions have led to outcomes that are not in line with what Australian governments intended. The responsibilities, as they are currently articulated, are too vague for workforces within each system to understand and apply consistently. The NDIS Review recognised this in Recommendation 2, 2.6

> *"National Cabinet should agree to a multilateral schedule to a new Disability Intergovernmental Agreement that replaces the principles for determining the responsibilities of the NDIS and other service systems, including the Applied Principles and Tables of Supports to better clarify respective responsibilities."*

The first reading of the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 [301] sought to include APTOS within the National Disability Insurance Scheme Act; however, after multiple public submissions [302 pp. 53-55] concerned about its inclusion, APTOS has been removed from the third reading of the Bill [54].

9.4 Transformative Systems Change Framework

Foster-Fishman and colleagues' transformative systems change framework combines qualitative and dynamic systems theories to assist with analysing and understanding systems functioning and identifying levers for change. The four steps within the framework are bounding the system, understanding fundamental system parts, assessing system interactions, and identifying levers for change. This framework is not rigid, and the elements can be used flexibly to suit each problem [248].

9.4.1 Bounding The System - Problem definition

When considering the formal supports of the NDIS PwPDs and life-limiting conditions, there are a multitude of factors that may impact them as they are dying. This research, through the scoping review and the interviews with research interviewees, revealed that critical issues are a lack of clarity around system responsibilities and siloing between systems, insufficient or no case-management funding, a lack of appropriate training to support PwPDs and life-limiting conditions in the NDIS, mental health and health systems, negative experiences with NDIS providers, the mental health and health systems, a loss of trusted workers when changing systems, under-the-grid unpaid work occurring in the NDIS, mental health and palliative care sectors impacting the sustainability of the workforce and the disability market.

9.4.2 Understanding Fundamental System Parts as Potential Root Causes

Below are the critical problems identified by the research with an exploration of the system norms, resources, regulations, and operations.

9.4.2.1 Siloing and Confusion regarding System Responsibilities

There was significant uncertainty about whether and how the NDIS would support PwPDs and life-limiting conditions, as well as considerable confusion about the responsibilities of the NDIS and other systems. This is of concern for all Australians with life-limiting conditions who are under 65. For those over 65, the aged care system provides in-home, equipment and personal care supports (up to $59,430 p.a. [303]) that eligible Australians can utilise if they develop life-limiting conditions.

For Australians under 65 with life-limiting conditions who have not previously been eligible for the NDIS under Section 24 of the National Disability Insurance Scheme Act [254], there can be confusion within the systems that support them about whether they should apply for the NDIS. Some life-limiting conditions, such as Patau syndrome and Leigh syndrome, are granted immediate access due to their inclusion on List A [161]. Other life-limiting conditions included on List B [277], such as motor neurone disease and Huntington’s disease, are granted access to the NDIS once the applicant can demonstrate substantial functional impairment. Other disabling life-limiting conditions, such as brain cancer, result in a more complicated and fraught NDIS access experience [10, 278].

The PC Clinicians interviewed expressed confusion and frustration about the lack of clarity from the National Disability Insurance Agency (NDIA) about the conditions likely to meet the access requirements. They spend excessive hours preparing reports for the NDIA without certainty of success or consistency in outcomes. They must constantly manage patient and family expectations and frustrations around the NDIS and the availability of supports from any system. At this time, if a patient needs support at home to limit their suffering and does not meet the criteria for residential aged care or the NDIS, there are strictly limited and insufficient resources available from the health systems around Australia for the under-65s. These extensive and regularly futile efforts expend scarce resources and prevent PC Clinicians from providing appropriate palliative care.

There are additional issues with understanding system responsibilities for PwPDs and participants with other disabilities and life-limiting conditions who already receive funding from the NDIS. The lack of clarity around system responsibilities results in NDIS providers and palliative care clinicians writing reports and applying for additional supports for PwPDs' life-limiting conditions. Again, inconsistent decision-making by NDIS planners and partner organisations results in confusion and distressing experiences for NDIS participants. Where additional NDIS funding for life-limiting conditions is not approved, NDIS participants and providers surreptitiously fund end-of-life support such as equipment and personal care, trying to juggle their limited NDIS funding budget and estimate how much longer they will live. Some NDIS participants, therefore, are left with no support at the end of their lives as they have exhausted their budgets.

It should be noted that PwPDs will not automatically transition to the aged care system when they turn 65. They can elect to transition, but many may not wish to do so as the funding may be less than what they receive from the NDIS, it is means-tested, and there are long wait lists for aged care services. Further, it will usually result in a complete change of support staff.

These issues for PwPD, both under and over 65, not receiving the support that they need to palliate at home and may result in premature hospital admissions. Australia's National Palliative Care Strategy [14] noted that people who receive palliative care at home have increased quality of life, reduced hospital-based care and provided cost savings for governments. Reducing hospital-based care, where possible, is particularly important given that Australia's public hospital system is beyond its capacity due to decreased funding, a reduced number of hospital beds per capita and an ageing population [304]. Further, the scoping review found that people with severe and persistent mental illnesses (SPMI) and life-limiting conditions can experience increased distress when admitted to hospitals and hospices due to prior negative experiences with the health system, stigma, health system neglect, and workforces that are not adequately trained to support them. Ethically, morally and financially, it is appropriate and preferable for PwPDs and other Australians living with SPMIs who have life-limiting conditions to be able to receive palliative care within the community, in their homes, as long as it is clinically appropriate and desired.

Most research interviewees from the formal systems did not have a comprehensive understanding of services and supports offered by other service systems. One PC Clinician stated that it is "*next to impossible to work out whose job it is to do anything"*. Significantly, few research interviewees were aware of or clearly understood the APTOS. This lack of awareness was clearly demonstrated by the expectations that the NDIS would fund therapeutic mental health supports, educational supports, equipment and personal care for PwPDs and life-limiting conditions. Specifically, PwPDs had equipment, home modifications, personal care, and massages funded by the NDIS, sometimes approved by the NDIA and other times, "*surreptitiously included*". PC Clinicians usually learn what the NDIA might approve through trial and error, and they have set up Facebook groups and communities of practice to share knowledge regarding access and plan requests for palliative patients with pre-existing disabilities. However, they noted that approvals from the NDIA were "*very random*" and were often related to "*luck*" and the advocacy that the PwPDs received from their informal and formal support networks. Significant distrust and poor relationships were described between the National Disability Insurance Agency (NDIA) and each of the cohorts. The continued uncertainty about what is likely to be funded in PwPDs' plans and whether plans will be reduced or whether they are likely to have their access to the NDIS revoked will, no doubt, result in increased fear and distress for PwPDs if they are diagnosed with life-limiting conditions.

The research found that system siloing has been having a very negative impact on PwPDs and their formal and informal supports, with one IS Interviewee describing her son as "*literally diced up*". All interviewees recognised that the siloing and lack of understanding of system responsibilities led to confusion, inefficiencies, and wasted resources across every system. Additionally, each of the cohorts interviewed recognised that the problems that PwPDs experience with the systems that support them were likely to be compounded if they develop life-limiting conditions, causing greater confusion and substantial additional distress for them and their informal supports and the workforces that support them.

9.4.2.2 Insufficient Case Management/Conferencing Funding

Case conferences are an essential part of palliative care; they bring the person, their family, and care teams together to plan for the current and future care of the dying person [305]. The PR Interviewees, MH Clinicians, IS Interviewees, and PC Clinicians discussed the importance of case conferencing, particularly when an NDIS participant is dying and requires the involvement of multiple systems. However, only very limited specific case management and case conferencing funding is available in the NDIS. The NDIS Pricing Arrangement and Price Limits 2024-25 advises that therapists, particularly rural and rural therapists, can hold case conferences about the specific care needs of participants, and clinical nurses can manage cases around specific disability-related health supports. These can include changing urinary catheters and teaching support workers about wound care and percutaneous endoscopic gastromy (PEG) devices [306]. PwPDs are unlikely to require or have nursing care included in their plans and if nursing care is required due to their life-limiting condition, it remains the health system's responsibility. As this research has found that many PwPDs do not have informal supports, it is even more critical that all of their care teams, including NDIS providers and key support workers, are involved in any case conferencing about their future care. Key NDIS workers and providers are inconsistently involved with case conferencing for dying NDIS participants. However, this work is currently occurring under the grid and may be either paid or unpaid.

Additionally, PwPDs may have multiple NDIS providers, who, to support PwPDs best, may need to be present at case conferences. Support coordinators do not have the capacity or funding to attend cross-sector case conferences and relay the information to all of a PwPD’s providers. The NDIS Review and the research interviews found that there are insufficient support coordination hours currently funded in NDIS plans and that the quality of support coordination and recovery coaching is highly variable. The research interviewees advised that NDIS providers participate in case conferencing to better support PwPDs and other participants with life-limiting conditions, and this work is occurring under the grid and is unpaid. Research interviewees advised that PwPDs and life-limiting conditions can have multiple services working on the same issues in different ways, and case conferencing could resolve duplication of services and overall confusion, which can drain resources across multiple systems.

9.4.2.3 Negative Experiences with NDIS, the Mental Health and Health Systems Impacting PwPDs with Life-Limiting Conditions

The research found that people with SPMI and PwPDs often have negative experiences with the NDIS, mental health, and health systems. This can include experiences with stigma, over or under-treatment of symptoms and poor or inconsistent service delivery. These histories may result in health system avoidance, leading to delayed diagnoses and late treatment of life-limiting conditions, distressing emergency department presentations, and poor pain management and functional support around their life-limiting conditions. The research found that often, palliative care services are not comfortable in supporting patients with pre-existing SPMI; therefore, they may wish to defer their mental health care to the mental health system, which is more experienced in managing people with SPMIs. However, many PwPDs are no longer connected with the under-resourced and over-stretched mental health systems; they may also have prior negative experiences with these services; both circumstances will create additional distress and barriers to optimal palliative and end-of-life care.

There were varied experiences with NDIS, some positive, but most were negative. PwPDs Interviewees expressed considerable concern about the welfare of PwPDs and life-limiting conditions due to their previous experiences; “*you’ve got to keep them away*”, “*they need continuity of care and you can’t get it”.* Additionally, prior negative experiences with the NDIA, it was felt, would create significant anxiety and distress for PwPDs and life-limiting conditions as they tried to understand and navigate system responsibilities. The current processes are exhausting and would be too burdensome for PwPDs and life-limiting conditions. Two PwPDs advised that their previous experiences with the NDIA led them to believe that the NDIA would “*want people to die as quickly as possible*”and “*if you are going to die, happy days, because it's one less person on the NDIS*”.

9.4.2.4 A lack of appropriate training to support PwPDs and life-limiting conditions in the NDIS, mental health and health systems

PR Interviewees advised that they would need substantial training to help them functionally and emotionally support a PwPD with a life-limiting condition. They understood this may be very distressing for NDIS workers and felt additional training and supervision was essential to help them manage their emotional responses and increased support needs of their life-limiting conditions.

Most research interviewees expressed concern about the training and sector experience of the NDIS workforce and the NDIA staff. They felt that these deficits would have a detrimental impact on PwPDs and life-limiting conditions. Further, the scoping review and research interviewees highlighted the importance of cross-training to enable workers from each sector to support the complexities experienced by people who have pre-existing severe mental illnesses and life-limiting conditions. This training should include clear instructions about the responsibilities of each system to ensure that expectations are well managed.

9.4.2.5 Loss of Trusted Workers Between Systems

Research interviewees from all cohorts felt that the NDIS should continue to support or provide increased support and emphasised that PwPDs' relationships with trusted NDIS workers are often the only social connection in the lives of PwPDs and could provide great comfort at the end of life. End-of-life support by NDIS workers is currently not approved, therefore funded, in health settings, which may result in PwPDs dying in hospital or hospice isolated. This study found that in some instances, NDIS workers are attending hospitals, hospices and residential nursing homes, sometimes paid by their employers under the grid, sometimes in their own time to support and care for dying NDIS participants, with one visit resulting in a formal warning for the worker.

Significant unpaid and under-the-grid work was described in the NDIS, mental health and palliative care workforces. This unpaid and unacknowledged work is often undertaken as these workforces want to ensure the best possible outcomes for Australians with disabilities, mental health, and life-limiting conditions. However, the research found that burnout and high staff turnover impact the workforces in all three sectors, and unpaid and excessive workloads are core contributors to these issues.

9.4.3 Assessing System Interactions

As stated in Section 9.3.2, there are any number of feedback loops, both balancing and reinforcing, that are or could occur around PwPDs and life-limiting conditions. Simple feedback loops demonstrate that PwPDs who do not receive appropriate support for both their mental and physical health conditions, Reinforcing Loops 1, 2 and 4 will likely need to be admitted to hospital due to being unsupported in the community. Balancing Feedback Loops 3 and 5 demonstrated that when NDIS funding is being used to support the functional and mental health declines caused by PwPDs' life-limiting conditions, there are improved outcomes and potentially fewer hospital admissions. However, where funding creep like this occurs it causes a feedback loop where confusion expends more resources within the health system, Reinforcing Feedback Loop 6, and a tragedy of the commons system trap occurs where inappropriate use of NDIS funding will cause the costs of the NDIS to escalate Feedback Loop 7. Finally, Balancing Feedback Loop 8 could work well for all stakeholders, where case conferencing is funded for all relevant NDIS providers with whom PwPDs and life-limiting conditions have arrangements. Key stakeholders, including the PwPD, their informal supports, NDIA planners, NDIS providers, and mental health and health system clinicians, could work together to minimise unnecessary hospitalisations and misuse of NDIS funds and ensure that PwPDs do not fall through the gaps between system and are well supported when they are dying.

9.4.5 Identifying Levers For Change

This research has revealed that the knowledge gap around the experiences and systems that support NDIS participants who develop life-limiting conditions is significant. This study, whilst broadly drawing on the significant experiences of the research interviewees, was primarily focused on the support that NDIS participants would receive from their formal support systems if they developed life-limiting conditions. PwPDs with life-limiting conditions were particularly selected for this study as it was assumed there would be a need for intervention and interaction with the mental health systems alongside the NDIS and health systems. Additionally, as the NDIS does not usually fund supports for PwPDs to assist with physical disabilities (unless they have an additional disability that the NDIS supports), it was felt this would increase the complexity of the experience if they develop life-limiting conditions. While this research specifically focussed on PwPD, the recommendations below can be generalised to support all NDIS participants with life-limiting conditions.

Using dynamic systems theory or systems thinking and the transformative systems change framework to inform the research, explore the data, and identify problems. These problems included the siloing of systems that creates gaps between systems, confusion for PwPDs, and informal and formal supports. The need to support NDIS participants with life-limiting conditions to ensure holistic care and good end-of-life outcomes is leading to funding creep. NDIS providers are usually not funded for case conferencing, and substantial and unsustainable amounts of unpaid and under-the-grid work occur across all systems. The poor training and development of NDIS workers was identified, particularly those working for the NDIA and their partners, and it was expressed that additional, specialised training was required to support NDIS participants with life-limiting conditions.

The Transformative System Framework’s final component is identifying levers for change. These levers must be feasible and influence or direct system behaviours. They and other recommendations can be found in Chapter 10 – Conclusion, Section 7 – Recommendations.

9.5 Summary

The scoping review and research interviews found that PwPDs, despite some excellent outcomes, are struggling with the NDIS. They feel that the model it is not well suited to supporting PwPD with the marketisation of the disability sector, resulting in an inexperienced workforce that needs significant training to uplift their capability. The NDIA and its workforce are also challenging for PwPDs and their informal and formal supports. The mental health and health systems are struggling with underfunding, under-resourcing and burnout. There is significant siloing between systems, and they feel that these issues will likely negatively impact PwPD if they develop life-limiting conditions. There was very limited understanding or knowledge of the APTOS, and this led to frustration, excessive labour in other systems and poor outcomes for PwPD and other NDIS participants, particularly if they develop life-limiting conditions. Systems thinking and the transformative systems change framework assist with understanding some of the feedback loops and interactions that lead to poor outcomes and help identify initial levers for change, which will be addressed in Chapter 10 – Conclusion.

CHAPTER 10 – CONCLUSION

10.1 Introduction

This thesis used a qualitative, dynamic systems theory or systems thinking approach [244] and the transformative systems change framework [248] to understand the formal system supports of NDIS participants with primary psychosocial disabilities (PwPD) and life-limiting conditions. Much of the focus of the National Disability Insurance Scheme (NDIS), to date, has been on accessing the scheme, providing early intervention support, and improving the lives of Australians with disabilities. However, there has been little consideration about how a combined system of supports, from the NDIS and other systems, should be delivered to NDIS Participants if they develop a life-limiting condition. The experiences of PwPD were investigated, firstly because they may also be supported by state mental health systems, creating additional complexities. Secondly, the NDIS does not fund supports for needs associated with physical disabilities unless they have cooccurring conditions supported by the NDIS. Therefore, this research was keen to explore the intersection of the state health systems and the federally funded NDIS.

The scoping review revealed that there are significant issues that occur here in Australia and internationally for people with severe and persistent mental illnesses when they develop life-limiting conditions. Statistically, they are likely to die earlier; they experience stigma within health systems, which leads to hospital avoidance, late diagnoses, poorer treatment and symptom management and quality of life. Additionally, palliative care teams struggle to manage the complexities of supporting patients with severe and persistent mental illnesses (SPMI), and mental health teams struggle to support dying clients. Further, the review found significant issues for PwPD with the NDIS, such as the appropriateness of the NDIS model, the quality of support, and the training of the NDIS workforce to support them. There were no specific studies on the experiences of PwPD and life-limiting conditions. Thirty-three research interviews were conducted with diverse stakeholders associated with this topic. These interviews were analysed using the transformative systems change framework to analyse the results of interviews.

10.1.1 Research Question

The research question and subquestions that were devised to explore the phenomenon were:

What are the death, dying and palliative care experiences of National Disability Insurance Scheme (NDIS) participants with primary psychosocial disabilities?

Sub-questions:

1. What support do NDIS participants with primary psychosocial disabilities receive from their formal service systems once diagnosed with a life-limiting condition?
2. Are the death, dying, and palliative care experiences of NDIS participants with primary psychosocial disabilities equitable to the experience of non-NDIS participants with a severe and persistent mental illness (SPMI) and/or other Australians without a pre-existing SPMI?
3. Is the support received by NDIS Participants with primary psychosocial disabilities seamless between systems, both their existing NDIS and mainstream supports? Once they receive a life-limiting diagnosis, do participants receive integrated planning and coordinated supports, referrals, and transitions between services? If so, what works? If not, what are the gaps and barriers?

10.2 Supports Received by PwPD and Life-Limiting Conditions

The research has found that unless PwPDs with life-limiting conditions are in hospital or hospice, they are likely to receive continued functional supports from their NDIS plans. These supports usually include cleaning, gardening, shopping, and transportation assistance. PwPD and life-limiting conditions will not receive personal care or equipment to support them with functional declines associated with their life-limiting condition. However, where sufficient unspent funds exist in NDIS plans, they may receive support "under the grid" unknowingly or surreptitiously. If PwPDs are receiving funding for a psychologist to improve functional capacity, this funding will likely be used for treatments to assist them in managing their mental health around their life-limiting conditions.

The research interviewees advised that the National Disability Insurance Agency (NDIA) is not responsive enough to manage any changes in circumstances or requests that may occur due to their life-limiting conditions. Further, they advised that whilst, for some, the NDIS has provided PwPDs with better support than they had previously received from state-funded programs, there are significant issues with the marketisation of disability support. They have indicated that NDIS workers do not have sufficient training or expertise to work with PwPDs, and this will likely lead to poor quality support for them if they develop life-limiting conditions. Research interviewees also raised concerns about predatory operators and a lack of regulation of NDIS providers. The research found that poor quality supports will likely result in PwPD and life-limiting conditions disengaging from NDIS and mainstream supports. The confusion around the Applied Principles and Tables of Support (APTOS) is causing significant distress, uncertainty, and confusion for PwPDs and life-limiting conditions, and their informal and formal supports.

10.3 Is this Support Equitable?

The research found that the support for Australians under 65 is not equitable; PwPDs and life-limiting conditions receive more support from formal systems than other Australians under 65 with or without pre-existing SPMIs. However, it should be noted that Australians without SPMIs are more likely to have been employed for longer and, research interviewees reported, are more likely to be able to fund functional supports privately through personal savings or private health insurance. However, The Centre For Social Policy Research found in May 2024 that 34.2 per cent of Australians are already under financial stress [307]. Therefore, Australians with life-limiting conditions may lose their incomes due to their inability to work. Due to the current housing crisis, they may be unable to liquidate their housing assets, as doing so may render them homeless. Ultimately, many Australians may be unable to fund these supports privately. A lack of functional support from mainstream systems for Australians under 65 is driving up requests to access the NDIS and unnecessary hospital admissions.

Australians with SPMI and life-limiting conditions who are not on the NDIS, either eligible under Section 24 of the NDIS Act [7] or not, may have considerable difficulty obtaining any functional support to support their functional declines appropriately. A lack of clarity and understanding in systems about APTOS makes applying for the NDIS an arduous, frustrating and distressing process for all parties. There are considerable resources used and reinforcing feedback loops within all systems for applying, writing reports, assessing, and reviewing requests for access to the NDIS. Australians with SPMI are likely to be admitted earlier to hospitals and will likely suffer trying to live independently in the community or elect for (in)voluntary assisted dying due to a lack of support within the community. Research interviewees were asked explicitly whether the support for PwPDs and life-limiting conditions would be equitable. In Figure 35, the results of all research interviews were pooled.

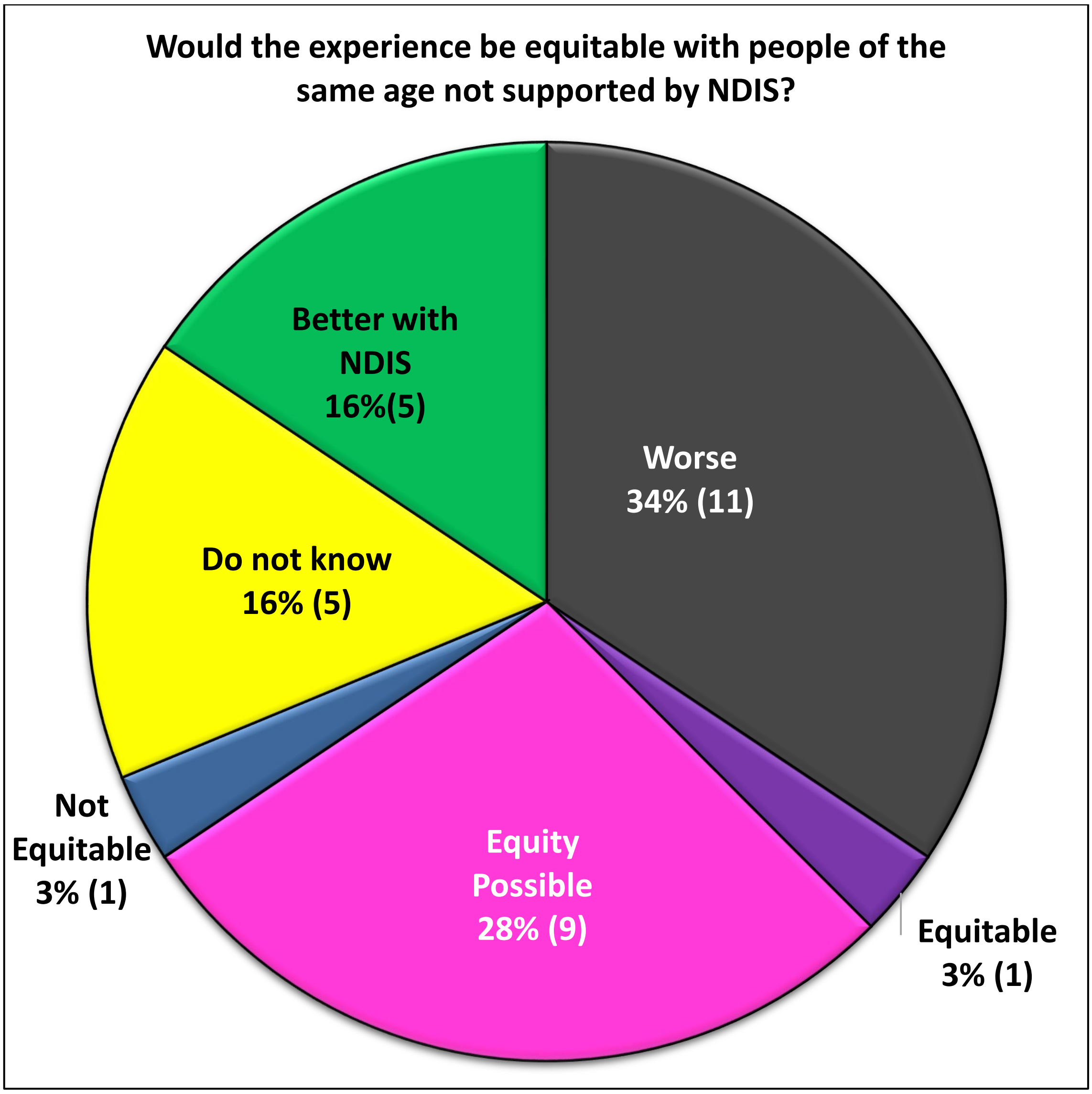

Figure 35: Would the Experience be Equitable? – Pooled Results from all Research Interviews

10.4 Is the Support Received by PwPD with Life-Limiting Conditions Seamless Between Systems?

Research interviewees in every cohort advised that the support between systems is not seamless for PwPDs with or without life-limiting conditions. There are significant gaps between systems. As the 2023 NDIS Review stated, [52 p.35, 66-68] APTOS "*has failed*" and all of the research interviewees indicated that there are significant gaps between systems and confusing duplication of services that impact the lives of PwPD. The siloing of systems was highlighted as a concern, as was the lack of clarity around system boundaries and responsibilities. The lack of case-conferencing funding available in NDIS plans was determined to be a critical area of concern, particularly when trying to coordinate services across systems. Further, PwPDs may have multiple providers, and it is essential that each provider fully understands what supports are being provided by which service. Without this knowledge, each of the care teams may be creating confusion, distress and poor end-of-life outcomes for PwPDs and life-limiting conditions and their informal supports.

This research found that the APTOS[8] are not well articulated or understood by PwPDs, their informal or formal supports. Research interviewees provided responses about which supports should and would be funded for PwPDs and life-limiting conditions, and there was no consistency in the responses. There was often a lack of awareness of the APTOS, and where knowledge existed, the lack of definitions and clarity provided within the document was noted. This lack of clarity was also recognised by the 2023 NDIS Review [52 p.35, 66-68], which recommended that APTOS be abolished and Australian governments come to new agreements that provide more specific guidance about what supports each system will fund and how this is to be actioned within each system.

10.6 Systems Theories and Transformative Systems Change Framework

Systems theories, particularly those regarding stocks, flows and dynamic equilibrium, shed light on the heart of the issues. The critical issues identified by this research are the lack of clarity around the APTOS and the lack of funding for functional supports for Australians who develop life-limiting conditions under the age of 65. Australians over 65 usually have sufficient private funding or can obtain aged care funding for functional supports in the community. Australians under the age of 65 are likely to be admitted to a hospital before they wish to and before it is clinically appropriate. This research found that Australian health systems are already beyond capacity, and hospital stays can cost an average of $2,370 per day [295]. These factors are driving many Australians and their informal and formal supports to seek functional support funding from the NDIS due to the disability brought about by their life-limiting conditions. It is, therefore, assumed that if a palliative patient is already an NDIS participant, they will be supported by the NDIS for their life-limiting conditions. For NDIS participants with life-limiting conditions such as motor neurone disease, obtaining functional support to remain in the community as long as possible is relatively straightforward. However, for NDIS participants with Autism, intellectual or psychosocial disabilities, who do not have pre-existing functional support needs due to physical conditions, this line is blurred, and significant funding creep can occur. This may lead to the NDIS funding support it does not have the resources or budget to provide and other systems not funding or budgeting for those supports. This can result in significant confusion for NDIS participants and their informal and formal supports and may leave participants and their families without the vital support they need atthe end of their lives.

Feedback loops occur in any system, and this research has found feedback loops due to the lack of functional supports outside the NDIS may lead to PwPDs with life-limiting conditions being admitted to hospitals earlier and in more significant numbers, creating runaway reinforcing feedback loops that not only cause significant distress for PwPDs and their informal and formal supports, but creating an excessive financial burden on state-funded health systems. Further, as many PwPDs are discharged from the overstretched state-funded mental health systems under the assumption that they are receiving support from the NDIS, they may not have the necessary therapeutic relationships within the mental health system required to treat them as they navigate their life-limiting conditions alongside their SPMIs. This, our research has found, may increase acute mental health crises and, therefore, presentation to the emergency department and admissions to mental health units. The APTOS indicate that treatment of mental illnesses is the responsibility of the mental health system. However, research interviewees advised that NDIS providers are currently engaging in activities associated with treatment, such as stabilisation, crisis and symptom management. These relationships and treatments may provide a balancing loop for PwPDs where they can manage their acute mental health crises, particularly if they have life-limiting conditions. Once again, however, this kind of funding creep will likely lead to runaway feedback loops within the NDIS system.

Whilst funding creep leads to runaway feedback loops and prevents, or at least delays, the recognition of gaps within and between systems, these actions can be easily explained by the Systems Theory principle of bounded rationality, where actors within each system are acting in ways that are rational within the context of their own system. Further clarity and operational guidance within each system could inhibit actions of this nature by reducing confusion and highlighting gaps within and between systems.

10.7 Recommendations

This research identified the following levers for change using the transformative systems change framework.

10.7.1 Replace the Applied Principles and Tables of Support (APTOS)

Since the APTOS have been in place and unchanged since 2015, the lack of sector and community awareness, guidance, and efficacy reviews is unconscionable. As stated by the NDIS Review, the APTOS, as found the NDIS Review[52 p.35, 66-68] "*has failed".* In lieu of the mutual recrimination between systems currently occurring, the NDIS Review recommended that a new agreement, the *Disability Intergovernmental Agreement* [52 p. 243], be developed between the states, territories, and federal governments to provide "*detailed working arrangements*" [52 p. 36]. This research has also identified this as a significant lever for change along with the need to develop specific guidelines and tools to ensure that NDIS participants with life-limiting conditions, their families, and frontline staff in every system can understand and apply the agreements effectively. This would include specific information regarding which life-limiting conditions will be supported by the NDIS (e.g. Motor Neurone Disease). In line with Systems thinking, the new *Disability Intergovernmental Agreement* must be regularly reviewed for effectiveness and its impact on the multiple systems that surround NDIS participants and other Australians with disabilities and updated where necessary. Regular marketing strategies should be deployed with clear information to reduce confusion and funding creep.

10.7.2 Foundational Supports

The NDIS review recommended that Australian governments invest in foundational supports to improve support outside the NDIS. Foundational supports were envisaged as more general supports for all people with disabilities that are not eligible for the NDIS [52 p. 31]. Most Australians with life-limiting conditions under the age of 65, need support with personal care, equipment, home modifications, cleaning, gardening, shopping and meal preparation. The 2023 NDIS Review [52 p 56-64] recommended that foundational supports, funded by the territory, state and Commonwealth governments, be available to all Australians with disabilities who are not eligible for the NDIS. The foundational supports were announced on the 30th of January 2024, via a Joint Statement by the Hon. Amanda Rishworth MP, the Minister for Social Services and the Hon. Bill Shorten MP, the Minister for the National Disability Insurance Scheme. The Department of Social Services website advises that the foundational supports will be progressively rolled out from mid-2025, with full rollout expected by mid-2027 [308]. The supports that the NDIS Review listed as potential foundational supports are aids, equipment and home and community care. Including personal care and equipment to support physical declines due to life-limiting conditions may alleviate some of the issues with outside-of-scope NDIS applications and early hospital/hospice admissions. There will need to be consideration that NDIS participants with disabilities that are not physical, such as Autism, intellectual disabilities and psychosocial disabilities, will need to access personal care and equipment outside of the NDIS, so they may need to access services from both the NDIS and the proposed foundational supports.

10.7.3 Case Conferencing Funding for NDIS Providers

To ensure that NDIS participants with life-limiting conditions receive holistic care, the NDIS should fund case conferencing hours for NDIS providers. As NDIS participants should be at the centre of decision-making, they should be involved in case conferencing as little or as often as they like. Case conferencing would assist NDIS participants and their informal and formal supports in identifying system gaps, stopping support overlap and funding creep, and minimising the current under-the-grid and unpaid work. Palliative care case conferencing tools and guidance documents should be developed to support decision-making for key stakeholders for NDIS Participants. These tools should be publically available and provide a granular understanding of the types of supports that each system will provide. These will need to reflect the responsibilities of each system and identify current gaps in service delivery for each service delivery area. These tools should be co-designed by NDIS participants and their informal and formal supports (particularly frontline staff in each sector) to ensure that all impacted parties can clearly understand them. Include clear information about when hospital or hospice is clinically appropriate to prevent disappointment and ensure that goals of care are both patient-centred and feasible.

10.7.4 Include Trusted NDIS Workers in Health, Mental Health, and Aged Care Settings

Explore ways that trusted NDIS or foundational support workers can be funded to provide support to NDIS participants and other people with disabilities when they are admitted to health, mental health or aged care settings. If it is clinically appropriate, it may assist in minimising the distress of NDIS participants and their informal and formal supports. It would also be ideal if either NDIS or foundational supports, such as cleaning, gardening, and shopping, are provided in readiness for discharge. Options could include co-payment or in-kind payments from other service systems.

10.7.5 Capability Uplift

Education packages should be developed and mandated for NDIS workers to support NDIS participants with life-limiting conditions. Training should be provided within all systems regarding the APTOS and the new Disability Intergovernmental Agreements as they occur. Specific training for key NDIA personnel should be developed and rolled out to support them with managing phone-based, difficult conversations around life-limiting conditions.

10.7.6 Comprehensive Localised Service Delivery Systems Maps

Build a comprehensive area services map that includes services for every health and human service provider, including foundational support providers, similar to the NDIA's Provider Finder tool. It would be helpful if providers could update support availability in real-time. This information could be monitored to understand the NDIS market capability.

10.8 Further Research Opportunities

As identified, there is a dearth of research about the experiences of NDIS participants with life-limiting conditions. Some initial areas for consideration are listed below.

10.8.1 Systems Thinking and Causal Loop Diagrams

This research has identified a substantial gap in knowledge of how the NDIS intersects with the state-funded health and mental health systems. The simple causal loop diagrams provided in Chapter 9, Section 9.3.2 helped demonstrate how a lack of clarity in the APTOS can create runaway feedback loops and how a corrective action in one domain, i.e. utilising NDIS funding to fund supports the NDIS does not have included in its budget (such as psychological treatment or equipment and personal care) may lead to runaway feedback loops (the rising costs of the NDIS). The APTOS includes other systems that intersect with the NDIS, early childhood development, child protection and family support, school education, higher education and vocational education and training, employment, housing and community infrastructure, transport, justice and aged care. Further research that can underpin building more complex causal loop diagrams that capture the great complexity and nuance in and across systems would enable policymakers to better understand the system parts and root causes, system traps and intersections across the systems before writing new policies.

10.8.2 Understanding Service Delivery for NDIS Participants with Life-Limiting Conditions

Further research is needed to understand the formal and informal supports of NDIS participants with life-limiting conditions. These could include:

- Additional studies with NDIS participants with life-limiting conditions and their informal supports to understand their perspectives and experiences.
- To understand gaps, barriers, system traps, and the effectiveness of implemented changes, studies should be conducted on report-writing, decision-making, and processes for NDIS, health, and other mainstream systems as they support NDIS participants with life-limiting conditions.
- Research the billed and unbilled supports delivered to NDIS participants with life-limiting conditions, ensuring to track which system is or should fund those supports.
- Further research on the experiences of frontline staff that includes the NDIA staff perspectives.
- The development of cross-sector training initiatives to improve the capability of the NDIA, NDIS, and mainstream workforces - assessment of the efficacy of this training.

- Development and assessment of the recommended NDIS/Palliative Care multi-system case management tool.
- Research on the efficacy of the proposed foundational supports and the interface between the NDIS and the aged care systems.
- Research on inequity for people with disabilities in the NDIS and the aged care systems.

10.9 Concluding Comments

Due to the infancy of the NDIS, there is very little understanding of the end-of-life experiences of NDIS participants, and there had been no investigation of the formal systems likely needed to support them. Using a systems thinking approach and the transformative systems change framework, this thesis sought to understand the problems raised by the research interviewees on this topic. Focussing on PwPDs who do not usually obtain NDIS-funded support for physical disabilities, this research set out to find out what support they would be likely to receive if they develop a life-limiting condition. Further, this research explored the understanding of the responsibilities of the NDIS and other systems and the APTOS agreed upon by Australian governments. Across the five cohorts interviewed for this research, unfortunately, there was a limited understanding of APTOS and how it is or should be applied. There is no additional guidance on operationalising the APTOS, which is causing confusion and funding creep and negatively impacts the experiences of NDIS participants and applicants with life-limiting conditions.

This research found, however, that Australians under 65 who are optimally supported by the NDIS, health and mental health systems are usually better supported by their formal systems than other Australians with life-limiting conditions under 65 whom the NDIS does not support, particularly Australians under 65 with SPMI. However, our research found that few PwPDs receive optimal support from the NDIS, mental health and health systems, so these experiences before or during their life-limiting conditions are likely to impact their quality of life adversely. The research findings regarding the gaps between systems, barriers to optimal support during life stages, and issues regarding the marketisation of disability support created by the NDIS should inform policymakers and researchers internationally as they consider introducing more person-centred approaches to disability support.

In keeping with systems thinking principles, any of the recommended changes that may be implemented within the NDIS and other systems must be introduced iteratively so that any systemic impacts, such as delays, oscillations, feedback loops and other relevant systems concepts, are analysed within their own system and other systems before making any additional changes.

Currently, there are 610,502 NDIS participants and that number is it projected that there will be 1,030,337 by 2030 [4]. Everybody dies, and each of these NDIS participants will die, and many will die from life-limiting conditions that will require multi-system support. Additionally, 4.4 million (18%) of Australians live with disabilities [3], including those brought about through life-limiting conditions, and it is important that the lack of equity between systems, including aged care, is addressed. Australia is a signatory of and, therefore, has obligations under the United Nations Convention on the Rights of Persons with Disabilities. Australians, regardless if they are over and under 65; whether or not they are NDIS participants, if they receive support from the aged care system or the proposed foundational supports should receive the support that they need to die well and equitably.

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APPENDICES

Appendix 1 - Search Terms

Psychoinfo and Medline Via Ovid

Theme 1 – NDIS and Psychosocial Disability

(National Disability Insurance) OR NDIS OR NDIA OR (Disabilit* AND personal budget*) OR (user led organi*) OR (individuali* funding package*) NOT (neurodevelopmental impairments) NOT (National death information system) NOT (Naphthalene diimides) NOT (neck disability indices) NOT (non-drug interventions)

Theme 2 - Psychosocial Disability, Death, Dying and Palliative Care (Limit to 2013+)

(severe persistent mental adj2 illness) or SPMI or (psychosocial adj2 disability) or schizo* or (Bipolar adj2 Disorder)

Theme 3 - Palliative, Death and Dying

Palliative or death or dying or (life adj1 limiting) or (end adj3 life) or (end adj1 stage) NOT (Geriatric or Euthanasia or Covid-19 or Alzheimer* or dementia or rat* or infant* or child* or adolescent or youth or dialysis or pharmac* or trauma or veteran or military or (cell adj3 death) or (death adj2 anxiety) or (death adj3 tumo*))

CINAHL

Theme 1 – NDIS and Psychosocial Disability

"National Disability Insurance" OR NDIS OR ndia OR "Disabilit* AND personal budget*" OR "user led organi*" OR "individuali* funding package*"

NOT "neurodevelopmental impairments" OR "National death information system" OR "Naphthalene diimides" OR "neck disability indices" OR "non-drug interventions"

AND "severe and persistent mental illness" OR SPMI OR "Psychosocial Disability" OR Schizophrenia OR Schizoaffective OR "Bipolar Disorder"

Theme 2 - Psychosocial Disability, Death, Dying and Palliative Care (Limit to 2013+)

TX(palliative OR death OR dying OR "life limiting" OR "end of life" OR "end stage") NOT (geriatric OR euthanasia OR covid-19 OR alzheimer* OR dementia OR rat OR rats OR infant* OR child* OR adolescent OR youth OR dialysis OR pharmac* OR trauma OR veteran OR military OR "cell death" OR "death anxiety" OR "death tumo*")

AND "severe and persistent mental illness" OR SPMI OR "Psychosocial Disability" OR Schizophrenia OR Schizoaffective OR "Bipolar Disorder"

Theme 3 - NDIS and Death, Dying and Palliative Care (Limit to 2013+)

"National Disability Insurance" OR NDIS OR ndia OR "Disabilit* AND personal budget*" OR "user led organi*" OR "individuali* funding package*"

NOT "neurodevelopmental impairments" OR "National death information system" OR "Naphthalene diimides" OR "neck disability indices" OR "non-drug interventions"

AND TX (palliative OR death OR dying OR "life limiting" OR "end of life" OR "end stage") NOT TX (geriatric OR euthanasia OR covid-19 OR alzheimer* OR dementia OR rat OR rats OR infant* OR child* OR adolescent OR youth OR dialysis OR pharmac* OR trauma OR veteran OR military OR "cell death" OR "death anxiety" OR "death tumo*")

Theme 4 - NDIS, SPMI & Psychosocial Disability, Death, Dying and Palliative Care)

"National Disability Insurance" OR NDIS OR ndia OR "Disabilit* AND personal budget*" OR "user led organi*" OR "individuali* funding package*"

NOT "neurodevelopmental impairments" OR "National death information system" OR "Naphthalene diimides" OR "neck disability indices" OR "non-drug interventions"

AND TX (palliative OR death OR dying OR "life limiting" OR "end of life" OR "end stage") NOT TX (geriatric OR euthanasia OR covid-19 OR alzheimer* OR dementia OR rat OR rats OR infant* OR child* OR adolescent

OR youth OR dialysis OR pharmac* OR trauma OR veteran OR military OR "cell death" OR "death anxiety" OR "death tumo*")

AND TX "severe and persistent mental illness" OR SPMI OR "Psychosocial Disability" OR Schizophrenia OR Schizoaffective OR "Bipolar Disorder"

SCOPUS

Theme 1 NDIS and SPMI

("severe AND persistent AND mental AND illness" OR spmi OR "psychosocial AND disability" OR schizophrenia OR schizoaffective OR "BiPolar Disorder") AND ("National Disability Insurance" OR NDIS OR ndia OR "Disabilit* AND personal budget*" OR "user led organi*" OR "individuali* funding package*" AND NOT "neurodevelopmental impairments" AND NOT "National death information system" AND NOT "Naphthalene diimides" AND NOT "neck disability indices" AND NOT "non-drug interventions")

Theme 2 – Limit to 2013

("severe AND persistent AND mental AND illness" OR spmi OR "psychosocial AND disability" OR schizophrenia OR schizoaffective OR "BiPolar Disorder") AND (TITLE-ABS-KEY ((palliative OR death OR dying OR "life limiting" OR "end of life" OR "end stage") AND NOT (geriatric OR euthanasia OR covid-19 OR alzheimer* OR dementia OR rat OR rats OR infant* OR child* OR adolescent OR youth OR dialysis OR pharmac* OR trauma OR veteran OR military OR "cell death" OR "death anxiety" OR "death tumo*")))

Theme 4

("National Disability Insurance" OR NDIS OR ndia OR "Disabilit* AND personal budget*" OR "user led organi*" OR "individuali* funding package*" AND NOT "neurodevelopmental impairments" AND NOT "National death information system" AND NOT "Naphthalene diimides" AND NOT "neck disability indices" AND NOT "non-drug interventions") AND (TITLE-ABS-KEY ((palliative OR death OR dying OR "life limiting" OR "end of life" OR "end stage") AND NOT (geriatric OR euthanasia OR covid-19 OR alzheimer* OR dementia OR rat OR rats OR infant* OR child* OR adolescent OR youth OR dialysis OR pharmac* OR trauma OR veteran OR military OR "cell death" OR "death anxiety" OR "death tumo*")))

Theme 5

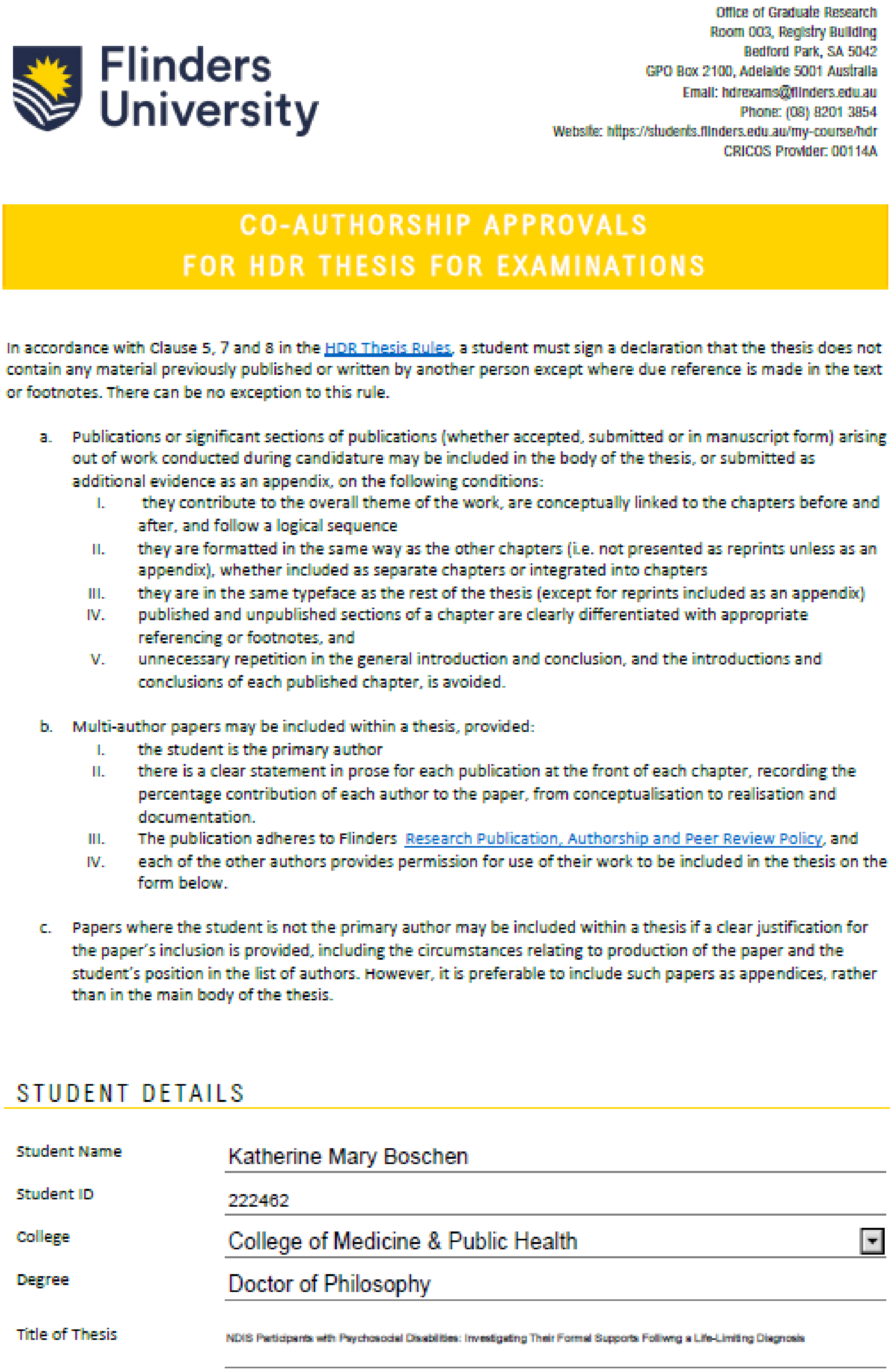
("severe AND persistent AND mental AND illness" OR spmi OR "psychosocial AND disability" OR schizophrenia OR schizoaffective OR "BiPolar Disorder") AND (TITLE-ABS-KEY ((palliative OR death OR dying OR "life limiting" OR "end of life" OR "end stage") AND NOT (geriatric OR euthanasia OR covid-19 OR alzheimer* OR dementia OR rat OR rats OR infant* OR child* OR adolescent OR youth OR dialysis OR pharmac* OR trauma OR veteran OR military OR "cell death" OR "death anxiety" OR "death tumo*"))) AND ("National Disability Insurance" OR NDIS OR ndia OR "Disabilit* AND personal budget*" OR "user led organi*" OR "individuali* funding package*" AND NOT "neurodevelopmental impairments" AND NOT "National death information system" AND NOT "Naphthalene diimides" AND NOT "neck disability indices" AND NOT "non-drug interventions")

Appendix 2 - Prisma Report

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	2 & 3
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualise the review questions and/or objectives.	2 & 3
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	3
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	3
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	19-21
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	3-6
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	7

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	3
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A
Synthesis of results	13	Describe the methods of handling and summarising the data that were charted.	7
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	4-6
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	7-18
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	7-18
Synthesis of results	18	Summarise and/or present the charting results as they relate to the review questions and objectives.	7
DISCUSSION			
Summary of evidence	19	Summarise the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	7
Limitations	20	Discuss the limitations of the scoping review process.	2
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	7-18
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	18 (N/A)

Appendix 3 – Co-Authorship Approvals



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CO-AUTHORSHIP APPROVALS FOR HDR THESIS FOR EXAMINATIONS

In accordance with Clause 5, 7 and 8 in the HDR Thesis Rules, a student must sign a declaration that the thesis does not contain any material previously published or written by another person except where due reference is made in the text or footnotes. There can be no exception to this rule.

a. Publications or significant sections of publications (whether accepted, submitted or in manuscript form) arising out of work conducted during candidature may be included in the body of the thesis, or submitted as additional evidence as an appendix, on the following conditions:
    I. they contribute to the overall theme of the work, are conceptually linked to the chapters before and after, and follow a logical sequence
    II. they are formatted in the same way as the other chapters (i.e. not presented as reprints unless as an appendix), whether included as separate chapters or integrated into chapters
    III. they are in the same typeface as the rest of the thesis (except for reprints included as an appendix)
    IV. published and unpublished sections of a chapter are clearly differentiated with appropriate referencing or footnotes, and
    V. unnecessary repetition in the general introduction and conclusion, and the introductions and conclusions of each published chapter, is avoided.

b. Multi-author papers may be included within a thesis, provided:
    I. the student is the primary author
    II. there is a clear statement in prose for each publication at the front of each chapter, recording the percentage contribution of each author to the paper, from conceptualisation to realisation and documentation.
    III. The publication adheres to Flinders Research Publication, Authorship and Peer Review Policy, and
    IV. each of the other authors provides permission for use of their work to be included in the thesis on the form below.

c. Papers where the student is not the primary author may be included within a thesis if a clear justification for the paper's inclusion is provided, including the circumstances relating to production of the paper and the student's position in the list of authors. However, it is preferable to include such papers as appendices, rather than in the main body of the thesis.

STUDENT DETAILS

Student Name	Katherine Mary Boschen
Student ID	222462
College	College of Medicine & Public Health
Degree	Doctor of Philosophy
Title of Thesis	NDIS Participants with Psychosocial Disabilities: Investigating Their Formal Supports Follwng a Life-Limiting Diagnosis

CO-AUTHORSHIP APPROVALS FOR HDR THESIS EXAMINATION

PUBLICATION 1

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

Full Publication Details	Bochen K, Phelan C, Lawn S. NDIS Participants with Psychosocial Disabilities and Life-Limiting Diagnoses: A Scoping Review. International Journal of Environmental Research and Public Health. 2022, 19(16).
Section of thesis where publication is referred to	Chapter 2 - Literature Review

Student's contribution to the publication

75	%	Research design
75	%	Data collection and analysis
75	%	Writing and editing

Outline your (the student's) contribution to the publication:

Conceptualisation, K.B., C.P. and S.L.; methodology, K.B., C.P. and S.L.; validation, K.B., C.P. and S.L.; formal analysis, K.B.; data curation, K.B. and C.P.; writing original draft preparation, K.B.; writing review and editing, K.B., C.P. and S.L.; supervision, S.L. and C.P.; project administration, K.B. All authors have read and agreed to the published version of the manuscript.

Acknowledgments: Research Centre for Palliative Care, Death, and Dying, Research Librarian Raechel Damarell.

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

Name of Co-Author 1 Prof Sharon Lawn Signed Sharon Lawn Date 01/07/2024

Name of Co-Author 2 Dr Caroline Phelan Signed CM Phelan Date 01/07/2024

Name of Co-Author 3 Signed Date

CO-AUTHORSHIP APPROVALS FOR HDR THESIS EXAMINATION

PUBLICATION 2

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

Full Publication Details	
Section of thesis where publication is referred to	

Student's contribution to the publication		%	Research design
		%	Data collection and analysis
		%	Writing and editing

Outline your (the student's) contribution to the publication:

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

Name of Co-Author 1 ____________ Signed ____________ Date ____________

Name of Co-Author 2 ____________ Signed ____________ Date ____________

Name of Co-Author 3 ____________ Signed ____________ Date ____________

PUBLICATION 4

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

Full Publication Details	
Section of thesis where publication is referred to	

Student's contribution to the publication

	%	Research design
	%	Data collection and analysis
	%	Writing and editing

Outline your (the student's) contribution to the publication:

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

Name of Co-Author 1 ______ Signed ______ Date ______

Name of Co-Author 2 ______ Signed ______ Date ______

Name of Co-Author 3 ______ Signed ______ Date ______

PUBLICATION 5

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

Full Publication Details	
Section of thesis where publication is referred to	

Student's contribution to the publication

______ % Research design

______ % Data collection and analysis

______ % Writing and editing

Outline your (the student's) contribution to the publication:

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

Name of Co-Author 1 ____________ Signed ____________ Date ________

Name of Co-Author 2 ____________ Signed ____________ Date ________

Name of Co-Author 3 ____________ Signed ____________ Date ________

PUBLICATION 6

This section is to be completed by the student and co-authors. If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

Full Publication Details	
Section of thesis where publication is referred to	

Student's contribution to the publication

_______ % Research design

_______ % Data collection and analysis

_______ % Writing and editing

Outline your (the student's) contribution to the publication:

APPROVALS

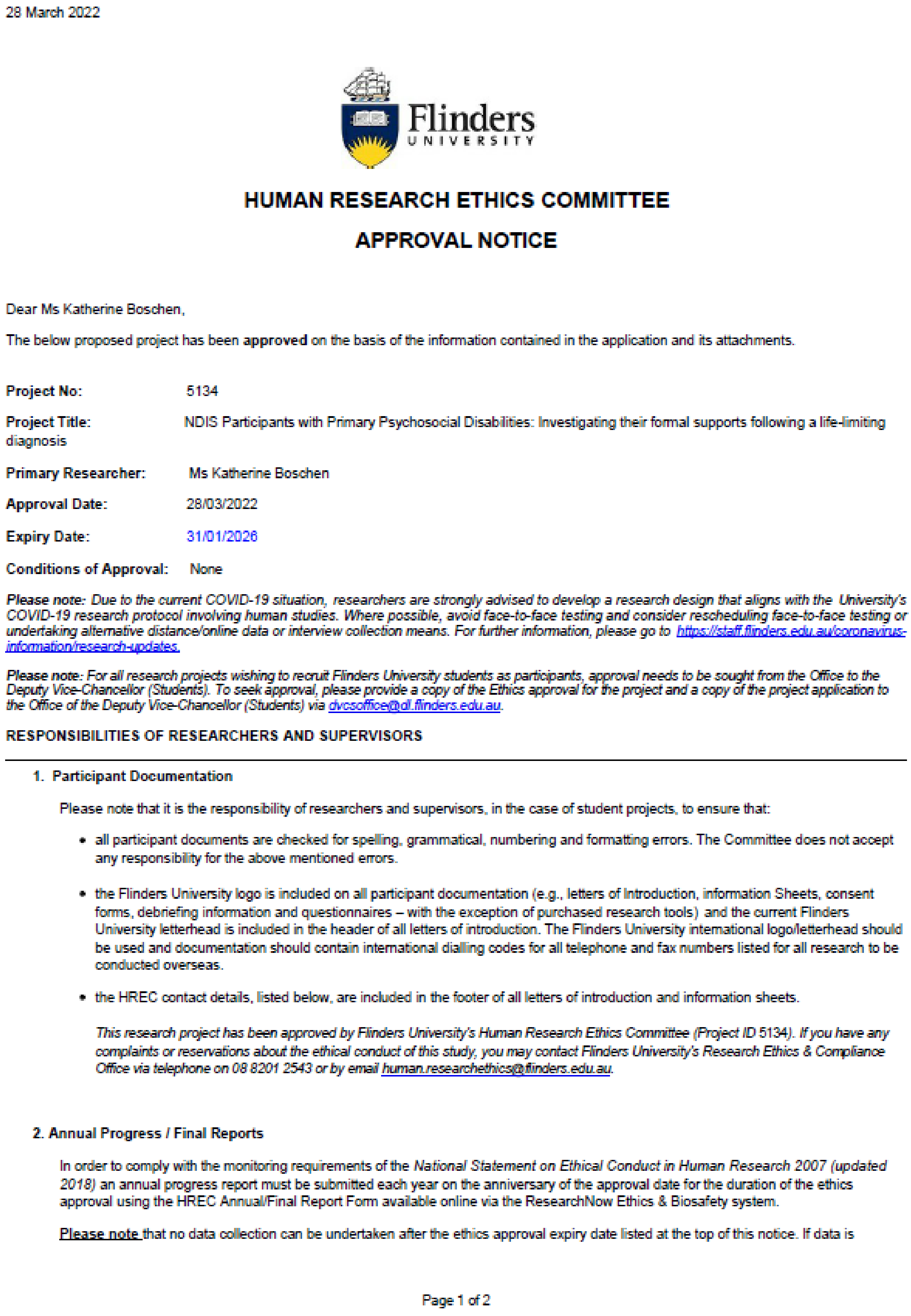
By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

Name of Co-Author 1 ____________ Signed ____________ Date ________

Name of Co-Author 2 ____________ Signed ____________ Date ________

Name of Co-Author 3 ____________ Signed ____________ Date ________

Appendix 4 – Ethics Approval Notice



28 March 2022

HUMAN RESEARCH ETHICS COMMITTEE

APPROVAL NOTICE

Dear Ms Katherine Boschen,

The below proposed project has been **approved** on the basis of the information contained in the application and its attachments.

Project No: 5134

Project Title: NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis

Primary Researcher: Ms Katherine Boschen

Approval Date: 28/03/2022

Expiry Date: 31/01/2026

Conditions of Approval: None

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.*

Please note: *For all research projects wishing to recruit Flinders University students as participants, approval needs to be sought from the Office to the Deputy Vice-Chancellor (Students). To seek approval, please provide a copy of the Ethics approval for the project and a copy of the project application to the Office of the Deputy Vice-Chancellor (Students) via dvcsoffice@dl.flinders.edu.au.*

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 Flinders University's Human Research Ethics Committee (Project ID 5134). If you have any complaints or reservations about the ethical conduct of this study, you may contact Flinders University's Research Ethics & Compliance Office via telephone on 08 8201 2543 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

Page 1 of 2

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.

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 participant remuneration;
- changes to information / documents to be given to potential participants;
- changes to research instruments (e.g., survey, interview 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 open the project, then select the 'Create Sub-Form' tile in the grey Action Menu, and then select the relevant Modification Request Form. 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 Human Ethics Research Committee on 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,

Hendryk Flaegel

on behalf of

Human Research Ethics Committee
Research Development and Support
human.researchethics@flinders.edu.au

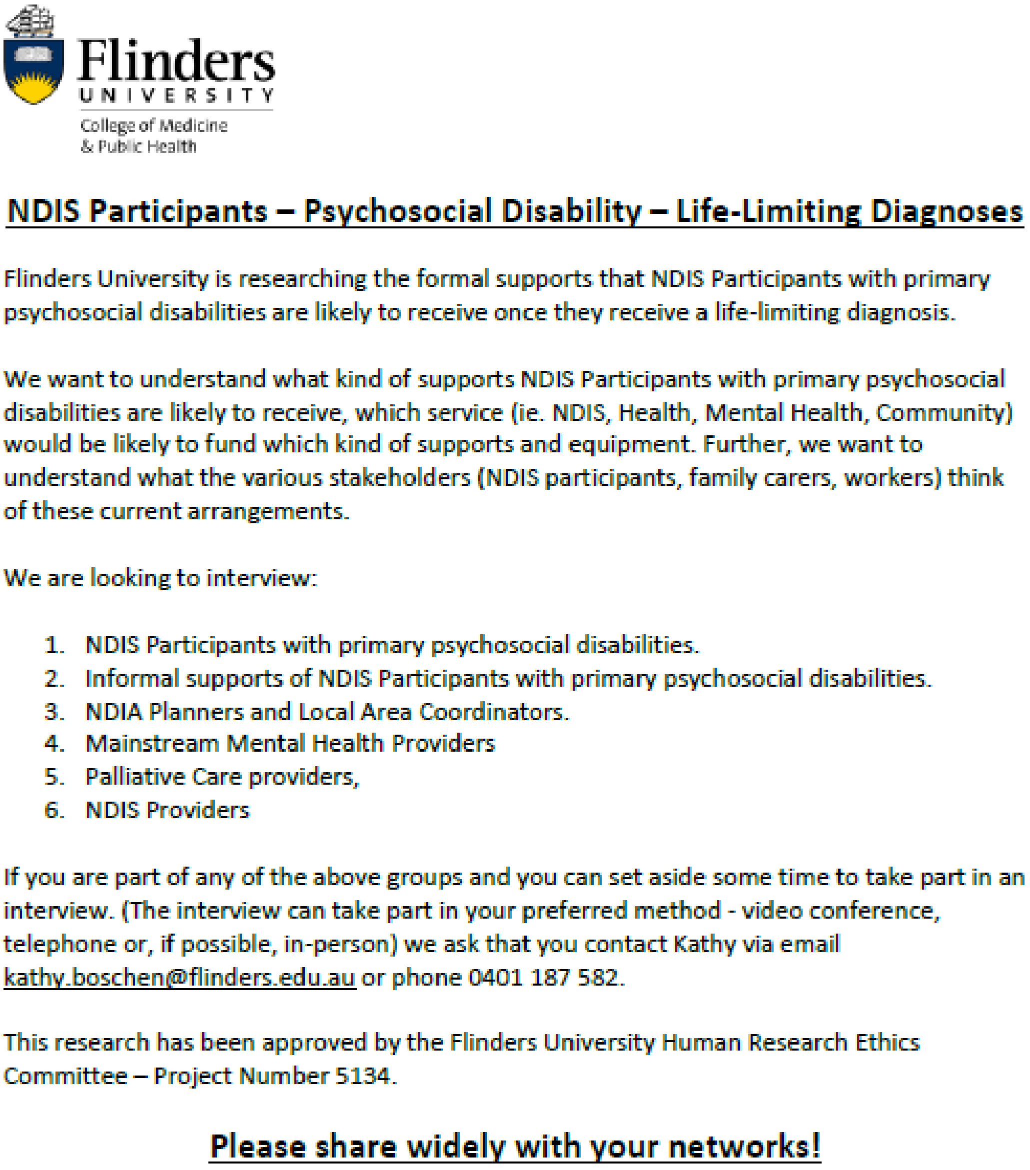
Flinders University
Sturt Road, Bedford Park, South Australia, 5042
GPO Box 2100, Adelaide, South Australia, 5001

http://www.flinders.edu.au/research/researcher-support/ebi/human-ethics/human-ethics_home.cfm

ResearchNow
Ethics & Biosafety

Flinders University
Proactively supporting our Research

Appendix 5 – Research Flyer



Flinders
UNIVERSITY
College of Medicine
& Public Health

NDIS Participants – Psychosocial Disability – Life-Limiting Diagnoses

Flinders University is researching the formal supports that NDIS Participants with primary psychosocial disabilities are likely to receive once they receive a life-limiting diagnosis.

We want to understand what kind of supports NDIS Participants with primary psychosocial disabilities are likely to receive, which service (ie. NDIS, Health, Mental Health, Community) would be likely to fund which kind of supports and equipment. Further, we want to understand what the various stakeholders (NDIS participants, family carers, workers) think of these current arrangements.

We are looking to interview:

1. NDIS Participants with primary psychosocial disabilities.
2. Informal supports of NDIS Participants with primary psychosocial disabilities.
3. NDIA Planners and Local Area Coordinators.
4. Mainstream Mental Health Providers
5. Palliative Care providers,
6. NDIS Providers

If you are part of any of the above groups and you can set aside some time to take part in an interview. (The interview can take part in your preferred method - video conference, telephone or, if possible, in-person) we ask that you contact Kathy via email kathy.boschen@flinders.edu.au or phone 0401 187 582.

This research has been approved by the Flinders University Human Research Ethics Committee – Project Number 5134.

Please share widely with your networks!

Appendix 6 – Research Information and Consent Form – NDIS Participants with Psychosocial Disabilities

Participant Information Sheet/Consent Form

Title:	NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis
Ethics Number:	**Project 5134**
Project Sponsor:	Flinders University
Principal Investigator:	Ms Kathy Boschen
Associate Investigators:	Professor Sharon Lawn, Dr Caroline Phelan
Location:	Flinders University

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called "*NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis*".

We would like to understand National Disability Insurance Scheme (NDIS) Participants with primary psychosocial disabilities who receive life-limiting diagnoses and investigate the NDIS' ability to support NDIS Participants as their illness progresses, particularly

- The support received from their formal service systems once diagnosed with a life-limiting condition.
- Is support received equitable to the experience of non-NDIS Participants with a severe and persistent mental illness and/or other Australians without a pre-existing severe and persistent mental illness?
- Is the support received seamless between systems, both their existing NDIS and mainstream supports?

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decideif you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.
If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

This research seeks to explore and report on the experiences of NDIS Participants with primary psychosocial disabilities and investigate the NDIS' ability to support NDIS Participants once they receive life-limiting diagnoses. There is potential for this research is to identify systemic issues and, if required, inform a framework to improve experiences of NDIS Participants with primary psychosocial disabilities and life-limiting conditions. Further, this research could inform future studies into the experiences of the NDIS Participants of all disability types and life-limiting diagnoses and Australians with severe and persistent mental illnesses that do not receive support from the NDIS.

This research has been initiated by Ms Kathy Boschen, a PhD Candidate at Flinders University under the supervision of Professor Sharon Lawn of the College of Medicine and Public Health and Dr Caroline Phelan of the College of Nursing and Health Sciences (Research Centre of Palliative Care, Death and Dying).

3 What does participation in this research involve?

Procedures

You have been approached as an NDIS Participants with primary psychosocial disabilities. People willing to participate in the study and who met the inclusion criteria will be provided with a Research Participant Information and Consent Form for consideration.

Participation in this study involves taking part in a single interview of about 30 – 45 minutes at a place and time of your choosing. The interview will examine the supports and services either received or expectations around types of funded support that an NDIS Participant with a primary psychosocial disability and a life-limiting condition would expect to receive.

The audio recording of the interview will be transcribed and you will be offered the opportunity to review the transcript for accuracy. If you choose to review the transcript, you will be contacted once more to confirm whether you wish to modify any information within the transcript. This is optional.

Bias

This research project has been designed to ensure the researchers interpret the results fairly and appropriately and avoid persons responsible/participants jumping to conclusions. There are no costs associated with participating in this research project. We will provide you with a $40 Coles voucher to thank you for the contribution of your time and expertise.

4 Other relevant information about the research project

The research seeks to understand perceived benefits, issues, and gaps in service provision for NDIS Participants with a primary psychosocial disability within the following research cohorts:

1. NDIS Participants with primary psychosocial disabilities.
2. Informal supports of NDIS Participants with primary psychosocial disabilities.
3. NDIA Planners and Local Area Coordinators.
4. Mainstream Mental Health Providers
5. Palliative Care providers,
6. NDIS Providers.

These interviews will inform the development of a larger on-line survey to understand these experiences across Australia.

This PhD Research Project will be monitored by Professor Sharon Lawn and Dr Caroline Phelan from Flinders University.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you may withdraw within a fortnight of the interview, data after this point will have been submerged into the research. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your participation in this study shall not affect any other right you may have to compensation under common law. If you do not wish to participate, your NDIS Plan will not be affected in any way.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include the identification of systemic issues. It could inform a framework to improve the experiences of NDIS Participants with primary psychosocial disabilities and life-limiting conditions. Further, this research could inform future studies into the experiences of the NDIS Participants of all disability types and Australians with severe and persistent mental illnesses who do not receive support from the NDIS.

7 What are the possible risks and disadvantages of taking part?

The study will comply with Flinders University policy regarding confidentiality. Nothing that could identify you will be made public and your name and contact details will be kept in a separate password-protected computer file away from any data that you supply. If you feel any distress from participation in this study. If this occurs, you may withdraw from the interview if you wish. None of your personal information will be available to any person or organization outside of this research and your NDIS Plan and NDIS supports will not be affected in any way. By participating in this study,you do not give up any of your legal rights.

If you become upset or distressed as a result of your participation in the research, the research team will, if you require, support you to connect with your regular mental health team, general practitioner, family, friend or usual support workers. Additionally, you can access 24/7 mental health support by contacting Lifeline on 13 11 14, www.lifeline.org.au.

8 What if I withdraw from this research project?

If you do consent to taking part, you may withdraw within a fortnight of the interview, data after this point will have been submerged into the research. If you decide to withdraw from this study, please contact the research team as soon as possible. All data and identifying information will be destroyed. Withdrawal from the study will not impact your NDIS Plan or any NDIS supports.

9 What happens when the research project ends?

At the end of your participation in the study, contributing to this study will not impact your NDIS Plan or any NDIS supports.

Outcomes:

If you would like a summary of the study results, please let the person who conducts your interview know.

Part 2 How is the research project being conducted?

10 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. You will be identified by a pseudonym and participant number, not your actual name.

Information required for the study will be entered into an electronic database on a password protected computer. Data will remain linked to a unique code number but without other details to identify you. All of your collected information will be kept by Flinders University for at least 7 years after the end of the study. Only members of the research team will have access to this data. After the 7-year period your identifying information will be destroyed.

Use of information:

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

Privacy:

Under Australian privacy law all information collected about you must be kept confidential, unless you agree to it being released. If you consent to take part in this study, the data collected for the study will be looked at by the research team and authorised persons from Flinders University. They may also be looked at by representatives of regulatory authorities to check that the study is being carried out correctly. All these people will have a duty of confidentially to you as a research participant and no information that could identify you will be given to anyone else.

Publications:

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission. No actual participant names will be used in presentation of results. However, you should note that as the number of participants involved in the study is small, it is possible that someone may still be able to identify you.

11 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. The researchteam will, if you require, support you to connect with your regular mental health team, general practitioner, family, friend or usual support workers.

If this occurs, you may withdraw from this study if you wish. By participating in this study, you do not give up any of your legal rights.

12 Who is organising and funding the research?

This research project is being conducted by PhD Candidate Ms Kathy Boschen under the supervision of Professor Sharon Lawn and Dr Caroline Phelan. It has been funded by the Flinders University Research by Higher Degree Program of the College of Medicine and Public Health.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

13 Who has reviewed the research project?

The study has been approved by the Flinders University Human Research Ethics Committee. If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may also contact the Flinders University Human Research Ethics Team human.researchethics@flinders.edu.au or telephone 8201 2543 .

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

14 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you may contact:

Research contact person

Name	*Kathy Boschen*
Position	*PhD Candidate*
Telephone	*0401 187 582*
Email	*kathy.boschen@flinders.edu.au*

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Complaints contact person

Name	Professor Sharon Lawn
Position	Professor – College of Medicine and Public Health PhD Supervisor
Telephone	0459 098 772
Email	Sharon.lawn@flinders.edu.au

:

Consent Form - *Adult providing own consent*

Title:	NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis
Ethics Number:	**Project No 5134**
Project Sponsor:	Flinders University
Principal Investigator:	Ms Kathy Boschen
Associate Investigators:	Professor Sharon Lawn, Dr Caroline Phelan
Location:	Flinders University

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language thatI understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) ______________________________

Signature ______________________________ Date ______________________________

Declaration by Researcher[†]

I have given a verbal explanation of the research project; its procedures and risks and I believe that the participant has understood that explanation.

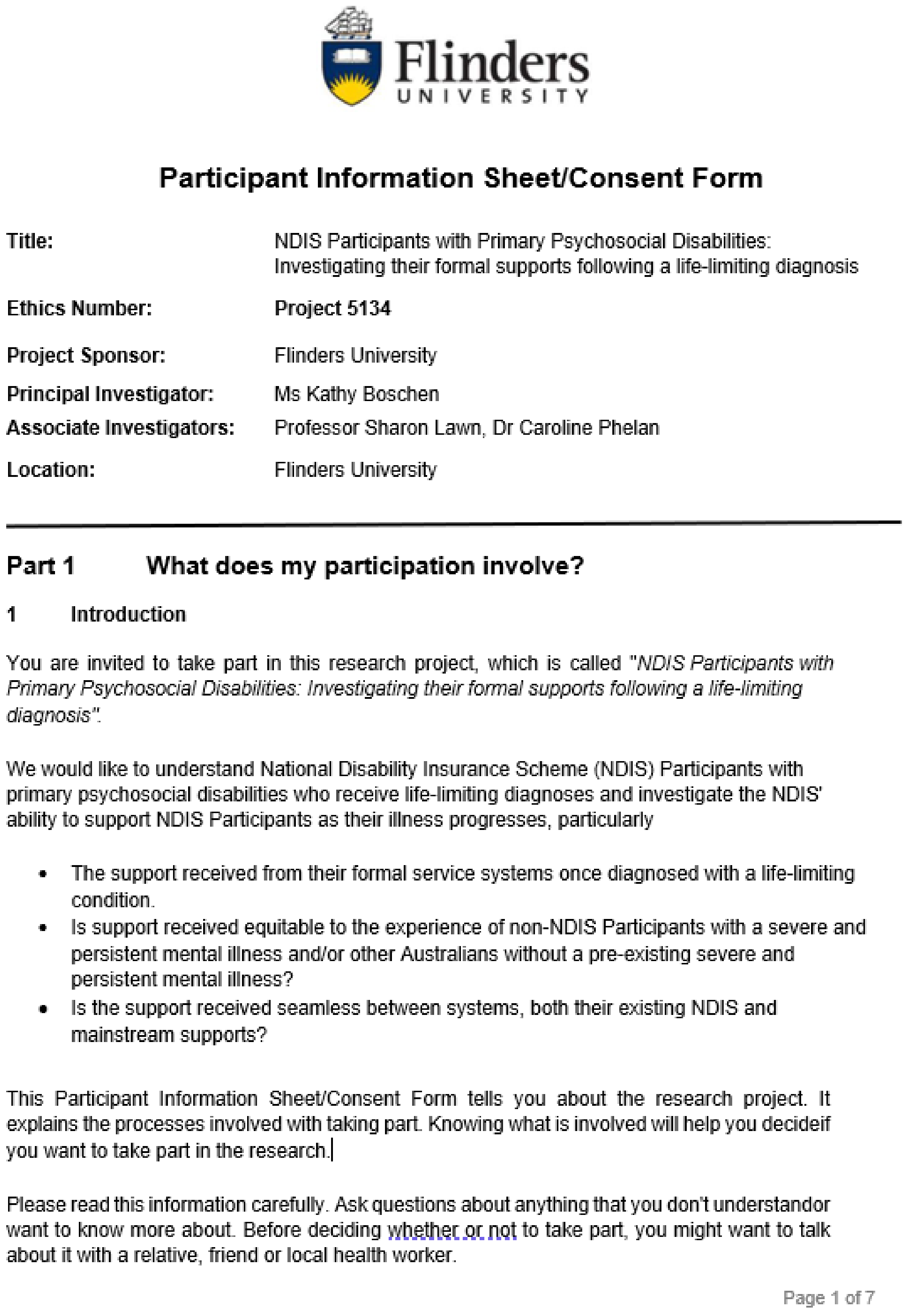
Name of Researcher[†] (please print) ______________________________

Signature ______________________________ Date ______________________________

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature

Appendix 7 – Research Information and Consent Form – Informal Support



Participant Information Sheet/Consent Form

Title: NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis

Ethics Number: **Project 5134**

Project Sponsor: Flinders University

Principal Investigator: Ms Kathy Boschen

Associate Investigators: Professor Sharon Lawn, Dr Caroline Phelan

Location: Flinders University

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called "*NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis*".

We would like to understand National Disability Insurance Scheme (NDIS) Participants with primary psychosocial disabilities who receive life-limiting diagnoses and investigate the NDIS' ability to support NDIS Participants as their illness progresses, particularly

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- Is support received equitable to the experience of non-NDIS Participants with a severe and persistent mental illness and/or other Australians without a pre-existing severe and persistent mental illness?
- Is the support received seamless between systems, both their existing NDIS and mainstream supports?

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decideif you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understandor want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.
If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

This research seeks to explore and report on the experiences of NDIS Participants with primary psychosocial disabilities and investigate the NDIS' ability to support NDIS Participants once they receive life-limiting diagnoses. There is potential for this research is to identify systemic issues and, if required, inform a framework to improve experiences of NDIS Participants with primary psychosocial disabilities and life-limiting conditions. Further, this research could inform future studies into the experiences of the NDIS Participants of all disability types and life-limiting diagnoses and Australians with severe and persistent mental illnesses that do not receive support from the NDIS.

This research has been initiated by Ms Kathy Boschen, a PhD Candidate at Flinders University under the supervision of Professor Sharon Lawn of the College of Medicine and Public Health and Dr Caroline Phelan of the College of Nursing and Health Sciences (Research Centre of Palliative Care, Death and Dying).

3 What does participation in this research involve?

Procedures

You have been approached as an Informal supports of an NDIS Participant with primary psychosocial disabilities. People willing to participate in the study and who met the inclusion criteria will be provided with a Research Participant Information and Consent Form for consideration.

Participation in this study involves taking part in a single interview of about 30 – 45 minutes at a place and time of your choosing. The interview will examine the supports and services either received or expectations around types of funded support that an NDIS Participant with a primary psychosocial disability and a life-limiting condition would expect to receive.

The audio recording of the interview will be transcribed and you will be offered the opportunity to review the transcript for accuracy. If you choose to review the transcript, you will be contacted once more to confirm whether you wish to modify any information within the transcript. This is optional.

Bias

This research project has been designed to ensure the researchers interpret the results fairly and appropriately and avoid persons responsible/participants jumping to conclusions. There are no costs associated with participating in this research project. We will provide you with a $40 Coles voucher to thank you for the contribution of your time and expertise.

4 Other relevant information about the research project

The research seeks to understand perceived benefits, issues, and gaps in service provision for NDIS Participants with a primary psychosocial disability within the following research cohorts:

1. NDIS Participants with primary psychosocial disabilities.
2. Informal supports of NDIS Participants with primary psychosocial disabilities.
3. NDIA Planners and Local Area Coordinators.
4. Mainstream Mental Health Providers
5. Palliative Care providers,
6. NDIS Providers.

These interviews will inform the development of a larger on-line survey to understand these experiences across Australia.

This PhD Research Project will be monitored by Professor Sharon Lawn and Dr Caroline Phelan from Flinders University.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you may withdraw within a fortnight of the interview, data after this point will have been submerged into the research. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your participation in this study shall not affect any other right you may have to compensation under common law. If you do not wish to participate, (your NDIS Plan / the NDIS Participant's NDIS Plan) will not be affected in any way.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include the identification of systemic issues. It could inform a framework to improve the experiences of NDIS Participants with primary psychosocial disabilities and life-limiting conditions. Further, this research could inform future studies into the experiences of the NDIS Participants of all disability types and Australians with severe and persistent mental illnesses that do not receive support from the NDIS.

7 What are the possible risks and disadvantages of taking part?

The study will comply with Flinders University policy regarding confidentiality. Nothing that could identify you will be made public and your name and contact details will be kept in a separate password-protected computer file away from any data that you supply. If you feel any distress from participation in this study. If this occurs, you may withdraw from the interview if you wish. None of your personal information will be available to any person or organization outside of this research and your NDIS Plan and NDIS supports will not be affected in any way. By participating in this study,you do not give up any of your legal rights.

If you become upset or distressed as a result of your participation in the research, the research team will, if you require, support you to connect with your regular mental health team, general practitioner, family, friend or usual support workers. Additionally, you can access 24/7 mental health support by contacting Lifeline on 13 11 14, www.lifeline.org.au.

8 What if I withdraw from this research project?

If you do consent to taking part, you may withdraw within a fortnight of the interview, data after this point will have been submerged into the research. If you decide to withdraw from this study, please contact the research team as soon as possible. All data and identifying information will be destroyed. Withdrawal from the study will not impact your NDIS Plan or any NDIS supports.

9 What happens when the research project ends?

At the end of your participation in the study, contributing to this study will not impact your NDIS Plan or any NDIS supports.

Outcomes:

If you would like a summary of the study results, please let the person who conducts your interview know.

Part 2 How is the research project being conducted?

10 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. You will be identified by a pseudonym and participant number, not your actual name.

Information required for the study will be entered into an electronic database on a password protected computer. Data will remain linked to a unique code number but without other detailsto identify you. All of your collected information will be kept by Flinders University for at least 7 yearsafter the end of the study. Only members of the research team will have access to this data. After the 7 year period your identifying information will be destroyed.

Use of information:

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

Privacy:

Under Australian privacy law all information collected about you must be kept confidential, unless you agree to it being released. If you consent to take part in this study, the data collected for the study will be looked at by the research team and authorised persons from Flinders University. They may also be looked at by representatives of regulatory authorities tocheck that the study is being carried out correctly. All these people will have a duty of confidentially to you as a research participant and no information that could identify you will be given to anyone else.

Publications:

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission. No actual participant names will be used in presentation of results. However, you should note that as the number of participants involved in the study is small, it is possible that someone may still be able to identify you.

11 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. The researchteam will, if you require, support you to connect with your regular mental health team, general practitioner, family, friend or usual support workers.

If this occurs, you may withdraw from this study if you wish. By participating in this study, you do not give up any of your legal rights.

12 Who is organising and funding the research?

This research project is being conducted by PhD Candidate Ms Kathy Boschen under the supervision of Professor Sharon Lawn and Dr Caroline Phelan. It has been funded by the Flinders University Research by Higher Degree Program of the College of Medicine and Public Health.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

13 Who has reviewed the research project?

The study has been approved by the Flinders University Human Research Ethics Committee. If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may also contact the Flinders University Human Research Ethics Team human.researchethics@flinders.edu.au or telephone 8201 2543 .

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

14 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you may contact:

Research contact person

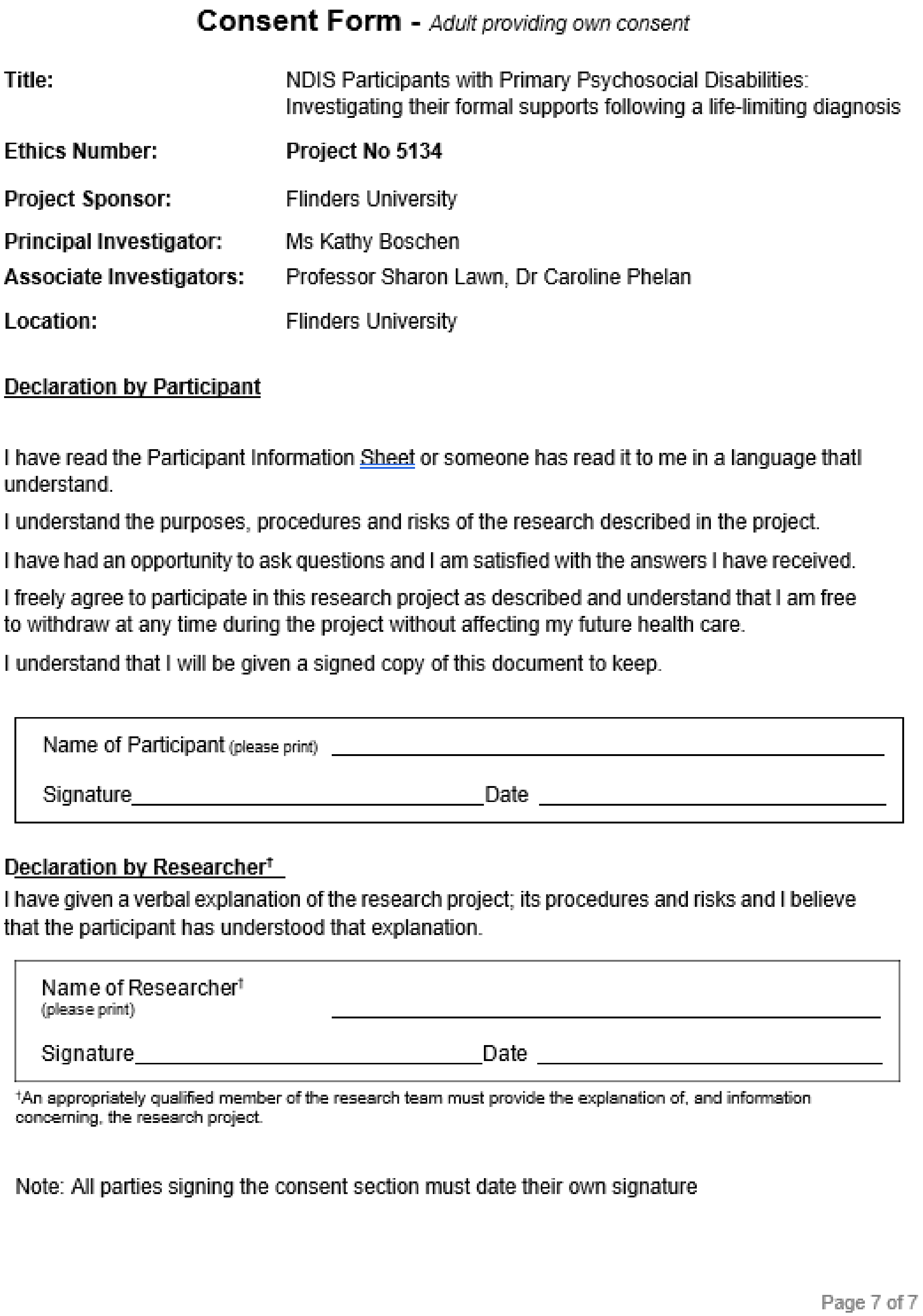
Name	*Kathy Boschen*
Position	*PhD Candidate*
Telephone	*0401 187 582*
Email	*kathy.boschen@flinders.edu.au*

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Complaints contact person

Name	Professor Sharon Lawn
Position	Professor – College of Medicine and Public Health PhD Supervisor
Telephone	0459 098 772
Email	Sharon.lawn@flinders.edu.au

:



Consent Form - *Adult providing own consent*

Title:	NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis
Ethics Number:	**Project No 5134**
Project Sponsor:	Flinders University
Principal Investigator:	Ms Kathy Boschen
Associate Investigators:	Professor Sharon Lawn, Dr Caroline Phelan
Location:	Flinders University

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language thatI understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) ________________________________

Signature ______________________ Date ______________________

Declaration by Researcher†

I have given a verbal explanation of the research project; its procedures and risks and I believe that the participant has understood that explanation.

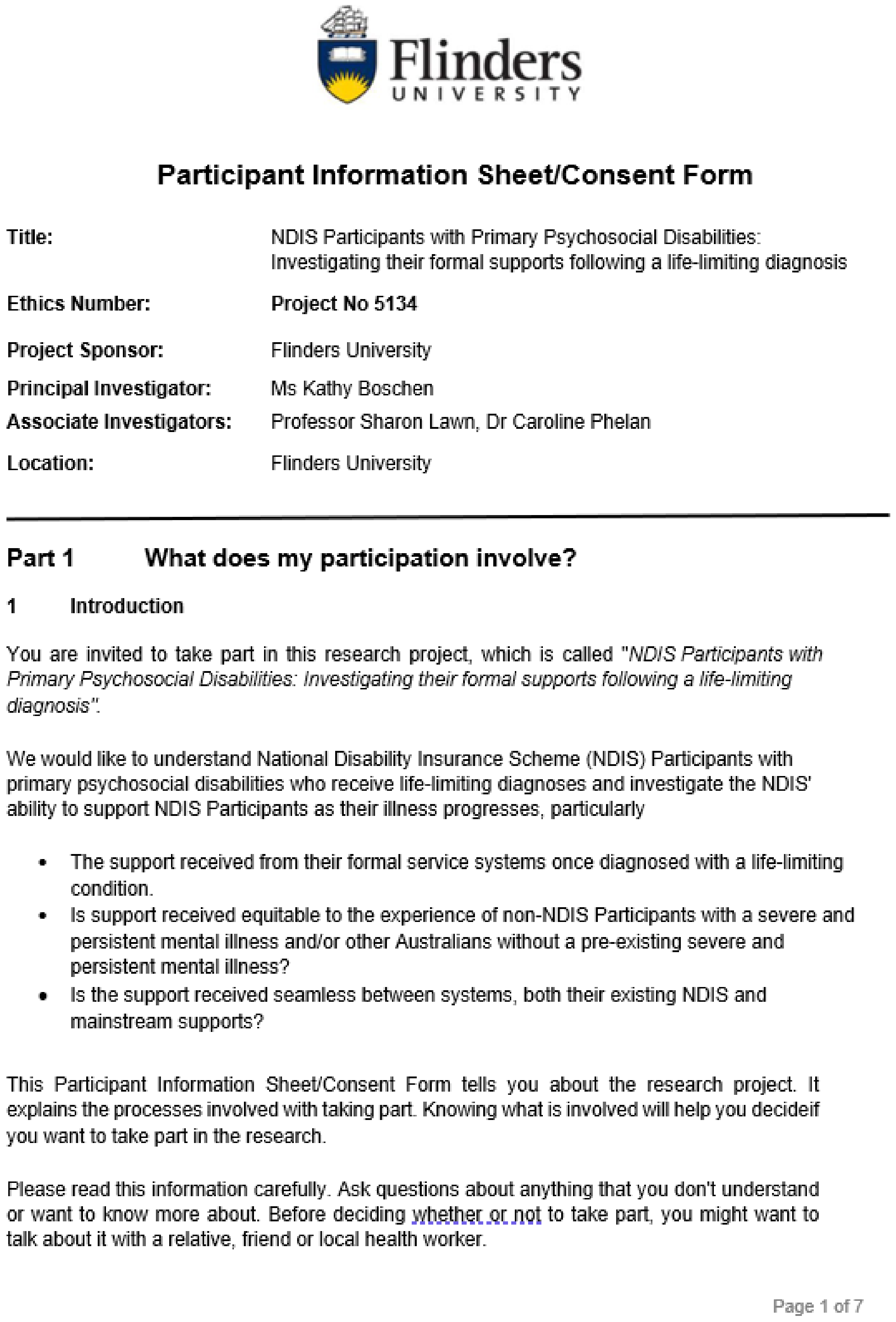
Name of Researcher† (please print) ________________________________

Signature ______________________ Date ______________________

†An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature

Appendix 8 – Research Information and Consent Form – Workforce



Participant Information Sheet/Consent Form

Title:	NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis
Ethics Number:	**Project No 5134**
Project Sponsor:	Flinders University
Principal Investigator:	Ms Kathy Boschen
Associate Investigators:	Professor Sharon Lawn, Dr Caroline Phelan
Location:	Flinders University

Part 1 What does my participation involve?

1 Introduction

You are invited to take part in this research project, which is called "*NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis*".

We would like to understand National Disability Insurance Scheme (NDIS) Participants with primary psychosocial disabilities who receive life-limiting diagnoses and investigate the NDIS' ability to support NDIS Participants as their illness progresses, particularly

- The support received from their formal service systems once diagnosed with a life-limiting condition.
- Is support received equitable to the experience of non-NDIS Participants with a severe and persistent mental illness and/or other Australians without a pre-existing severe and persistent mental illness?
- Is the support received seamless between systems, both their existing NDIS and mainstream supports?

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decideif you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or local health worker.

Page 1 of 7

Participation in this research is voluntary. If you don't wish to take part, you don't have to.
If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

This research seeks to explore and report on the experiences of NDIS Participants with primary psychosocial disabilities and investigate the NDIS' ability to support NDIS Participants once they receive life-limiting diagnoses. There is potential for this research is to identify systemic issues and, if required, inform a framework to improve experiences of NDIS Participants with primary psychosocial disabilities and life-limiting conditions. Further, this research could inform future studies into the experiences of the NDIS Participants of all disability types and life-limiting diagnoses and Australians with severe and persistent mental illnesses that do not receive support from the NDIS.

This research has been initiated by Ms Kathy Boschen, a PhD Candidate at Flinders University under the supervision of Professor Sharon Lawn of the College of Medicine and Public Health and Dr Caroline Phelan of the College of Nursing and Health Sciences (Research Centre of Palliative Care, Death and Dying).

3 What does participation in this research involve?

Procedures

You have been approached as a (NDIA Planners/ Local Area Coordinator / Mainstream Mental Health Clinician / Palliative Care Clinician / working for an NDIS Provider)
People willing to participate in the study and who met the inclusion criteria will be provided with a participant information and consent form for consideration.

Participation in this study involves taking part in a single interview of about 30 – 45 minutes at a place and time of your choosing. The interview will examine the supports and services either received or expectations around types of funded support that an NDIS Participant with a primary psychosocial disability and a life-limiting condition would expect to receive.

The audio-recording of the interview will be transcribed and you will be offered the opportunity to review the transcript review for accuracy. If you choose to review a summary ortranscript, you will be contacted once more to confirm whether you wish to modify any information on the summary or transcript. This is optional.

Bias

This research project has been designed to make sure the researchers interpret the results ina fair and appropriate way and avoids persons responsible/participants jumping to conclusions. There are no costs associated with participating in this research project, nor willyou be paid.

4 Other relevant information about the research project

The research seeks to understand perceived benefits, issues, and gaps in service provision for NDIS Participants with a primary psychosocial disability within the following research cohorts:

1. NDIS Participants with primary psychosocial disabilities.
2. Informal supports of NDIS Participants with primary psychosocial disabilities.
3. NDIA Planners and Local Area Coordinators.
4. Mainstream Mental Health Providers
5. Palliative Care providers,
6. NDIS Providers.

These interviews will inform the development of a larger on-line survey to understand these experiences across Australia.

This PhD Research Project will be monitored by Professor Sharon Lawn and Dr Caroline Phelan from Flinders University.

5 Do I have to take part in this research project?

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you may withdraw within a fortnight of the interview, data after this point will have been submerged into the research. If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your participation in this study shall not affect any other right you may have to compensation under common law. If you do not wish to participate, your employment will not be affected in any way.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include the identification of systemic issues. It could inform a framework to improve the experiences of NDIS Participants with primary psychosocial disabilities and life-limiting conditions. Further, this research could inform future studies into the experiences of the NDIS Participants of all disability types and Australians with severe and persistent mental illnesses that do not receive support from the NDIS.

7 What are the possible risks and disadvantages of taking part?

Risks:

The study will comply with Flinders University policy regarding confidentiality. Nothing that could identify you will be made public and your name and contact details will be kept in a separate password-protected computer file away from any data that you supply. If you feel any distress from participation in this study_ If this occurs, you may withdraw from this studyif you wish, and your employment will not be affected in any way. By participating in this study, you do not give up any of your legal rights.

If you become upset or distressed as a result of your participation in the research, the research team will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staff who are not members of the research project team. Additionally, you can access 24/7 mental health support by contacting Lifeline on 13 11 14, www.lifeline.org.au.

8 What if I withdraw from this research project?

If you do consent to taking part, you may withdraw within a fortnight of the interview, data after this point will have been submerged into the research. If you decide to withdraw from this study, please contact the research team as soon as possible. All data and identifying information will be destroyed. Withdrawing from this research will not impact your employment.

9 What happens when the research project ends?

At the end of your participation in the study, you will (continue your employment as usual.

Outcomes:

If you would like a summary of the study results, please let the person who conducts your interview know.

Part 2 How is the research project being conducted?

10 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. You will be identified by a pseudonym and participant number, not your actual name.

Information required for the study will be entered into an electronic database on a password protected computer. Data will remain linked to a unique code number but without other details to identify you. All of your collected information will be kept by Flinders University for at least 7 yearsafter the end of the study. Only members of the research team will have access to this data. After the 7-year period your identifying information will be destroyed.

Use of information:

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

Privacy:

Under Australian privacy law all information collected about you must be kept confidential, unless you agree to it being released. If you consent to take part in this study, the data collected for the study will be looked at by the research team and authorised persons from Flinders University. They may also be looked at by representatives of regulatory authorities to check that the study is being carried out correctly. All these people will have a duty of confidentially to you as a research participant and no information that could identify you will be given to anyone else.

Publications:

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission. No actual participant names will be used in presentation of results. However, you should note that as the number of participants involved in the study is small, it is possible that someone may still be able to identify you.

11 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

If this occurs, you may withdraw from this study if you wish. By participating in this study, you do not give up any of your legal rights.

12 Who is organising and funding the research?

This research project is being conducted by PhD Candidate Ms Kathy Boschen under the supervision of Professor Sharon Lawn and Dr Caroline Phelan. It has been funded by the Flinders University Research by Higher Degree Program of the College of Medicine and Public Health.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

13 Who has reviewed the research project?

The study has been approved by the Flinders University Human Research Ethics Committee. If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may also contact the Flinders University Human Research Ethics Team human.researchethics@flinders.edu.au or telephone 8201 2543 .

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

14 Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you may contact.

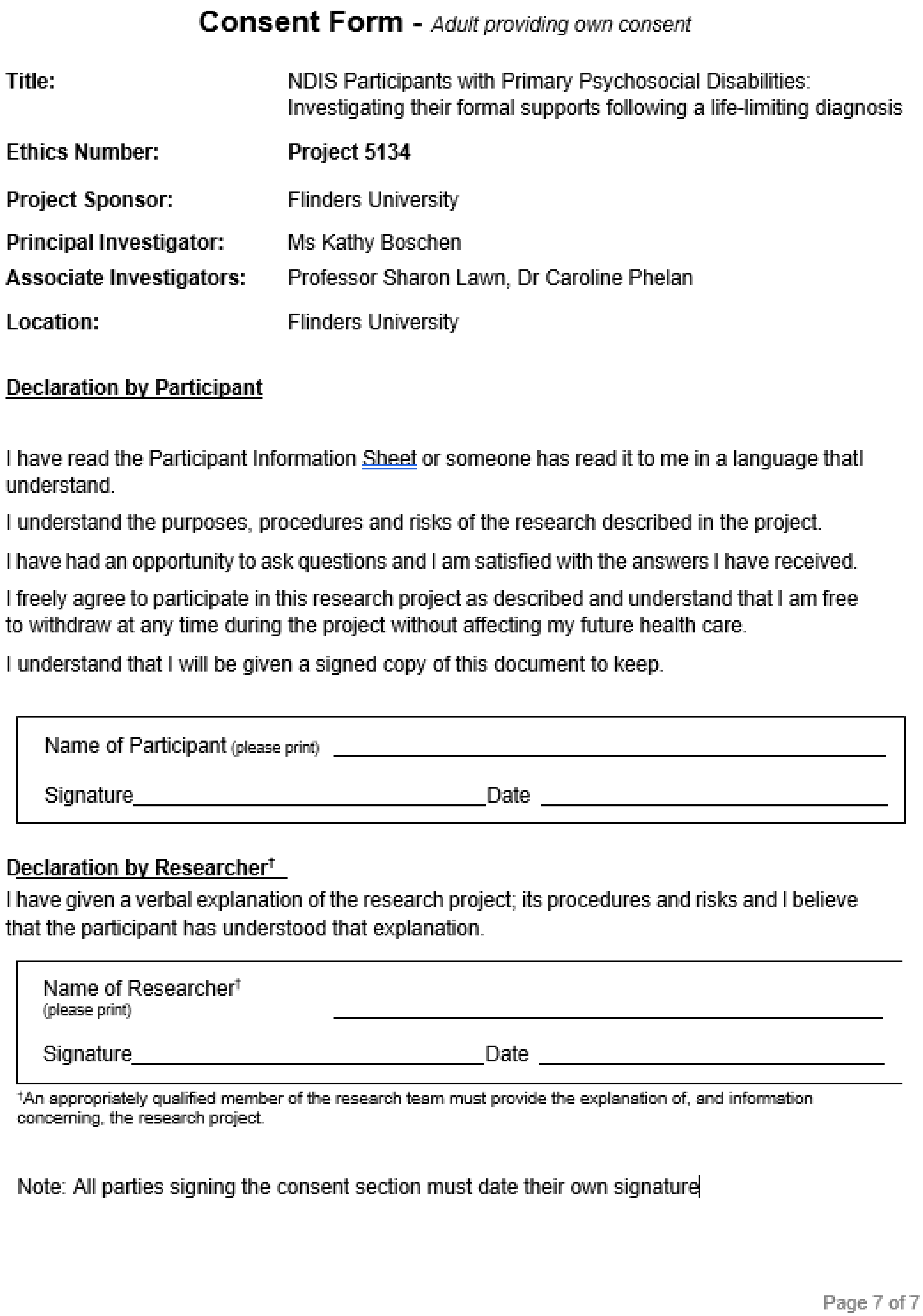
Research contact person

Name	*Kathy Boschen*
Position	*PhD Candidate*
Telephone	*0401 187 582*
Email	*kathy.boschen@flinders.edu.au*

If you have any complaints about any aspect of the project, the way it is being conducted orany questions about being a research participant in general, then you may contact:

Complaints contact person

Name	Professor Sharon Lawn
Position	Professor – College of Medicine and Public Health PhD Supervisor
Telephone	0459 098 772
Email	Sharon.lawn@flinders.edu.au



Consent Form - *Adult providing own consent*

Title:	NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis
Ethics Number:	**Project 5134**
Project Sponsor:	Flinders University
Principal Investigator:	Ms Kathy Boschen
Associate Investigators:	Professor Sharon Lawn, Dr Caroline Phelan
Location:	Flinders University

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language thatI understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) ______________________________

Signature ______________________________ Date ______________________________

Declaration by Researcher[†]

I have given a verbal explanation of the research project; its procedures and risks and I believe that the participant has understood that explanation.

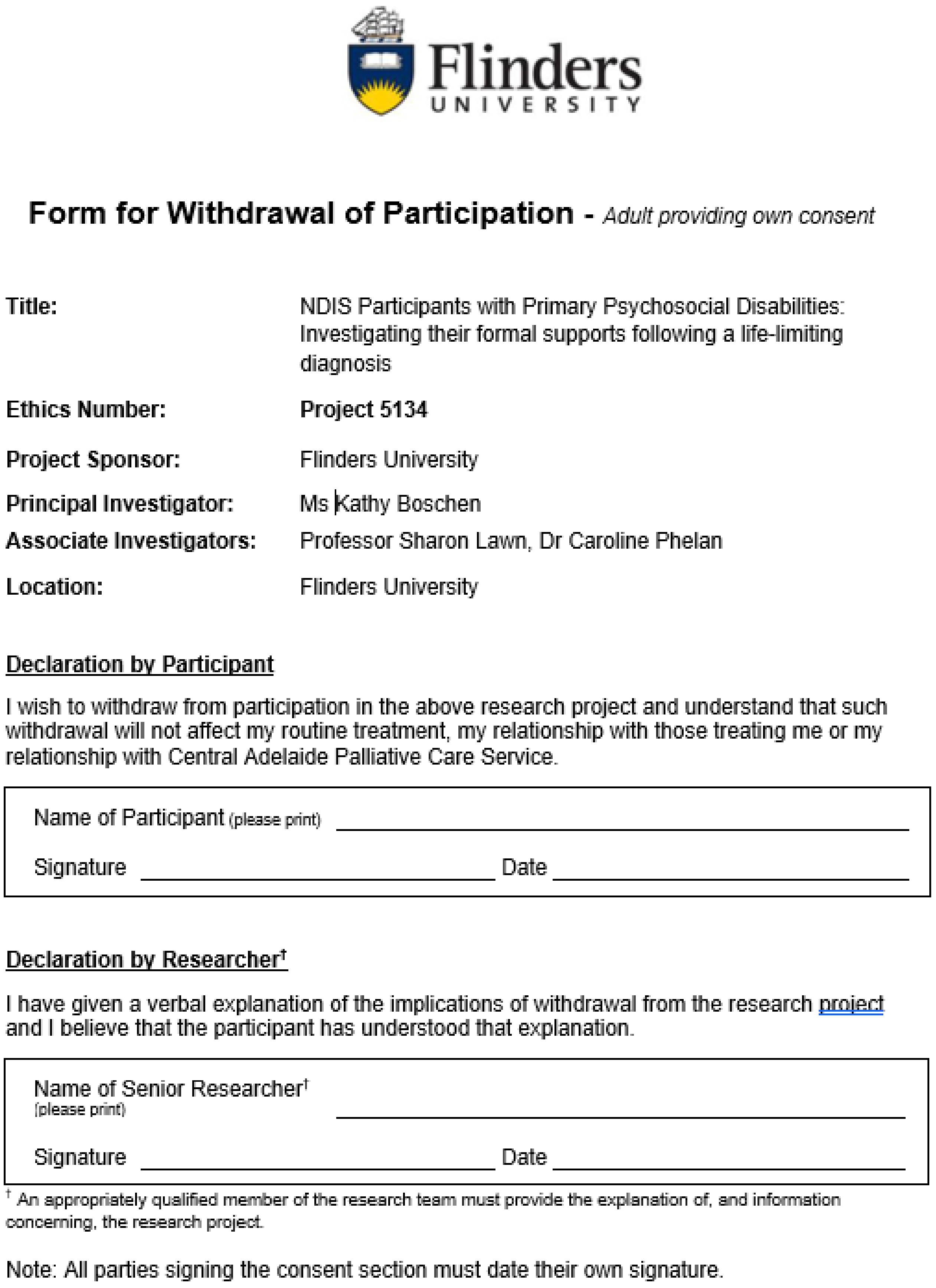
Name of Researcher[†] (please print) ______________________________

Signature ______________________________ Date ______________________________

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature

Appendix 9 – Research Withdrawal Form



Form for Withdrawal of Participation - *Adult providing own consent*

Title:	NDIS Participants with Primary Psychosocial Disabilities: Investigating their formal supports following a life-limiting diagnosis
Ethics Number:	**Project 5134**
Project Sponsor:	Flinders University
Principal Investigator:	Ms Kathy Boschen
Associate Investigators:	Professor Sharon Lawn, Dr Caroline Phelan
Location:	Flinders University

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment, my relationship with those treating me or my relationship with Central Adelaide Palliative Care Service.

Name of Participant (please print) ______________________

Signature ______________________ Date ______________________

Declaration by Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Senior Researcher[†] (please print) ______________________

Signature ______________________ Date ______________________

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Appendix 10 – Interview Guide

Demographics		
Expert in Which Subject Matter? • Palliative Care Nursing • Palliative Care Allied Health • Palliative Care Medicine • Mental Health Nursing • Mental Health Allied Health • Mental Health Medicine • NDIS Planner/LAC • NDIA Executive • NDIS Support Coordinator • NDIS Support Worker • NDIS Participant (psychosocial disability) • NDIS Participant Informal Support (supporting a person with a primary psychosocial disability)	***For Professionals:*** Manager? Operational Staff How long been employed in the profession and working with this subject area? ***For Participants and Informal supports***: How long have you been an NDIS Participant or supporting NDIS Participants?	***Age***: 20-30 30-40 40-50 50-60 60 years or over ***Gender***: Female Male Intersex Non-binary Prefer not to say
Questions	**Cues** **(informed from the literature review)**	**Prompts**
What is your understanding of palliative care?	What sort of care is involved when someone receives palliative care?	
What is your understanding of psychosocial disability?	This is the term used by the NDIS Often used in place for severe and persistent mental illness where the	

	impact causes substantial impairment across a numb	
Tell me about your experiences/s of working with/caring for/being a person with a serious and persistent mental illness who had/has a life limiting illness?	Have you ever worked with someone who had a severe and persistent mental illness prior to receiving a life limiting diagnosis?	How did this make you feel? What was that like for you?
Was that person a NDIS Participant? If not, would they have met the criteria to be an NDIS Participant? (Provide information about access to the NDIS during the interview) To be called "Person eligible thereafter"	Explain Section 24 of the NDIS Act (access requirements) if required.	
What is your understanding of the types supports that the NDIS funds for NDIS Participants with a primary psychosocial disability?		Can you think of any other of supports the NDIS might provide?
What is your understanding of the types supports that the NDIS funds for NDIS Participants with a primary psychosocial disability who have a life-limiting illness?		Can you think of any other of supports the NDIS might provide? Do you feel that there would be additional supports that the NDIS might fund?
If you supported /are a NDIS Participant with a primary psychosocial disability with a life limiting illness can you tell me about that experience?		How did that make you feel? What do you think caused that issue? Did you feel supported by___________? What could have been done better, do you think? Can you tell me more about that?

If you have not supported a NDIS Participant with a primary psychosocial disability who has a life limiting diagnosis, but a person would have been eligible for the NDIS – what do you believe the NDIS would have on the quality of supports and services experienced by this cohort?		How did that make you feel? What do you think caused that issue? Did you feel supported by___________? What could have been done better, do you think? Can you tell me more about that?
In your opinion do you/participants/persons eligible have/had an appropriate level of support from all of their services combined?	T	What impact did this have on you/the Participant/s/ person eligible?
Do you believe that the support received by the NDIS Participant or person eligible / you was seamless? Were support needs met in a timely manner?		Can you tell me more about that? What impact did this have on you/the Participant/s person eligible?
The NDIS upholds the right of NDIS Participants to live an "ordinary life"or one that is equitable, do you believe the NDIS can supports NDIS Participants with primary psychosocial disabilities and life-limiting diagnoses to experience support that is equitable as compared to (your) peers of their (your) own age?		Can you tell me more about that?

Appendix 11 – NDIS Participants Discuss the NDIS as a System

NP Interviewee	Positive	Negative
Anita	1. the NDIS comes in and gives you supports, good supports really good support	1. unfair 2. I was invalided out and so I still can't work, the NDIS doesn't see that as being enough. 3. the government doesn't want to approve things like that [transport] for psychosocial illnesses. 4. My plan is very limited and they're not open to negotiation
Nigel	1. I was lucky enough to, firstly get into the NDIS, have I felt reasonably lucky.	1. It was worse than having nothing 2. There’s been blocks every step of the way 3. takes a huge toll 4. no follow up 5. very disparate and fragmented and uncoordinated 6. There aren’t many options in a fairly small community 7. It’s impenetrable. And it’s not supposed to be 8. it’s very, very taxing 9. They turn the initial specific requests into something vague 10. Because it's all in code and unclear the you can't follow the chain of funding here.
Sam	1. it’s a lot better than nothing.	1. a nightmare for me, a nightmare

NP Interviewee	Positive	Negative
		2. it adds so much to stress to me 3. adding to my craziness in me head. 4. No one listens to me, 5. Just knocked me head off and sent me backwards very quick. 6. I was that pee'd off with everything that was going on 7. But no one cared 8. you've got to keep them [*the NDIS*] away
Rhonda		1. it's all different in the country 2. Even in the city, sometimes, it doesn't work. 3. There's too many on the scheme, and there's not enough getting off. 4. goes to a AAT, and that's where the problem is 5. they will actually take funding off me, yes. Because I am not, oh, how do I explain it, because I am psychosocial. 6. Continuity of care? No, it doesn't work on the NDIS 7. At the moment, it's not working terribly well, at alll.
Lucy	1. Extremely helpful 2. Seeing a psychologist which is proving to be the most beneficial part of it.	1. It's just not gone very smoothly 2. I feel I have no control over my life and I feel I'm just tossed around.
Kelsey	1. I was very lucky 2. It's saved my brother thousands a week with all the treatments I was having.	1. It's a lot of wasted money in the wrong area. 2. Once you don't use the money, you lose the money. 3. Confusing

NP Interviewee	Positive	Negative
	3. With NDIS, once you have a plan, no one really knows what you do with the plan. 4. I've never had the coordination I have that I've got now. 5. Everything's so fantastic, but I'm lucky.	4. I would not know how to work the NDIS system without [*my support coordinator]* I'd be so overwhelmed. I wouldn't know how to talk to them 5. NDIS is that the whole setup between the physical and the psychosocial, it's not a holistic approach. 6. When you're setting up for the first time with NDIS, it's a very depressing process, very depressing, and it actually sets you back 7. made me a bit more disabled. 8. a lot of lack of knowledge [*about the NDIS*] amongst the health professionals. 9. the majority would fall through the cracks. 10. Where's the point of being independent and then someone's stepping in? 1. But I don't think I could have had such success getting on NDIS if I didn't have that coordination first. 2. everyone had to write, all the reports that came back, had to say how bad I was. 3. I've heard cases on the news where, and I feel bad about being on NDIS when I hear these things. 4. you get scared to be too empowered because you get scared that your services will be taken away from you,

NP Interviewee	Positive	Negative
John	1. I make sure I get what I need.	1. I was quite pushed into going into it, and I did go into it after almost committing suicide because of it. 2. I don't trust them 3. Useless 4. they're very deceptive in terms of, they say that they're there to help you and that they'll listen to you 5. there's not many groups that are mental health focused. And that's a big problem with the NDIA. 6. there's not enough service provision, especially here in [*Inner regional town*]. 7. in a monetary sense in terms of remuneration, they're [*NDIS Workforce*] not getting what they deserve and then they don't feel that they want to come into it. 8. do not value psychiatrists
Kym	1. Really helpful. 2. I managed to get a really, really good plan, 3. I'm feeling very grateful	
Donna	1. the NDIS have been, at first, I didn't think much of it, and then, I struggled a bit with it. But once you get the right people, they're helping you, amazing. 2. A lot of people really love it	1. I don't really fully understand how the NDIS works 2. I didn't want the NDIS to be in my house. I was really angry when it happened.

Appendix 12 – NDIS Participants Discuss the NDIA

NP Interviewee	Positive	Negative
Anita		1. My plan is very limited and they're not open to negotiation 2. the government doesn't want to approve things like that [transport to therapeutic supports] for psychosocial illnesses. 3. we put in an appeal that wasn't processed and I became unwell
Nigel		1. the one person who wrote the first plan ignored most of what I said and put in some cut and paste general, vague statements, 2. So there’s this antipathy between support coordinators at local level and LACs 3. The LAC, set up meetings, before this, back a step, she set up teleconference meetings, she didn’t show didn’t show to discuss my plan. didn’t turn up, 4. LACs would not return calls 5. LACs walk away from it. They turn the initial specific requests into something vague. 6. “The plan is sometimes explained verbally, but it is not articulated in writing so it can be difficult to keep track of what funding has been allocated.”

NP Interviewee	Positive	Negative
		7. “The plan, the one person who wrote the first plan ignored most of what I said and put in some cut and paste general, vague statements, and many of them. How will this be accomplished? 8. The NDIA fraud team did not assist with a fraud issue I had with my provider.
Sam		1. My experience with the independent assessor made me want to pull out of the application process. 2. Was a very cold, “tick-a-box” process. 3. My worker [planner/LAC]in the NDIA he made the mistake. We couldn’t do it simply over the phone, and he didn’t recognise that he’d made the mistake. He wouldn’t take responsibility at all. It’s become a nightmare for us. 4. I relied on a local area person as a guide for me, mostly in the initial meetings I just sat there. I believe what everyone was telling me, the providers, the workers the whole lot, box and dice. I was just, I was getting dragged along I think without being able to put too much input in. 5. The planner asked me what my plan was to get off the NDIS. It was terrible, it left me feeling like a piece of shit.
Rhonda		1. I feel like if I ask for a review the NDIA will take money away from me.

NP Interviewee	Positive	Negative
		2. they took 20 grand off me 3. Because I have a bit of a problem because I am trying to get involved with the community, but to get the supports I need, I have to be sick enough to get the supports I need... but once you get out in the community, they want to stop them.
Lucy	No comments about the NDIA	
Kelsey	1. They [the NDIA] actually hired Mission Australia and trained them [as LAC's] specifically to get people on the NDIS. But they were so successful that the government was running out the money.	1. But they log you all into the same system, like the same diagnosis, the same experience or diagnosis. And they're making decisions on that without actually talking to the health professionals. And I'd like to know who's making these decisions because... Where in that does it say that art therapy may not be as good as CBT, in a mainstream system? 2. I lost money. And I'd love to know what credentials they have to make their suggestions. Because they were actually giving me suggestions on what sort of treatment I should have, basically. Which is quite extraordinary, I think, to be honest.
John		3. They're very deceptive in terms of they say that they're there to help you and that they'll listen to you. I don't want any more than what I need, they've said, "This is what you are going to get, regardless of your need. You get the funding for what they think you need. 4. the NDIA do not value psychiatrists

NP Interviewee	Positive	Negative
		5. my psychiatrist was dumbfounded, they won't even talk to him and he had to speak to a bean counter out of his own time for an hour 6. Because there's no value in the person doing something back in the community. That's what the NDIA wants. They don't have compassion for this side of thing because you're not going to go into work. You're not going lessen your funding and they don't see value in you. So if you are going to die, happy days, because it's one less person off the NDIS. 7. . They [LAC's] don't like me talking to them because I'm very matter of fact. I don't trust them, and I say to them, "These are my needs." And I say, "Don't piss in my pocket, I won't piss in yours 8. They actually hold off providing support. They actually hold off because it saves their funding.
Kym	1. I got a very good plan.	
Donna	No comments about the NDIA	

Appendix 13 – NDIS Participants Discuss the NDIS Workforce

NP Interviewee	Positive	Negative
Anita	1. She's my support coordinator with [Provider] and she's great she liaises with everyone. And so she's invaluable. 2. She's on top of it. It's just extraordinary. She'll go and search out groups that I can join. She'll go and things that I don't even know how to access. 3. I'm feeling very grateful	
Nigel	1. The new one who's diligent and ethical with the council 2. He was a nice guy	1. Ripped off by the first service provider, the support coordinator 2. He had said "I'm not really sure what I'm doing" 3. Not trauma-informed and I don't think he was informed about anything else. 4. I learned more about his personal problems than he did about mine. 5. he was not trained and he was likely to do more harm than good. 6. They seem to have no basic training in therapeutic support, or individual support. 7. A little bit of training would go a long way. 8. I don't think they don't seem equipped or confident or willing to really do very much on anything. 9. I'd prefer to have pay someone twice as much and get an adequate level of support for half the time, 10. You're stuck with people who are not capable staff

NP Interviewee	Positive	Negative
		11. that they don't want to 12. It's just it's just not part of their skill set or knowledge set.
Sam	1. Allotted hours and time with [*NDIS Psychologist's Name*] which is my number one. So I rely on it so much. 2. I've got a physio who does a lot of work for me and I, I use him also as a sounding board he's very good. 3. He was, he was well educated, and he run his business to the letter of the law, like [*NDIS Pschologist's name*]. I felt comfortable, he's helping me anytime 4.	1. I was never told from the lady that all the providers that were coming and assisting me, supposedly they ended up being all one family. 2. The coordinator whose mum was involved with my ex and the affairs and all that were going on in the local community. 3. She finally opened up to me a bit, and said yes it's happening. And so did these workers. So this is all happening and adding to my craziness in me head. 4. I took on a role where I felt I was responsible for them too. 5. Issues [would] come up that weren't really her fault, created by family, people the providers. But she wouldn't listen to me. 6. One bloke was driving me because he got a flat tyre, just left me there. I had to walk from one end of [Rural Area] to the other to get to my, my appointment. I was just left there. 7. I need this exercise, it's better for my brain than having someone come in and sit with me who I don't know and just sit there for an hour or two hours. 8. They wouldn't listen to me.
Rhonda	1. The one I had today was really good	1. They're limited in what they can do

NP Interviewee	Positive	Negative
		2. I had one support worker, for about two and a half, three weeks, and they gave her the axe because she didn't turn up for a week. 3. was more kid orientated 4. Most of them have been less experienced. 5. I'm tired of training people.
Lucy	1. Extremely helpful 2. Things were going well, I'd got used to her coming into my house. 3. makes such a difference. 4. the plan manager is excellent	1. insensitive 2. really fucking bad 3. really harmful 4. I don't really want her in the house anymore. 5. her empathy and ability to provide emotional support was zero 6. She knew that she had a client who was really sick who should be in hospital and she just left. She didn't arrange any support like CAT team assistance or anything. She just left. 7. Ended up dreading the appointments 8. She was completely useless, absolutely useless 9. I didn't feel comfortable with her coming in 10. I've dealt with through the NDIS who are really crap 11. recovery coaches haven't met expectations 12. unreliable

NP Interviewee	Positive	Negative
Kelsey	1. very successful, it's working. 2. I have a really good coordinator 3. I have a wonderful team now	
John		1. They're not qualified enough. 2. They haven't got enough training.
Kym	1. I had two or three really good ones 2. My support coordinator has been very supportive	1. I started getting random people and not-so-efficient workers, I guess, towards the end.
Donna	1. She is amazing, she has been so great to me	1. When the first couple people came in, I wasn't very happy at all. 2. There was one girl there I felt really sorry for it, but she just drove me nuts.

Appendix 14 – Informal Supports Discuss the NDIS as a System

IS Interviewee	Positive	Negative
Penny	1. NP Almost died just before the NDIS came on board. 2. [T]he NDIS started, and we could start seeing a light at the end of the tunnel. 3. Oh my god. It's amazing 4. We really love the NDIS we know it's transforming lives, or it can transform lives. 5. Since he's been with NDIS he's had no [*psychiatric*] hospitalisations, it's quite remarkable. 6. I have a friend who gets so much more support than she used to get before the NDIS. 7. We've been so lucky. But in so many ways that's also frustrated me because I think it shouldn't all be dependent on luck.	1. Now they're starting to cut. They don't want to encourage people to to have what we've had 2. I have to say there are a lot of problems with the NDIS 3. there was a lack of understanding about psychosocial disability. 4. we're just frustrated for other people 5. NDIS that supplied support to *participant*] that was insufficient, and this was demonstrated by the fact that he nearly died 6. they [the NDIS] hate the word but there needs to be a case manager who looks at the whole of life of NDIS participant. 7. personally can't understand why people need to get $200 an hour to do a job. Sorry. I just think this is crazy 8. They rang her and told her the money had run out months before the end of the plan. She's got no support now. 9. Just not confident about anything at all, Honestly, it's just a lie at night worrying about the future. And I don't just like worrying about my son's future.
Sally	1. We've got excited about it actually, we've loved sending the applications in. And we've got an I love NDIS sticker	1. People with NDIS with psychosocial disabilities are not getting into it. Yes, they're not getting enough funds.

IS Interviewee	Positive	Negative
		2. They don't necessarily have the capacity particularly at the beginning to manage their own supports. You know, even when given support coordination, or they're given the lowest level of support coordination.
Simone	1. the NDIS, it's all about helping someone to become a functioning member of society, to be able to access the community to the best their ability, and live their life so that they can function, not be impaired by their disability just because they can't afford to get the proper supports. So that's where the NDIS steps in, which I find really great for so many people. 2. been a real godsend, because I can't afford that. 3. I guess fundamentally they probably do a good job,	1. When you go on the NDIS website, in the very first instance that you think, "This is a good idea," it's busy, it's daunting. And if you have a disability that affects your mental state, you can't navigate that. That would be impossible, I would imagine. 2. NDIS is a tick-a-box. 3. They're not looking at the person, they're looking at the paper 4. The focus of NDIS, is what can't you do 5. We were rejected right at the first hurdle 6. It was all about language. So everything was in that application, but the language was incorrect. 7. It's not normal language. And that's what I find with NDIS. It's very confusing for a lay person to enter into the NDIS. 8. When you consider your NDIA and you got NDIS, we'll hang on up, they're the same thing, then you have the LAC. Well, what do they do?

IS Interviewee	Positive	Negative
		9. Once the application was approved, I still didn't know what was going on. I had nothing, really. 10. Even, if she knew NDIS could help, she wouldn't want to talk to them, because she doesn't know them and they're a faceless thing 11. I put down everything that I could think of that could pertain to failed attempts in becoming a functioning member of society. And I figured that that's the focus of NDIS. 12. They're just tick and flick, they just want the money. And they don't make you feel better, they just, it's kind of like, "Yeah, move on, go away." 13. if I were to do a review myself, I'd find that really daunting, because of the experience that I had in the application. 14. I think where NDIS falls down in terms of being able to deliver it, is in their accessibility from talking to them direct and talking to a person, not a telephone, and then pushing that out to a LAC that really is the same, I find. I don't find them to be any different, and I don't really understand the difference between the two fully. Neither of them can give you advice, they can just point you in the direction. 15. because now they're approving mental health supports, But it's probably nowhere near the amounts that people with a physical

IS Interviewee	Positive	Negative
		disability get. It's probably nowhere near the understanding that a person with a physical disability has. 16. your mental health's included, but nobody's able to support that.
Stella	1. They're a lot more responsive now to reviews and change of circumstances. 2. it's been much easier. I don't have to jump through hoops. I don't have to put any more reports….. So I think they believe, and maybe understand a little bit better now.	1. The NDIS is an incredibly complex chaotic system that is very reactive, it's not proactive 2. Incredibly difficult, and frustrating 3. The NDIS wouldn't know where he was, what he was up to. There's no checking to see where he's up to 4. And I worked with [*Health Department]* for [*decades*], and I thought that was pretty chaotic, and bureaucratic etcetera. But the NDIS is so much worse. 5. Once the application was approved, I still didn't know what was going on. I had nothing, really. 6. for some reason the NDIS is like this big mountain over here, and nobody really understands, or touches.
Barbara	1. We know they're doing great work 2. look don't get me wrong, I'm very grateful to have NDIS both for my son and in Australia, like you know, … my	1. To deal with the NDIS can cause mental health issues, certainly a lot of psychological distress. 2. It's just, it's not equitable at all, because for some people where depending on who their service provider is, or what services they get

IS Interviewee	Positive	Negative
	past clients and everything, like I can see it's like a life changer	3. Really rigid 4. It's so piecemeal. I mean even within the NDIS it is – it's not seamless within the NDIS, you know, it's all down to who you talk to on the day. 5. They all have a different interpretation or a different level of experience as well. And so, then that's influencing whatever you're getting from them, rather than how it should be or how the legislation has been written, or the policy, it's all just so piecemeal and ad hoc, and down to the interpretation of people, 6. how do we approach them, or who they are it's – it's really quite bizarre. I think it's just too … and too complex for people. 7. Such a lack of continuity. 8. It's not seamless in any way. 9. This crazy, unwieldy beast of NDIS.
Jack		1. setting up an adversarial thing is, in my experience, not necessarily the best model. 2. It's too cumbersome. 3. There's too many non-professionals

IS Interviewee	Positive	Negative
Brad	1. [S]ince NDIS they've got more funding than what they had especially with the one on one CP [community participation] stuff. 2. I've noticed a lot more staff there than what there has been pre NDIS 3. The NDIS has improved their services to a small extent 4. prior to NDIS they really didn't do much at all	1. Workers not funded by NDIS to do that [support a person in hospital] because basically NDIS make it really clear 2. NDIS is very much "we're NDIS that's healthcare". There's no cross over. 3. NDIS is not responsive. 4. NDIS has created a lack of trust in the quality of providers. 5. This person was living in an SDA, the NDIS doesn't really have a space or place or funding for those very important cultural events.

Appendix 15 – Informal Supports Discuss the NDIA

IS Interviewee	Positive	Negative
Penny	1. [W]onderful NDIA planner.	1. [T]he NDIA are really trying to cut down 2. [P]eople with psychosocial disability. I don't think they're at all given the attention that they need from the NDIA. I really don't. 3. Mental health have pushed NDIS towards a recovery orientation? I just think this is crazy. And I think I've written it didn't undo the paper that you know, I think that's confused. It's considerably confused the NDIA. 4. People with NDIS with psychosocial disabilities are not getting into it. They're not getting enough funds.
Sally	1. Understanding from the NDIA planner was totally non existent. Because they were asking the wrong questions. It wasn't getting to what he actually needed and, and it was only because I was there and the worker was there, or probably me because I've had that knowledge of the NDIS.	1. They [*the NDIA*] said can we get an OT assessment? I said, Well, it's that's not a trauma-informed response because [*participant name]* don't like to talk to people they've not built up trust 2. Understanding from the NDIA planner was totally non existent 3. I am skeptical about the NDIA's intentions. 4. I don't trust the NDIA.
Simone		1. [W]e were rejected right at the first hurdle 2. I've never really spoken to anyone at the NDIA.

IS Interviewee	Positive	Negative
		3. [*Regarding an LAC*] t I felt like they are limited in what they're allowed to do. So they're not allowed to recommend, they're not allowed to guide or coach or anything 4. I don't think they really understand all of the mental health issues 5. So to have that dietary support was essential, but it wasn't included. And so now we're having to go through heaps of review to include that.
Stella	1. It has improved a lot from the beginning. 2. So it's been much easier. I don't have to jump through hoops. I don't have to put anymore reports. I mean there's an update from the support coordinator, or the behaviour support people. So I think they believe, and maybe understand a little bit better now. 3. They're a lot more responsive now to reviews and change of circumstance.	1. They couldn't grasp the concept of waxing and waning, relapsing, and recovery. 2. I still don't think that they understand the complexity of it. And how it can change 3. They don't have a great grasp on specific diagnosis within mental health [schizophrenia]. 4. It was a matter of educating the NDI[A] that yes that does happen, it can happen, and here's all the evidence, and the reports. But there was a little bit of scepticism, or disbelief. 5. Very intrusive questioning about specific incidents, and traumatic experiences that I've experienced, or witnessed with my son 6. They don't ask me anymore. They don't ask is he still hearing voices? Is he still suicidal? Is he – I mean it was very, very intrusive,

IS Interviewee	Positive	Negative
		and triggering, like retraumatising in the beginning. Having to relive – literally I had to relive memories 7. I think the hidden agenda was - is this really true that such a young person can have such a history of psychosis, and – and mood disorder to the extent that they're saying? And how bad is it? 8. I could tell that they probably didn't have any training, or experience in the mental health sector at all, because I was explaining what a diagnoses meant, and the medications. They don't understand when I said, here's the medication list and what they're for. I had to spell it out. And so I could tell that they weren't on the same page knowledge wise 9. [I]t depends on who picks up that piece of work, and what they – how they triage it. What is their understanding of it. 10. If I talked about the goal being recovery, which is what it's all about when you have a psychosocial disability, they were really confused about that. So – okay so you won't need NDIS, you won't need supports once he's recovered? And what does – what's the baseline? So has he reached his baseline yet? So it was very frustrating to have to explain the concept – the theory of recovery. And that the person still needs a multitude of supports, and that picture can change in hours.

IS Interviewee	Positive	Negative
		11. So they've cut my son up into pieces – because he has neurological issues as well. So he's diced up. Now so we're not going for neurology, or psychiatry, but we'll pay for music, and this vocational program. Okay, so it's not a holistic view anyway, it's very fragmented.
Barbara		1. They ended up with these goals that – not overly happy with, that have apparently been reviewed and revised, but actually, officially haven't been, and he – then I had, I checked with him, 2. Then lo and behold, my – he'd left, you know, he only lasted a few months at the most, and then I've had two other LAC's since then. No one's even told me when they've left. There was months there where I've had no one and I couldn't – I tried to get in touch with them, and I couldn't get in touch with them. They kept on referring me back to him, but he had gone from the organisation and his supervisor wasn't communicating with me. 3. So he's had a review since then, and pretty much all the things that I argued with this original coordinator about, this other person has said, yep, he can have those things. But they haven't put it in writing, and they won't put it in writing.

IS Interviewee	Positive	Negative
		4. She said she changed the goals, and she didn't, at the review meeting – she's just rolled it over 5. They questioned just really basic things that are actually important to, actually even just to his actual safety.
Jack	1. I think having been there for a couple of years now, a lot of the processes are maturer, in terms of dealing with people with mental health issues.	1. [D]isease progression advances faster than one can write reports and get things approved. So I would say there's a huge catch up. If there is a life limiting disease process occurring, the NDIA would never be able to keep up with that 2. [Discussing an LAC] He's there for a job but he's not there for actually supporting the scheme : He wasn't a true believer. He's just ticking boxes.He was a new grad, no life experience, thought he knew everything. 3. They're just there for the job, they just bubble along and don't really make any headway. 4. I think there's very much a training and skills gap [for NDIA staff and the NDIS workforce]. 5. I think the people in the NDIA are insufficiently qualified to do what they do. I think that there's, that has a lot of flow on effect from the perspective of what reports do I have to do for these people. Because they lack skills and qualifications,

IS Interviewee	Positive	Negative
		6. they're looking for key words, they don't necessarily understand what the key words mean. But if I get the key word then it's a tick, I've met that criteria.
Brad	Nil comments regarding the NDIA or NDIA staff.	

Appendix 16 – NDIS Providers Discuss the NDIS as a System

NP Interviewee	Positive	Negative
Adam	1. A vast number of people are now working privately instead of for big companies.	1. Information is not shared, within the NDIS or between systems 2. they're not doing anything but continuing the status quo 3. I don't think that the NDIS, we want to talk about that for a minute, is really able to cope because people with psychosocial disabilities along with the whole raft of other disabilities. 4. they needed Recovery Coaching, but they weren't getting it 5. it's hit and miss 6. the NDIS is paying for people to do a half-arsed job. 7. NDIS can leave people in risky situations through lack of support. 8. it's a bit sad that the costs associated if you go to become NDIS registered are so high 9. The registration process is too long. 10. So more and more people are turning to becoming private, and the reason is that the pay rates are so low, the expectations are so high. 11. the NDIS has limitations because they try and put everyone in the same box doesn't work. 12. the biggest issue because there is a significant amount of wastage.

NP Interviewee	Positive	Negative
		13. The support workers, because to a large degree, there are going through a rotating door and they don't hang around, and because of the pay scales they're on. They'll move for five dollars for 2, 3, 4 or $5 now. The participant, at the end of the day has no continuity of support with their workers. 14. You do not get paid to write up incident reports. 15. Not enough funding for training
Tina	1. participants who know the system very well can get what they want because they know they know how to get it	1. and then other participants who really need help and support and they're very confused about the whole process and because they don't know what to do to get the help up because they're unable to tick the right boxes 2. The NDIS workers who work closely with a participant have the least ability to support them during the planning process. 3. PwPD have different people coming in and out, which is a big issue in the industry at the moment, leaving companies because of high volumes of work , burnout, stress . 4. PwPD often have little knowledge of how it works. 5. You can build a rapport with a PwPD then their plan is reduced, and your support is no longer funded. 6. You don't have much power so you're tied to what you can do. And then you can be emotionally distressed. Because you know

NP Interviewee	Positive	Negative
		that there's so much more that you can do and you want to be able to do that you can't. 7. Capacity building supports are rarely funded. 8. I think that a lot, a huge gap in weakness in the way that the NDIS has been structured is that a lot of, not all, but you know, in most, more cases than not, the support coordinators don't need to be qualified in any mental health related area. 9. A lot of the work we do is unbillable. 10. Families often don’t know what’s going on.
Peter	1. The NDIS has enabled us to build a large company supporting many participants.	1. Conflict of interest is not well managed – providers offer plan management services and then pay themselves for other supports they provide to PwPD. 2. PwPD poorly understand the system, and providers are taking them to court if they make mistakes when booking and receiving services. 3. The current system makes it difficult to complain or take action against unregistered providers. 4. Plan managers have to take on a debt recovery role for overpayment. 5. Providers do not understand the NDIS and inappropriately book PwPD to supports that have not been approved.

NP Interviewee	Positive	Negative
		6. The guiding principles of the Act that are relevant to a number of matters have now been altered and no longer aligned to the UN Convention. 7. It misses out the insurance principle, the principles you develop work with people and their communities. So they can participate to the full extent and therefore reduce dependency on welfare. So all those things have been removed the quality components around investment in potential improvements and technologies that's been amended. So quality now becomes a compliance issue. 8. It uses the words of medical model 9. we won't know the person's disability or until we speak to the person and then it largely based upon the the nature of the engagement 10. A good worker,if we keep them for eight months, we're very happy. So the funding affects everything. Yes, everything. So our ability to develop staff around psychosocial disability is is difficult and our ability to retain people. 11. The funding model can be really difficult for PwPD to manage, it can be too much. They can run out of funds before the end of their plans and this can put them at risk.

NP Interviewee	Positive	Negative
		12. Good outcomes depend entirely on the informal and formal supports around the PwPD. 13. The NDIS model means that providers can, or can threaten to, withdraw multiple participants if their, not the PwPD's, unreasonable demands are not met. 14. Some providers are controlling all aspects of PwPD’s lives. 15. The unfortunate reality of, whilst the NDIS aims to make disability mainstream in many ways, it has separated from developing a holistic model, it has become something that you'd never design, that no human being would ever design. 16. The NDIS system has young NDIS workers, 20 years old, on award wages, making significant decisions that impact and can harm participants. It’s nonsense. 17. Whilst this is an insurance scheme, based upon the principles of longitudinal insurance, based on quite inspirational social policy on behalf of the Australian People's Government, its actually now becoming an insurance scheme that reads like an insurance product disclosure statement. So if your window breaks, it can be repaid but only that breaks this way. Not that way.

NP Interviewee	Positive	Negative
		18. [A] participant's NDIS plan is a financial plan. It may have the person-centred statements - all about me - and all the rest of it. But once it goes from that, write-up, it's a financial plan.
Sofia	1. NDIS is flexible. It is considerate of the individual's needs and it is accepting of many say therapies that would have never had access to government funding to exist. 2. I feel NDIS is more responsive and within a reasonable timeframe.	1. [T]here are limitations as far as what you can charge and what hours you're supposed to work in. I find it very hard to stick to those guidelines and I'm forever working for free 2. The supports and services are very basic and there are limitations on quality. 3. Unfortunately, clients take their information from places like Facebook, or one example in an article and they say oh, I would either really love that. But there's only 10 across Australia 4. There's massive waiting lists. 5. I've financially backed another provider to provide hours of care to a PwPD, it saves me a lot of time cleaning up crises if she is on the NDIS-funded hours. 6. There probably be more work in offering your own justification for needing funding that you use what you what work you needed to make into a presentable document to only be paid for that work anyway 7. [I]t's unrealistic

NP Interviewee	Positive	Negative
Michaela		1. It's an industry problem. It's it's the fact that we the minimum wage is so low and the minimum qualifications and entry into these roles are very low or if not none. 2. The NDIS tends to put this black and white line up and say no.
Kelly		1. I think that they were much more intending the scheme to be for more intellectual and neurological and physical kind of disabilities and psychosocial was kind of an afterthough 2. There is not a single day goes by that somebody doesn't ask for the NDIS to fund something. And so it grates against my values. 3. In terms of the quality, that people are getting, it's hugely variable 4. The NDIS does not recognise the importance of case management or care coordination. we're having fortnightly team meetings, you know, and that's been for months. Who pays for that?
Blake		1. I still think that a lot of the NDIS is targeted more towards other types of disabilities really, and that one is not necessarily the be all and end all of what is needed to support someone with a psychosocial disability. 2. it doesn't necessarily reflect the type of support that I've worked on psychosocial where you might be coaching people while

NP Interviewee	Positive	Negative
		you're doing that kind of thing. It's more of a get into the job get out type arrangement. 3. I think the NDIS is almost too far the other way that it's just on the support, it doesn't actually consider the other elements that go into creating a really intentional, effective evidence based service 4. I think it puts our staff under immense pressures where we're talking logistics in our program. 5. [*The NDIS does not allow time for staff to debrief*] for their well being in the you know, longevity of their time in the role and also for the customer to make sure that, you know, the supports are actually planned and considered. It's not just you doing the same thing every week and you know, you don't have to think about it. It's actually progressive and planning and responding and, you 6. know, trying to reduce behaviours, training, increase capacity. 7. [W]e've invested a lot in technologies to make it easier for people to provide that information [*incident reporting*] on to flag risk factors in the system but I know a lot of providers wouldn't necessarily have that. So I think there is a real risk 8. [T]here's a bit of a difficulty [with] flexibility….. with block funding had a more fluid approach.

NP Interviewee	Positive	Negative
		9. Not funding case management is unhelpful to participants and service providers. 10. The psychosocial recovery coach model is difficult to interpret.
Tabitha	1. It is absolutely possible for them to get a good level of support under the NDIS.	1. [The NDIS] can easily divide a person up into pieces. 2. The, the whole conceptualisation of how human beings present with their range of needs, is problematic the way that we conceptualise distress, the way that we need to medicalise distress in order for it to be validated. The way that we need a diagnosis in order to receive any kind of funding and support to overcome things. And so it actually just begets more diagnoses. 3. There is a skills deficits in the whole NDIS space 4. Section 34 of the NDIS Act that talks about what's reasonable and necessary. Including supporting families and carers is quite often dismissed as not being the responsibility of the system even though it's in the legislation. 5. There is a lot of unpaid work happening. The model isn’t working, I’ve seen a number of big providers in this space [psychosocial disability] close down. It’s unacknowledged. Market failure says, well, we can't afford to do this anymore. So you'll have less providers available.

NP Interviewee	Positive	Negative
		6. [I]n place of an attuned therapeutic response. You'll have an administrative response, funded by this system. And which leaves people in their distress alone. 7. [I]t's not possible to provide professional development at a $57 an hour price point in support work 8. Reducing everything to line items to stop flexibility of provision of support is a problem in itself. I mean, I've heard it said that it was ex workers at the ATO who actually moved to the NDIS and drafted the price guide, and it fits their ways of thinking but it doesn't fit. It doesn't fit humanistic practice. To be so reductionist. Yes, it's just actually quite disrespectful, I think, to reduce a person's life down to a series of line items. Yes. And to presume that we can then craft out a schedule of supports. It's we're not making a Ford vehicle. It's not Henry Ford and the production line. I just find this as the antithesis of what we need to do good work with people and to really support them in their lives. 9. the system's [NDIS] set up in a very middle class fashion, as though everyone has the same capacity to self represent when in fact that's not the case.

NP Interviewee	Positive	Negative
		10. I feel like the framing of this whole space needs reconsidering and that's not news. It's been addressed in a number of reports for a long, long time. We keep restating the obvious Yeah. But for some reason, this is an area of knowledge that there's not huge there's not a tipping point of public understanding to get a political will around. I think.
Heidi	1. The NDIS has made participants lives much better. 2. Workplace is learning how to provide capacity building supports due to NDIS funding And it's been a learning experience for everyone. But are they're, a lot better, a lot better 3. Before the NDIS it was not busy. Now the NDIS has come in and I'm just like working. I barely, I do not finish what I need to do. 4. I think things have changed. And I think it's huge, hugely improved. And I think it will continue to improve. 5. In my opinion, it could be better but I mean, what their life was before. What is now Yeah, I mean, they were so oppressed before. They, you know, ask for what they want. Is just hugely improved. Hugely.	1. I think that on another level people with anxiety may not get support from the NDIS, who need it 2. they all need more individual support that they don't get 3. At the end of the shift. I'm working a lot on my own time. The paperwork, it's just it's a full-on job now.

Appendix 17 – NDIS Providers Discuss the National Disability Insurance Agency.

PR Interviewee	Positive	Negative
Adam		1. The NDIA does not tell the participants why they have been allocated psychosocial recovery coaching, I don't know why and they won't talk. 2. The NDIS Planners and LAC's have too many clients. 3. the NDIA, they have a very huge turnover of planners and lacs. I can't speak to their skills or knowledge. I can speak to the fact that everything is in a hurry and everything is rushed. And we are dealing with people's lives. 4. I think that, at the LAC level, it's like, put it in military terms it's like you've got a whole pile of privates. There's limited, limited knowledge and limited skills. 5. What happens is the LAC can write up and agree to anything they want. Then it goes to the NDIS planner who generally knocks about 80% of it out without actually understanding, knowing anything about the individual or his specific, his or her, specific needs or requirements. So it's just knocked out and that's that's it and you can go to review, and I know from anecdotal evidence going to review really isn't really worth the

PR Interviewee	Positive	Negative
		effort because you get knocked back and you end up having this massive fight
Tina		1. The NDIA need boxes ticked to grant funding. 2. Support workers are very isolated from the NDIA if if there was a way that we could communicate directly with the NDIA and update them with notes and progress, like I think that would really make a big difference.
Peter	1. the best thing about NDIS is as the NDIA the worst thing about the NDIS is the NDIA. It's one of those really is unfortunately, very haphazard. (In both postive and negative columns.) 2. We have worked together ith the agency to help a participant where a provider was trying to claim fees inappropriately.	1. The NDIA if they detect something they feel is an overpayment, it's not in accordance with our rules. You the plan manager now have to get the money back from the provider. is provided mostly accommodation. If not, then you're liable to pay the full amount. 2. The NDIA are litigious. 3. it's very, very rare that I will have someone on the end of a phone call or a meeting like this in which the the level of understanding means that we can't unravel a problem other than to quote legislation each other. 4. The NDIA make very arbitary decisions what supports should be funded then take steps to recover money for supports that have been paid for. This can leave the plan manager or the participant

PR Interviewee	Positive	Negative
		with debt which can impact their housing situation and wellbeing. 5. [If a participant dies and providers charge for a no warning cancellation] the agency will ask us to persue a debt recovery from the provider, you have never seen anything so insensitive in your life. 6. [T]he amount of people in the agency who have that understanding is it's not where it needs to be.Understanding of disability compassion, empathy, these things. 7. the best thing about NDIS is as the NDIA the worst thing about the NDIS is the NDIA. It's one of those really is unfortunately, very haphazard. (In both postive and negative columns.) 8. The agency do not understand the responsibilites that fall on plan managers, they tell us we are just there to pay invoices. 9. The agency doesn’t have a a handle on how providers can influence or take over a person’s life. 10. We've had battlegrounds with the agency 11. he agency has to continually amend the legislation, the statutory rules to adopt its stance 12. There's so much that has on a superficial level. The participant service guarantee is there but the mechanisms behind all of that,

PR Interviewee	Positive	Negative
		gee it's very hard to get through the rhetoric of the NDIA and DSS isn't it there's a lot of rhetoric and look at what great work we're doing and you know, and so finding going back in through what they're actually doing can be quite challenging
Sofia		1. Don't say the word crisis to an NDIA Planner. They are just like, No, we don't deal with crisis. 2. The planners secretly think that you are lying when asking for support. 3. So NDIA refuses anything if you say crisis, it's actually the opposite of mental health.
Michaela	1. NDIA Planners are not consistent, you may get one planner that really agrees with your approach really understands mental health and is empathetic, empathetic and wants to do what they can to help and then you will get a very good package that supports the participant in a very, very well. But that is the best case scenario. I would say more than not, it's the opposite. (In both positive and negative columns.)	1. The NDIA are not responsive enough. 2. NDIA Planners are not consistent, you may get one planner that really agrees with your approach really understands mental health and is empathetic, empathetic and wants to do what they can to help and then you will get a very good package that supports the participant in a very, very well. But that is the best case scenario. I would say more than not, it's the opposite. (In both positive and negative columns.) 3. The NDIA tends to put this black and white line up and say no.

PR Interviewee	Positive	Negative
Kelly	1. If someone was dying the NDIA would want to help, I can’t answer whether they could actually do it.	1. they didn't have enough staff in the email section. And I called the NDIA five times and they kept saying, “Yep, I've escalated it to a team leader. Yep, this and that”, but it literally took four months to get even get these documents uploaded. Nevermind actually get them to the review team to look at it. 2. Because she [PwPD] also has physical disability in her second plan, she got a heap of money for OT and trialing equipment, and hire of equipment. And so there was 10s of 1000s of dollars spent. That OT request went in. And the planner just decided that psychosocial was her main disability and so therefore, she didn't need any equipment. So her third plan had zero equipment in it and less OT and it took nine months. You know, appeals and things and I finally took it to the federal member. And but she was due for her review anyway. But then, so who knows whether it was taking it to the federal member or just she was due for renewal. And she actually got all the equipment she needed in this current plan. 3. Variability in NDIA Planner’s capability is a humungous issue. 4. Not being able to contact NDIA Planners is a massive problem. I guess their addresses sometimes and I’m sure they just look at it and go delete.

PR Interviewee	Positive	Negative
		5. Well, I made like six phone calls. So every time that every time they have to go through your ID Yeah. And then tell you that you don't have ID you don't have consent, and you argue with them and say yes, I do. And then they go, Oh, look, I found it.
Blake	No comments regarding the NDIA	
Tabitha		1. Review meetings are traumatic for families. 2. It's definitely a directive inside the agency to limit funds being disseminated to this group. [PwPD]
Heidi	No comments regarding the NDIA	

Appendix 18 - Mental Health Clinicians Discuss the NDIA

MH Clinician	Positive	Negative
Brenda	1. The NDIS gives some PwPD the opportunity to live independently, which they didn't have before. 2. I think one of the really good things that the NDIS has done for psychosocial disabilities, like validate the disability element. And that up to the point of the NDIS. We didn't validate it. You know, basically, it was about scrounging and finding things for people and you know, we had the community mental health support sector, but they weren't providing [functional] support.	1. The requirements of the NDIS for access and planning are placing other systems under exceptional strain producing evidence and resports. They will not accept functional assessment reports. 2. NDIS does not appropriately address housing issues. 3. They [PwPD] have to stay in hospital a lot longer than we would hope because of the NDIS. 4. It is very slow to respond. 5. Inequitable, you need to have good advocacy around you to possibly achive equity or have access to allied health support. 6. Plenty of inconsistencies. So it is planner to planner. It's bureaucrat to bureaucrat, it's, you know, it's a very inconsistent scheme. 7. It has its own language, don't talk about recovery, definitely don't talk about substance abuse. 8. There are no checks and balances for providers, no standards. The NDIS is provider dependent. 9. NDIS does not see a person holistically. 10. They don't like psychosocial because it's so grey. You know they can't deal with it.

MH Clinician	Positive	Negative
		11. the NDIS said at the beginning oh it's not about diagnostics, but it is absolutely about diagnostics, at every turn. 12. In the area of psychosocial support, it has declined a lot.
Jordana		1. I think that if you've replaced the word ordinary with bland Yeah, that is what they found that minimum necessity. Yeah. Yeah, they want to find them to live, to live. To survive. Yes. Not to thrive and flourish and, and have quality of life. Just just enough. 2. A lot of friends that I have that are OTs, that previously have worked with NDIS have left the field, not because they didn't enjoy it, but just over the years, the expectations and requirements of reports have just become so ridiculous that, you know, they're spending 15 to 20 hours on a report and it's just not sustainable for them. So trying to understand and work within a framework that is not clear. It just makes burden on everybody. 3. I can tell you straight out I don't know how it all works. So how can I give them the best information when I don't understand? Yeah, and every time I think I do they change the rules, where they adjust something.

MH Clinician	Positive	Negative
		4. The NDIS push for independent living options instead of supported independent living will increase risks. 5. Causes people to disengage. 6. NDIS has such a physical focus, its less based on purpose. 7. For people with borderline [personality disorder] and itself is difficult to work with and within NDIS it's an absolute nightmare
Alice		1. Everything takes time. 2. There's a real lack of education and a real lack of understanding about what NDIS can do, what it does, how you who, who's eligible. I really think it fails this. 3. It’s hard to get help and services, there’s quite a lot of fighting. 4. They need to better support carers.

Appendix 19 - Palliative Care Clinicians Discuss the NDIS

PC Clinicians	Positive	Negative
Sylvia		1. it's been a bit tricky 2. it's a long process, long time-consuming process 3. Knowing that you use NDIS funding every time you speak to a support coordinator is very stressful. You worry about the participants running out of support coordination funds.
Amy	1. NDIS Providers really want to come from an empowerment perspective and, give this back to participants wherever they can to do it for themselves. 2. It is good that participants can change providers and get a fresh start, lose the baggage. 3. The PwPD and life-limiting illness is beautifully supported where he lives [in a SIL setting that has access to nursing staff].	1. I can't see how its consumer directed for a start. 2. I've had a very recent and very steep introduction to the NDIS. Yes, and it's been quite shocking to me in lots of ways. 3. NDIS which is actually so controlled from the top down in terms of what people can and cannot access and what, even what they can and cannot define as being useful to themselves.
Joelene		1. Do not react quickly enough. People have died before services can be put in place. 2. The system is so complicated, you need support coordinators and plan managers it is very difficult to self manage. 3. It has its own language

PC Clinicians	Positive	Negative
		4. The requirement for a mental health diganosis can be a signficant barrier to accessing the NDIS. 5. Choice and control can lead to detrimental outcomes when PwPD have impaired thinking. Particularly if the PwPD has significant behaviours of concern and may end up homeless. 6. The compartmentalising of the system responsibilities has a negative outcome on participants that are not in-line with the insurance principles. 7. Young people in care who will be the adults with mental health disabilities that are not going to be out there will not be supported by the NDIS because they can't navigate systems. 8. The NDIS has caused funding cuts to other services. 9. There's no consistency and continuity. 10. it's so, so random at times, you know, and I think in order for it to be successful for someone, so many things have to go well for them.. They have to have a great support coordinator. They have to have a great plan manager. They have to be connected with services that are engaged and wanting to see them, you know, reach their full potential in life. They have to have so much going for them, in order for it to succeed.

PC Clinicians	Positive	Negative
		11. It has caused a drop in the workforces and providers of other sectors. 12. A lot of people do not understand the NDIS and the importance of undestanding how someone met access. PwPDs are encouraged not to give their plan to providers to prevent exploitation, but it can lead to a lot of confusion.
Becky	1. You are better off than your peers with life-limiting conditions if you have support from the NDIS.	1. Completely disconnected from other systems.
Stuart	1. Participants receive excellent end-of-life support in SIL settings.	1. We have challenges with NDIS. 2. NDIS Participants should have access to their NDIS workers while they are admitted to hospital or hospice. 3. The NDIS adds significant time to hospital admissions. 4. I feel that having having two layers of government add complexity.

Appendix 20 - Palliative Care Clinicians Discuss the NDIA

PC Clinicians	Positive	Negative
Sylvia		1. We then have to wait again for a planning meeting, which before that we need to do some reports to help provide some evidence of what they might need. 2. The NDIA do not explain why they consider a person's functional impairment is a health responsibility. 3. The NDIA do not provide any guidance. 4. I've tried to speak to our local area coordinator. And I didn't get far at all, 5. The NDIA's too slow to support dying participants. Some die in hospital waiting for planning meetings and NDIS providers to become available. 6. The NDIA did not allow a PwPD to die in a nursing home as was their wish, so they had to stay in an acute hospital bed. This caused significant distress for them and their family. 7. Writing reports for the NDIA takes hours, sometimes days to do full functional assessment reports. 8. They need three quotes, which takes so much time.

PC Clinicians	Positive	Negative
Amy		1. The planner [complex team] just wanted to get off the phone as quickly as possible. She, we had requested an interpreter and that had not been organised before the call. 2. It was one of the most horrendous things I've I've ever had the displeasure of observing in terms of absolute communication breakdown. And poor process. 3. She said I can't guarantee you that they will call at that time and I can't guarantee that you'll be told it's been canceled. 4. the woman who called us seemed flustered, hurried not at all prepared for the time and and patience that dealing with this particular participant
Joelene		1. They don't understand the impact that their mental health diagnosis can have on someone's functioning. 2. The NDIA do not understand supported decision making which impacts the quality of plans and leads to poor outcomes. 3. Planner asked a participant with a life-limiting condition their 5 and 10 year plans. It broke my heart. 4. Equity is all dependent on the planner, there is no continuity or consistency across the planning process.

PC Clinicians	Positive	Negative
		5. They are notoriaous. It’s very hard to talk to the NDIA, I wish they would work more collaboratively. 6. I was outraged by the LAC’s recommondation of providers which delayed urgent support for a dying participant. They weren’t proactive enough because they thought they had time. 7. Planners cut plans without understanding the practical impact that can have.
Becky		1. We have a palliative program in our state that is dependent on an negative outcome from the NDIS. The NDIA are too slow and this can negatively impact a palliative patients supports. 2. The NDIA are so slow in decision that people’s support needs can change significantly before the change of circumstances is approved and actioned. 3. They do not understand palliative care or palliative care funding. 4. Planners are just literally saying they're going to pull out existing NDIS supports, because they can now be funded by palliative care. But palliaitve care do not fund those levels of supports.

PC Clinicians	Positive	Negative
Stuart		1. We have found on occasion the misalignment between what the patient and family would desire and what the NDIA feels is appropriate for them.

Appendix 21 - APTOS Responsibilities for Supports for PwPDs and Life-Limiting Conditions

Below is a list of the supports that research interviewees from all cohorts stated that the NDIS would or should fund for PwPD, alongside the APTOS responsibilities as interpreted in Section 1.2.5, with additional information about time-frames and potential barriers.

Support Expected from NDIS	APTOS Responsibility	Additional Information
Increased NDIS support coordination hours Specialist support coordination	NDIS	There will need to be a review of the PwPD's current NDIS plan with a request for an increase in support coordination hours or funding for specialist support coordination hours. Not all support coordinators can deliver specialist support coordination, which may require a provider change. Changing NDIS providers can burn through funding hours, as a new specialist support coordinator must meet with the PwPD, research and understand the PwPD's NDIS plan, current bookings and plan balances.
Additional transport	NDIS Varied Community Transport Options across the states	The NDIS is unlikely to fund additional transport for a life-limiting condition, as the levels are indexed and dependent on work or study requirements.
Gardening	NDIS	Currently cannot be billed if the PwPDs is an in-patient in a hospital, hospice or respite facility.
Cleaning	NDIS	Currently cannot be billed if the PwPDs is an in-patient in a hospital, hospice or respite facility.
Additional support worker hours	NDIS	Existing supports may continue if not in an acute or sub-acute hospital setting. The "*adjustments in scope and frequency*" [8] (p. 5) of APTOS does not indicate whether this means an increase or a

Support Expected from NDIS	APTOS Responsibility	Additional Information
		decrease due to services being delivered through sub-acute health services.
NDIS workers to support in hospital and hospice.		NDIS does not fund this unless support is required to educate hospital and hospice staff about communication issues or challenging behaviours.
Flexible in-home support	NDIS and health systems	Existing supports may continue if not in an acute or sub-acute hospital setting. The "*adjustments in scope and frequency*" [8] (p. 5) statement within APTOS does not indicate whether this means an increase or a decrease due to services being delivered through sub-acute health services. There are minimal in-home supports for palliative patients in the last weeks of life. The availability of health-funded in-home support is varied across the country.
Meal preparation	NDIS	Meal preparation will continue if this support existed before acquiring the life-limiting condition. It is unlikely to be approved due to the life-limiting condition. This support is unlikely to be funded by the health system but may vary by location.
Respite for carers	NDIS	There is potential to use PwPDs' NDIS funding if sufficient or excess funding can be diverted from other supports. A plan review requesting increased funding for respite due to the life-limiting condition is unlikely to be approved.

Support Expected from NDIS	APTOS Responsibility	Additional Information
	Health system/Carer Gateway	
Support for Carers	Health system/Carer Gateway	
Tailored exercise	NDIS Health system	New funding requests for exercise physiology to support life-limiting conditions are unlikely to be approved. These may be offered by specialist palliative care occupational therapy or physiotherapy services or there may be limited rebates through Medicare for 5 visits with a physiotherapist or exercise physiologist.
Increased psychological support (therapeutic)	Mental health or health system	
Wheelchair	Health system	
Shower chair	Health system	
Personal care (showering, toileting etc)	Health system	
Hi-Lo Bed	Health system	
Mobility aids (grab rails, ramps)	Health system	
Supported Independent Living	NDIS	Support would continue if already living within supported independent living accommodation for

Support Expected from NDIS	APTOS Responsibility	Additional Information
		their mental health condition, however, if support needs around health needs increase beyond the capacity of the SIL workforce, they may need to move to a hospital or hospice. New applications for PwPDs to obtain SIL/SDA funding due to their life-limiting conditions are unlikely to be approved.
24-hour care	Health Mental health system	24-hour care is required for life-limiting conditions. 24-hour care is required due to a decline in PwPDs mental health condition.
Nursing care Wound management	Health	The NDIS does fund some nursing support, but this must be directly related to a participant's primary disability.PwPDs would rarely or never require this kind of support.
Physiotherapy	Health	The NDIS funds physiotherapy to improve function but must be directly related to a participant's primary disability.
Massage	Health system/privately funded	One of the PC Clinicians advised that they had known of a participant having massage therapy using their NDIS funding, but this may have occurred surreptitiously and would not have been approved by the NDIA if the participant had been agency-managed (where the NDIA manages a participant's plan).
Orthotic shoes	Health system/privately funded	As above.