Visual Cognitive Behavioural Intervention: An Adaption of Cognitive Behavioural Therapy for People with Intellectual Disability and Mental Health Difficulties

by

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GLOSSARY

AAC	Augmentative and Alternative Communication
ABA	Applied Behaviour Analysis
ACER	Australian Council for Educational Research
ATAPS	Access to Allied Psychological Services; enables GPs to refer consumers to mental health professionals who deliver focussed psychological strategies services
BPD	Borderline Personality Disorder
CBI	Cognitive Behavioural Intervention
CBT	Cognitive Behavioural Therapy
CIDDR	UK Centre for Intellectual and Developmental Disabilities Research
COMPIC	COMmunication PICtures
CRPD	United Nations Convention on the Rights of Persons with Disabilities, 2006, see UNCRPD
CSW	Community support workers
DCSI	Department of Communities and Social Inclusion, part of South Australian Government
DD	Dual disability
DLS	Daily living skills
DSA	Disability South Australia
EAMHID	European Association for Mental Health in Intellectual Disability
ExPRT	ExPRT Excel® Package of Randomization Tests. Version 2.1 (2016)
FaHCSIA	Families, Housing, Community Services and Indigenous Affairs
FBA	Functional Behaviour Assessment
GP	General practitioner
HRC	Australian Human Rights Commission (formerly HREOC)
HREOC	Australian Human Rights and Equal Opportunity Commission
ID	Intellectual disability
IOA	Inter-observer agreement
MaGIC	Manualised Group Intervention Checklist

mental illness	see MHD q.v.
MHD	Mental health difficulty; in this thesis, *mental illness* is referred to as *mental health difficulty*, with the view that recovery and self-management are possible
NADD	US National Association for the Dually Diagnosed
NAP	Non-overlap of All Pairs; a statistical calculation
NASMHPD	National Association of State Mental Health Program Directors
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
NMHCCF	National Mental Health Consumer and Carer Forum
PAS	Picture Activity Schedules
PBS	Positive Behaviour Support
PCS	Picture Communication Symbols
pica	Persistent eating of substances such as dirt or paint that have no nutritional value
polypharmacy	Simultaneous use of multiple drugs to treat a single ailment or condition, or simultaneous use of multiple drugs by a single patient, for one or more conditions
R-IRD	Robust Improvement Rate Difference
self-injury	non-suicidal injury to self
self-harm	deliberately harm to self with suicidal intent or ideation
SCED	Single Case Experimental Design
SDM	Supported decision making
SM	Self-manage, self-management
TAU	Treatment as usual (protocol)
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities, 2006
WHO	World Health Organisation

ABSTRACT

Evidence indicates that people with intellectual disability (ID) are at greater risk of developing mental health difficulties (MHD) than the general population (Bennett, Pridding & Lawrence, 2004; Tonge, Einfeld & Mohr, 2010). The impact of MHD has significant costs for individuals, their families and the community. Currently, pharmacological treatment is the primary intervention used for adults with the dual disability (DD) of ID and MHD. To date, there has been limited research on the use of Cognitive Behaviour Therapy (CBT) for people with DD. Researchers have suggested adapted versions of CBT combining visual material with cognitive behavioural treatment may be an appropriate approach (Taylor, Lindsay & Willner, 2008). This study utilised a multiple baseline, single-case experimental design to investigate whether five adults with ID could (a) increase their self-management to (b) decrease their mental health difficulties using a visual CBI system. Social validation interviews considered the impact of the intervention in everyday life. Results demonstrated that visually adapted cognitive behavioural intervention (CBI) can be effective for some persons with DD. Randomisation tests indicated the overall result for participants was not statistically significant for reduction of mental health difficulty ($p=0.76$ providing a rank of 544 out of 720) or for self-management ($p=0.45$ providing a rank of 327 out of 720). However, clinical significance of the overall intervention was determined by calculation of a medium effect size of *d*-0.72 for reduction of mental health difficulty and an overall medium NAP effect size of 0.34 for self-management. Several factors impacted these findings, including frequency of use, functional level of disability, capacity and readiness, and commitment to the intervention. Implications for policy, practice and further research are also considered. This study highlighted the need for people with DD to be better represented in policy provision, so that resources can be directed towards their needs. At a practice level, it demonstrated the need for mental health training to be delivered to staff and parents and/or carers. There is also a need for further research to be conducted with persons with DD, including investigating suitable interventions for management of MHD. Without attention to these issues people with DD will continue to experience significant barriers to receiving appropriate and timely treatment for their MHD, which directly impacts on their day-to-day living and quality of life.

DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: M. Carney

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1. INTRODUCTION

For many years, people with intellectual disability (ID) were considered incapable of developing mental health difficulty (MHD). This belief was predicated on the assumption that their impaired cognition precluded them from developing these conditions (Bongiorno 1996; Hemmings, Shoumitro, Chaplin, Hardy & Mukherjee, 2013; Prout & Nowak-Drabik, 2003; Simpson, 2002). Researchers in the 1990s dispelled this assumption and it is now widely recognised that people with ID are at greater risk of developing a MHD compared to their peers in the general population (Bakken et al., 2010; Bennett, Pridding & Lawrence, 2004; Paech, 2007; Priest & Gibbs, 2004; Tonge, Einfeld & Mohr, 2010). A person with ID and MHD is referred to as having a dual disability (DD) (Department of Communities and Social Inclusion, 2013). Although there is consensus on the increased incidence of DD, there is a lack of consensus on the actual percentage, as the numbers identified vary between studies, although this may be dependent on the methodology and diagnostic criteria used (Tonge, Einfeld & Mohr, 2010). Bennett et al. (2004, p.10), for example, conservatively suggested that people with ID have a higher risk of developing MHD (35%), compared to 20% in the general population (Australian Bureau of Statistics, 2007). The Australian Bureau of Statistics (2012) census revealed that there are 668,100 Australians living with ID. The Monash University *Lifespan* project findings suggested the rate of people with ID experiencing MHD could be as high as 40% (Tonge et al., 2010, p.9). Dossetor firmly asserts that MHD are "the greatest reversible handicap in people with ID" (2011b, p.312).

MHD can occur due to a myriad of factors including organic brain dysfunction, genetic factors and psychosocial aspects (Chan, 2015; Howlett, Florio, Xu & Trollor, 2015). MHD can significantly interfere with an individual's cognitive, emotional or social abilities and can be extremely debilitating to the person experiencing the illness. MHD does not discriminate, transcending race, culture and gender (ABS, 2007). Any person could potentially develop a MHD at some time in their lives, when specific factors occur. However, as previously noted, there is overwhelming evidence that people with ID are at a greater risk of MHD than that of the general population (Weiss, Lunsky, Gracey, Canrinus & Morris, 2009; Paech, 2007; Tonge, Einfield & Mohr, 2005; Bennett, et al., 2004; Priest & Gibbs, 2004),

People experience MHD as complex symptoms that vary from individual to individual, and this is reflected in the strategies used in treatment. People with ID have the same range of MHD as the general population. However, there are common themes and characteristics with people with ID that include atypical presentation (Dossetor, 2011c; Bakken et al., 2010; McCabe, McGillivray & Newton, 2006); longer than average stays in hospital and often recurrent re-admissions (Bennett, 2013; Bennett et al., 2004; Pridding & Proctor, 2008); few alternatives to drug treatment (Brown & Marshall, 2006; Taylor et al., 2008; Brown, Duff, Karatzias & Horsburgh, 2011; Scior, 2009), lack of appropriate accommodation (Drake, 2010; Simpson, 2002; Weiss et al., 2009); increased social isolation (Paech, 2007; Saunders, 2006; Scott & Havercamp, 2014); deterioration of daily living skills (Dossetor, 2011c; Priest & Gibbs, 2004); and increased incidences of state intervention through guardianship, detention, or community treatment orders (Dowse, Wiese & Smith, 2016; Webber et al., 2010). The longer an individual experiences acute symptoms, lack of support, or increased isolation, the more difficult it is for that individual to recover and self-manage. This creates substantial emotional and financial cost for the person with DD, their immediate network of family and friends, and the community (Bartak, Bottroff & Zeitz; 2006; Bennett, 2013; Dossetor, 2011a; Werner, Strawski, Polakiewicz & Levav, 2013).

Currently, pharmacological approaches are the main treatments used, with few alternatives considered or offered (Brown & Marshall, 2006; Hudson & Chan, 2002; Matson & Neal, 2009; Sheenan, Hassiotis, Walters, et. al., 2015; Taylor et al., 2008; Thomas, Corkery-Lavender, Daffern, Sullivan & Lau, 2010). There is a pressing need for further research to determine effective intervention strategies, particularly given concerns associated with pharmacological approaches such as diagnostic overshadowing; dependency; side effects of medication; "off label" use of medication; the exacerbation of symptoms that medication may have on other physical, mental and behavioural issues; polypharmacy; and lack of review (Haider, Ansari, Vaughan, Matters & Emerson, 2014; Hassiotis et al., 2013; Paech, 2007; Reiss, 2000; Thomas et al., 2010; Torr, 2013; Trollor, 2014).

There is much evidence that Cognitive Behaviour Therapy (CBT) with and without drug therapy is an efficacious intervention for the general population (Beck, 2005a; Beck, 1995; Cooney, Tunney & O'Reilly, 2018; Cuijpers, Berking, Andersson, et al., 2013; Greenberger & Padesky, 1995; Hofmann, Asnaani, Vonk et al., 2012; Hollinghurst, Peters, Kaur et al., 2010; Wiles, Thomas, Turner et al., 2016). Scattone and Mong (2013) advised that CBT is the preferred treatment for anxiety and depression in the general population. However, the use of CBT for people with ID has been under or inadequately researched (Beail, 2003; Vereenooghe & Langdon, 2013). Given that people with ID have the same right to access treatment as people without ID (United Nations *Convention on the Rights of Persons with Disabilities, 2006*; Jennings & Hewitt, 2015), it is imperative that more robust research on suitable psychological treatment is undertaken.

The few studies conducted with people with DD used conventional CBT and were found to be less effective as this group of people have difficulties with conceptual thinking, problems with communication or literacy and side effects from medication (Cooney, Tunney & O'Reilly, 2017; Hassiotis et al., 2103; Hofmann, Asnaani, Vonk, Sawyer & Fank, 2012; Paech, 2007; Scattone & Mong, 2013; Szymanksi, 1980; Taylor et al., 2008). Some researchers suggest that an adapted and individualised version of CBT, using visual aids, could be an appropriate non-invasive treatment for people with DD to assist with difficulties in communication, comprehension and executive function (Chan, 2013; Burford & Jahoda, 2012; Hassiotis et al., 2013; Taylor et al., 2008; Jacobelli & Watson, 2008).

Despite increased incidences of DD and repeated calls for research interventions as alternatives to or supplements for pharmacological treatment (Brown et al., 2011; Scior, 2009; Thomas et al., 2010), there has been a paucity of such research. In particular, there has been insufficient research into designing adapted CBT interventions and measuring their efficacy (Willner, 2009; Taylor et al., 2008; Pridding, Watkins, & Happell, 2007; McCabe et al., 2006). When adaptations are made, researchers rarely report on how they adapted the therapy (Brown et al., 2011; Grahame, 2011). This lack of research may be reflected in the lack of expertise, interventions or services for people with DD, who are doubly disadvantaged by their DD and are at risk of remaining in a cycle of illness and dependency.

It is imperative that appropriate psychological interventions are developed and researched, as people with ID already experience poorer health outcomes than individuals without ID (Emerson & Hatton, 2014; Emerson & Baines 2010; Samele et al., 2006; Scheepers et al., 2005; Wallace & Beange, 2008). When MHD is implicated as an additional layer of co-morbidity, it further exacerbates poorer health outcomes. Howlett, Florio, Xu and Trollor (2015), for example, advised that physical illness increases the risk for MHD. Kerr and Cardoza (2010) indicated the converse is also true: that MHD may predispose people with ID to physical illness. It is clear people with DD have increased physical illnesses and there is a need to address the issue of MHD (and other factors) for this vulnerable population (Torr et al., 2008).

The *Strong Voices* report (South Australian Social Inclusion Board, 2011) echoed earlier findings that people with disability experience poorer health outcomes than others and more effort is needed in preventative health (for example, Ward, Nichols & Freedman, 2010). The *Strong Voices* report recommended that both disability-specific and universal agencies must be highly responsive to the needs of people with disabilities and that they must report on how they are responding to the needs of this population (South Australian Social Inclusion Board, 2011, p.11). As yet, there appears to be little evidence of either of these occurring, particularly in the area of DD.

Despite the prevalence of people with DD and the social and economic costs involved, this population is underrepresented in mental health policy and planning, and is also underrepresented in service provision, whether in mainstream or specialised settings. When specialised services exist, they are often under resourced and have lengthy waiting lists (Thomas et al., 2010). It must be noted that there is considerable international debate on whether services for people with DD would be best delivered in specialist or generic service models (Jess et al., 2008). While this debate continues between service providers and policy makers, people with DD and their families are left to locate treatments for their MHD, usually relying on generic services, such as General

Practitioners (GP), mainstream mental health facilities and hospitals. These service providers often have little training or experience in DD and in the complexities that surround its presentation and management (Paech, 2007; Pridding & Proctor, 2008; Trollor, 2014; Warr et al., 2017). Adding further complexity to the above issues is the fragmentation of service provision and resources for people with DD. Government delivers funding arrangements into the two main sectors, disability services and mental health services. The two service sectors have different philosophical orientation, professional training and treatment approaches and often seem in opposition to each other (Fyffe, 2007). Mental Health Services are underpinned by a treatment philosophy with core tenets of disease, individual pathology and rehabilitation. Conversely, Disability Services embody a philosophy of a condition, teaching skills, self-determination and habilitation (National Association of State Mental Health Program Directors, 2004).

International literature suggests similar issues occur in many western Countries: particularly, competing philosophical orientations, inadequate services and lack of education and training for professionals (Bouras & Holt, 2010; Gough & Morris, 2012; Hassiotis, Barron & O'Hara, 2000; Jess et al., 2008; Thomas et al., 2010; Torr et al., 2008; Webber et al., 2010; Werner et al., 2013). In the Australian context, the *National Disability Strategy 2010-2020* (NDS) is anticipated to change the landscape of disability services and offer hope for a brighter future for people with disabilities. This will be achieved through several legislative initiatives, including the implementation of the National Disability Insurance Scheme (NDIS) launched in July 2013. The NDIS was developed to address the deficit of funds, services and equipment for people with disabilities as the Australian system, prior to the NDIS, left "more people with disabilities living at or below the poverty line than any other OECD country" (Bonyhady, 2013, p. 2). Several major Australian sources informed the NDS during the development of the NDIS, including the Australian Productivity Commission (2011), National People with Disabilities and Carer Council (2009) and the South Australian Social Inclusion Board (2010). A recurrent theme in all the reports was the lack of adequate services, particularly for mental health.

The NDS acknowledged research findings, stating "psychiatric disorders are among the conditions that are frequently not well diagnosed or managed in people with an intellectual disability" (National Disability Strategy, 2010, p. 60). To tackle this, the NDS included Objective 6: Health and Wellbeing "keeping our minds healthy" (p. 22), which will expand strategies and supports to address the explicit mental health needs of people with disabilities, where they have previously experienced disadvantage. It would seem therefore that developing and researching the effectiveness of CBT adaptations for this population is both timely and appropriate.

Research Aim

The aim of this research is to investigate the effectiveness of a visual adaptation of CBT using photographs, line drawings and symbols, or by using emoticons and simplified text so individuals with ID can self-manage the symptoms of their MHD, with an emphasis on depression and anxiety, and some behaviours (anger, self-injury, self-harm with suicidal ideation), which may present as a result of the MHD.

This research posed the question: how effective is visual cognitive behavioural intervention (CBI) in assisting people with DD to self-manage their MHD symptoms or behaviour?

The following specific sub-questions were posed to investigate the broader aim of the research:

1. How effective is visual CBI in decreasing symptoms or behaviour of MHD?
2. How effective is visual CBI in increasing self-management of symptoms and behaviours of MHD?
3. Will significant improvement in self-management occur once the intervention moves from behavioural therapy (phase one) to cognitive therapy (phase two)?
4. To what extent do people with DD independently use their cards and associated strategies to self-manage their MHD when experiencing symptoms or distress? Will they require prompting from supporters?

Structure of the Thesis

The thesis is divided into six chapters. Chapter 1 provides a general introduction to the study, statistical information on the prevalence of MHD in the ID population and barriers to effective treatment in relation to policy and practice in Australia.

Chapter 2 provides an overview of the researcher’s orientation and the theoretical framework used to guide the study. The chapter focuses on learning, behaviour and cognitive models, the influence of key theorists and the evolution of knowledge.

Chapter 3 explores the literature and current trends in treatment for people with DD, with a focus on CBT and the need to develop adaptations for this population’s unique needs. The chapter also focuses on the major debates in the literature and in the field and connects these debates to this study.

Chapter 4 describes the methods, aims and design of this study, including ethics protocols, procedural integrity and rationale for data analysis. Detailed information is also presented regarding participants and the MHD identified as the target behaviour for the intervention.

Chapter 5 presents the findings of the study to determine the effectiveness of the visual CBI in assisting participants to self-manage their MHD. Analysis of effect, non-overlap of all pairs, robust-improvement rate difference and rank, significance and social validity are provided. Results from procedural integrity measures are also presented, establishing fidelity and rigour for this intervention.

Chapter 6 discusses the key findings of the study. Specific components of the intervention are also discussed, including discrepancies or issues raised from the results, and overall conclusions of the intervention efficacy. This chapter also considers this study’s contribution to existing knowledge, implications for further research and policy, and limitations of this study. The chapter concludes by offering recommendations for improved practice to support persons with DD.

2. THEORETICAL FRAMEWORK

To better understand the purpose of the research and the questions posed by the researcher, it is necessary to consider the researcher's orientation, theoretical perspectives (including key theorists) and conceptual framework. These provide the foundations of this research and determine the parameters for the study, as they influence the choice of methods and critically, the results of the study (Crotty, 1998).

Researcher's Orientation

A researcher's orientation consists of paradigms – ontology (reality) and epistemology (knowing) – that guide each study. These are what Crotty (1998) highlights as the "scaffolding" or pillars of research (p. 2). By using the table "themes of knowledge" in Lincoln, Lynham and Guba (2011, p. 100) to unpack orientation, the researcher's orientation for this study is an ontological stance of critical realism, with the epistemological lens of objectivism.

Ontology – the assumptions of reality

Ontology is the metaphysics of "what is reality". Reality and how to explain reality mean different things to different people and are dependent on the individual's definition of what reality is and influences how each sees reality (Crotty, 1998). Blaikie (2007) provides a broad definition of realism as "natural and social phenomena that exist independently of human observation" (p. 12). As this research seeks to pursue objective, empirical data to determine whether the visual CBI was effective through visual and statistical analysis, it meets the ontological assumption of critical realism as defined in Lincoln, Lynham and Guba (2011).

Epistemology – the assumptions on the ways of knowing

The epistemological assumptions, "the ways of knowing", are of equal importance to research. With this, the researcher must evaluate his or her epistemology and the impact that this may have on the research being undertaken. Neuman (2003) defines objectivism as scientific knowledge that is not based on values, opinions, attitudes or beliefs. Objectivism aims for research to be value free, pure and factual.

Theoretical Perspectives

Theoretical perspectives are the reasoning (logic) used in research which guides the choice of methodology (Crotty 1998). Crotty (1998) advises the choice of theory used to underpin research "makes a big difference to the truth claims proffered on its behalf" (p.16). It is here the theory needs to align with the ontological and epistemological assumptions of the research.

Positivist research aims to explain or confirm human behaviour with data collected using scientific standards (with verification), and then to make predictions about causal links (Johnson &

Onwuegbuzie, 2004; Roth & Metha, 2002). Positivism postulates that scientific methods are considered the only true and reliable means of acquiring and confirming knowledge (Neuman, 2003). However, post-positivism proposes that it is not possible to be objective and value-free as pure positivism demands, and that all researchers by their nature of being, come with inherent values and lenses (De Anstiss, 2011). Neuman (2003) states researchers need to acknowledge their personal beliefs, biases and prejudices as part of the research process. This is particularly important when the researcher is embedded in a study, as is the case in the present research.

In this research, a post-positivist theoretical lens will be used to investigate the effectiveness of a visual CBI using Single Case Experimental Design (SCED).

Theories of behaviour

The seemingly simple question of "how do people learn?" is deceptive, and cannot be comprehensively answered with one single theory, particularly when it comes to behaviour. Several theories are relevant when considering how people learn, including people with disabilities, such as behavioural theory, cognitive theory and the fusion of these two, cognitive-behavioural theory (sometimes termed *neo-behaviourism*) (Westwood, 2004).

Behavioural theory is underpinned by the notion of *Tabula Rasa,* a blank slate that is written on when behaviour is produced as a result of an individual's actions within an environment. Behaviour is a conditioned response to stimuli and is maintained or terminated depending on the reinforcement received (Gosch, Findiesen & DiTomasso, 2010). Behaviourists believe that all behaviour is measurable and have little regard for the emotional content of behaviour (Kellogg, 2012). The evolution of behaviourism influenced many of the contemporary practices in the field of disability, most notably Applied Behaviour Analysis (ABA) and Positive Behaviour Support (PBS) (Dunlap, Carr, Horner, Zarcone & Schwartz, 2008), and is further discussed in Chapter 3. Sheldon (1995) summarises behaviourism by amending Descartes' famous proposition to "*ago ergo sum":* I act; therefore, I am (p. 27).

Conversely, cognitive theory is based on how the internal processes of the mind, such as perception and metacognition, influence behaviour (Zahn, Zehrung & Russo-Innamorato, 2010). Cognitivists believe the hierarchy of thoughts influence feelings and subsequently behaviour. Cognitive theorists, Kelly and Ellis (Beck, 2005a), illustrated how the individual gathers information, internally processes that information, develops a hypothesis and then acts upon it. Ellis's ABC concept – Activating event, Belief, Consequences – can be summarised in the following way: an event occurs that is then interpreted in a certain way to produce a belief or set of beliefs about oneself and the environment (Dagnan, Chadwick & Proudlove, 2000). The consequences experienced following the event can lead to the maintenance of the belief, regardless of whether it is or is not rational (Beck, 2005a). In essence, the individual seeks evidence to support the interpreted belief, so it becomes a self-fulfilling prophecy that, in turn, maintains the belief.

Cognitive psychology is based on identifying beliefs (perceptions) and how those perceptions influence emotions and behaviours (Kellogg, 2012). Fundamentally, cognitive theories are premised on the notion "*cogito ergo sum"* – I think; therefore, I am (Sheldon, 1995, p. 28).

Cognitive behavioural theory combines the two theoretical models and recognise that both external stimuli and internal processing are interrelated and impact on each other, thereby affecting our thoughts, emotions and behaviours (Simmons & Griffith, 2009). The cognitive triad as depicted in Figure 2.1 shows the interconnected relationships between domains. Cognitive Behaviour Therapy (CBT) is based on Socratic questioning in order to analyse errors in perception and interpretation of stimuli or events; to encourage metacognition to monitor, modify and self-regulate through cognitive and behavioural practices (Beck, 2010; Bransford, Brown & Cocking, 1999; Zahn, Zehrung & Russo-Innamorato, 2010).

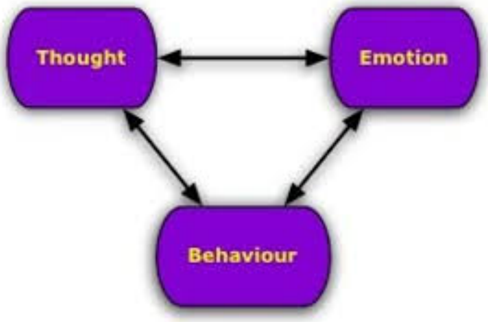


Figure 2.1. Cognitive Behavioural Model.

Conceptual framework for the study

A. T. Beck's seminal work in CBT acknowledges the work that key behavioural or cognitive theorists, such as Epictetus (knowledge and self-discipline), Ellis (rational emotive behaviour therapy), Adler (individual psychology) and Bandura (observational learning theory) had on influencing the development of CBT (Beck, 2005a).

Beck (2011, p. 3) summaried CBT as a treatment model that addresses:

> Dysfunctional thinking which influences the patient's mood and behaviour is common to all psychological disturbances. When people learn to evaluate their thinking in a more realistic and adaptive way, they experience improvement in their emotional state and in their behaviour.

As inherent with most cognitive psychology, CBT works on correcting a deficit or problem in individuals (Grahame, 2011).

In contrast, Vygotsky's (1978) research operates from a strengths perspective and is integral to understanding the development of cognition and how a person with ID learns.

Vygotsky's theory of learning stems from his life's work in institutions alongside children with various disabilities in the early 1900s. His ground-breaking concept is *positive differentiation,* where each individual's existing and potential skills are appraised for a capacity to learn, rather than being culturally determined deficits of their disability (Gindis, 1999). Vygotsky's z*one of proximal development* theorises that individuals can learn developing skills more effectively with scaffolding assistance from others (Rutland & Campbell, 1996; Stott, Charlesworth & Scior, 2017; Wang 2009) and that people with disabilities need modified alternatives to compensate for their impairment (Gindis, 1999). These principles are inherent in contemporary ABA and PBS practices.

Adding further weight to Vygotsky's argument that people with disabilities can learn effectively given the correct support is the work by special educator Marc Gold, creator of "Try Another Way" (Gold, 1976), whose pioneering philosophies were used to teach people with severe and profound disabilities. Gold (1980) asserted that the responsibility for skills development in people with disability lay with professionals who are assisting them with their learning. He stated that when people with disabilities do not learn it is initially "a result of inappropriate or insufficient use of teaching strategy, rather than inability on the part of the learner" (p. 3). As people with ID are often functioning at what Piaget termed the "concrete operational" level and may have difficulty in abstract reasoning (Grahame, 2011; Westwood, 2004), they learn most effectively through experience in applied settings (Westling & Fox, 2009).

Both Beck and Vygotsky guide the methodology of this research. While Beck and Vygotsky's theories may seem opposed, they can be successfully combined to assist people with DD to learn how to manage their MHD effectively, using CBT protocols. Beck's theory and extensive history of CBT applications in clinical settings provides an established treatment base, while Vygotsky's zone of proximal development theory assisted with modifying CBT to best suit participants with ID.

3. BACKGROUND AND REVIEW OF THE LITERATURE

This chapter provides and overview on the background and the literature on people with dual disabilities (DD) that have informed this study. People with DD and their supporters experience significant barriers to receiving appropriate and timely treatment for their MHD. DD impacts their day-to-day living in several key areas.   This chapter explores these issues, as well current trends in treatment, with a focus on cognitive behaviour therapy (CBT) and the need to develop adaptions for this populations unique needs.

People with disabilities, particularly people with ID, are one of the most vulnerable and disadvantaged populations. They repeatedly experience devaluation, inequality, poorer health outcomes, lower socioeconomic status, lower levels of education, and reduced social and civic participation (Australian Human Rights and Equal Opportunity Commission, 1993; Australian Human Rights and Equal Opportunity Commission, 2008; World Health Organization, 2014). Discrimination and disadvantage are historical features in the lives of people with ID (DePoy & Gilson, 2011; Duffy, 2005; Duffy, 2008a; Goodey, 1999; Dodd & Walsh, 2009; Oliver, 2009).

Over the last 50 years in western countries, there has been intense interest in philosophies and initiatives that align with human rights, including social role valorisation (Osborn, 2006; Wolfensberger, 1983; Wolfensberger ,1991), normalisation (Dodd & Walsh, 2009), deinstitutionalisation (in Dosseter, 2011a), citizenship and social inclusion. This interest reflects the belief that people with disabilities should have access to basic tangible resources to improve their lives and become part of society. However, initiatives, policies, funds and mechanisms designed to provide these continue to be insufficient to support people with ID (Bouras & Holt, 2010; Cain et al., 2010; DePoy & Gilson, 2011; Pridding & Proctor, 2008). Service provisions and the community, for the most part, are inadequately prepared to cope with the needs of people with disability. It seems that people with ID “are *in* the community, but not *of* the community” (Ware, Hopper, Tugenberg, Dickey & Fisher, 2007).

People with ID remain on the margins of society, have limited autonomy and have a lack of meaningful engagement (Duffy, 2008b). Low engagement may contribute to MHD (Tonge, Enfield & Mohr, 2010; Williams & Fidock, 2012). The impact of MHD can have serious implications on the functional abilities and quality of life of the person with the ID and on their supporting networks (Bartak, Bottroff & Zeitz, 2006; Bennett, 2013; Dossetor, 201c; Werner et al., 2013; Williams & Fidock, 2012). Currently, there are limited treatment options for people with DD (Brown & Marshall, 2006; Hassiotis et al., 2013; Paech, 2007; Reiss, 2000; Taylor et al., 2008; Thomas et al., 2010; Trollor, 2014). Without appropriate policy, improved service provision and effective interventions to support their MHD, people with DD are more vulnerable and at risk of remaining in a cycle of illness and dependency.

Policy Context

Policy provides guidance and leadership while converting social values, visions and principles into legislation (Bacchi, 2011). In Australia, the rights and responsibilities of people with disabilities are held to be the same as those without disabilities. This principle is captured in the United Nations *Convention on the Rights of Persons with Disabilities, 2006* (UNCRPD), which is the principal international instrument for the protection and provision of fundamental human rights for people with disabilities, including people with psychiatric disability. UNCRPD has significant implications for policy directions of ratifying countries, including the UK, USA and Australia. UNCRPD Article 25, "Health", endorses the provision for people with disabilities to have the same range, quality and standard of free affordable health care and programs as those provided to people without disabilities (United Nations, 2006). UNCRPD Article 26, "Habilitation and Rehabilitation", promotes the development of policies and services, including specific health interventions needed due to a person's disability, and the training of professionals for habilitation and rehabilitation (United Nations, 2006).

The Australian Human Rights Commission (HRC) (formerly HREOC), and the World Health Organisation (WHO) have provided evidence regarding continuing inequalities for people with disabilities of poorer health outcomes, including poorer mental health (Australian Human Rights and Equal Opportunity Commission, 2008, World Health Organisation, 2014). In March 2013, the WHO tabled *Disability: Report by the Secretariat* (World Health Organisation, 2013), which made several recommendations for improving the status of people with disabilities, including that each country adopt their own national disability strategy and plan of action that aligns with the WHO report.

The *National Disability Strategy 2010-2020* (NDS) is a comprehensive plan designed to guide the direction of the Australian disability sector (National Disability Strategy, 2010). The NDS is Australia's response to several reports or standards recommended by international organisations, including those of the UNCRPD and WHO, or HRC noted above. Shorten (2009) defined the NDS as the charter for "the right to an ordinary life". The NDS provided the overarching framework for the National Disability Insurance Scheme (NDIS) which was launched in July 2013 receiving rare bi-partisan support from all sides of politics. The impetus for developing the NDIS came from several reports (South Australian Social Inclusion Board, 2011; Australian Productivity Commission, 2011; National People with Disabilities and Carer Council, 2009), which highlighted the appalling socio-economic position of Australians with disability (Bonyhady, 2013). These reports became the NDS blueprint for the development and implementation of the NDIS.

The NDS recognised the debilitating nature of mental illness and included psycho-social disability in the scope of funded supports within the NDIS (National Disability Strategy, 2010). Furthermore, the NDS acknowledged research findings that MHD was poorly diagnosed and treated in the ID population and created specific objectives to remedy this (National Disability Strategy, 2010). Despite these two noteworthy inclusions within the NDS, significant barriers to effective treatment are likely to remain while the DD population continues to be absent in mainstream mental health policies and strategies.

The National Mental Health Policy (2008), the National Standard for Mental Health Services (2010) and the National Mental Health Strategy (2014) has no specific mention of people with ID, despite the identified mental health disparity between people with and without ID (Department of Health, 2014). Instead mental health care initiatives and funding attachments are directed at other “at risk” populations. This lack of consideration was surprising given the “Fourth National Mental Health Plan” (Department of Health, 2009), identified “people with intellectual disability are at an increased risk, yet this is often overlooked and access to appropriate treatment for both disabilities is limited” (p. 70). The NDIS will not replicate services provided within other mainstream sectors, such as health or education (National Disability Insurance Scheme, 2014). As mental health treatment services remain in the Department of Health (rather than the NDIS), it is imperative that people with DD are represented adequately in mental health policies.

Advocates of the NDIS suggested that some of the issues surrounding a lack of services could be alleviated by the new scheme, as each individual can purchase services for their specific needs (Foster et al., 2016; Wallace, 2014; Windholz, 2014). Theoretically, people with DD could purchase services they require to treat or manage their MHD from either the disability sector or the mental health sector and the NDIS would interface between these service systems to ensure adequate service provision for the individual, although the early stages of the NDIS rollout has uncovered difficulties with interface between systems. (Dowse, Wiese & Smith, 2016). Additionally, given the large number of people with DD, along with long waiting list for specialised services and a lack of trained professionals expected to provide services, the said objective of improving the poorer mental health outcomes of people with DD may not be realised for many years to come, if at all (Harrison, 2013; Regan, 2012; Warr et al., 2017).

A major concern is the “permanent” eligibility criterion, which does not address the issue of the transitory and cyclic nature of some mental illnesses, such as schizophrenia, bi-polar, depression and anxiety, from which people can experience periods of wellness or times of long debilitating illness (Cooper, 2004; Mental Health Australia, 2017; National Mental Health Consumer and Carer Forum, 2011). This criterion is also at odds with the “recovery” model utilised in mental health care.

Given the above Australian Government policy and plans (mental health and disability) have identified specific objectives to improve the lives of people with disability, with the assumption that these documents include people with DD, there is a discrepancy between policy intention and direct service provision. Without specific DD legislation or a framework to guide treatment (Bigby, 2006), service provision will remain inconsistent and fragmented, often differing between and within countries and even within states within countries (Gough & Morris, 2012; Jess et al., 2008).

Service Provision

Two issues add to the complexity of supporting people with DD. First is the continuing debate on whether generic or specialist services provide optimal treatment for this population (Chaplin, 2008). Second is evidence that people with DD are in fact disadvantaged and made more vulnerable by services that do not know how to cope with a person's ID when treating his or her MHD (Bennett et al, 2004; Gravestock, Bouras & Holt, 1996).

Some countries, such as Canada, Israel and Australia, have responded by delivering services in generic mental health models (Gough & Morris, 2012; Jess et al*.,* 2008, Torr et al*,* 2008; Werner et al*.,* 2013) whereas other countries, such as the United Kingdom, United States and Sweden, have responded by providing specialist services (Bennett, 2000). Bouras and Holt (2004) and Hassiotis et al. (2000) propose a third option: embedding DD specialists in generic or mainstream services. There are significant strengths and limitations with each of these models; these are explored in the following subsections.

Generic services

The premise underpinning the provision *generic* services for people with disabilities is aligned with principles of normalisation, anti-discrimination and social inclusion ideologies (Evans et al., 2012; Torr et al., 2008). That is, people with disabilities are people first and foremost and they have fundamental rights to have their needs met in services provided in the same way as their peers without disabilities. This side of the debate advances that if specialised services were implemented, not only would it contravene principles of normalisation, as specialised segregated services are paradoxical to inclusion and participation, but could also lead to reduction in services (Bouras & Holt, 2010; Fyffe & McLean, 2006). Advocates for inclusion in mainstream services assert that people with disabilities have fought for too long to be included in all areas of life, including the areas of social and health care.

However, there have been concerns over the quality of treatment or care for people with DD within generic mental health service providers or by General Practitioners (Bennett, 2000). Generic professionals often have limited training or experience in treating this group of people (Ward et al., 2010). This lack of training or experience can be compounded by communication or behavioural difficulties person with ID often experience, further impacting on diagnosis and treatment. Pharmacological approaches are the primary treatments used, with few alternatives offered (Fergerson, 2001; Freeman, Lightner & Golden, 2010; Thomas et al*.,* 2010). Several researchers have expressed concerns associated with pharmacological approaches, such as diagnostic overshadowing, side effects of medication, and dependency (Bennett, 2013; Paech, 2007; Reiss, 2000; Zehtner, 2011).

Specialised services

Advocates for *specialised services* propose that the unique needs of people with DD and the lack of experienced professionals in mainstream settings require specialised service provision (Bennett, 2000; Jess et al., 2008; Wallace & Beange, 2008). In addition, that by offering specialised services to people with DD, much of the disadvantage these people currently experience would be ameliorated (Rubin & Crocker, 2006). Specialised services are reported to address the barriers experienced by focusing on the exclusive needs of people with DD. Specialised services have improved service planning and delivery that are directed toward the unique needs of the population, including service coordination, needs analysis, assessment, treatment/rehabilitation and follow-up (Bennett, 2000). Such services should, theoretically, also have scope for professional education and training programs, research initiatives and input into policy development.

Specialists embedded in generic services

Several key investigators offer a compromise between the choice of “generic” versus “specialist” (Bouras & Holt, 2010; Hassiotis et al., 2000; Werner et al*.,* 2013) by recommending embedded specialists within generic settings. Bouras and Holt (2010) and Hassiotis et al. (2000) and Lunsky et al., (2010) posit many of the issues currently faced by people with DD could be addressed by implementing a model of embedded specialists in a generic setting. Firstly, embedded specialists would see people with DD receiving treatment in community settings, the same as their peers without ID. This is in line with human rights legislation of peak organisations such as the UNCRDP (United Nations, 2006), HREOC (Australian Human Rights and Equal Opportunity Commission, 2008) and WHO (World Health Organization, 2014), as well as supporting countries’ notions of social inclusion and anti-discrimination. This model addresses the issue of people with DD being moved to and fro between disability and mental health services, with neither sector being able to adequately meet their needs (Castle, 2013; Torr et al*.,* 2008). Dossetor (2011a) stated that currently people with DD “fall through the cracks of both the disability and mental health service system” (p. 223). Without a newer service model, people with DD:

> Will continue to be poorly serviced and experience delays in treatment, while separate agencies with different philosophies of care and service delivery are distracted by whose mandate the person with DD is, then persist in making confused diagnosis, creating back and forth cross referrals. (Mohr, Curran, Coutts & Dennis, 2002a, p. 173)

To overcome a number of obstacles and better accommodate the needs of people with DD, collaborative partnerships with shared interests, resourcing and cooperation between disability and mental health services must be established (Castle, 2013). Further to this, service flexibility within and across human service agencies is highly desirable, particularly as people with DD may have contact with a network of service providers for their often-interrelated everyday living needs.

There is a lack of specific professional education and training on DD for professionals and human services workers (Pridding & Proctor, 2008). The development of specific DD education and training is urgently needed to improve some of the difficulties currently experienced by people with DD (Taua & Farrow, 2009). There is a need to provide access and similar levels of treatment as that of their peers without disabilities (Evans et al., 2012) and for a commitment to including people with DD in service planning (Trollor, 2014). Brown et al. (2011) recommended developing partnerships with key supporters, including parents/carers, to assist with assessment, diagnosis and feedback. In addition, the development of targeted education campaigns for parents/carers and front-line staff could improve the awareness of high incidences of MHD, encouraging prompt treatment and providing support to families (Rhodes & Whatson, 2011; Sigan et al., 2015).

The National Roundtable on the Mental Health of People with Intellectual Disability (Dossetor, 2013) considered many of the barriers to treatment experienced by people with DD and developed a framework for mental health professionals and multidisciplinary teams to improve access and services (Trollor, 2014). The framework recommended changes to clinical practice, including adequate preparation for consultations, allowing for longer consultations, involving the persons with ID in decision making and working effectively with families and carers. Recommendations for sector development included access to mainstream mental health services with atypical care pathways, availability of specialised ID mental health services and the availability of training and education for professionals. The framework could provide conciliation between differing philosophical orientation, professional training and treatment approaches for mental health services and disability services, which at times seem incompatible (Fyffe, 2007; Trollor, 2014).

Australia is yet to establish a specific national research body to address issues important to people with DD, although some states and universities have implemented separate research initiatives and projects aimed at understanding and treating DD, including some research on CBT (McCabe, McGillivray & Newton, 2006). Research divisions have been established in other first world countries, such as the University College London which brings together researchers with an interested in ID and DD, to the Centre for Intellectual and Developmental Disabilities Research (CIDDR), the European Association for Mental Health in Intellectual Disability (EAMHID), and the US National Association for the Dually Diagnosed (NADD). The development of a national DD research centre could increase interest in developing intervention and early prevention strategies, garner interest for specialisation in DD, and add to the body of international research. Clearly, there is a need to address the underrepresentation of people with DD in policy and service provision. Resolving some of the issues highlighted above could improve treatment options and produce a positive impact on the everyday lives of people with DD.

Impact of Mental Health Difficulties on People with Intellectual Disability

People with ID experience the same types of MHD seen in the general population. However, for people with ID their symptoms often present atypically and they are more likely to take longer to recover from a mental illness than people without ID (Sheehan et al., 2015; Szymanski, 2002; van Schrojenstein Lantman-de Valk & Walsh, 2008**)**. The biopsychosocial model of mental illness in people with ID includes several risk factors that are implicated in the onset of MHD. Biological risk factors can include genetics, neurological and medical conditions. Psychosocial risk factors can include poor coping mechanisms, communication issues, adverse life events and socio-economic disadvantage (Hemmings et al., 2013; Torr, 2013).

The area of DD is complex as symptoms and treatment strategies vary depending on the functional level of ID and the classification of the MHD. Despite this, there are some common themes surrounding the impact that their MHD has on everyday life (Bennett, 2013; Bennett et al., 2004; Dossetor, 2011b; Dossetor, 2011c; Priest & Gibbs, 2004; Webber et al., 2010). Frequently problems occurring in one life domain will impact significantly on another domain. These problems are discussed in the following subsections in an effort to highlight the extreme disadvantage that MHD can have in the lives of people with ID and their parent/carers.

Hospital admission

Since deinstitutionalisation occurred in western countries, most people experiencing DD who require hospital admission, present as in-patients in mainstream hospital settings. However, people with DDs: (a) experience longer hospital stays than people without ID (Bennett et al., 2004; Hassiotis, Barron & O'Hara, 2000); (b) experience increased psychological dependency on professional and nursing staff for their perceived wellbeing (Bennett et al., 2004); (c) require different management strategies and increased levels of staffing due to their behaviours (Bennett, 2013; Weiss et al., 2009); (d) have significant issues surrounding consent and education for their illness; and (e) "may unintentionally put themselves at risk due to intrusive behaviours and a greater risk of exploitation" (Bennett et al., 2004, p. 46).

Given this information, it is not surprising that 61% of nursing staff are reluctant to work with people with DD (Bennett et al., 2004), advocating for a specialised facility more suited to their unique needs and behaviours (Chaplin, 2008). Many studies have called for specialist service provision for this population (Thomas et al., 2010; Torr et al., 2008; Werner et al*.,* 2013). Weiss et al. (2009) provided insights into the reasons that carers of people with ID access emergency psychiatric departments, including a lack of mental health services in the community and carer inability to manage escalating behavioural or MHD crisis situations.

Accommodation

A further complication for people experiencing DD is the lack of community accommodation. Lack of suitable accommodation for people with disabilities, particularly ID, is a long-standing issue (Chan, 2015; National Disability Insurance Scheme, 2014; National People with Disabilities and Carer Council, 2009; Australian Senate Standing Committee on Community Affairs, 1990). For people with DD, their MHD further compounds issues with securing and maintaining appropriate accommodation (Weiss et al., 2009). Many people with DD find themselves unable to return to the family home after an acute episode of MHD and may instead be referred to supported accommodation (Drake, 2010; Simpson, 2002). Supported residential facilities or community based housing are frequently understaffed due to resource limitations, staff are not prepared or skilled to take on people with DD, particularly if aggressive or demanding behaviour is exhibited, and individuals require extra support with daily living skills (Pridding & Proctor, 2008; Simpson 2002; Weiss et al., 2009). In the face of a lack of suitable accommodation and support, a person with DD admitted to hospital may need to remain in hospital. In the event that the person with DD finds or returns to supported accommodation, and staff are unable to cope with their behaviours, he or she may lose the accommodation and could be re-admitted to hospital (Pridding, Watkins & Happell, 2007). These factors further exacerbate the issues of dependency and hospital staffing.

There is an overrepresentation of people with MHD in the homeless population (Wiesel, 2015). Drake (2010) cites several studies that consider mental illness as precipitating or maintaining homelessness. However, there is limited research and literature on the contribution that ID and co-existing MHD have on homelessness (Clapton, Chenowith, McAuliffe, Clements & Perry, 2014; Families, Housing, Community Services and Indigenous Affairs, 2010). Bigby (1996) includes anecdotal evidence indicating people who are clients of disability services may be housed (short-term) in budget hotels or motels in emergency situations, as government agencies have a mandated duty of care to these clients. Such people in emergency accommodation may not be represented in traditional definitions and analysis of homelessness. This sort of temporary accommodation could be described as *secondary* homelessness, as it has a lack of secure tenancy (Chamberlain & MacKenzie, as cited in Drake, 2010).

Daily living skills

After an acute episode of mental illness, many people with DD may find themselves unable to complete tasks they may have been previously able to do (Dossetor, 2011c; Kwok & Cheung, 2007). They may have to repeatedly learn and re-learn simple tasks, with what can seem as limited skill retention. For some people, this reduction in skills has a rapid onset, for others the loss is gradual. While anecdotal evidence from the disability sector suggests that daily living skills (DLS) significantly deteriorate for people with DD, there is a lack of research on this issue (Gustafsson et al., 2009).

Skills that are most often affected are motor skills and DLS, particularly self-care, feeding, bathing, dressing, and using the toilet/incontinence (Moss, 2015; Nuovo & Bouno 2007). Sheldon (1995) and Gustafsson et al. (2009) advise that poor regulation of presentation, hygiene and nutrition are indicators of MHD in the general population. For those people with ID, who are often reliant on other people for support, the need to introduce assistance with personal care they were once able to complete can be disempowering, further “disabling” this marginalised group of people (Dossetor, 2011c). This feeling of disempowerment, even despondency, can be particularly heightened, not only for the individual with the DD, but also for their families and carers, if gaining the skill in the first place was a hard-fought battle. The longer the person experiences acute symptoms and loss of skill, the longer the period of dependency on others and the more difficult it is to self-manage the symptoms effectively or to recover. Although there has been limited research in this area of people with DD, Drahota, Wood, Sze & Van Dyke (2011) found that CBT improved the DLS for children with high functioning autism who experienced concurrent anxiety disorders.

Financial issues

Many people with ID are able to secure either supported employment in shelters/workshops or open employment within the community. Even after developing a MHD some people can return to work gradually, often at a reduced rate of hours or being reassigned to a different role or task (Simpson, 2002). There has been limited research into the impact of MHD on the financial status of people with ID. The National Mental Health Consumer and Carer Forum (2011) described many of the same issues that people with MHD experience, including financial hardship, loss of employment and under-employment. These issues are mirrored in the DD population who are disadvantaged further by their ID.

In Australia, the NDIS proposes to alleviate issues around insufficient funds for services and equipment. Even so, basic welfare benefits will remain unchanged (National Disability Insurance Scheme, 2014). Without increases in benefits for daily living, it is likely that people with DD will remain in a cycle of financial disadvantage.

Social inclusion

For many years, research has highlighted the impact of isolation on health and wellbeing in disadvantaged groups, such as people with disabilities and their families who support them (Department of Communities and Social Inclusion, 2013; Paech, 2007; Saunders, 2006; Scott & Havercamp, 2014). People experiencing DD may immediately withdraw from activities in which they had previously engaged, such as employment, education or social groups (Dossetor, 2011c; Holden & Gitlesen, 2009; Hollins, 2011). This is particularly evident if a hospital admission occurs and symptoms or effects from medication impede functioning and reconnecting with these activities (Weiss et al., 2009). Other people experiencing DD may withdraw from activities or develop avoidance behaviours more gradually (Simpson, 2002). This is particularly noticeable if secondary or tertiary illnesses arise (Bartak, Botroff & Zeitz, 2006). The result of this withdrawal can further compound feelings or symptoms of the illness (Tonge et al., 2010). Acute MHD symptoms, the fear of exacerbating symptoms and side effects of medication can significantly reduce an individual's ability to engage socially (Pridding & Proctor, 2008). Compounding this, parents, carers, friends and support staff often have little understanding of what is being experienced by the individual and have unrealistic expectations of behaviours and tasks for the person with the DD (Pridding & Proctor, 2008).

Health and well-being

Health outcomes are poorer for people with ID than for those without ID (Emerson & Hatton, 2014; Emerson & Baines, 2010; McCarthy & OHara, 2011; Samele et al., 2006; Wallace & Beange, 2008). This is due to biological factors, harmful health behaviours and poor access to health care directly affecting their morbidity and mortality rates (Mencap, 2004; O'Hara, 2010; Pridding, Watkins & Happell, 2007; Scheepers et al*.,* 2005). People with ID receive limited information and education on the effects of poor life style choices; they are more likely to be obese, have increased incidence of diabetes, consume a poor diet, and are less likely to engage in adequate physical exercise (Wallace & Beange, 2008). In regards to ill health, they have higher incidences of gastro-intestinal diseases (Davis, 2010) and respiratory and cardiovascular disease (Kerr & Cordoza, 2010). There is limited research on co-morbidity of DD and comparative health outcomes. There is a pressing need to address the many health issues including the issue of MHD for this vulnerable population (Torr et al., 2008).

State intervention orders

People with DD have higher incidences of state intervention through Guardianship, Compulsory Treatment Orders, Detention and Admission Orders (Kaal, Brand & van Nieuwenhuijzen, 2012; Webber et al*.,* 2010). When state intervention orders are imposed, these negate or eliminate an individual's right to make decisions about their life or an aspect of their lives, such as treatment for their MHD. According to Millar and Renzaglia (2002) seeking guardianship should be well considered after other options have been explored and considered unsuitable:

> Guardianship should always be considered as the last resort, and if ever imposed, should be temporary and used to encourage the development of self-reliance (p.465).

The assumption when applying for an order is that the individual does not have the capacity to make the decision for him or herself (Kwok & Scully, 2005) or that without state intervention the individual would be at significant risk to themselves or others (Webber et al., 2010). Orders are often sought when families no longer have the capability to support the individual and relinquish care and responsibility, or as a result of contact with the criminal justice system.

People with ID also have increased risk of involvement with the criminal system or with forensic mental health than their peers without ID (Chan, 2015; Dias, Ware, Kinner & Lennox, 2013; Lunsky, Gracey, Bradley, Koegl & Durbin, 2011; Murphy & Clare 2012). Kaal et al. (2012) recognise that behavioural and psychiatric problems are contributing factors in the perpetration of offences. Murphy & Clare (2012) acknowledge that dysfunctional backgrounds with disordered lifestyles and poor life chances of people with ID may be an antecedent to both mental illness and offending. It is recognised that current treatments for juvenile offenders with ID are not suitable, and there is a need for individualised treatment adapted to their cognitive capacities, for instance increasing opportunities for repetition and rehearsal, concretisation, shorter sessions and smaller steps (Kaal et al., 2012).

Improving mental health outcomes for prisoners with DD is an important issue. Research into effective interventions to assist individuals with DD to cope more effectively with their MHD, could help "with pathways out of criminal justice system" (Dias et al., 2013, p. 943). Some studies have highlighted the benefits of CBT when working with offenders in correctional settings for issues involving anger and aggression, arson and sexual offending (Hassiotis & Hall, 2009; Lindsay & Michie, 2013; Murphy & Clare, 2012; Webber et al., 2010). However, these results were not maintained over time (Gustafsson et al., 2009).

Impact on parents and carers

If and when a person with DD returns from hospital to the family home, the family can be unprepared for what ensues. Parents, carers and family members reported finding themselves at a loss to effectively support their family member with DD and meet their increased support needs (Dossetor, 2011a). The impact of living with the stress of caring for someone with ID and MHD can result in health issues for parents and carers (Dosseter, 2011b). Parents caring for children with autism indicates that more than 90% of mothers and 20% of fathers were prescribed anti-depressants (Bartak, Botroff & Zeitz, 2006, p.256). According to Carers Australia (2015), the 2.7 million carers in Australia are one of the poorest, most disadvantaged groups of people due to the unique characteristics of their role impacting on their own health and wellbeing, often leaving them at the lowest end of socio-economic strata as they are unable to seek employment.

Reduced levels of health and wellbeing and increased levels of social isolation have been reported by people with disabilities and their families/carers (Paech, 2007; Saunders, 2006). The multiple stressors and emotional impacts on carers and families are immense and they may look for respite through organisations for some short-term relief for themselves, as well as an opportunity for social interaction for the person with DD. There has been limited high quality research on effective interventions for family wellbeing (Gustafsson et al., 2009).

Family or community-based care

In Australia, families have access to Community Support Workers (CSW), who are employed to take clients out for social support or to provide respite for the carer or family (Mental

Health Australia, 2017). CSWs are employed by government and non-government agencies, who have competitively tendered for funds to deliver services to people with disabilities, or privately through the NDIS. There is a lack of general training for CSWs, and more specifically training on MHD, limited developmental focus for personal growth and a lack of consistency in staff levels of care (Dodd & Walsh, 2009; Dowse et al., 2016; Paech, 2007). Often people with inadequate training are supporting some of our most vulnerable members of society, particularly those people with DD (Mevissen & de Jongh, 2010; Paech 2007; Pridding & Proctor, 2008; Werner & Stawksi, 2012.

There is potential for the CSW role to be expanded beyond its current scope so they can assist people with DD to manage their recovery or symptoms more effectively (Brown et al., 2011; Bradley, Goody, McMillan & Levitas, 2009; McGillivray, McCabe & Kershaw, 2008). The assistance of CSWs could be vital in aiding successful management as they are in the advantageous position of being able to report back to case managers, clinicians, and families as to which issues, behaviours and interventions are successful or problematic. With training and on-going maintenance for CSWs, their regular contact could help people with DD embed interventions into their everyday lives (Edelstein & Glenwick, 2001; McGillivray et al., 2008). As the push for genuine social inclusion in society increases, CSWs could be an under-utilised resource. CSWs working directly with people with DD have indicated a preference to be trained on and to implement behavioural interventions, either solely or in combination with pharmacological interventions (Christian, Snycerski, Singh & Polling, 1999).

There is a pressing need for a multi-system approach to address the multiple factors that lead to social disadvantage of people with DD and their families. One such area is the development and researching of psychological interventions that can be delivered immediately to people with DD, with the view to inform policy and practice from the bottom-up.

Current Trends in Treatment for People with Dual Disability

There are several common MHD for which people with and without ID seek treatment. They include depressive disorders, anxiety disorders, and psychotic disorders (Dossetor, 2011; Hassiotis et al. 2013; Smith & Howie, 2009; Ruedrich 2010). Both depressive disorder and anxiety disorders are often treated at the primary care level, through accessing general practitioners and psychologists, although people experiencing persistent or major depression may be referred to psychiatrists (Lindsay, 2011). Psychotic Disorders, such as schizophrenia and bi-polar disorder, require treatment from psychiatrists initially, but once stabilised can be monitored at the primary care level (Lindsay, 2011). Symptoms of depression and anxiety are frequently experienced by people with psychotic disorders and can interfere with their level of daily functioning, and often lead to an increased risk of suicide (Buckley, Miller, Lehrer & Castle, 2008; Emsley, Oosthuizen, Joubert, Roberts & Stein, 1999; Karpov, Joffe, Aaltonen, et al., 2016).

Depression and anxiety are identified as disorders when symptoms and behaviour interfere with everyday life (Hassiotis, et al., 2012). Presentations of these MHD may manifest as physical conditions, such as headaches, digestive complaints (Dossetor, 2011c; Kwok & Cheung, 2007), sleep disturbances, including distressing dreams, insomnia, persistent tiredness (Bakken et al., 2010), and eating issues, including loss of or increased appetite (Moss, 2015). In addition to these symptoms, people with ID may also have atypical presentations compared to their counterparts without disability (Dossetor, 2011c; Bakken et al., 2010; Holden & Gitlesen, 2009; McBrien, 2003; McCabe et al., 2006), such as: deterioration of daily living skills (Bakken et al., 2010; Dossetor, 2011c; Moss, 2015); self-injury, including head-banging, cutting, biting (Hollins, 2011; Pridding & Proctor, 2008); faecal and/or urinary incontinence (Hollins, 2011); property destruction (Mevissen & de Jongh, 2010); and pica (Hudson & Chan, 2002).

One of the most common presentations of MHD in people with ID can be “challenging behaviour", particularly aggression or non-compliance (Hurley, 2008; Matson & Neal, 2009; Sturmey, 2004). The symptoms of MHD are often misattributed to be “challenging behaviour by a badly-behaved individual” and parents or carers seek assistance with addressing this behaviour (Holden & Gitlesen, 2009; Hudson & Chan, 2002; Matson & Neal, 2009; Taylor, et al., 2008). Emerson and Einfeld (2011, p. 4) defined challenging behaviour as:

> Culturally abnormal behaviours of such intensity, frequency or duration that the physical safety of the person or others is likely to be put in jeopardy, or behaviour which is likely to limit the use of, or result in the person being denied access to ordinary community facilities, cause injury to self or others.

Much of the thinking around challenging behaviour is predicated on the myth that people with ID have impaired cognition, which further precluded them from developing mental illnesses (Bonjourno, 1996; Sharfstein, Dickerson, Oldham, 2009; Hemmings et al., 2013). Since the 1990s, it has been shown that people with ID do experience MHD and at a higher rate than the general population (Bakken et al., 2010; Bennett et al., 2004; Einfeld, 2005; Hassiotis et al., 2013; Paech 2007; Priest & Gibbs, 2004; Tonge et al., 2010). Assessment tools have been developed that provide a comprehensive description of emotional and behavioural problems experienced by people with ID to assist professionals with identification of MHD (Einfeld & Tonge, 1994; Einfeld & Tonge,1991; Hatton, 2002; Mohr, Tonge & Einfeld, 2010; Mohr, Tonge & Einfeld 2005; Moss, 2015; Myrbakk & von Tetzchner, 2008; Tonge & Enfield, 2000; Tonge, et al., 2008; Tonge et al., 2005; Willis & LaVigna, 2004).

Despite the findings and the tools for identification of MHD, many workers still cling to the notion of “challenging behaviour" as a first line response (Holden & Gitlesen, 2009; Hudson & Chan, 2002; Matson & Neal, 2009). A. Rymill, Project Manager, The LifeSpan Report, postulated (personal communication, 2009) that many of these mental illnesses could have existed in the population group for decades and been undiagnosed, often classified as challenging behaviour. As a result, punitive corrective measures, such as imposed isolation, were enforced instead of exploring alternative causes of the behaviour of concern. Carr & Durrand (1985) developed Functional Communication Training after they determined some people with ID or those with limited communication use challenging behaviour to communicate their distress. People with DD, who have limited communication may have a lack of awareness regarding the reason why MHD symptoms may be occurring, possibly resulting in behaviours of concern as a form of communication (Hassiotis et al., 2012).

In an effort to support an individual and his or her behaviour, pharmacological treatment and behaviour management protocols are often initiated as a first line response (Hudson & Chan, 2002; Sheenan et al., 2015), rather than a mental health assessment for possible MHD (Chan, Hudson & Vulic, 2004; Hudson & Chan, 2002; Torr, 2013). Few alternatives to drug treatment appear to be used (Thomas et al., 2010). This practice is particularly disturbing given issues associated with pharmacological approaches, such as diagnostic overshadowing, dependency, side effects of medication, “off label” use of medication, the exacerbation that medication may have on other physical, mental or behavioural issues, poly-pharmacy and lack of review (Hassiotis et al., 2013; Paech, 2007; Reiss, 2000; Thomas et al., 2010; Tyrer et al., 2008). Furthermore, when an underlying MHD is not identified, untreated, or is treated inappropriately, tertiary illness or behaviours can emerge. Even for those people who do not display externalising challenging behaviour, but may display issues with moods or emotional regulation, pharmacological interventions are a first line response (Matson & Neal, 2009; Hurley, 2006; Sturmey, 2004). Matson and Neal (2009) share their alarm regarding the over-prescription of sedatives with observation that the “prescription of multiple psychotropic medications appear to be the rule rather than the exception” (p. 573).

Anti-depressants, such as selective serotonin reuptake inhibitors (SSRI’s) and tricyclic anti-depressants, are also commonly prescribed to treat MHD difficulties in people with DD (Branford, Bhaumik & Naik, 1998; Lindsay, 2011; Rai & Kerr, 2010; Ji & Findling, 2016). However, Young and Findling (2016) cautioned the specific use of anti-depressants with people with ID, due to the side effects produced such as irritability, increased aggression and sleep difficulties. Wiles et al.’s (2016) study conducted within the general population, reported favourable results for the use of CBT with people who had not responded to anti-depressant medication

Primary care General Practitioners continue to use pharmacological treatment as their primary treatment method, despite the side effects (Fergerson, 2001; Freeman et al., 2010; Hemmings et al., 2013). GPs themselves identified the urgent need for education and training on behavioural and mental health issues including the availability of psychological interventions, although in the interim they predominantly prescribe pharmacological treatment (Phillips, Morrison & Davis, 2004). Similarly, mainstream psychiatrists agreed regarding the lack of training and overuse of prescription medication (Torr et al., 2008). A study of 201 randomly assigned client files (Thomas et al., 2010) highlighted the overuse of medication in people with ID. The study found that 98% of participants were being prescribed psychotropic medication either regularly or on an as-needed basis and that 88% (*n*=177) of those receiving medication needed an independent review.

Currently there are few if any formal guidelines to monitor the use of medication for people with DD. Thomas et al. (2010) and Trollor (2014) call for protocols and guidelines to be established, regular reviews for individuals on medications for MHD, and training for professionals, including psychiatrists, GPs and service providers. Both researchers suggest psychological and behavioural interventions as treatment options initially, relegating pharmacological treatment as a last resort. Importantly, Beck (1987) believed that sole use of psychotropic medication without implementing alternative strategies such as CBT, either solely or in conjunction with medication, can reduce an individual's ability to cope and self-regulate. If tolerance to the medication occurs and the individual lacks alternative skills, this can lead to increased dosages and dependency.

Positive Behaviour Support is used widely in the disability sector, with principles originating from behavioural and biomedical science (Dunlap et al., 2008). The premise behind PBS is that behaviours serve a function for the individual. Functional Behaviour Assessment (FBA) seeks to understand and contextualise the function that the behaviour of concern serves (Carr, Innis, Blakeley-Smith & Vasdev, 2008; Luiselli, 2012), teaching the individual appropriate replacement skills and behaviours that serve an equivalent purpose. The new skill or behaviour is reinforced at specific schedules for superior outcomes for the individual (Rhodes & Watson, 2011; Smith & Howie, 2009). FBA and PBS were not designed specifically for MHD, although they may prove helpful in investigating and changing some of the contributing factors to specific challenging behaviours, such as ecological antecedents, consequences of maintaining the behaviour, and the dimensions of the behaviour (topography, intensity, duration, frequency) (Emerson, Hatton, Thompson & Parmenter, 2004; Hassiotis et al., 2014). However, PBS lacks an explicit focus on metacognition, which Beck (2011) deems underpins all psychological disturbances affecting mood and behaviour.

A trans-diagnostic model (Chamberlain & Norton, 2013; Newby, McKinnon, Kuyken, Gilbody, Dalgleish, 2015) is a psychological approach that focuses on the identifying the common characteristic of disorders, such as maladaptive behaviours and faulty cognitions that underpin a range of psychological presentations. The trans-diagnostic model enables evidence–based practice from specific treatments, such as relaxation training to be amalgamated and administered with CBT (Chorpita, Taylor, Francis, Moffitt & Austin, 2004). For those people with ID whose MHD presents as challenging behaviour, a trans-diagnostic model approach has the potential for treating both behaviour and cognition (Lindsay Tinsley, Beail, Hasting, Jahoda, Taylor & Hatton, 2015). Other treatments used within this model can include psychodynamic therapy, visual imagery exposure, role modelling, graded exposure, occupational therapy and life skills training. Each of these treatments administered individually may alleviate distress or difficulties, however an individual's underlying meta-cognition remains unchanged. A trans-diagnostic approach helps individuals become aware of their dysfunctional thoughts which often leads to improved behaviour and mood (Beck, 2011; Beck, 2005b; Belfer, Munoz, Schachter & Levendusky, 1995; Greenberger & Padesky, 1995; Hofmann & DiBartolo, 2001; Reaven, 2010). This developed understanding can increase internalisation of the skill and transferability to other settings (Taylor et al., 2008).

Cognitive Behaviour Therapy for People with Dual Disability

The principles of CBT are built on the tenets of autonomy and self-determination to develop a collaborative alliance between the participant and therapist, while being aligned with medical ethics (Barron & Winn, 2009; DiTomasso, Knapp, Golden, Morris & Veil, 2010; Dossetor, 2011b). For the general population the success of CBT, with or without drug therapy, is a primary and well-documented treatment for mental health problems. CBT is a present focussed ("here and now"), time-specific therapy (Brown et al., 2011) that emphasises how self-destructive thoughts and beliefs maintain disorders (Beck, 2011; Beck, 2005b; Belfer et al., 1995; Greenberger & Padesky, 1995; Hofmann & DiBartolo, 2001; Michaelson & Marchione, 1991; Reaven, 2010). CBT assists individuals to confront and alter such thoughts, creating more realistic expectations (Beck, 2011; Linden & Lenz, 1997; Young & Beck, 1980). The person with MHD is encouraged to focus on positive successes and attainable goals. The techniques are learned and may take time to master, but once internalised they cannot be withdrawn, unlike pharmacological treatment, and generally "maintain their gain" (Hofmann & DiBartolo, 2001).

CBT relies on the ability of the person with MHD to understand the link between thoughts and behaviours (Taylor et al., 2008). The difficulty that traditional CBT has for people with ID is that these people often have impaired cognition or comprehension, limited communication skills, few literacy skills, and difficulty with some executive functions, such as self-regulation and planning (Brown & Marshall, 2006; Chan et al., 2004; Sturmey, 2004; Taylor et al., 2008). People with ID have historically been precluded from psychological interventions (so called "talking therapies", such as psychoanalysis and narrative therapy), due to their limited intellectual, self-regulation and communication skills. Bender, (1993, as cited in Brown et al., 2011) refers to a philosophy of therapeutic disdain towards people with ID, labelling the phenomenon as the "unoffered chair" in which people with ID are precluded from participating in psychological treatment based on their perceived deficits. In addition, people with ID have been considered unsuitable for CBT, which is a time-limited intervention (DiTomasso et al., 2010), as these people usually require interventions to be delivered more frequently and for longer periods of time (Scior, 2009).

There is limited good-quality research on delivering CBT to people with DD (Beail, 2003; Vereenooghe & Landon, 2013). Most of the current research with diverse groups of people has been focused towards people with autism, who generally are much more likely to experience anxiety and MHD than their peers in the general population (Anderson & Morris, 2006; Attwood, 2004a; Attwood, 2004b; Evert, 2014; Reaven, 2010; Scarpa, White & Attwood, 2013; Scattone & Mong, 2013; Wright, 2013). People with autism also have higher incidences of ID (American Psychiatric Association, 2013); according to Centers for Disease Control and Prevention (2008), 38% of American children with autism had ID. Groden, LeVasseur, Diller and Cautela (2001) acknowledged that people with ID and autism are more susceptible to stress and anxiety, having limited coping skills or specialised supports to assist with management.

The studies conducted on the use of CBT with people with ID focus mainly on managing anger and aggression. This focus may be due to the imminent threat that anger and aggression pose to the individual or to others and due to their presentation in emergency departments or as inpatients (Weiss et al., 2009; Pridding & Proctor, 2008; Bennett et al., 2004).

Many researchers advocate for *adapted* CBT as an intervention for the DD population (Burford & Jahoda, 2012; Hassiotis et al., 2013; McCabe et al., 2006; McBrien, 2003; Scattone & Mong, 2013; Simpson, 2002; Taylor et al., 2008; Vereenooghe & Langdon, 2013; Willner, 2009). These adaptions include flexible and simplified tasks to challenge unhelpful thinking, graded exposure to desensitise the individual, a problem-solving framework, self-regulation and homework (Hassiotis et al., 2012; Scattone & Mong, 2013). For optimal treatment outcomes to be achieved, concepts and tasks need to be simplified and made concrete by using visual aids and practical applications (Taylor et al., 2008). In addition, adaptations need to be relevant and meaningful to the individual to assist with engagement (Hassiotis et al., 2013; Jahoda, Dagnan, Jarive & Kerr, 2006; Keeling, Myles, Gagnon & Simpson, 2003; Reaven, 2010; Willner, 2009).

Taylor et al. (2008) reviewed some of the counter arguments for engaging in CBT with people with DD, including a difficulty understanding cognitive distortions and the effect that low verbal IQ has on outcomes, and concluded that *adapted* CBT is a prompt, effective and individualised treatment suitable for people with mild to moderate ID. As 80% of people with ID fall within this range, Taylor et al. (2008) advocated for CBT to be routinely offered to these people. Burford and Jahoda (2012) also supported the use of modified and individualised CBT and emphasised the use of “psycho-educational or behavioural elements to compensate for any difficulty in communication and comprehension” (p. 187). These findings indicate people with ID have the capacity to engage in CBT with correctly adapted supports. It is the therapist’s responsibility to build a person-centred adaptation that is relevant and meaningful to each individual, and to assist with his or her understanding and engagement (Gold, 1978).

There are several other factors implicated in the successful engagement of participants with DD. Studies focused on the capacity for people with ID to engage in CBT (Chadwick, Trower & Dagnan, 1999; Dagnan, Chadwick & Proudlove, 2000; Dagnan & Proudlove 1997; Dunn, Dunn, Whetton & Burley, 1997; Oathamshaw & Haddock, 2006; Reed & Clements, 1989) indicate that many people with ID can engage in CBT, although some participants display limited emotional awareness. Scior (2009) advised that for people with DD to be able to understand and engage in CBT, they must be able to recognise their emotions and beliefs and be able to link them to events. Some people with ID may not have developed emotional literacy and may be unable to identify feelings and emotions adequately, even in their own bodies. Mirrow (2008) suggested that for some people with ID to engage in CBT they may need to be taught about "feeling language or what our bodies may be telling us" (p. 37). Persons with ID have demonstrated the ability to identify emotions in clinical settings during Dagnan and Proudlove, (1997) and Oathamshaw & Shaw's, (2006) research. However, Oathamshaw & Shaw (2006) queried whether participants could identify emotions in real life contexts.

Participants with ID often have difficulty transferring skills developed in clinical settings into their everyday life. However, they generally understand emotions and behaviours when they can link them to their own experiences or situations (Grahame, 2011; Hassiotis et al., 2012; Mirrow, 2008; Westwood, 2004). When CBT is delivered in naturalistic settings, individuals, with initial assistance from the therapist, explore the interrelationship of behaviour, mood and thinking (Willner, 2009), in order to "shift negative core schema and improve adaptive reasoning" (Jahoda et al., 2006, p. 85).

The readiness of participants to engage effectively in therapy, including motivation, confidence and self-efficacy has also been examined (Keeling et al., 2003; Taylor et al., 2008; Stott, Charlesworth & Scior, 2017). To increase therapy outcomes, using an individual's interest in a preferred topic or activity can increase engagement and motivation and can garner willingness for the participant to use the intervention independently. This may then lead to individual's generalising the intervention across conditions and settings (Keeling et al., 2003; Lindsay & Taylor, 2008).

There has been criticism of the use of CBT for people with DD, with suggestions that some studies were using Applied Behaviour Analysis (ABA) rather than genuine cognitive therapies and results were confounded by other factors, such as relaxation techniques (Sturmey, 2004). Sturmey cites a study by Rose and West on anger as an example (Sturmey, 2004, p.226). There have been responses and debate about Sturmey's criticisms (Emerson, 2006; Beail, 2005; Taylor, 2005). Beck (2005a), DiTomasso et al. (2010), Farmer & Chapman (2008) and Young & Beck (1985) suggested that CBT is not one single therapy but a group of therapies and strategies, and that some rely on a stronger behavioural component, particularly in the early stages.

Fundamentally, Sturmey does not support the use of cognitive therapies for people with ID, suggesting that ABA or psychotropic medication has a larger evidence base. ABA and Positive Behaviour Support (PBS) have a large evidence base to support their use, although they do not specifically address cognitive processes. However, there is increasing evidence that cognitive approaches are being incorporated into contemporary PBS practice as a greater understanding of meta-cognition on behaviour develops (Luiselli, 2012). Cognitive therapies, delivered as part of CBT, enable the development of metacognition, further enabling individuals to understand and challenge their own thinking, which, in turn, affect their behaviour and mood (Edelman, 2013; Hassiotis et al., 2013). These can increase internalisation and transferability (Taylor et al., 2008). Components of PBS, such as reinforcement of positive behaviour, instruction in naturalistic settings and teaching alternative behaviour, can be incorporated into CBT in the behavioural phase of the intervention and as such, could be considered as part of a group of strategies used in CBT as suggested by Beck (2005a), DiTomasso et al., (2010), Farmer & Chapman (2008) and Young & Beck (1985).

In terms of a larger evidence base for psychotropic medication, this base may in fact be confounded, particularly as sedating medication is used for the convenience of staff and for behavioural control and compliance rather than to treat underlying MHD (Matson & Neal, 2009; Simpson, 2002; Holden & Gitlesen, 2009; Taylor et al., 2008). An over-reliance on medication to manage behaviour can affect or bias research findings. Sedating medication such as benzodiazepines may blur cognitive procedures and interfere with learning processes of therapies such as CBT, rendering them less effective (Salas Henninger, Stern & Prout, 2010). Simpson (2002) states that pharmacological therapy should not be a sole and exclusive form of treatment, but if used in conjunction with other therapies, such as CBT, it is beneficial, especially at the beginning of the therapy (Haddock et al., 2001). The goal should be for the individual's physician to gradually decrease the amount of medication as cognitive behavioural skills in the individual become more effective.

Several researchers support modified CBT as a suitable treatment option for people with DD, although they requested that descriptions of the adaptations used by each study be provided (Brown et al., 2011; Grahame, 2011; Hassiotis, et al., 2013; Scattone & Mong, 2013). Methodological issues with existing studies are said to include a lack of theory, rigor and integrity (Scattone & Mong, 2013; Prout & Nowak-Drabik, 2003 Vereenooghe & Langdon, 2013). Sturmey (2004) recommended further research using experimental designs, such as randomised controlled trials or single case experimental designs, were necessary to conclude whether CBT interventions for people with ID actually cause the changes or improvements they proffer.

Delivering Cognitive Behaviour Therapy to People with Dual Disability

A lack of trained professionals and services to assist people with DD at a "grass-roots" level has resulted in inappropriate care in generic mainstream services, long waiting lists for psychiatric or psychological services, development of secondary or tertiary illness while waiting for services and unsuitable interventions, such as isolation and punishment (Bennett et al., 2004; McGillivray et al., 2008; Mohr, Phillips, Curran & Rymill, 2002b; Pridding & Proctor, 2008). DiTomasso et al. (2010) discussed the need for therapists to have undertaken training and licensing for delivery of psychological interventions including CBT. Conversely, Rose, Kent & Rose (2012) reviewed staff training in supporting people with DD and found, despite some issues with rigor and methodology, that generally frontline staff could, with training, effectively implement therapeutic practices. Given the lack of DD specialists or services, frontline staff (e.g., Community Support Workers) could be an under-utilised resource. Willner et al. (2013) used disability program assistants (termed "lay therapists"), who were familiar to the participants, to deliver, under supervision, adapted CBT in a group setting. Disability program assistants were deemed as appropriate due to their unique knowledge of the nuances of the people they work alongside (Willner et al., 2013). Integrity and validity of the randomised control trial was measured with a fidelity scale as used in Jahoda et al., (2013).

In relation to individualising and adapting the CBT technique being utilised, therapist competency influences the success and outcomes of an intervention, particularly his or her experience and attitude (Taylor et al., 2008; Scior, 2009). People with DD may take longer to internalise management and may require extra scaffolding, including modelling, role play and direct instruction techniques to develop skills (Scior, 2009). If the therapist lacks specific training and experience, developing an understanding of how people with ID learn may be advantageous and may assist with the delivery of CBT interventions. Sheldon (1995) claimed that superior results are produced when interpersonal skills of "non-possessive warmth, genuineness and empathy" (p. 25) are displayed by therapists, rather than professional credentials.

Due to the vulnerability of people with DD all therapists, whether licensed or frontline (including lay therapists (Willner et al., 2013)), need to take care and reflect on their practice regularly to ensure they are working from a human rights and citizenship perspective (Evans et al., 2012). In addition, Willner (2009) and Mirrow (2008) advised that people with ID may need to have a more instructional or didactic approach than traditional CBT. Some therapists may find this "an uncomfortable position to adopt but it must be accepted as inevitable" at least in the initial sessions (Willner, 2009, p. 418).

Parents, carers and supporters are important in an intervention and can be used as facilitators, particularly in the early phase. They can assist in application of the skills learned in the session into the broader environment (for example, generalisation and transferability) (Brown et al, 2011; Hassiotis et al., 2012; Sigan et al., 2015). However, Grahame (2011) and Hassiotis et al. (2012) offered some considerations when using parents, carers and supporters. Firstly, Grahame (2011) advised that the beliefs and interpretations of parents and carers may impact on and maintain problem behaviours of participants. This issue was evident in Oathamshaw, Barrowcliff & Haddock (2012), who noted how attitudes of paid carers (along with environmental issues) undermined the engagement of participants and affected the outcome of the study. Incorporating PBS by examining the environmental and social factors (e.g., parents or carers) that influence behaviour has merit, with a view to mitigating such external factors that could be affecting mood, and hence behaviour. Opportunities for vicarious learning for parents, carers and supporters to address contributing personal or environmental factors and lessen their own stress levels could be presented as an unexpected benefit of this study (Mirrow, 2008; Hatton, 2002).

Hassiotis et al., (2012) state that parents and carers are useful as supporters as they know the person and the person generally trusts them. However, the use of these support people needs to be delicately balanced within the research protocol, as these supporters are already burdened with responsibilities from their caring role and as a result, may have health issues of their own (Bartak et al., 2006). Even so, a study of CBT on psychosis reported a reduction of stress-related problems in families supporting people with MHD when the supporters were involved in interventions (Haddock et al., 2001). Hassiotis et al., (2012) also cautions when using supporters that the participant does not become over-reliant on the support person, as the overall goal is for the participant to become independent and self-manage their own MHD.

Adaptations

When developing adaptations for CBT, special attention must be made when providing alternative approaches so that each participant understands the requirements and is assisted in developing self-management skills. Supporters may also need alternative approaches to aid understanding of their role in the development of participant’s skills. For participants, issues with language and communication can hinder the CBT process, therefore therapists will need to consider these issues and find productive alternatives to communicating by using Augmentative and Alternative Communication (AAC). Alternatives include PCS, for example, Mayer-Johnson (2017); COMPIC, for example, Burns (2016); and other AAC systems, for example, Barron & Winn (2009) and Scior (2009).

For people with mild to moderate ID, their level of literacy can be one of the biggest barriers to understanding concepts. These people learn best visually, for example, through pictures, maps, video or photographs (Chan, 2013; Cooney, Tunney & O’Reilly, 2018; Burford & Jahoda, 2012; Jacobelli & Watson, 2008). Picture Activity Schedules (PAS), which use visual cues for skill acquisition, self-regulation and maintenance, are used widely in the disability and special education fields (Lequia, Machalicek & Rispoli, 2012; Kayoma & Wang, 2011; Jaime & Knowlton, 2007; Mesibov, Browder & Kirkland, 2002). Chebuhar, McCarthy, Bash and Baker (2013) used visual supports successfully to assist with management of anxiety in acute hospital settings for patients with special needs.

Visual supports can be preferred by people with ID to other types of communication and can augment or be an alternative to spoken language (Joseph & Chapman, 2013; Mesibov, Shea

& McCaskill, 2012). For people who can communicate using speech, but who have difficulty with comprehension and expression (including emotions and feelings), AAC can be useful and appropriate to compensate for both receptive and expressive difficulties, including the static nature of the visual supports to reduce cognitive load (Mesibov, Shea & McCaskill, 2012; Pardini et al., 2012).

Furthermore, visual aids such as photographs, images and symbols provide valuable information from primary sources, such as participants in live settings. Information from primary sources is integral to good research (Burford & Jahoda, 2012; Hatton, 2002). Simpson (2002) considered it devaluing to obtain information from others when the individual can self-report, if given assistance or adaptation of the therapy. Simpson (2002) advised researchers that engaging people with disabilities directly is the “least intrusive or restrictive method possible” (p. 9). This lack of engagement from primary sources has been a criticism of current assessments and diagnostic tools that are completed by a third party, who relays information on the person with the DD (Holden & Gitlesen, 2009). This approach may be warranted for those people with severe ID who have complex communication needs and may not be able to self-report due to severe expressive and receptive communication difficulties. However, people who have either a mild or moderate ID could self-report on symptoms or interventions (Taylor et al., 2008), although they may also benefit from the use of visual supports to understand and communicate more complex language that may not be in their linguistic repertoire.

As identified, there is a need for more research into adapted psychological interventions to assist people with DD to manage their MHD. The broad aim of this research is to investigate the effectiveness of a visual adaptation of CBT using photographs, line drawings and symbols, or by using emoticons and simplified text so individuals with ID can self-manage the symptoms and behaviours that may present as a result of the MHD. To evaluate the broader aim of the research, the following sub-questions will assess (a) how effective is visual CBI in decreasing symptoms or behaviour of MHD (b) how effective is visual CBI in increasing self-management of symptoms and behaviours of MHD, (c) will significant improvement in self-management occur once the intervention moves from behavioural therapy (phase one) to cognitive therapy (phase two), (d) to what extent do people with DD independently use their cards and associated strategies to self-manage their MHD when experiencing symptoms or distress? Will they require prompting from supporters?

In addition to the research questions, social validation interviews explore the perceptions of the effectiveness of the intervention from participants and supporters to determine if the intervention was helpful in everyday life. Kazdin (2011, p. 208) defines social validation as “impressions of the client or those who interact with the client that the treatment change makes a perceptible difference”. The visual system has the potential to support the person with DD and be an additional resource for parents, carers and frontline staff to understand MHD and provide support to people with DD.

Summary

This chapter established that people with DD and their supporters experience significant barriers to receiving appropriate and timely treatment for their MHD. There is a demonstrated need to address treatment disadvantages by developing interventions that are appropriate for people with ID to self-manage their MHD, to increase their autonomy and reduce dependency on limited and under-funded services.

4. METHOD

This chapter discusses the methodology used in the research; the methods, aims and design of this study, including ethics protocols, procedural integrity and data analysis. Detailed information is also presented on participants, their MHD and target behaviours for intervention. The overall adaptations from the original CBT model have been comprehensively described within the content and structure of the intervention (Grahame, 2011; Brown et al., 2011; Hassiotis, et al., 2013).

Design – Single Case Design

The research method utilised was single case experimental design with a multiple baseline design and randomisation procedures to observe changes in behaviour before and during the introduction of the adapted CBI and follow-up at two and six months. Shadish, Rindskopf and Boyajian (2016) advised that randomised control trials (RCT) are the gold standard in research. However, RCT can be costly, resource and time intensive and require large numbers of participants. In comparison, single case design (SCD) is beneficial in determining intervention efficacy for small exploratory studies, such as this study (Shadish, 2014; Horner et al., 2005). SCD is useful in establishing evidence-based practice (Shadish, 2014; Horner et al., 2005), as the research focuses on the individual while seeking active interventions and practical procedures that can be used at home, school or in a community setting (Horner et al., 2005; Westling & Fox, 2009). Individuals with a disability or disorder may present differently to other individuals who have the same disability, it can be difficult to obtain a sufficient number of participants to develop a control group. SCD is well suited to small participant numbers as SCD is predicated on the development of an individual baseline for each participant, in which they become their own control, rather than assigned to a control group. The intervention itself is measured in many ways: before, during and after initiation of the intervention, within and across participants. If intervention elicits change then this is seen as causal effect (Kazdin, 2011; Kennedy, 2004; Maggin & Odom, 2014; Richards, Taylor & Ramasay, 2014).

SCD provides an opportunity for continuous feedback that enables adaptation and flexibility to accommodate the participant's skill set (Kazdin, 2011). In addition, SCD enables an opportunity for non-invasive inspection of change at the point where the intervention is introduced (Kennedy; 2005), and the ability to see "important reliable occurrences" (Kazdin, 2011, p. 287). SCD can determine intervention efficacy for establishing evidence-based practice when investigating the effectiveness of newly developed or adapted interventions, such as in this study (Horner et al., 2005; Rizvi & Nock, 2008; Shadish, 2014).

This intervention study utilises both quantitative and qualitative data. The quantitative design employs multiple baselines to establish a functional relationship between the dependent and independent variables (Carr et al., 2008). The qualitative section uses semi-structured social validation interviews to examine whether the visual CBI has been effective from the perception of the participant and the supporter.

The aim of this research was to teach self-management skills that, once taught, cannot be withdrawn or reversed. A multiple baseline design was selected over ABAB design, which requires withdrawal or reversal of the intervention (Kazdin, 2011; Knock, Michel & Photos, 2007; Richards et al., 2014). In addition, the multiple baseline design allows for replication of effect across participants. Traditionally, at least three replications of intervention effect are necessary to be considered a causal relationship between dependent and independent variables (Kazdin, 2011). This research aimed to recruit at least 6 participants to allow for demonstration of intervention effect, should that be the case.

Historically, multiple baseline design requires a stable baseline and intervention for participant one to be established before participant two can proceed from baseline to intervention phase. This systematic staggering occurs for all participants in the study (Horner et al., 2005; Richards et al., 2014; Rindskopf, 2014). The researcher decides when sufficient stable data has been gathered before introducing the intervention. A decision based predominantly on visual inspection has the benefits of being able to detect early changes in level and trend, observe emerging patterns and consider outliers (Horner et al., 2005; Kazdin, 2011; Kennedy, 2005; Knock et al., 2007; Richards et al., 2014). Richards et al., (2014, p. 335) suggest that visual inspection has “some subjectivity”. In particular, there have been some concerns regarding errors and bias with response-guided practices, with calls for statistical procedures to be developed to improve validity and rigor (Kratchowill & Levin, 2014; Maggin & Odom, 2014). As a result, various statistical procedures have been developed to support SCD (Fisher & Lerman, 2014; Levin, Ferron & Gafurov, 2014; Moeyart, Ferron, Beretvas & Noortgate, 2014; Rindskopf, 2014; Shadish, 2014). To supplement visual inspection Gafurov & Levin (2013, 2015, 2016) developed the *ExPRT Excel® Package of Randomization Tests* (ExPRT)[i],(Version 2.1, 2016) a comprehensive statistical package for analysis of SCD that is easy to use for early-career researchers and practitioners.

ExPRT (Version 2.1, 2016) is based on a non-parametric procedure that fits well with small sample sizes that are inherent in SCD, and allows flexibility with dependent variables such as behaviour, which varies for each individual in this study (Rindskopf, 2014; Shadish, 2014; Swaminthan, Rogers & Horner, 2014). Non-parametric statistical analysis was necessary as the researcher was embedded in the study in the role of therapist and was teaching participants and supporters the intervention, and reported on progress (Richards et al., 2014). The researcher-therapist role is discussed later in this chapter (see “Researcher-Therapist Role”).

Randomisation Procedures

To ensure internal validity two randomisation procedures were utilised. ExPRT (Version 2.1) software randomly selected an intervention start point for each participant, prior to commencement of the study (Gafurov & Levin, 2016). Case randomisation by lottery, where participants pulled a numbered tile from a bag, was the second procedure obtained prior to beginning the baseline condition (Kratchowill & Levin, 2014).

ExPRT (Version 2.1, 2016) enables a stagger of one data point between each participant's intervention start point. This normally contravenes multiple baseline designs which generally require a stable baseline to be established for each participant, before proceeding with the introduction of intervention with the next participant (Gafurov & Levin, 2015). Levin, Ferron & Gafurov (2016) suggest a reduced stagger of one data point might simply come down to the researcher's desire to have "equal-sized between-case staggers" (p. 16) which allows the researcher to conduct randomization tests post intervention using the ExPRT (Version 2.1, 2016) software. Given this information, the researcher reasoned the reduced stagger of one to uphold an ethical imperative, as some participants of this study had experienced previous suicide attempts or ideation. Longer baseline periods with longer staggered intervals could leave participants at risk of self-harm, particularly if they were not receiving ongoing counselling or medication, as even one episode of self-harm can have a catastrophic outcome (Rivzi & Knock, 2008).

To ensure internal validity with multiple baseline designs, the researcher assisted each participant to gather a minimum of four individual data points prior to commencement (Alberto & Troutman, 2006; Kratchwill & Levin, 2014) and introduced 40 data points per participant throughout the intervention to examine whether any changes occurring in behaviour were due to the intervention (Kazdin, 2011). A preselected number of data points overall (baseline and intervention) is also necessary to conduct the randomisation procedures using the ExPRT (Version 2.1) software (Gafurov & Levin, 2016). ExPRT (Version 2.1) (Gafurov & Levin, 2016) was utilised to increase accuracy and determine effect size for the behaviour and self-management of each participant. ExPRT (Version 2.1, 2016) also calculated the effect size and significance value for the entire study (i.e., pooled results for all participants).

Selection Criteria

Participants were six adults aged 18-51 years of age who met the study selection criteria.

Inclusion criteria were:

- Adults aged 18-65 registered with a state disability service agency ensuring a classification of ID.

- Diagnosis of a mental health difficulty as assessed by professional such as a GP, psychologist, psychiatrist.

- Ability to demonstrate an understanding of the meaning of photographs and symbols.

- Access to parent, carer or supporter to assist with out-of-session homework tasks.

- Active case file with a case manager so that the participants had extra support (if required).

Exclusion criteria were:

- People with dual disability who were experiencing crisis psychosis.

- People with dual disability who had existing drug and alcohol misuse.

The behaviour of each participant was *not* determined at the outset of the research but was negotiated with each individual participant prior to his or her commencement in the study. Disability case managers and service coordinators identified which clients met the inclusion criteria and may be suitable to participate in the research study. In total, eleven clients were considered for participation in the study. However, on investigation, two did not have sufficient supporter assistance to commence, one had undertaken medical investigation to determine if MHD was of a neurological origin, and one person was assessed by mainstream mental health professionals who deemed the behaviour to be disability related rather than MHD.

Information was distributed to the remaining six clients (and supporters). Clients who expressed interest in participating in the research could contact the researcher directly or through their case manager, parent, carer, or other nominee. The researcher met with each participant and provided information on (a) how the intervention would be conducted, and (b) what was required as a participant and supporter prior to consent.

Six people with DD completed the study. One participant, Raj, did not record sufficient data for inclusion in the analysis, however, information gathered from him could be used to improve future treatment design and protocols as recommended by Sheridan (2014) and Rivzi & Knock (2008). As such, some information obtained from Raj is discussed in chapter 6.

Ethics Approval

As the participants of the study have increased vulnerability due to both their ID and their MHD, the ethic of non-maleficence was paramount. The study design was developed in line with information from Emerson et al. (2004), Freedman (2001), Jepson’s (2015) and complied with recommendations of Medical Research Council (2006) and NICE Mental Health Guidelines (2016). Research Ethics Approval was obtained from (a) Flinders University of South Australia and from

(b) the Department of Communities and Social Inclusion (DCSI). Ethical protocols observed in this study included a statutory declaration ensuring confidentiality, informed consent (see "Informed Consent" subsection), the right to withdraw without prejudice and the contact details of independent persons to discuss any grievances, if they occurred. Participants and supporters were provided with emergency contacts for mental health crisis services. The researcher had previous training in emergency mental health assessment and protocols, including processes for referral to crisis services.

Informed Consent

Informed consent is the principle that people engaging in research or treatment can make their own decision about participation. There has been much discussion about the ethical and practical challenges surrounding people with ID and their capacity to understand the nature of their involvement, particularly in regards to the benefits and risks (Freedman, 2001). Many people with ID may not have opportunities to make decisions, and so the use of concrete visual aids and role-play to help the participant understand and facilitate choice is encouraged (Freedman, 2001).

Jepson (2015) provided guidelines for working with people with ID, including an accessible format, concrete examples and revisiting verbal consent at each session to help ensure the research was ethical, empowering and inclusive.

This study used the following measures to ensure informed consent prior to commencing the intervention:

- Information sheet (Appendix A)
- Consent forms, including reader-friendly version (Appendix B)
- Verbal Script
- Pictorial consent for intervention (Appendix C), research (Appendix D) and interviews (Appendix E)
- Constant checks that the participant understands the elements properly: "it is not sufficient to just simplify" (Gallagher, 2002, p. 207)

Participants were given two days after the information session to consider and discuss their participation before signing the consent forms. To ensure ongoing consent, the researcher checked in at the beginning of each session to confirm whether the participant was happy to continue with the session and with the intervention in general (Freedman, 2001; Gallagher, 2002; Jahoda et al., 2013).

Role of the Supporter

A supporter was someone the participant had expressly chosen and trusted to help him or her learn this new way of managing the MHD. Supporters could include a parent, carer, family member, friend or staff person. The choice of supporter was built on the Supported Decision Making (SDM) framework whereby “individuals are provided with the necessary supports and accommodations to make and communicate decisions according to his or her wishes” (Gooding, 2014, p. 434), so that effective self-management and autonomy can prevail. Supporters attended the information session with the participant and discussed their involvement. It was essential the supporter attended twice weekly sessions with the participant and researcher to learn how to best assist the participant challenge their MHD using the strategies from the visual CBI cards. Both the participant and the supporter were required to separately record the number of episodes of the MHD and self-management (SM) on data collection sheets provided by the researcher. Other activities for the supporters included helping with the homework tasks, including taking photographs of the participant practicing new skills, providing transport and accompanying the participant to the meetings and places where they could practice new skills. The role of the supporter (and researcher) was an empowering process for the participant as he or she is the primary decision maker rather than be forced or coerced into completing activities that may produce difficulties (Khon & Bulmenthal, 2014). All supporters signed a confidentiality agreement and a consent form agreeing to take part in the study. At the end of the project the supporter undertook a social validation interview.

Researcher-Therapist Role

During the intervention, the researcher took on the dual role of therapist during the delivery of the intervention as described by Ledger (2010). For this research, the insider position of the researcher-therapist was considered beneficial as the researcher had adapted this CBI from Beck’s (1976) original CBT model and had experience working with the DD population.

Participants and Target Behaviour

Six participants with ID and various MHD who were community based, took part in the 20-week intervention: three men and three women, ages ranging from 18 to 51 years. Four participants identified self-management of their anxiety as the goal for intervention; two participants identified anger as their goal. Several participants had severe mental illness and various comorbidities, however, no participant had active psychosis and their severe mental illness was considered sufficiently stable to be able to participate in the study. Each participant identified common mental health difficulty that they perceived to be impacting on their daily life as the target behaviour of the CBI, mainly depression or anxiety, or behaviours such as anger, self-injury, self-harm with suicidal ideation.

Three participants had a functional assessment of mild ID; three had a moderate ID. Participants had a history of a variety of behaviours of concern, including self-injury, significant property damage, and self-harm with suicidal ideation. All participants had taken part in previous psychological treatments to assist with management of their MHD. Four of the six participants were receiving pharmacological treatment to assist in the management of their MHD, but were experiencing problems and were seeking a further means of management. A summary of participants can be seen in Table 4.1, which lists personal details, ID functional range (column *ID*), mental health diagnosis (*Diagnosis*), the MHD for self-management (*MHD*), and supporter.

Table 4.1. Participant details

Name	Gender	Age	ID	Diagnosis	MHD	Supporter
Niamh	Female	26	Mild	Depression	Anger with self-harm and suicide attempts	Partner
Raj	Male	51	Moderate	Schizophrenia with paranoia, depression, unresolved grief	Anxiety	Case manager
Rodney	Male	18	Mild	Anxiety disorder, chronic depression, unresolved grief	Anxiety with avoidance behaviour	House manager
Connor	Male	30	Mild	Schizophrenia / schizo-affective disorder, borderline personality disorder	Anxiety with self-harm and suicide attempts	Developmental Educator
Gyan	Female	26	Moderate	Generalised anxiety disorder, panic attacks	Anxiety	House manager
Katherine	Female	22	Moderate	Depression	Anger with self-injury and property damage	Foster parent

Target Behaviours

In this study, the target behaviours for MHD and SM were negotiated with each participant prior to his or her commencement in the study. As the intervention was individually personalised, each participant's target behaviours for MHD were different. Determining the target behaviours in collaboration with the participant made the intervention relevant and meaningful and capitalised on each participant's motivation and engagement as described by Burford & Jahoda, (2012) and Keeling et al., (2003). MHD for each participant are defined for each participant below. While participants had different mental health diagnoses, the two behaviours for which assistance was sought were anxiety and anger. For some participants, it was anticipated that management of their MHD would see a reduction in other behaviours, such as suicide ideation or attempts, self-harm, self-injury and property damage.

Self-management

Ramdhani, Widjaja and Rahmawati (2015) defined psychological self-management as developing methods, skills and strategies where the individual takes responsibility for achieving a desired objective or goal. As the "self-management concept states that there is a strong relationship between the mind, emotions and behavior" (p.179), it sits well within a CBT framework

Self-management (SM) for each participant in this study was defined as the use of the visual CBI cards with strategies, including cognitive restructuring component, to reduce the symptoms or behaviour of the MHD in line with their own specific goal. The cards were developed during the sessions with the therapist using photographs from the experiments along with emoticons or text. During the first stages (first 29 sessions) of the intervention the participant could be prompted by the supporter or the researcher to use the visual CBI cards, however the final ten sessions required independent SM.

Niamh

Niamh was a 24-year-old woman with a mild ID and a diagnosis of depression with anger management issues. Niamh had epilepsy which was managed through medication. Niamh's goal was to self-manage her episodes of anger. Prior to presenting for participation in the study, Niamh had been hospitalised after an episode of self-injury. She had a history of self-injurious behaviour and self-harm with suicidal attempts and ideation. Reports indicated that self-harm usually followed altercations where she had been verbally or physically aggressive and then felt remorseful. It was anticipated Niamh's goal for self-management of her anger could assist with providing alternative strategies instead of self-injurious or self-harming behaviours. Niamh's anger and subsequent behaviours had impacted her feelings of self-worth and confidence, as well as adversely affecting the relationships she valued.

Niamh spent long periods of time at home unoccupied, often ruminating on issues of concern, her previous problematic behaviours, or reflecting on her distressing life events. She presented regularly at a local hospital with injuries resulting from her behaviour or with preoccupation about her health. Niamh requested her partner be her supporter for the study.

Niamh described the behaviours that indicated that she was angry. She could identify that they were on a hierarchy of intensity that escalated from feeling angry to physical aggression.

Niamh's target behaviours were defined as:

- Feeling anger – angry mouth and making fists
- Verbal aggression – swearing, making threats to hurt others
- Physical aggression – property damage, screaming, harm to self or others, suicidal thoughts or behaviours

Self-management goal

To use the strategies (diaphragmatic breathing, distraction techniques and helpful thinking) depicted on her CBI cards to reduce her anger and subsequent behaviours of threats, property damage, harm to self and others, suicidal thoughts or behaviours.

Raj

Raj was a 51-year-old man with a moderate ID and a diagnosis of schizophrenia with high levels of paranoia and anxiety. He received a fortnightly depot injection and oral medications to manage his schizophrenia. Raj's goal was to reduce his anxiety, to cease his behaviour of making numerous phone calls to multiple agencies, including emergency services, requesting assistance with whatever problem he was anxious about at the time. Raj lived independently, receiving 14 hours of support a fortnight from a disability support agency. Raj's anxiety appeared to be a result of feeling unsafe, while living in his family home. His aged parents had recently passed away and the memories of his parents were reported to be impacting on his schizophrenia and anxiety. Raj had limited social networks, having ceased all independent activities and was reluctant to recommence them, despite having a history of supported employment and recreational activities. His main social contacts were with paid workers.

When Raj was in a heightened state, he would repeatedly ring service providers, including emergency services reporting he had been assaulted. While there had been recorded incidents of hostility or abuse, some of the statements were confabulated and may have been a result of his schizophrenia. Raj had a history of aggression, when in a heightened state of anxiety. Discussions with Raj, his case manager and his support agency identified he could benefit from the intervention and learn new ways to manage his anxiety and behaviour. Raj requested a case manager be his supporter. Raj's data were collected by support staff. Given Raj's moderate ID and reduced concentration due to medication for his schizophrenia, it was unlikely he would reliably report the data. The support staff had daily contact and agreed to record the times he contacted them due to his anxiety.

Raj's target behaviours were defined as:

- Mild anxiety – telephoning agencies to "chat" with no apparent cause for concern.
- Anxiety – ringing agencies stating he has intruders and he needs to move.
- Heightened anxiety – ringing agencies in a distressed state (yelling, crying) reporting he is dying or has been attacked.

Self-management goal

To use the strategies (diaphragmatic breathing, distraction techniques and helpful thinking) depicted on his CBI cards to reduce anxiety and subsequent behaviours of ringing agencies

Rodney

Rodney was an 18-year-old male with mild ID and diagnosis of anxiety disorder (generalised anxiety, social and panic attacks) with avoidance behaviour. He was deemed at risk of developing agoraphobia. He also had a formal diagnosis of chronic depression, with unresolved grief and anger management issues. Rodney's goal was to manage his anxiety, which affected his quality of life and access to community activities. His heightened levels of anxiety often resulted in aggression with substantial property damage. Rodney had a documented history of anxiety and aggressive behaviour since childhood with various school-based interventions undertaken to address this, including medication and behaviour plans. He was reviewed regularly by a psychiatrist specialising in DD, but was reluctant to take medication due to previous debilitating side effects.

Rodney did not identify as having ID, but acknowledged his high levels of anxiety. The goal for Rodney was to self-manage his anxiety to allow him to live independently and to access community-based activities he was currently avoiding. It was anticipated that self-management of his anxiety could also assist in reducing his angry outbursts by providing alternative strategies. Rodney's constant high levels of anxiety increased his reactivity.

Rodney had experienced traumatic events, with the loss of important people in his life. He reported these losses impacted on his anxiety and depression. He had limited social networks and his only contact with people was through paid professionals. Rodney wanted to have a social world like that of his same age peers, stating he wanted to try to do things, but didn't want staff to push or coerce him. He talked about fears of having a panic attack or not being able to control his anxiety in front of others. Rodney lived in supported accommodation with 24-hour support. Rodney invited his key worker to be his supporter. The supporter provided relevant information from the study to other staff members and stakeholders.

Rodney's target behaviours were defined as:

- Mild anxiety – feeling worried or nervous, can't stop worrying or asking the same questions.
- Anxiety – feeling anxious, sweating, going to the toilet, can't sleep well, can't stop thoughts.
- Panic – avoidance or leaving a situation due to high levels of anxiety.

Self-management goal

To use the strategies (diaphragmatic breathing, distraction techniques and helpful thinking) depicted on her CBI cards to reduce his anxiety and panic and subsequent behaviours of repetitious questioning, avoidance or leaving situations due to high levels of anxiety.

Connor

Connor was a 30-year-old man with mild ID, a formal diagnosis of schizophrenia/schizoaffective disorder and Borderline Personality Disorder (BPD). He received a monthly depot injection and oral medication for depression. Connor's goal was to self-manage anxiety, as it was his anxiety that prevented him from functioning effectively in everyday life. It was anticipated that self-management of his anxiety would allow him to engage in meaningful activities, and gradually reduce his overall anxiety. In addition, his self-harming behaviours and suicidal ideation would be replaced with more effective coping strategies.

Prior to presenting for participation in the study, Connor had a traumatic life event and was hospitalised after self-harming. Connor's anxiety was acute, constant and debilitating. He had little motivation to leave the house and anxiety left him feeling exhausted resulting in sleeping for long periods throughout the day. Connor's anxiety affected his quality of life. He had a long-standing recreational interest that he engaged in weekly although he also experienced long periods of time where he stayed home unoccupied, often ruminating on issues that concerned him. After the adverse life event, Connor's anxiety was significantly heightened with negative and circular thinking. He was reviewed by a psychiatrist, psychologist and GP regularly. Connor lived in supported accommodation with other people of a similar age. He requested a developmental educator be his supporter for the study. The supporter provided relevant information from the study to other staff members and stakeholders.

Connor's target behaviours were defined as:

- Mild anxiety – feeling worried or nervous, can't stop worrying, can't concentrate.
- Anxiety – feeling anxious, sweating, going to the toilet, can't sleep well, racing thoughts.
- Heightened anxiety – avoidance, self-harming (suicidal) thoughts or behaviours.

Self-management goal

To use the strategies (diaphragmatic breathing, distraction techniques and helpful thinking) depicted on his CBI cards to reduce anxiety and subsequent behaviours of avoidance and self-harming suicidal thoughts and behaviours.

Gyan

Gyan was a 30-year-old woman with moderate ID and a diagnosis of Generalised Anxiety with panic attacks. She had regular reviews by a psychiatrist specialising in DD, who prescribed anti-depressants to help manage her anxiety. Gyan's goal was to self-manage her anxiety more effectively. Gyan lived an active lifestyle and interacted with many people, from whom she sought advice or reassurance. The advice from others was often conflicting and counterproductive, and engaging in conversations with many people appeared to increase her anxiety. The use of visual CBI was anticipated not only to enable Gyan's self-management, but also to give other people from whom she sought reassurance a unified framework to draw upon.

Previously, Gyan had engaged in interventions to assist her in managing her anxiety, including counselling at a local mainstream mental health facility. The psychologist had provided a short-term outlet for her distress with narrative therapy, encouraging Gyan to use self-care strategies such as relaxation music, to counter ongoing stress. However, Gyan had not maintained the recommended strategies. Several issues created anxiety for Gyan although all produced the same outcome of increasing Gyan's generalised anxiety, at which time she would seek assistance from others. Gyan lived in supported accommodation with other women of a similar age with intellectual disabilities. One housemate had behaviours of concern that triggered Gyan's anxiety, and she had reported "not feeling safe". Gyan had a documented history of abuse. Gyan invited her house manager to be her supporter who provided the relevant information from the study to other staff members and stakeholders.

Gyan's target behaviours were defined as:

- Mild anxiety – feeling worried or tense, can't stop worrying or asking the same questions to many people.
- Anxiety – feeling anxious, sweating, going to the toilet, can't sleep well, can't stop thoughts, seeking help from people.
- Panic attacks – avoidance or leaving a situation due to high levels of anxiety or panic.

Self-management goal

To use the strategies (diaphragmatic breathing, distraction techniques and helpful thinking) depicted on her CBI cards to reduce her anxiety, panic attacks, automatic thoughts and subsequent behaviours of avoidance or leaving a situation due to high levels of anxiety or panic

Katherine

Katherine was a 24-year-old woman with moderate ID and a diagnosis of depression and anger with self-injury. She was reviewed regularly by a psychiatrist specialising in DD who prescribed anti-depressants to help manage her depression and subsequent anger. She had epilepsy which was also managed with medication. Katherine's goal was to self-manage her anger and self-injurious behaviour. Prior to presenting for participation in the study, Katherine had many episodes of anger with self-injurious behaviour, both at her home and at her supported employment workplace. Katherine was on her final warning at her workplace and needed to demonstrate that she was involved in an intervention aimed at managing her anger to ensure her employment was not terminated.

Katherine had been in various accommodation settings due to problematic behaviour after being removed from her family home. She requested that her current foster mother become her supporter. Her angry outbursts included self-injury, property damage and physical assault to her foster parent. This behaviour had created problems within the home, but all parties were seeking ways to avoid this placement becoming "at risk" of termination. Previously Katherine had engaged in other interventions to assist in managing her anger, including work with a psychologist specialising in ID. This intervention used photographs with the goal of increasing independence, although Katherine did not maintain their use.

Katherine's target behaviours were defined as:

- Feeling angry – eyes roll, sighing, comments like "you can't tell me what to do".
- Verbal aggression – making fists and punching hand, yelling, swearing, obvious muscle tension.
- Physical aggression – property damage, screaming, injury to self and others.

Self-management goal

To use the strategies (diaphragmatic breathing, distraction techniques and helpful thinking) depicted on her CBI cards to reduce her anger and subsequent behaviours of threats, property damage, harm to self and others.

Settings

The researcher met each participant with his or her supporter, at a setting most suited to working on the target behaviours, which included the researcher's office, the participant's home or place in the community. Wherever possible, at least one of the sessions in each of the 20 weeks was conducted in the community. This was to encourage participants to engage in their surroundings and become aware of the benefits of their participation, including positive changes in behaviour, mood and thought processes.

Procedures

Baseline

The baseline phase of the research was treatment as usual (TAU), which meant participants were not engaged in the visual CBI. At least four baseline observations were recorded prior to intervention commencement, as suggested by Richards et al. (2014). The need for a TAU baseline was explained to participants and supporters, some of whom may have been seeking immediate solutions for their MHD.

Cameras were provided to each participant for recreational activities, so they could familiarise themselves with camera use and operation. It also created discussion points to build rapport and engagement between the participant and researcher, as recommended by Jahoda et al., (2013). Participants and supporters were provided data sheets for recording the number of episodes of MHD that occurred each week (Appendix F).

Cognitive-Behavioural Intervention

The content and structure of the intervention followed the CBT protocols as originally devised by Beck (1976) and used extensively by others (Beck, 2011, Farmer & Chapman 2008; Freidberg & McClure, 2002; Simmons & Griffiths, 2009; Young & Beck, 1980). Adaptions that best suit people with DD were developed using recommendations from Hassiotis et al. (2012) and Taylor et al. (2008). The 20-week intervention consisted of two 60-minute sessions each week, giving a total of 40 active intervention sessions per participant. This number and intensity of sessions was needed in order to achieve superior outcomes, as people with ID require more intense and longer number of sessions to attain skill mastery (Scior, 2009; Taylor et al., 2008)

The 20-week program was broken down into two phases. Phase one (Weeks 1-9; Sessions 1-19) consisted of behavioural therapy where participants engaged in behavioural tasks to address the presenting problem, such as using diaphragmatic breathing, distraction or visual imagery. Phase Two (Weeks 10-20; Sessions 20-40) consisted of cognitive therapy where participants considered the impact their cognitions had on their behaviour and mood. Two maintenance sessions we conducted at 8 and 16 weeks post intervention.

Content – Learning Visually

The use of pictures, images and colours to understand and communicate information is a popular teaching and learning approach that builds on existing learning strengths (Joseph & Chapman, 2013), especially for people with ID (Jacobelli & Watson, 2008). The visual CBI used in this study integrated photographs, symbols and simple text onto a discreet wallet sized card, to assist participants with DD to address and self-manage an identified target behaviour. Each card was individually tailored to the stage of self-management for each participant, and reviewed and updated as the participant's skills developed.

Photographic elicitation was used as part of the intervention. Photographic elicitation is beneficial when used with participants, as photographs have been shown to evoke a more detailed response, sharpen memories and invite open expression (Shaw, 2013). The photographs were a foundational therapeutic tool of the intervention to assist with self–regulation. Participants viewed the photographs of themselves while engaging in a task or activity aimed at addressing their MHD. The participant was asked to comment on the photograph and reflect on how he or she felt at the time of the activity, particularly in terms of thoughts and behaviours. While the participant generally took the lead for discussing their experience, the researcher drew on observations made while participants were engaging in the photographed activities.

Phase One: Behaviour Therapy

Week 1: Rapport building and defining the problem

In sessions one and two, participants identified the exact problem or part of the problem they wanted to address to ensure that the intervention was meaningful and relevant to them (Taylor et al., 2008; Hassiotis et al., 2013; Jahoda et al., 2006; Keeling et al., 2003; Reaven, 2010; Willner, 2009). This was done to improve motivation and engagement, increase independence and assist with challenging their self-destructive thoughts and behaviour (Young & Beck, 1980; Keeling et al., 2003; Oathamshaw & Haddock, 2006). The researcher now took on the primary role of therapist (Ledger, 2010).

The importance of the consistent use of cameras was elaborated on during the first two intervention sessions. The researcher explained the cameras would be used to collect evidence of participants successfully managing the problem they had chosen to address. Participants and supporters were asked to take photographs of people, activities and locations that assisted the participant to relax or feel happier.

Week 2: Designing a personalised intervention

In the second week, the therapist and the participant collaborated to build individualised, visual CBI around the identified problem (Haddock et al., 2001; Young & Beck, 1980). This collaboration created a "therapeutic alliance" between the therapist and the participant, instilling confidence about the treatment and the therapist (Young & Beck, 1980, p. 7). All participants stated they had previously felt they had been pushed or coerced into managing their MHD or related behaviours and others had become frustrated or angry by their inability to challenge or manage episodes. Participants were assured they would not be forced or coerced to challenge their MHD or trigger and that they would be 'treated as an equal' as described in Pert, Jahoda, Kroese, Trower, Dagnan & Selkirk, (2013, p.365)

Week two developed a personalised intervention, using Vygotsky's strength perspective, building on the existing and potential capacity of the individual (Gindis, 1999). Personalised designs also assist with identifying individual barriers to treatment and address obstacles on a case-by-case basis (Willner, 2009). In the early phase of treatment therapy, behaviour goals are more likely to be achievable and relevant than cognitive goals (Young & Beck, 1980) and are more likely to be effective in helping to improve functionality, mood and participant retention rates (Ahmed & Lawn, 2013). Participants were taught and practised skills such as diaphragmatic breathing and distraction techniques (Edelman, 2013; Hassiotis et al., 2012; Greenberger & Padesky, 1995) for de-escalation of MHD symptoms and identified people, activities and situations that assisted with relaxation or feeling happier (Edelman, 2013). Photographs were taken depicting participants engaging in the de-escalation strategy. From these photographs, cards for each participant were created. The participants were encouraged to make the cards themselves to develop a sense of ownership (see Appendices J, K, L, M, & N).

Weeks 3-4: Live settings

In Weeks 3-4 the participant, with support from the therapist, began with small tests of exposure (Edelman, 2013; Greenberger & Padesky, 1995) to challenge their MHD in a "live" setting (Grahame, 2011; Hassiotis et al., 2012; Mirrow, 2008; Westling & Fox, 2009; Westwood, 2004). These were termed "experiments". These sessions focused on observing and understanding the behavioural aspects of the problem in a live setting. Training conditions in settings and phases were kept as consistent as possible across participants.

Participants practised their de-escalation strategies, engaged in rehearsal and observed modelling as appropriate, prior to the experiment. During such practice, success is paramount for the confidence of the participant (Dana, 1999). Therefore, practice consisted of small tasks guaranteeing success and error-free learning. This approach to learning is particularly beneficial to people with ID as traditional therapy sessions are unlikely to replicate actual experience.

Photographic evidence was used as proof of success and provided "immediate and unambiguous feedback" to participants (Young & Beck, 1980, p. 19). The notion of taking a photograph while a participant engaged in a challenging task can help the participant view the task and self-regulate a response (Mechling, 2007). Digital technologies are ideal as they show immediate results (Mechling, 2007). The immediate acknowledgment of the task, assisted to reinforce success and provided the foundation for skill development and self-management. The photographs became the "evidence of self-management" and allowed the therapist to check on the participant's understanding of the tasks and their perceptions of the progress of intervention. Participants' photographic evidence of SM increased as the intervention progressed, which aided in developing confidence in their ability to self-manage (Dana, 1999).

In Week 4 an audit of potential triggers was undertaken with each participant (Attwood, 2004a; Attwood, 2004b). These audits provided insight into what could provoke episodes of MHD. Participants, with assistance from the researcher, identified triggers, such as certain people and situations that affected behaviour or mood. A prioritised list of triggers the participant wished to address was developed for future sessions.

Week 5: Developing a personalised card

Each participant, with the therapist, developed a personalised card for the participant to carry. The card outlined self-management tasks and strategies for the participant to employ when experiencing specific behaviour, mood and thoughts. For example, a person who became anxious at facing a crowd of people could use controlled breathing as a management strategy or could use "diversion techniques" (Young & Beck, 1980, p. 20). Cards were updated regularly as participant skills developed.

During this week, participants began to distinguish between the different levels of mood or behaviour, such as the difference between feeling annoyed and rage, between nervousness and panic, between sadness and despair. The ability to differentiate between levels assists with self-awareness (Scior, 2009) and emotional literacy (Mirrow, 2008). Participants learned to identify triggers so that strategies could be used to de-escalate emotions before they reached extreme levels. This awareness was an ongoing skill and continued to develop throughout the remainder of the intervention.

In terms of anxiety, panic and avoidance, many therapists assert it is important to stay in the situation where the difficulty arises until it dissipates (Ashfield, 2010; Branch & Wilson, 2010; Bourne, 2005; Fox, 1993; Hassiotis et al., 2012). Conversely, this intervention allowed the participant to leave the situation before it became critical, find somewhere safe while reducing the feelings of anxiety with a practised technique (e.g., breathing, distraction or imagery). Once the anxiety was reduced to manageable levels, the participant re-entered the situation and re-engaged in the activity. This opt "in" and "out" is seen as a legitimate strategy to increase the likelihood of success, as one can control the pace without coercion (Greenberger & Paedsky, 1995).

Week 6: Introduction of homework

In Beck's model of CBT (Beck, 1976), homework is an integral concept in the success of the therapy (Beck, 2011; Willner, 2009). Homework in this intervention encouraged participants to seek new situations to practice their skills and to challenge themselves. The therapist, participant and supporter negotiated homework tasks that would be challenging, but not overwhelming for the participant and supporter. Participants were asked to provide evidence of their homework by producing photographs of themselves in at least three different situations at their next session. Participants used their intervention cards to assist with completing their homework. The supporter and other significant people in each participant's life, such as families, carers and staff, were viewed as a resource to assist with homework and to regularly prompt participants to use their cards (Hassiotis et al., 2011; Willner, 2009).

Weeks 7-9: Ongoing practice

In Weeks 7-9 participants were encouraged to increasingly challenge their MHD by addressing the triggers identified in Week 4. Where triggers were identified as multiple, participants practised with the researcher prior to attempting self-management in the homework sessions. Participants were required to provide photographic evidence of this ongoing practice as part of their homework sessions.

The prompting of participants to use the cards was gradually reduced to intermittent during therapy sessions and homework activities, although the ratio could be increased as necessary to ensure mastery. (Cadette, Wilson, Brady, Dukes & Bennett, 2016; Kayoma & Wang, 2011; Lequia et al., 2012; Mesibov et al., 2002; Wolery, Ault & Doyle, 1992).

Phase Two: Cognitive Therapy

Weeks 10-13: Understanding the impact of cognition on mood and behaviour

With the establishment of personalised cards and successful behaviours, the cognitive phase commenced. This phase was devoted to assisting each participant to identify and understand the mediating effects cognitions have on mood and behaviour (Oathamshaw & Haddock, 2006; Young & Beck 1980). The process of understanding how cognition affects behaviour and emotions is underpinned by Vygotsky's "Zone of Proximal Development", in which learning for the participant is scaffolded with assistance from the therapist (Gindis, 1999; Stott et al., 2017; Wang, 2009). Concepts of "My Thinking" (Hassiotis et al., 2012) and "Hot Thoughts" (Greenberger & Padesky, 1995, pp. 46-69) were introduced to assist with analysing thoughts.

The central theme of "My Thinking" comprises of "unhelpful thoughts" and "helpful thoughts" (Hassiotis et al., 2012). Unhelpful thoughts are thoughts that are typically distorted and can be negative, catastrophic or overgeneralised and often increase MHD (Grahame, 2012; Hassiotis et al., 2012; Willner, 2009). Helpful thoughts do not attempt to dismiss the negative thought, but instead attempt to find a more balanced, accurate thought (Hassiotis et al., 2012). "Hot thoughts" are defined by Greenberger & Padesky (1995, pp.55-61) as the automatic thought which somatic symptoms or moods are attached to, such as palpitations, nausea, panic, confusion, fear, anger or hopelessness. To familiarise participants on the use of my thinking and hot thoughts, participants practised scenarios where they changed unhelpful thoughts of a fictitious person into more helpful thoughts. Once participants mastered this, therapist and participant viewed photographs from their live experiments in Phase One, in order to recall or explore what some of their unhelpful thoughts may have been at the time. The therapist used photographic elicitation, as outlined in Shaw (2013), to assist the participant to comment on the photograph and to reflect on how they were feeling at the time of the activity, particularly in terms of thoughts and behaviours. The therapist offered prompts, observations and questions to assist the participant to understand his or her thinking processes. This assistance from the therapist helped participants to identify the hot thought experienced at the time and the impact these thoughts had on behaviour or emotions. Viewing the photographic evidence retrospectively and adding the "My Thinking" and "Hot Thoughts" protocols, provided the participants with an additional sense of achievement, as they had coped with any previous unhelpful thoughts and managed their MHD using strategies from visual CBI cards.

Live experiments using both behavioural and cognitive approaches then commenced. Initially, participants used their established behavioural strategies to manage symptoms. Then, over several sessions with assistance from the therapist, participants learned to realign their thinking to be more helpful. As participants practised and mastered these skills, the therapist gradually reduced assistance and provided prompts intermittently as outlined in Kayoma & Wang (2011). Supporters were also advised to reduce prompts gradually.

Throughout the continuing experiments, individuals were encouraged to identify, confront and alter negative thought patterns in favour of more helpful thoughts, creating more realistic expectations and alternatives, as in Beck (2005a), Linden & Lenz, (1997) and Young & Beck (1980). If a difficulty with identifying or addressing an unhelpful thought occurred, the thought was discussed in the following session with the researcher, so that it could be broken down into smaller increments to re-attempt management of their thoughts.

Weeks 14-15: Transferability of skills

During Weeks 14 and 15, participants were encouraged to focus on their successes, so that they could generalise and transfer their skills to other settings or areas of difficulty as suggested by Jahoda et al., (2006) and Keeling et al., (2003). The audits undertaken in the sessions of Week 4 were reviewed, in order to highlight any triggers that remained, with a view to addressing these in the remaining weeks.

Two participants identified an inability to assert themselves or to challenge other individuals. As a response to this identified need, some sessions were individualised to feature assertiveness training (Farmer & Chapman, 2008; Taylor, et al., 2008). The strategies included drawing or writing the problem down with the desired outcome, inserting verbatim, meaningful phrases into cards "it's not telling tales" or "it's my right to be heard" and outlining key people who will listen and assist in developing a plan to address the issue. Edelman (2013) advises passivity is a common feature of many people with MHD with and without ID and needs to be considered during interventions.

Weeks 16-19: Independent use

As the goal of the intervention was to create independence for self-management (Cadette et al. 2016; Kayoma & Wang, 2011), participants were required to use their cards without prompting from others during the final ten sessions: Weeks 16-19. Participants were asked to provide evidence of their homework by producing photographs using their intervention cards in at least three different situations at the next session. These photographs indicated whether self-management had occurred.

Week 20: Exit strategy

The final week focussed on the participant's CBI journey, discussing the successes and challenges encountered, as described in Hassiotis et al*.,* (2012). Copies of the photographs and older cards, including templates of cards, were bound into booklets to document evidence of success and provide an opportunity to reflect on how prior negative thoughts, feelings and behaviours had been overcome. This booklet could be re-used during times of setback. Post-intervention maintenance sessions were conducted at two and six months to determine if the skill learned were maintained. These sessions consisted of measuring the extent to which skills had been maintained using the same method as the main part of the intervention. Once the data had been collected, discussion regarding any problems experienced were addressed. The maintenance sessions also created a more gradual "step-down" approach to the intervention for participants and supporters, rather than an abrupt termination (Emerson et al., 2004)

Data Collection

Dependent Variables

There were two dependent variables, MHD and SM, in this study (defined within Target Behaviours above). Participants recorded the number of times per week the target behaviour (MHD) occurred, and the number of times per week they self-managed (SM) using the CBI cards (Appendix F). These data were verified by the supporter through direct observation who also recorded the information. The researcher recorded these on a separate data sheet to track participant progress and examine whether participants met the criteria of 80% independent self-management of MHD by week 20 (Appendices G, H).

Data Analysis

Data analysis was conducted using visual inspection and statistical analysis using the ExPRT (Version 2.1) software to conduct randomisation tests (Gafurov & Levin, 2016). Several researchers highlight the need to demonstrate a functional relationship between variables (Kazdin, 2011; Kennedy, 2004; Kratchowill & Levin, 2014; Manolov, Gast, Perdicies & Evans, 2014; Shadish, 2014). Introduction of the intervention (independent variable) produces the change in target behaviours (dependent variables). To demonstrate this relationship, both visual and statistical analysis is recommended to improve the rigour and internal validity of single case experimental research (Kratchowill & Levin, 2014; Manolov et al., 2014; Shadish, 2014; Swaminathan et al., 2014).

Visual inspection

Visual inspection is an important means of analysis of data in single case design to deduce a functional relationship between variables exists (Kratchowill & Levin, 2014; Manolov et al., 2014; Shadish, 2014). Data for the MHD and SM were graphed, examined and interpreted to establish trend, level and variability between baseline and intervention conditions. Visual analysis also assessed whether there was an increase in the frequency of independent SM of MHD once the intervention moved from the behaviour (phase one) to cognition (phase 2).

Statistical analysis and randomisation

Statistical analysis can be used to supplement visual inspection to accurately determine the "magnitude of the functional relationship" using effect size and significance value (Maggin & Odom, 2014, p. 239). ExPRT (Version 2.1) (Gafurov & Levin, 2016), a statistical package developed specifically for SCD data analysis, was used to analyse significance through randomisation testing and magnitude of intervention. Alpha was set at 0.05 when testing for significance. Randomisation conducted with ExPRT (Version 2.1, 2016) increased the internal validity of the multiple baseline design by random selection of the intervention start point for each participant, prior to the introduction of the CBI. Intervention start points are detailed in Table 4.2. Case randomisation was a second internal validity procedure recommended by (Kratchowill & Levin, 2014). Case randomisation was obtained prior to beginning the baseline condition. Participants selected a number between one and six from a bag of numbered tiles. The number selected became the participant's case number (see Table 4.2).

Table 4.2. Participant case and randomisation start points

Name	Start point	Case number
Niamh	4	Participant 6
Raj*	6	Participant 3
Rodney	7	Participant 1
Connor	8	Participant 4
Gyan	9	Participant 2
Katherine	10	Participant 5

*Note that data for Participant 3 were not included in data analysis due to missing data.

Effect size

Effect size is described as the degree or magnitude of the functional relationship between a behaviour and an intervention (Kratchowill & Levin, 2014; Maggin & Odom, 2014; Sullivan & Fein, 2012). Two effect size calculations were produced for multiple baseline data analysis by the ExPRT (Version 2.1, 2016) software: Cohen's *d* and Non-overlap of all pairs (NAP). Cohen's *d* compares means against the standard deviations (Shaughnessy, Zechmeister & Zechmeister, 2003), while NAP compares non-overlapping data points in a baseline to those in intervention (Kratchowill & Levin, 2014; Parker & Vannest, 2009).

A Robust Improvement Rate Difference (R-IRD) Formula in Parker, Vannest & Davis, (2014, p.134) was used to calculate the proportion of improvement between baseline and phase two independent SM intervention sessions (31-40). An improvement rate effect size is generally obtained by dividing the number of improved data points in each phase by the total number data points. However, Vannest, et al. (2014) refined this formula for improved sensitivity, therefore accuracy. The steps required for the R-IRD is the removal of overlapping data points from both baseline and independent (last 10 sessions) self- management. Followed by the development of four quadrants of W, X, Y, Z (W = baseline not improved, X = independent SM not improved, Y =baseline improved, Z= independent SM improved). From this the values of quadrants must be balanced with overlapping data points so that the total number of data points in each of the baseline and independent SM phases is the same as the total number of original data points. An example of the R-IRD calculation is provided below in figure 4.1 (For full details see Parker et al., 2014; Vannest & Ninci, 2015). Parker, Vannest, and Brown (2009) advised R-IRD effect size ranges are as follows: small effects: 0–0.50; medium effects: 0.50-0.70; large effect: 0.70 and higher–1.0 (p.147). It should be noted that R-IRD was only calculated for independent SM (final 10 sessions), not all SM sessions. NAP was used to calculate effect sizes for overall SM.

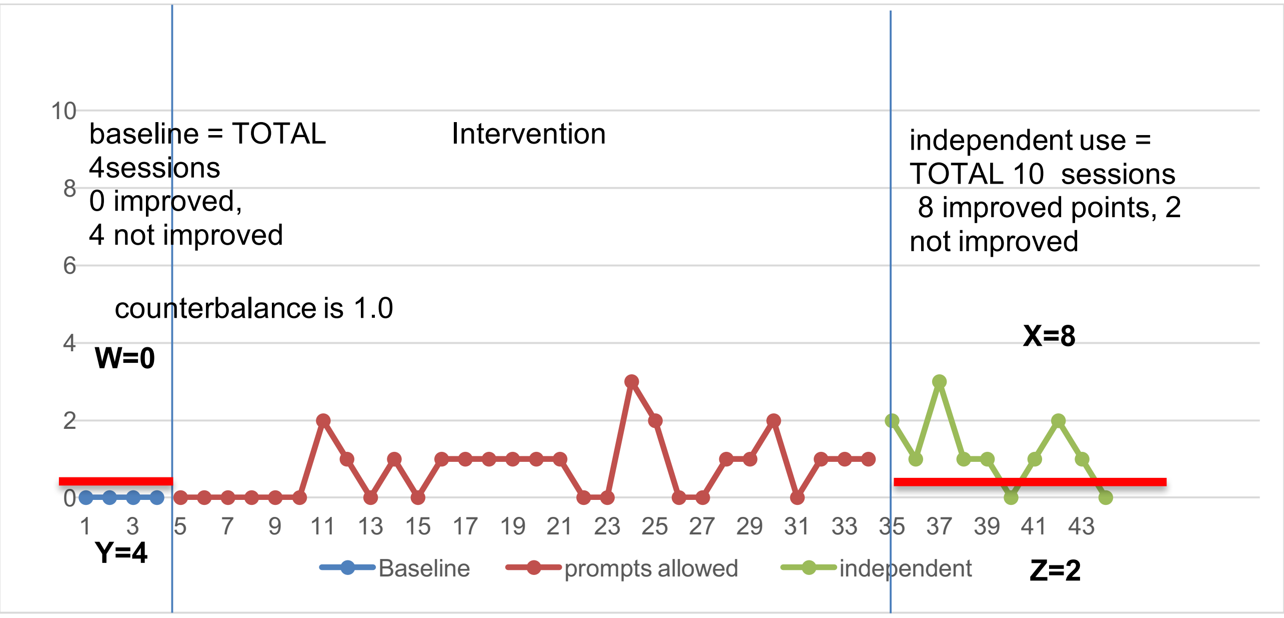


Figure 4.1. Example of robust improvement rate difference of independent SM use compared to baseline

** counterbalance is the number of data points not improved in the independent use (quadrant Z) divided by 2. In this case 2.0/2 =1.0. The counterbalanced amount is applied to the number of not improved in the baseline improved (quadrant W).

W + counterbalance/ Y =
0 + 1 =1 / 4 =0.25

X+Z/counterbalance
8 + 1=9 / 10= 0.9

R-IRD = X – W
0.9- 0.25=**0.65**

Social validation

Social validation, as defined by Kazdin (2011), seeks to ensure the goals of an intervention have made a difference and are relevant to the participant’s everyday life (p. 53). Perceptions of the difference the intervention has made to everyday life was sought from participants and supporters. Semi-structured interviews on social validation were conducted with participants (Week 18) and supporters (Week 20). The questions asked were:

- What was the most beneficial element of the intervention?
- What was the least beneficial element of the intervention?
- What elements of the intervention could be improved?
- What was the impact on everyday life?

This information was used to strengthen the findings and offer triangulation to confirm results as recommended by Neuman, (2003) and Seale, (2012). Social validation also provided a source of information for refinement of future improvement of the intervention.

Procedural Integrity

Inter-observer Agreement

Inter-observer agreement (IOA) is used to ensure integrity of the intervention and reliability of data collection (Kennedy, 2005). Separate observations were conducted by the researcher and a supporter and then agreement was reached over the number of times the behaviour was observed (Richards, Taylor & Ramasamy, 2014). IOA was utilised for 20% of the observations in each phase, occurring in Weeks 5, 10, 15 and 20. The formula used to calculate the number of observations was a frequency ratio where the smaller number of observations (from either the researcher or supporter) was divided by the larger number of observations, then multiplied by 100 to calculate the percentage of agreement (Kennedy, 2005). Observational reliability was assumed if agreement was greater than 80%.

Treatment fidelity

Fidelity is used to determine how closely an intervention was implemented in line with the original protocols of a treatment. Bellg et al., (2004) emphasised the importance of fidelity in establishing validity and reliability of an intervention. Fidelity reports can also assist with future replications of a study. To ensure fidelity of the CBT model, two independent observers used the Manualised Group Intervention Checklist (MaGIC) a rating scale developed by Jahoda et al., (2013). This scale was developed from the original CBT scale of Young and Beck (1980). The MaGIC rating scale was an appropriate tool to use in this study as it was designed to assess the skill of the lay therapist, as well as consider the unique context when working alongside people with ID (Jahoda et al., 2013). The researcher reviewed the MaGIC assessment tool for this study and considered it to have a suitable fidelity measure once "group processes" had been removed. The remaining nine key principles from MaGIC were used for assessment of intervention fidelity. These included:

- Coverage of session plan
- Feedback
- Understanding
- Interpersonal effectiveness
- Engaging participants

- Accessibility of presentation
- Focus on key cognitions
- Focus on key emotions
- Homework

Within each of the nine principles, three criteria exist, generating a potential score of 27. For each criterion of each principle, each independent observer marked 1 (one) if the item was observed and 0 (zero) if the item was not observed (Appendix I). The formula used was a frequency ratio, where the observer recorded agreement of the therapist adhering to the nine principles. The number of observations of each principle is divided by the number of potential observations (27), then multiplied by 100 to calculate the percentage of agreement. Fidelity of intervention implementation was assumed when there was greater than 80% agreement (Kazdin, 2011).

Summary

This chapter discussed the method used in this study, including study design, ethics protocols, participants, data collection and intervention procedures. A rationale for methods of data analysis; visual and statistical was provided as a basis for presentation of results in the next chapter.

5. RESULTS

This chapter presents the results of the study to determine the effectiveness of the visual CBI in assisting five people with dual disability to self-manage their mental health difficulty. Visual and statistical analysis were used within a multiple-baseline single case experimental design to establish a causal relationship, individual effect sizes, (non-overlap of all pairs and robust-improvement rate difference), rank and significance. Analysis was undertaken using ExPRT (Version 2.1) Gafurov & Levin (2016) to calculate the effect size and statistical significance combining results for all participants, as well as the MHD and SM for each participant. The raw data from all sessions, including baseline, intervention and maintenance, were entered into the ExPRT (Version 2.1, 2016) statistical package using the randomised intervention start point (ISP) session number for each participant: Niamh ISP 5, Rodney ISP 7, Connor ISP 8, Gyan ISP 9 and Katherine ISP 10. Two separate data sets were produced for the two dependent variables. One data set generated results for the dependent variable, mental health difficulty (MHD). The second data set generated results for the dependent variable, self-management (SM).

Social validation interviews were undertaken to seek qualitative information from participants and supporters and to give participants “a voice” in the process (Roberts & Kim, 2014). The results of the semi-structured interviews on social validation are presented. Lastly, results from procedural integrity measures are presented, establishing fidelity and rigour for this intervention.

Visual analysis

Visual analysis was conducted using Excel[ii]-generated line graphs to establish the trend, level and to determine whether change in target behaviours occurred, following introduction of intervention. Each participant’s graph illustrates both MHD and SM dependent variables to determine the frequency with which participants used the intervention to self-manage their MHD and whether SM was related to a reduction in frequency of observed MHD (Figure 5.1). Figure 5.1 depicts participant frequency of MHD and SM data recorded weekly, including data from two maintenance sessions (MT 1 and MT 2). Visual analysis also assessed if frequency of SM increased once the intervention moved from behavioural therapy (phase one) to cognitive therapy (phase two). The two phases cannot be analysed separately (i.e., compared) due to expected carry-over effects (Kratchowill & Levin, 2014; Shaughnessy et al., 2003).

Visual analysis comparing all participant data (Figure 5.1) demonstrated that the visual CBI was effective to varying degrees when assisting participants to self-manage their MHD. Participants Niamh (anger), Connor (anxiety) and Katherine (anger) demonstrated the highest frequency of use of the cards when experiencing mental health difficulties. Participants Rodney (anxiety) and Gyan (anxiety) however, demonstrated low frequency use of the visual CBI when experiencing MHD. Individual outcomes for the effectiveness of the visual CBI are summarised in Table 5.1.

Table 5.1. Participants' characteristics and mean frequency of MHD and SM

Name	Functional level ID	MHD for visual CBI	MHD baseline mean frequency and range	MHD intervention mean frequency and range	*Mean intervention SM
Niamh	Mild	Anger with self-harm	2.25 (3-4)	1.67 (0-6)	0.86
Rodney	Mild	Anxiety	2.38 (1-10)	0.79 (0-6)	0.21
Connor	Mild	Anxiety with self-harm	1.57 (0-3)	0.80 (0-3)	0.49
Gyan	Moderate	Anxiety	2.38 (0-5)	1.57 (0-4)	0.21
Katherine	Moderate	Anger with self-injury	2.44 (0-4)	1.33 (0-4)	0.21

*Baseline frequency for SM was zero as the visual CBI had not been introduced.

Niamh

Niamh's results demonstrated a substantial increase in the use of SM (visual CBI cards) to manage her MHD. While Niamh continued to experience episodes of anger throughout the intervention with a slight decrease in frequency, she demonstrated a substantial increase in self-management, particularly in phase two, cognition (Figure 5.1).

Niamh met the criterion of independent use of the card (80% independent use) by Session 34. She did not engage in any incidents of self-harm during baseline sessions, the 20-week intervention, and up to and including maintenance session one, which occurred eight weeks after termination of intervention. However, during the 16-week gap between maintenance session one and maintenance session two, she engaged in one incident of self-harm.

Raj

Insufficient data were recorded during the intervention for Raj, with only 16 data points verified. Due to extensive missing data, his results were excluded from analysis. However, Sheridan (2014) and Rivzi & Knock (2008) justify using outlier, non-respondents and treatment failure to improve treatment design and protocol. To this end, Raj's social validation interview and anecdotal information from his participation have been included in the social validation results and in the discussion chapter to assist with refining future interventions.

Rodney

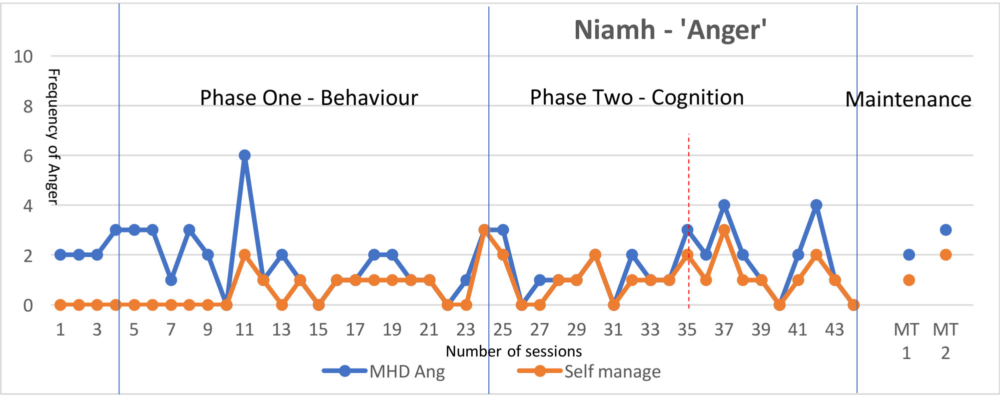
Rodney's results demonstrated a small improvement outcome: The visual CBI did not assist him in self-managing his anxiety. Although Rodney's data (Figure 5.1) demonstrated that during intervention, MHD (anxiety) decreased in frequency compared to baseline, he continued to experience anxiety throughout the study, with limited increase in SM skills. Rodney's frequency of use of the card was low. He used the visual CBI cards a total of seven times during the study, with six of these times through prompting.

Rodney did not meet the criterion for independent use of the card by session 37. He reported that he used his card independently once during maintenance Session 1. Sessions 32, 33, 34 and 35 denote zero levels of MHD (anxiety), although he reported a four-week depressive event, where he did not experience the target behaviour. Data were not recorded for Sessions 16, 20 and 25.

Connor

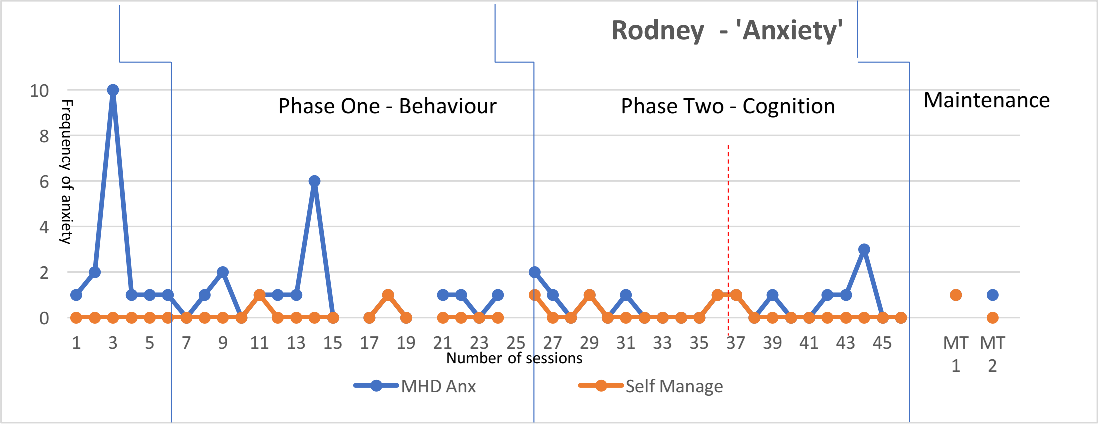
Connor's results demonstrated substantial improvement in the use of the visual CBI for effective self-management of his anxiety. Figure 5.1 depicts Connor's data. The frequency in which he experienced episodes of MHD (anxiety) decreased as his frequency of card use increased for SM. There were 25 sessions in which Connor reported having no anxiety during the intervention: 15 sessions of zero anxiety occurred in phase two; nine in phase one; compared to only one session of zero anxiety in baseline. This indicated the intervention provided Connor with enhanced self-management in phase two, the cognition phase.

Connor met the criterion of independent use of the intervention for self-management by Session 38. Data are missing for Session 25. Connor was hospitalised in Sessions 11 and 14 for self-harm and suicidal behaviour and his anti-depressant medication was increased. He did not engage in any incidents of self-harm after Session 14 of the intervention.



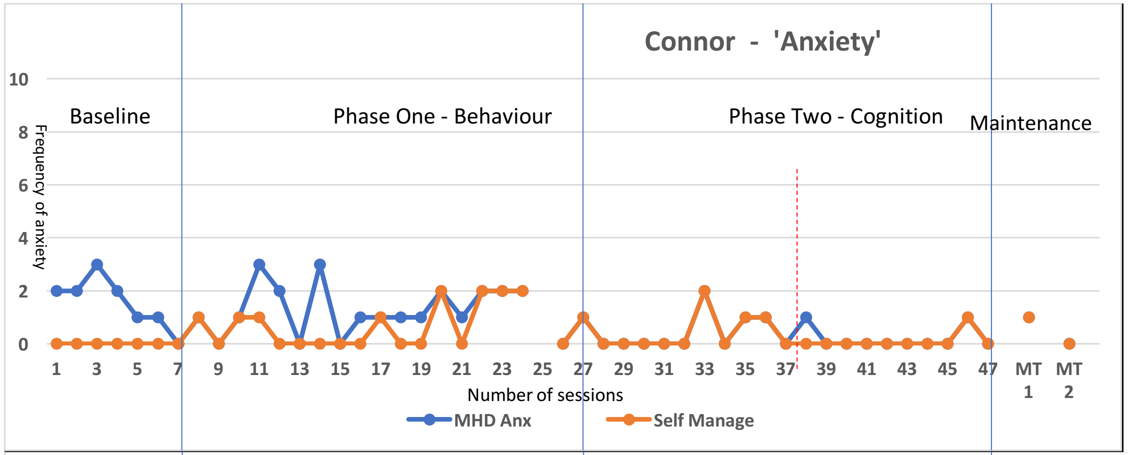
MHD results
Baseline Mean = 2.25
MHD (Anxiety) Mean = 1.67
Baseline SD = 0.50
Effect Size *d* = -1.17
Effect Size NAP = 0.39

SM results
Baseline Mean = 0.00
SM (Anxiety) Mean = 0.86
Baseline SD = 0.00
Effect Size *d* = N/A
Effect size NAP = 0.62
R-IRD =1.00



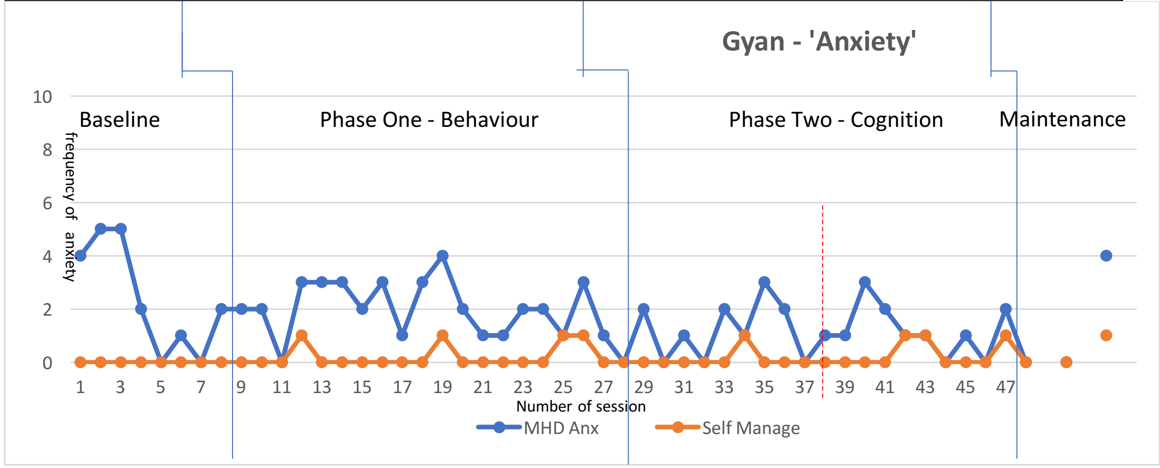
MHD
Baseline Mean = 2.67
MHD (Anger) Mean = 0.79
Baseline SD = 3.61
Effect Size *d* = -0.52
Effect Size NAP = 0.53

SM results
Baseline Mean = 0.00
SM (Anger) Mean = 0.21
Baseline SD = 0.00
Effect Size *d* = N/A
Effect Size NAP = 0.21
R-IRD =0.02



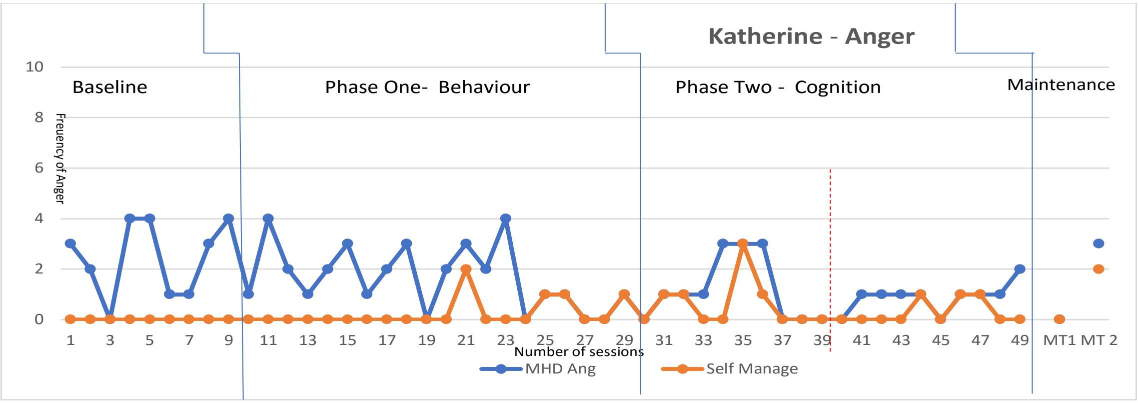
MHD results
Baseline Mean = 1.57
MHD (Anxiety) Mean = 0.80
Baseline SD = 0.98
Effect Size *d* = -0.79
Effect Size NAP = 0.44

SM results
Baseline Mean = 0.00
SM (Anxiety) Mean = 0.49
Baseline SD = 0.00
Effect Size *d* = N/A
Effect Size NAP = 0.37
R-IRD = 0.76



MHD results
Baseline Mean = 2.38
MHD (Anxiety) Mean = 1.57
Baseline SD = 2.07
Effect Size *d* = -0.39
Effect Size NAP = 0.20

SM results
Baseline Mean = 0.00
SM (Anxiety) Mean = 0.21
Baseline SD = 0.00
Effect Size *d* = N/A
Effect Size NAP = 0.21
R-IRD =0.41



MHD results
Baseline Mean = 2.44
MHD (Anger) Mean = 1.33
Baseline SD = 1.51
Effect Size *d* = -0.74
Effect Size NAP = 0.43

SM results
Baseline Mean = 0.00
SM (Anger) Mean = 0.21
Baseline SD = 0.00
Effect Size *d* = N/A
Effect Size NAP = 0.31
R-IRD =0.37

Figure 5.1. Participant data recording frequency of MHD and frequency of self-management

Gyan

Gyan's results demonstrated a small increase in the frequency of use for the visual CBI cards to self-manage her anxiety, although only during times of panic attacks. Gyan's data (Figure 5.1) illustrates that she continued to experience anxiety with frequency slightly decreasing throughout the 40 sessions of intervention and two maintenance sessions compared to baseline. The results demonstrated limited increase of SM between phase one; behaviour, and phase two; cognition. Gyan's frequency of use of SM was lower than desired, as demonstrated in Figure 5.1. Gyan reported six sessions in phase two where she did not experience anxiety (Sessions 30, 32, 37, 44, 46, 48) compared to two sessions in phase one (11, 28) and two sessions in baseline (5, 7).

Gyan did not meet criterion for independent use by session 40. Gyan independently used the visual CBI card (SM) when she experienced panic attacks in Sessions 42 and 43. However, she only used SM independently to manage her generalised anxiety twice, in Session 47 and in maintenance session two (MT 2). When she experienced generalised anxiety (sessions 40, 41, 42 and 46) she engaged in pre-intervention behaviours, where she would seek out other people to discuss her anxiety.

Katherine

Katherine increased the use of the visual CBI to self-manage her anger following intervention (Figure 5.1). However, Katherine did not use the visual CBI cards to self-manage her anger until session 21 of her intervention. Once she began to use the visual CBI cards (SM), the frequency of MHD (anger) decreased. Given that Katherine did not use SM in phase one, comparisons between frequency of SM and MHD between phases cannot be made. Katherine refused to use the visual CBI cards in most sessions in phase one.

Katherine did not meet criterion of independent use of the visual CBI by session 40. She independently self-managed sessions 44, 46 and 47, however failed to use the cards to self-manage her anger in sessions 48 and 49. Sessions 27, 28, 37, 38, 39, 40, 45 and maintenance session one denotes zero levels of anger.

Summary of Visual Analysis

Kratchowill & Levin, (2014) and Richards et al., (2014) advise that for an intervention to be effective a functional relationship between the variables must be established. Visual analysis compared frequency and trend of all five participant graphs in Figure 5.1. This comparison determined that a functional relationship between two dependent variables, MHD and SM, existed. That is, as SM increased in frequency, MHD decreased in frequency. Visual analysis also demonstrated a functional relationship existed between the dependent and independent variable, meaning the visual CBI assisted some participants to self-manage their mental health difficulty. It was effective for Niamh, Connor and Katherine, although visually, effect was limited as a method to self-manage for Rodney and Gyan. While Rodney and Gyan both demonstrated small reductions in frequency of MHD, this could not be attributed to SM (use of the visual CBI) as frequency of SM was limited.

Mental Health Difficulty Results

Effects of the visual cognitive behaviour intervention on mental health difficulty for participants are summarised in Table 5.2.

Table 5.2. Effects of intervention on mental health difficulty

Name	MHD baseline mean frequency and range	MHD intervention mean frequency and range	NAP	NAP effect size	Cohen's *d*	*d* Effect size
Niamh	2.25 (3-4)	1.67 (0-6)	0.39	Medium	-1.17	Large
Rodney	2.38 (1-10)	0.79 (0-6)	0.53	Medium	-0.52	Medium
Connor	1.57 (0-3)	0.80 (0-3)	0.44	Medium	-0.79	Medium
Gyan	2.38 (0-5)	1.57 (0-4)	0.20	Small	-0.39	Small
Katherine	2.44 (0-4)	1.33 (0-4)	0.43	Medium	-0.74	Medium
Average			0.39	Medium	-0.72	Medium

Effect size using Cohen's Formula – magnitude of difference

The effect sizes for MHD were calculated using Cohen's *d* formula (using ExPRT, Version 2.1, 2016) for individual participants (Table 5.2). An average effect size *d*-0.72 was determined for the overall intervention. Sullivan and Fein (2012) advise that an effect size of *d*-0.72 is considered medium when using Cohen's *d* formula (p.280). This suggests that overall, the visual CBI had a medium effect on the decrease of target behaviours associated with MHD. Sullivan and Fein (2012) advise that Cohen's *d* effect range is as follows: small effect: 0.2; medium effect: 0.5; large effect: 0.8 (p.280). Individual effects varied from large for Niamh through to small for Gyan (Table 5.2). This negative score of *d* -0.72 was expected as the frequency of MHD decreased when compared to baseline and indicated the direction of the improvement, not that CBI had adverse effects on participants, as explained by Matteo, Preti, Edwards, Dow and Wykes (2017). This is somewhat consistent with visual analysis of Figure 5.1., indicating greater reduction of MHD for Niamh, Connor and Katherine compared to Rodney and Gyan.

Effect size for non-overlap of all pairs

An average non-overlap of all pairs (NAP) effect size was also calculated to determine the difference of improvement between baseline and intervention phases for MHD. NAP effect size was calculated in addition to Cohen's *d* as it is a more conservative measure of effect size. This resulted in an average score of 0.39, as depicted in Table 5.2. The average NAP was aggregated from each participant's individual NAP results (Figure 5.1). Parker and Vannest's formula (2009) determines improvement by measuring the non-overlapping data points in baseline compared to those in intervention. Parker and Vannest (2009) inform an overall score of 0.39 for the intervention is in the medium effect range. (p. 364). They advised NAP effect size ranges are as follows: weak effects: 0–0.31; medium effects: 0.32–0.84; large or strong effects: 0.85–1.0 (p. 364). Individual participant NAP results were calculated using ExPRT (Version 2.1, 2016). Using Parker and Vannest's (2009) ranges, this indicates that the visual CBI had medium effect on MHD for Niamh (0.39), Rodney (0.53), Connor (0.44) and Katherine (0.43), and a weak effect for Gyan (0.20), as shown in Table 5.2. This does not appear to be consistent with visual analysis for Rodney. The medium effect may have been impacted by an outlier of frequency of MHD during baseline for Rodney (Figure 5.1).

Significance

ExPRT (Version 2.1, 2016) randomisation tests determined that the overall variation in frequency of MHD that occurred between baseline and intervention conditions across participants were not significant with a probability value of $p=0.76$ providing a rank of 544 out of 720. An alpha of 0.05 allowed for type one errors. This result indicates that the likelihood of these results occurring by chance is high (Prasad, 1994).

While the results report that the reduction of MHD is not statistically significant, the study has clinical significance due to the overall effect size of *d*-0.72, which is considered medium (Sullivan & Fein, 2012). It is ideal to have both clinical and statistical significance for an intervention to be considered robust and effective, but in terms of whether one outweighs the other, will depend on the lens of the researcher and of the intervention in question (Cicchetti, Lord, Koenigh, Alin & Volkmar, 2014; Sedgwick, 2014).

Self-Management Results

The differences in proportion of improvement between baseline and intervention for self-management (SM) were calculated using Non-overlap of All Pairs (NAP) and Robust- Improvement Rate Difference (R-IRD) (Table 5.3). An effect size using Cohen's *d* formula could not be generated using ExPRT (Version 2.1) without comparison data above zero from baseline (Gafurov & Levin, 2016 p. 9). All participants logically had baseline data of zero-value, due to no previous experience with this visual adaptation of CBT. To calculate effect sizes of self-management, non-overlap of all pairs (NAP) (in Table 5.3) and Robust Improvement Rate Difference (R-IRD) (in Table 5.4) were determined.

Table 5.3. Effects of intervention on self-management

Name	Baseline mean frequency	SM mean frequency and range	NAP	NAP effect size
Niamh	0.00 (0)	0.86 (0-3)	0.62	Medium
Rodney	0.00 (0)	0.21 (0-1)	0.21	Small
Connor	0.00 (0)	0.49 (0-2)	0.37	Medium
Gyan	0.00 (0)	0.21 (0-1)	0.21	Small
Katherine	0.00 (0)	0.40 (0-3)	0.31	Medium
Average			0.34	Medium

Effect size of non-overlap of all pairs

An aggregated effect size for SM using ExPRT (Version 2.1, 2016) NAP generated a score of 0.34. The average NAP was aggregated from each participant's individual results. Parker and Vannest (2009, p. 364) inform an overall score of 0.34 for the intervention is in the medium effect range. Individual effects were Niamh 0.62, Rodney 0.21, Connor 0.37, Gyan 0.21, Katherine 0.31 as detailed in Table 5.3. According to Parker and Vannest (2009), Niamh and Connor's results were within the medium effect range. Effect sizes for Katherine, Rodney and Gyan were within the small range of effect. The visual CBI, had a medium effect on SM for two participants and a small effect for three participants. These results are relatively consistent with visual analysis, demonstrating higher frequencies of SM for Niamh, Connor and Katherine and low frequencies of SM for Rodney and Gyan.

Robust improvement rate difference

The differences in proportion of improvement between baseline and intervention phase two for self-management (SM) are depicted in Table 5.4. The improved frequency of use for SM during the last 10 sessions of the intervention was compared to frequency of use at baseline (Figure 5.1), using a Robust Improvement Rate Difference (R-IRD) calculation (Parker, Vannest & Davis, 2014).

Participants were expected to be able to use visual CBT cards (SM) independently for the last 10 sessions of the intervention (not including the maintenance sessions). R-IRD was used as an alternative to the NAP generated using the ExPRT (Version 2.1, 2016) software because the final 10 sessions could not be isolated from all intervention sessions. Gafurov & Levin (2016) advised that ExPRT (Version 2.1) cannot generate a Cohen's *d* effect size when the baseline data has a value of zero (p.9). Results are shown in Table 5.4

Table 5.4. Effects of phase 2 on self-management using Robust-Improvement Rate Difference

	Baseline (N=5)		**Intervention (N=10)**		**Counter balanced**	**R-IRD**	**Effect**
Name	Improved	Not improved	Improved	Not improved			
Niamh	0	4	10	0	0.0	1.00	Very Large
Rodney	0	6	2	7	3.5	0.02	Very small
Connor	0	7	2	1	0.5	0.76	Large
Gyan	0	8	4	5	2.5	0.41	Small
Katherine	0	9	4	6	3.0	0.37	Small
Average						0.52	Medium

The aggregated result of the intervention for all participants was 0.52 (Table 5.4). This score is considered a medium score using the scale from Parker, Vannest, and Brown (2009, p.147). They advised R-IRD effect size ranges are as follows: small effects: 0–0.50; medium effects: 0.50-0.70; large effect: 0.70 and higher–1.0 (p.147). This means that Niamh and Connor's results were within the large effect range. Rodney, Gyan and Katherine's were within the small effect range, with Rodney being barely noticeable at 0.02. An independent assessor also calculated R-IRD for 3 of the 5 participants of the intervention to ensure reliability of calculations, generating a score of 100% reliability. These results are consistent with visual analysis indicating Niamh and Connor had high frequencies of independent SM compared to Gyan and Rodney's limited use of independent SM.

Significance

The differences between baseline and intervention conditions for SM were not significant through randomisation testing using ExPRT (Version 2.1, 2016), with p=0.45 providing a rank of 327 out of 720. An alpha of 0.05 was allowed for type one errors. This result indicates that the likelihood of these results occurring by chance, not the intervention, is high (Prasad, 1994).

Significance of the Intervention

While the results report that the overall variation between conditions was not statistically significant, the study has clinical significance due to the overall medium effect size of *d*-0.72 in reduction of MHD (Sullivan & Fein, 2012). The overall R-IRD effect of 0.52 for *independent* self-management (phase two) was considered moderate (Parker, Vannest & Brown, 2009). Conservatively, the NAP results demonstrated a medium effect size of 0.39 on MHD and small to medium effect size of 0.34 (Parker & Vannest, 2009) on self-management (phases one and two respectively). While it is ideal to have both statistical and clinical significance for an intervention to be considered robust and effective (Cicchetti et al., 2014; Sedgwick 2014), clinical significance may impact practices in applied settings and be beneficial to particular individuals, rather than to the population of people with DD (Sedgwick, 2014).

Social Validation Results

Social validation interviews were used to seek qualitative information from participants. Semi-structured interviews on social validation explored, from the perception of the participants and the supporters, the effectiveness of the intervention on the everyday life of participants.

Table 5.5 reports the responses of the participants and their supporters. People with ID can have difficulty answering open ended questions, preferring closed questions (Prosser & Bromley, 2012), so statements or reminders of the question were produced by the researcher to elicit more information from the participant or supporter if necessary. Such prompts are included in Table 5.5 with the prefix “R:”.

The perception of the participants and supporters appears to be that the intervention was effective to varying degrees for improving the self-management of the different MHD experienced by participants. Four supporters reported improvement on the everyday lives of the participants. Gyan and Katherine’s supporters questioned if these two participants would continue to use the CBI post-intervention. At times Katherine had to be prompted to use her CBI cards, however, Katherine’s supporter reported that there was a marked improvement in her MHD when she used the CBI cards. Rodney and Gyan identified that they continued to experience ongoing MHD that they could not successfully manage.

Several participants and supporters identified completing the data sheets to be the most problematic element of the intervention. Participants and supporters easily identif elements of the intervention they found helpful or enjoyed participating in, such as the breathing cards, de-escalating rage or activities in the community. Participants and supporters offered suggestions to refine future interventions or inform current practice, such as attending staff team meetings or to train staff in use of the visual CBI techniques.

Table 5.5. Summary of social validation interviews with participants and supporters

Name	most beneficial	least beneficial	how to improve	help with everyday life
Niamh	"The breathing and the cards."	Remembering the data sheets.	Going to psychology appointment.	"Yep…I will go somewhere if I get angry and I can do some of some breathing."
Niamh's supporter	"Niamh was much better when you came."	Data sheets: "Sometimes I did remember and sometimes I forgot."	"Nothing, everything was good."	"Yep, she is less agitated; she's less angry."
Raj	"Feeling better in the sunshine." "Happy thoughts." "I am moving (to a new home)."	"Intruders keep coming to my house."	Raj was not able to provide suggestion.	Raj was not able to comprehend the question adequately to provide a response.
Raj's supporter	"Raj formed a good working relationship with the Researcher based on trust and respect. Once Raj feels like he has that with a worker then the possibilities to engage, explore and work with Raj increase significantly. Raj was able to gain the confidence he needed to make informed decisions around moving, what his needs were/are, he reduced his calls to the office, his anxiety was reduced and we had less incidents of aggressive behaviour. Using the strategies that were implemented assisted Raj to work through those emotions and work out for himself what the best next step for him was. His actions followed his behaviours, which were noticed by our workers. Worked with the Researcher to structure support that will be beneficial for Raj's needs."	"The only down side to the intervention is now Raj relies on the relationship formed with the Researcher, he seeks that social outlet to go to the movies etc to help him work towards his goals of living in the community. However we are working on seeking a volunteer to take over that role."	"Perhaps the exit of the Researcher could be improved, so the client doesn't feel attached to them as stated before. Maybe implemented a way of reducing contact, linking them in to other services and stepping out"	"We have a client who is maintaining a clean home, not calling the office with repetitive conversation, no aggression, the client isn't as emotional- he appears more in control of his emotions and feelings, our workers are happier to support him as he is in a better head space wiling to engage/ happier / non aggressive/ not as repetitive/ easier to converse etc."

Rodney	“Getting out of the house” “Not being pushed, I guess.”	“Kept losing my cards.”	“Nah.”	“It helped a little bit; I still get anxiety… and angry.”
Rodney’s supporter	“The tips given by the researcher to Rodney were very practical.”	“Rodney did not apply any of the tips given by the researcher”.	Get Rodney to use the tips.	Rodney is more confident and independent.
Connor	“Getting my anxiety under more control with breathing and cards.”	“Homework, sometimes I forgot to do it, sometimes I remembered.”	“That’s a hard one. Nothing” R: Attending the team meeting so staff could ask questions? “Yes, that would have been a good idea.”	R: Do you think that you would have been able to do some of the activities, that you are going to now? “Probably not.”
Connor’s supporter	“Seeing Connor have new opportunities and to manage the anxiety with support.”	Connor used the intervention to seek extra input from the supporter and staff when he was bored and lonely. This caused difficulty with staff using the intervention.	Finding correct key staff person to support in accommodation; training all staff; finding out how Connor has responded in the past; improved homework response.	“Absolutely”. “Everything seems to have improved”
Gyan	“It was good. The best thing going to out to places… And just having fun, yeah just having fun.” R: What does it help with…? “The anxiety… and the anxiety and stuff… and the anxiety and that’s how I feel and stuff inside.”	“Yeah the data sheets and stuff like that.”	Attend team meetings; train staff.	“Erm (uncertain) yeah it has, yeah it has, yeah.” “Calm me down and then show it to staff and that.”
Gyan’s supporter	“Being able to make the cards that help with her anxieties”. The breathing slowly builds on previous interventions.	Data sheets. Different staff had varying levels of consistency in completing it. Even if they used the	Attend more team meetings in the beginning. Catch up with the supporter more.	“A little bit.” “It’s something that has been happening for so long (anxiety), that benefits (of management) will

		intervention in the live setting, remembering to fill the data sheet out when then came back was a problem. Understanding the paperwork.		happen more over a long term, so she will learn it, but now it will be just time… if she sticks to it.”
Katherine	“I was in the black” (RAGE).	Didn’t like the cartoons or pictures (Compix, Boardmaker, icons or photos).	Talk more about getting angry is ok; it how it’s managed that’s important.	“Sometimes it helped.”
Katherine’s supporter	“Fantastic! Does work with Katherine if she looks like at them.” R: Does Katherine use them? “Now and again (independently).” “If we prompt her she will look at them”	Data sheets: for Katherine “remembering them bit too much for her. And got in her way.” For the supporters: “too busy, and forgot.”	Go to work more, especially as supervisor has now changed. More observation at work.	Cards have helped Katherine if she gets prompted. “If she uses the cards, she is a different person.”

“R:” indicates a researcher statement to elicit further information.

Procedural Integrity

CBT fidelity measure

The researcher adapted the specific rating scale Manualised Group Intervention Checklist (MaGIC) to ensure fidelity to the original CBT model (Jahoda et al., 2013). An independent assessor observed and rated procedural integrity during one CBI session with the researcher and each participant. The assessor marked 1 if the items was observed and 0 if the items was not observed, in the 27 possible items on the template (Appendix I). The results are contained in Table 5.6.

The average percentage score was 79.26%, which falls below the minimum standard of 80% (Kennedy, 2005) according to the fidelity protocol (Appendix I). However, overall fidelity of implementation was assumed, as four out of five participants met the minimum individual score of 80% (Richards et al., 2014): Niamh (100%), Connor (92.6%), Gyan (100%) and Katherine (100%). Rodney with a percentage of 3.70%, was the only participant who scored lower than the minimum requirement, primarily due to his reluctance to engage with the researcher and the visual CBI when an observer was present. All participants, including Rodney consented to the observer's presence prior to the meeting, however at the time of the scheduled observation, he declined to participate.

Table 5.6. Fidelity Assessment for visual Cognitive Behavioural intervention

Participant	Date	Score (27)	Reason for reduced score	Percentage
Niamh	18/04/2016	27		100
Rodney	15/04/2016	1	Participant refused to engage in session with observer present	3.7
Connor	15/04/2016	26	Omitted feedback question from the last session	92.6
Gyan	18/04/2016	27		100
Katherine	18/04/2016	27		100

Inter-observer agreement

Inter-observer agreement (IOA) with the researcher and an observer (supporter or staff person) occurred four times for each participant during the 20-week intervention, to ensure reliability of data collection (Kennedy, 2005). The observers separately reported the frequency of episodes of MHD and self-management. Kennedy's (2005) formula was used to calculate percentage of agreement. Observational reliability was assumed given an average total IOR of 93.83%, above the acceptable standard of 80%. Four participants out of five had scores above the minimum of 80% with Niamh (100%), Connor (100%), Gyan (100%) and Katherine (91.65%). Katherine's IOR 4 results of 77.5% were due to one discrepancy between observers of whether the recorded SM, was actual *independent* SM or not. Rodney was the only participant whose score was lower than the minimum at 77.5% due to his inconsistent recording in the first IOR assessment as depicted in Table 5.7.

Table 5.7. Summary of results for inter-observer agreement

Participant	IOR 1 %	IOR 2 %	IOR 3 %	IOR 4 %	Total IOR
Niamh	100	100	100	100	100.0 %
Rodney	10	100	100	100	77.5%
Connor	100	100	100	100	100.0%
Gyan	100	100	100	100	100.0%
Katherine	100	100	100	66.6	91.65%

Summary

This chapter presented the results of the study to determine the effectiveness of the visual CBI in assisting people with DD to self-manage their Mental Health Difficulty. Visual analysis suggested that all participants demonstrated a decline in MHD compared to baseline, ranging from small to large reduction of MHD across participants. Visual CBI had substantial effect on SM for three of five participants: Niamh and Connor demonstrated substantial increases in SM while Katherine demonstrated moderate increase in phase two. Two participants, Rodney and Gyan, had only slight increases in SM.

In terms statistical analysis of the overall effectiveness of the visual CBI in assisting participants to reduce their MHD and increase their SM, the results demonstrated a medium effect. Both the Cohen' *d* and the NAP effect confirmed a medium effect for the reduction in MHD. Effect size calculations using NAP and R-IRD demonstrated a medium effect overall of the intervention on SM. Although statistically, variations between baseline and intervention conditions were not significant for both MHD and SM, the intervention demonstrated clinical benefits for some participants and socially valid outcomes were reported by participants and supporters. There are several factors implicated in these findings, including frequency of use of the visual CBI cards by individuals, functional level of each participant’s disability, readiness for the visual CBI and commitment to the intervention by participants and supporters. These factors are discussed in the following chapter.

6. DISCUSSION

The findings from this small-scale exploratory study demonstrated that the visual Cognitive Behaviour Intervention (CBI) was effective in assisting some participants with intellectual disability (ID) to self-manage their mental health difficulty (MHD). These findings were consistent with the literature that people with ID can benefit from CBT when adaptations are made to accommodate their ID (Hassiotis et al., 2013; Jahoda et al., 2006; Keeling et al., 2003; Reaven, 2010; Willner, 2009) and individual learning strengths (Gindis, 1999; Rutland & Campbell, 1996).

The results demonstrated the visual CBI was effective for three of the five participants with limited effect for the remaining two. This was confirmed by visual and statistical analysis as well as triangulated by social validation interviews. In terms of the effectiveness for decreasing MHD, all participants had some reduction in frequency of MHD during the intervention. The intervention had a medium effect on reduction of MHD for Niamh, Rodney, Connor and Katherine and small effect for Gyan. In terms of effect on SM, the findings varied between participants. Visual CBI had a large effect on independent SM (phase two) for Niamh and Connor, medium effect for Katherine (phase one), small effect for Katherine (phase 2) with small to negligible effects on SM for Rodney and Gyan during both phases one and two.

Participant frequency of use for the visual CBI was implicated in these results, as consistent use of the visual CBI cards directly corresponded with a reduction in episodes of MHD and an increase in SM. Participants who had higher frequency use of the visual CBI cards demonstrated decreased episodes of MHD with increased self-management of symptoms. Participants with lower frequency of use demonstrated poorer outcomes.

Frequency of use was one component that may have influenced these results. Other factors may have contributed, including the ability to understand the effects of thoughts on behaviour and mood (Brown & Marshall, 2006; Chan et al., 2004; Sturmey, 2004; Taylor et al., 2008), individualisation of the intervention (Taylor et al., 2008; Hassiotis et al., 2013; Jahoda et al., 2006; Keeling et al., 2003; Reaven, 2010; Willner, 2009), the functional level of each participant's disability (Hassiotis et al., 2013; Taylor et al., 2008), capacity (Chadwick et al., 1999; Dagnan et al., 2000; Dagnan & Proudlove, 1997; Dunn et al., 1997; Oathamshaw & Haddock, 2006; Reed & Clements, 1989), readiness (Keeling et al., 2003; Taylor et al., 2008; Stott et al., 2017), commitment to the intervention and the use of medication (Reiss, 2000; Thomas et al., 2010; Tyrer et al., 2008). These factors are discussed separately in the following sections, in recognition of the complexity of factors that contributed to the progress of each participant as they relate to the research questions.

The Mediation of Cognition on Behaviour and Mood

There has been much debate on whether people with ID can understand the cognitive components of CBT due to their impaired cognitive capacity and limited comprehension. They may have difficulty understanding the link between thoughts and behaviour (Jahoda et al., 2006; Taylor et al., 2008; Willner, 2009), as well as difficulty with self-regulation and planning (Brown & Marshall, 2006; Chan et al., 2004; Sturmey, 2004). This study attempted to address participant cognitive limitations through adapted CBT using photographs, emoticons and simplified text, along with photo elicitation and practice in live settings to accommodate some of the barriers people with ID can experience when engaging in CBT.

Supported learning

All participants responded well to the behavioural phase of the intervention, successfully completing experiments in live settings to reduce the effects of their MHD. These findings supported the view of Sturmey (2004) that behavioural interventions improve outcomes for people with DD. All participants in this study could identify existing strategies and learned new strategies to assist with SM of their MHD, including diaphragmatic breathing, visual imagery or distraction. Participants demonstrated use of these skills within live settings to manage their MHD. This finding is consistent with outcomes of other researchers (Grahame, 2011; Mirrow, 2008; Westwood, 2004). These tests in live settings, termed “experiments”, were completed in small increments so as not to overwhelm the participant as described by Hassiotis et al., (2012). Learning was scaffolded by the therapist or supporter (Gindis, 1999; Stott et al., 2017; Wang, 2009). Dana (1999) highlighted that successful outcomes improve confidence, which in turn can assist with motivation and engagement. Once the experiment was successfully completed, photographs were taken to be used as concrete evidence of SM and to improve confidence. As the intervention progressed and photographic evidence of participant’s successful management increased, participant confidence developed.

During the behavioural phase, audits of potential triggers were undertaken with each participant (Attwood, 2004a, 2004b). These audits provided insight into what could provoke episodes of MHD. For participants who could not identify triggers or differentiate between high and low levels of emotion or behaviour, exercises were introduced to increase self-awareness and emotional literacy. This approach is in line with Mirrow’s (2008) findings that some people with ID will require teaching on emotional literacy for the intervention to be beneficial. At the completion of the behavioural phase, Niamh (anger) Connor (anxiety) and Rodney (anxiety) could identify most triggers for their MHD. Conversely, both Gyan (anxiety) and Katherine (anger) had difficult identifying triggers. Gyan could only identify specific triggers that caused panic attacks, but was unable to identify triggers for her generalised anxiety. This could be as the symptoms of panic attacks are usually acute and distressing, whereas the symptoms of generalised anxiety can be somewhat subtler. Katherine could not differentiate between the levels of escalating anger without assistance, but could self-manage the onset of rage for the most part.

To ensure sustainability of treatment, individual homework was set for each participant to complete between each therapy session, as recommended by Beck (1976) and supported by others, including Grahame (2011), Hassiotis et al., (2012), Pert et al., (2013) and Young & Beck (1980). There were varying degrees of commitment to these homework activities. Despite some lack of commitment, each participant had sufficient experience with the behavioural components of the intervention to proceed to the cognitive phase within the designated time frame.

It was important that participants understood the role that thinking played in mood and behaviour, as all participants had engaged in some type of previous intervention, yet none had not maintained the recommended strategies for management of their MHD. Participants were encouraged to use inform the researcher of any previous SM strategies that they had found useful and if they used the previous strategy to record this on the data sheet in a separate column (Appendix F). This would prevent any confounding between previous interventions and the visual CBI. Participants did not use strategies used from previous interventions, only using SM strategies that were used as part of the CBI.

Independent self-management

Participants had varying levels of success with the cognitive phase (phase two) of the intervention. Understanding the role that cognition plays in mood and behaviour is essential in CBT, so that self-destructive thoughts and beliefs that maintain disorders can be confronted and altered to improve emotions and behaviours (Beck, 2005a, 2011; Hofmann & DiBartolo, 2001; Greenberger & Padesky, 1995; Reaven, 2010). Without this understanding, the intervention becomes solely behavioural therapy.

Niamh and Connor demonstrated that they could understand the role that thinking played in mood and behaviour (Brown & Marshall, 2006; Chan et al., 2004; Sturmey, 2004; Taylor et al., 2008) and were able to address their thinking processes using the “My

Thinking" (Hassiotis et al., 2012) and "Hot Thought" (Greenberger & Padesky, 1995) concepts, while engaging either in experiments in live settings and/or in photographic elicitation. The intervention was developed to accommodate their functional level of mild ID (Hassiotis et al., 2013; Taylor et al., 2008) and capacity (Dagnan et al., 2000; Dagnan & Proudlove, 1997; Dunn et al., 1997; Oathamshaw & Haddock, 2006), which assisted with motivation and engagement (Keeling et al., 2003).

Niamh used helpful thinking described in Hassiotis et al., (2012) to counter some of the negative thoughts that reduced her reactivity, thus episodes of verbal or physical aggression decreased. Containment of verbal or physical aggression was paramount for Niamh as her previous outbursts resulted in increased remorse, which may have contributed to her disassociation (Lovell; 2007) and depressive symptoms with suicidal thoughts and behaviours (Beck, 1979, as cited in Hassiotis et al., 2012).

Connor understood the impact of his unhelpful thinking by paying attention to the increased symptoms within his body when he had a particularly catastrophic hot thought (Greenberger & Padesky, 1995). He countered his anxiety with a more productive alternate thought and a behavioural strategy to de-escalate his anxiety.

Katherine had mixed results when understanding how thoughts affected her mood and behaviour. At times, she was able think of more helpful statements, which improved her behaviour, but generally did not understand the impact of her thought process on her mood. Her functional level of moderate ID (Hassiotis et al., 2013; Taylor et al., 2008) and capacity (Chadwick et al., 1999; Dagnan et al., 2000; Dunn et al., 1997; Oathamshaw & Haddock, 2006) may have contributed to this.

The results for Rodney and Gyan in the cognitive phase demonstrated limited improvement. They fared better using the phase one behavioural strategies as they were not able to fully understand the role that cognition played in increasing or maintaining the symptoms of their MHD (Jahoda et al., 2006; Willner, 2009), or were not able to independently generate alternative helpful thoughts without assistance from others (Kayoma & Wang, 2011).

Rodney expressed negative beliefs and thoughts about himself that were often unhelpful and catastrophic. Arden (2010), Branch & Wilson, (2010), and Harmon-Jones, (2012) explain that unhelpful thinking can become habituated after traumatic or stressful experiences. Rodney's early life had been traumatic which could have contributed to his unhelpful thinking patterns, although other factors, such as personality traits or characteristics of his disability could also be contributing factors. Even with assistance, Rodney would seek evidence to support his catastrophic thinking to create self-fulfilling prophecies, often discounting alternative, contradictory evidence. This perpetuated Rodney's anxiety. Stott et al., (2017) explored readiness as a barrier to the uptake of an intervention which may have led to a limited effect on MHD and SM.

Gyan preferred discussing her anxiety with various people. This habituated behaviour was hard to disrupt as its function appeared to have a social element (Dunlap et al., 2008; Luiselli, 2012). She did not understand how constant retelling of her concerns without questioning the role cognition plays, and disparity in advice contributed to maintaining her generalised anxiety. Beck, (2005a, 2011), Greenberger & Padesky, (1995) and Reaven, (2010) advised that improvement occurs when thinking errors are challenged and then modified. Gyan did not challenge or modify her thinking, therefore her anxiety remained at high levels. Furthermore, she did not use her CBI card when she was discussing her concerns with other people. The CBI card could have provided a consistent framework for management rather than the conflicting advice she received which reinforced her anxiety. The functional level of her moderate ID (Hassiotis et al., 2013; Taylor et al., 2008), the relevance of the intervention (Jahoda et al., 2006; Keeling et al., 2003; Reaven, 2010; Taylor et al., 2008; Willner, 2009), her readiness to engage (Keeling et al., 2003; Taylor et al., 2008; Stott et al., 2017) and commitment to the intervention are likely to have influenced results.

Prompting

Verbal prompting was integral to the design of the intervention and was gradually reduced as participant skills for SM developed (Kayoma & Wang, 2011; Lequia et al., 2012; Mesibov et al., 2002). To explore whether participants could independently self-manage their MHD, participants were expected to use the visual CBI without prompting by the last ten sessions of the intervention. Participants demonstrated varying success with this expectation, indicative of the need for improved instructional delivery, such as repetition and mastery prior to prompt or reinforcement fading (Cadette et al., 2016; Wolery, Ault & Doyle, 1992).

Prompting for Niamh and Connor was delivered according to the design. Both received intermittent prompting until the last ten sessions, where independent self-management of MHD was required. Niamh and Connor met this requirement, which suggested the intervention was successfully integrated into natural settings and routines (Mesibov & Shea, 2010). Katherine independently self-managed at times during the last ten sessions, however, her overall management was more effective when prompted to use the

CBI cards. In comparison, Gyan, Raj and Rodney needed constant prompting to use the cards in both phases of the intervention, and demonstrated low levels of independent SM during the last ten sessions. Cadette et al., (2016) and Mesibov & Shea, (2010) suggested that constant prompting demonstrates that participants have not mastered the skills. These three participants had not mastered the skills required for SM by the conclusion of the study. Scior (2009) recommended extending the period the intervention was offered, and Taylor et al., (2008) found that twice weekly sessions rather than weekly sessions were necessary. While these recommendations were built into this study, it may be necessary to deliver the intervention for longer periods, more frequently or to have all staff members trained in the application of visual CBI so it is consistently delivered, for mastery to occur. This may be particularly relevant for people with moderate to severe ID, as they often take longer to learn skills, require systematic instruction and repeated practice to attain mastery (Cadette et. al, 2016; Scior, 2009; Westling & Fox). For some people with ID full mastery may not occur, however using the CBI card with prompting could be considered one of the least restrictive practices available compared to pharmacological or behavioural interventions. In addition, this promotes independence. Indeed, some persons with ID will always require supervision when in the community and intermittent prompting could be delivered long-term by support workers, carers or family members.

Generalisation

The investigation into whether techniques from live settings can be generalised had mixed results. Jahoda et al., (2006) emphasised generalisation into everyday life as an essential component for sustainable change. Connor, Rodney and Katherine demonstrated they could generalise their skills to other settings, whereas generalisation of SM was limited for Niamh and Gyan. Connor successfully generalised his skill set into other settings, improved his social networks and sought opportunities to interact and take risks, possibly improving his quality of life (Tonge et al., 2010; Williams & Fidock, 2012).

Bouchard et al., (1996), Hassiotis et al., (2012) and Simpson (2002) discussed the benefits that graded exposure in multiple settings can have in reducing anxiety or avoidance. Their findings were reproduced in Rodney's participation as he learned to manage some MHD through graded exposure during the experiments in the community, rather than through use of visual CBI. In addition, this exposure resulted in increased social networks as he sought further opportunities to interact with others, which in turn led to skill generalisation (Tonge et al., 2010; Williams & Fidock, 2012).

Katherine generalised skills learned to other environments with relative ease, including recreational activities and a change of employment, all of which had the potential to trigger behaviour symptomatic of MHD. Initially, the intervention was sought to assist her to manage her anger, as a condition for retaining employment and mitigating potential accommodation breakdown. By the end of the intervention, Katherine generalised the skills more widely than anticipated, for example, during social activities. This finding supported Keeling et al's., (2003) study that when an intervention is relevant to the individual, it is more likely to be generalised into broader settings.

Niamh had limited opportunities beyond one setting to generalise her self-management skills. She had impoverished social networks, which Bennett et al., (2004) and Williams & Fidock (2012) identified as a contributing factor to MHD, along with an over-reliance on certain individuals within her small network who triggered her MHD. Nezu, Cos & Nezu, (2012) and Edelman (2013) discussed the detrimental impact that passivity and over-reliance can have on development of independent problem-solving necessary for CBT interventions. For Niamh, these factors may have restricted her opportunities to generalise the intervention.

Gyan did not regularly use the visual CBI cards, therefore she could not confidently generalise the CBI and SM to other areas of her life, except for two occasions when panic attacks occurred during the independent SM sessions. At these times the visual CBT cards were her successful first line response to reduce the overwhelming panic she was experiencing. She sought assistance from others later to reduce the higher levels of generalised anxiety that she was experiencing.

Individualisation of the Intervention

It was critical the visual CBI was individualised to be relevant and meaningful to each participant in order to facilitate motivation and engagement (Hassiotis et al., 2013; Jahoda et al., 2006; Keeling et al., 2003; Reaven, 2011; Taylor et al., 2008; Willner, 2009) and were reviewed regularly to meet the participant's changing needs.

Participants whose cards were the most relevant appeared to generate the most improvement. Similar findings were reported by Keeling et al., (2003), Reaven (2010) and Taylor et al., (2008) where utilising specific interests facilitated engagement and positive outcomes for participants. Katherine was keen to have photographs taken during the experiment, but was reluctant to use the cards with any photographs or icons as she perceived these as "babyish". Once her visual CBI cards were amended using only coloured text, as described by Gray (1997) and Gray & White (2002), and combined with sight word reading instruction, she used the cards consistently and demonstrated improvement.

Niamh's and Connor's individualised cards contained ideas of activities to engage in to promote more balanced thoughts rather than self-harm as detailed in Hassiotis et al., (2012). Both participants reported back to the researcher that the cards were beneficial when used during times of extreme distress and self-harming thoughts occurred. However, the intervention did not specifically target self-harm alone, therefore, these incidences were not documented separately from other MHD data. Future research could investigate the use of visual CBI to manage self-harm and thoughts of self-harm.

In addition, both Niamh and Connor's cards incorporated individualised strategies for improving assertiveness as recommended by Edelman (2013), further increasing the relevance for these participants and may have assisted with a more consistent use of the intervention. While both participants demonstrated some improvement in becoming more assertive, it is likely that ongoing support (post-intervention) was needed to further develop these skills.

In contrast, participants whose CBI cards were not as personally meaningful demonstrated less improvement. Despite regular reviews and updates, Gyan did not consistently use the visual CBI cards to manage her anxiety, although she did use them independently to self-manage panic attacks when they occurred. This indicated that the cards were most meaningful for Gyan during panic attacks, which she experienced less often than her generalised anxiety. This is again consistent with Keeling et al.'s, (2003) study that interventions must be meaningful for them to be used consistently. While Rodney participated in the experiments successfully, he refused to have his photograph taken or to use the visual CBI. His CBI cards were revised to contain text only as per his request. Even with his input, his cards use remained limited, indicating the intervention design may have been unsuccessful in generating motivation and engagement (Jahoda et al., 2005; Reaven, 2011; Taylor et al., 2008; Willner, 2009).

Functional Level of Intellectual Disability

Several researchers have advocated for adaptations of CBT for people with mild to moderate ID (Hassiotis et al., 2013; Reaven, 2010; Willner, 2009; Jahoda, et al., 2006; Keeling et al., 2003). Taylor et al., (2008) suggested that people with mild to moderate ID are suitable candidates for adapted CBT, although also highlighted some studies with contrary evidence where people with moderate ID had poorer outcomes. The results of the study support their findings. Niamh, Connor and Rodney were functionally assessed as having mild ID. The intervention had successful clinical outcomes for Niamh and Connor, although not for Rodney. Niamh and Connor were able to consistently follow intervention protocols as designed. Rodney's mild ID had little bearing on understanding the requirements of the intervention, however he was reluctant to use the visual CBI due to a possible lack of readiness (Stott et al., 2017).

Gyan and Katherine had functional assessment scores of moderate ID. The assessments indicated that Gyan's receptive and expressive language was at a higher developmental level than Katherine's. Therefore, it would be expected that the intervention would have been more effective when used by Gyan for the management of her anxiety. The findings did not support this. Katherine's results demonstrated a larger effect for reduction in MHD and a higher frequency of use of the CBI cards for self-management compared to Gyan. Readiness may have been a greater influencing factor than severity of ID.

Capacity and Readiness

Capacity and readiness of individuals are identified in studies by Dagnan et al., (2000), Dagnan & Proudlove (1997), Oathamshaw & Haddock (2006) and Scior (2009) as potential obstacles to engaging in CBT. Capacity is usually determined by various assessments that evaluate individual's skills, including emotional awareness (Dagnan et al., 2000; Dagnan & Proudlove, 1997; Oathamshaw & Haddock, 2006; Scior, 2009). However, Mirrow (2008) advised emotional literacy can be taught to people with ID, and according to Grahame (2011) and Westwood (2004), is most effective when delivered in applied settings and contexts. In this study, capacity and readiness were considered satisfactory if the individual was willing to engage in the study and they experienced a MHD they wished to self-manage, rather than using assessment tools (Stott et al., 2017). Capacity and readiness were not used as inclusion or exclusion criteria, aligning with the supported decision making framework (Gooding, 2013).

The notion of assuming readiness through participatory consent was beneficial when considering Katherine and Rodney's involvement. Katherine had a moderate ID, a lack of emotional awareness and low literacy levels. As such she could have been deemed to lack the capacity to participate effectively in the intervention. Due to problematic behaviour, Katherine was at risk of having her employment terminated, therefore, she was willing and motivated to engage in the intervention assisting her to manage her anger at work. Conversely, Rodney had a mild ID, demonstrated greater emotional awareness, had satisfactory levels of reading literacy and a strong understanding of informed consent. Despite these characteristics, which theoretically meant he should have the capacity to engage successfully, he generally refused to use the visual CBI. His poor engagement may have centred on his reluctance to accept he had ID or MHD rather than issues with capacity or readiness (Stott et al., 2017). Rodney stated on more than one occasion that he wished to be “normal” like his same age peers and that having ID and using visual supports, such as the CBI cards was perceived as stigmatising. Many researchers, including Ali, King, Strydom & Hassiotis (2016) and Jahoda et al., (2006) highlighted the discrimination that people with ID face and the effect that stigma can have on self-esteem or self-worth. For Rodney, using an intervention designed for and used by people with ID, may have been perceived as reinforcing his own ID diagnosis. Some people with ID do not wish to identify as having an ID. By doing so, these individuals may inadvertently preclude themselves from engaging in interventions which may assist them. Rodney may have benefitted from the intervention being delivered in a more inconspicuous format, such as having a specific function or folder on his mobile phone that had information for SM. Further research could investigate whether alternative formats improve frequency of use and increase effectiveness for these individuals who perceive the intervention as stigmatising.

Both Katherine and Rodney wished their DD would “just go away” and desired immediate solutions to their MHD which may have also impacted on their initial participation. However, Katherine did engage with the intervention once the CBI cards were amended. After which she used them consistently and improved her SM. Conversely, Niamh, Connor and Gyan were accepting of their DD and had participated in previous interventions in their adult lives. Furthermore, Niamh and Connor appreciated the need to engage with the intervention and commit to using the CBI consistently for the benefits to be realised. In this study, it appears that capacity was less of an issue than readiness.

Commitment to the Intervention by Supporters

Commitment by supporters and other staff affected the results. This study’s design encouraged the participants to select their own supporter in line with the Supported Decision Making framework (Gooding, 2013; Killeen, 2016) and UNCRPD Article 12, principles of increased autonomy and agency (United Nations, 2008). The supporter role facilitated participant decision making (Gooding, 2014; Killeen, 2016), and assisted with embedding the intervention into the everyday lives of the participants (Brown et al., 2011; Hassiotis, et al., 2012; Jahoda et al., 2013). However, as identified in Bennett et al., (2000), the social networks of many people with ID are impoverished. This was the case for the participants in this study where they had few choices of potential supporters available, resulting in several participants choosing key staff members as their supporter throughout the intervention.

Brown and Marshal (2006) and Jahoda et al., (2013) highlighted the benefits of using staff to implement the intervention. Having a key staff person as a supporter was anticipated to be beneficial in providing information to other staff members supporting the participant, to monitor any problems experienced and to be a conduit for feedback between the researcher and staff. However, this research encountered several difficulties with the inclusion of staff. These difficulties were primarily around their workloads. Supporters and staff had other responsibilities resulting in being unable to assist participants consistently or provide regular feedback to the researcher. These issues affected the integration of the intervention into participants' daily lives and the quality of the data recorded. This was particularly evident with Raj, when staff were unable to provide him with adequate support in order to embed the intervention in to his daily life, or reliably record data. It is imperative that a commitment to the intervention be secured from the organisation to allow staff to include the intervention as part of their usual workloads so they can actively support the participant, rather than consider the support as an extra responsibility. This organisational commitment could improve outcomes for participants as providing sufficient time for support is important for people with moderate to severe ID, as they generally require extra assistance to develop skills. Brown & Marshall's (2006) study demonstrated improved participant outcomes when an agency provided staff with sufficient extra hours dedicated to the delivery of the intervention.

In addition, staff exhibited limited understanding or training as to the impact MHD can have on people with disabilities. The lack of MHD training is a long-standing issue within the disability sector (Mevissen & de Jongh, 2010; Paech, 2007; Pridding & Proctor, 2008 and Werner & Stawski, 2012). In this study, some staff were open to developing an understanding of the impact of MHD, past trauma and behaviour, while others were resistant. Literature confirms that people with ID have higher incidences of trauma and stress in their lives than peers without ID (Mitchel & Clegg, 2005; Hurley, 2008; Wigham & Emerson, 2015). Higher incidences of trauma and stress compounded by compromised coping skills and functional limitations of ID have detrimental consequences on the health and well-being of persons with ID (Bradley et al., 2009; Scott & Havercamp, 2014). These long-term consequences can lead to lower sense-of-self, poor self-regulation and may contribute to self-harm (Chenowith, 2011; Lovell, 2007). Given the higher incidences of MHD, trauma and stress in the ID population, it is necessary that staff routinely receive training on these issues to better equip them to respond effectively to people with DD.

Training could also reduce the overuse of pharmacological treatments or improve understanding of behaviour that may otherwise be labelled as challenging. In addition, some people with moderate ID may require extended, possibly on-going support, to master the intervention, as they may never achieve independent self-management (Scior, 2009). Therefore, it is critical that staff are suitably trained in delivering interventions to be able to support the participant as required. As identified in Paech's (2007) study, many staff or professionals working with people with DD, welcome training, supervision and mentoring on these issues. However, Dowse, Wiese & Smith (2016) question the availability of funding in Australia, as the NDIS funding framework focusses on funding for individual supports, rather than workforce training and supervision. This responsibility will remain with providers as consumers gain control over who will provide such supports.

In terms of commitment of supporters from participant's informal networks, Niamh chose her partner to be her supporter. Niamh and her supporter followed the intervention as it was designed, reliably recording data and using the intervention consistently. Even though Niamh's supporter had a learning disability, they worked in collaboration to obtain the best outcome for Niamh. The supporter identified that self-regulation of anger was an issue for him, even though he did not have a diagnosed MHD. The visual CBI could have provided some vicarious learning for this supporter as in Hatton (2002). The training prior to the intervention could have assisted with this.

Carers often report fatigue and become overwhelmed with the caring role (Bartack, et al., 2006). Katherine's supporter reported feeling some burnout with the demands of the caring role, and was herself reactive at times. Haddock et al. (2001) found that interventions can provide assistance in reducing stress for families of people with MHD. This intervention presented the carer with an opportunity for vicarious learning to self-manage her own reactivity and high levels of stress. However, at other times the supporter's own bias and interpretations contributed to Katherine's anger. Grahame (2011) considered the impact that parents or carers beliefs can have on influencing problematic behaviour. In addition, the strengths perspective framework used in the study often challenged the supporter's own beliefs in terms of resolving the behaviour through reprimanding Katherine. Nonetheless, the supporter's commitment saw both supporter and participant develop skills to address these issues. To reduce some of the issues encountered by supporters, it is recommended that future research includes independent training for supporters prior to the commencement of intervention.

Social Isolation

Isolation has a negative impact on the health and well-being of people with ID (Paech, 2007; Saunders, 2006; Scott & Havercamp, 2014). Participants and supporters commented on their experiences and the negative impact MHD had on their independence, community acceptance and participation in the past. Niamh, Connor and Rodney experienced social disadvantage due to limited social and recreational opportunities. These were further limited by episodes of their MHD which precluded them from engaging in social opportunities, increasing their isolation and perpetuating the symptoms of MHD (Hassiotis et al., 2012; Williams & Fidock, 2012). Compared to the other three participants, Gyan and Katherine had better social networks with which to engage in the community, although most engagement was with disability-specific service providers and was not genuine community inclusion (Simpson, 2002; Ware et al., 2007).

The visual CBI intervention provided participants with opportunities for self-management of their MHD, as well as benefits of social inclusion and community participation, as the experiments in the live settings included youth events, live entertainment and mainstream community activities. Connor and Rodney continued to participate in these community activities beyond the intervention. Niamh had increased participation and reduced social isolation during the main body of the study, but this was not sustained during the maintenance periods. The reason this was not sustained is not clear. It is essential to maintain community participation post intervention to assist with self-management of MHD (Tonge, et al., 2010; Williams & Fidock, 2012). Hassiotis et al., (2012) suggested that social connections may assist in mitigating risk of future self-harm in some people. This study supports previous findings from Bartak et al. (2006), Paech, (2007), Saunders (2006), Scott & Havercamp (2014) and Tonge et al. (2010) that improved social connectedness can contribute to a reduction in MHD.

Limitations and Delimitations

Sample size and Generalisation

Sample size and external validity were limitations of this study, which included a small number of participants. As single-case experimental research is predicated on the participant acting as their own control (Kazdin, 2011; Kennedy, 2004), the findings of this study may not be generalised to a larger population of individuals with DD (Richards et al., 2014). However, this study did not seek to generalise these findings to the population of people with DD, rather to explore the efficacy of an intervention.

This preliminary study supported the effectiveness of a visual CBI in assisting participants with DD to manage their MHD. The effects were reproduced for three of the five participants. It is recommended that further research is needed to replicate these effects. As is necessary with single case experimental design, multiple replications across several groups of researchers must be established for evidenced-based interventions (Kratchowill & Levin, 2014). Currently, there is insufficient evidence to conclude that visual CBI is effective for the population of persons with DD to decrease frequency of MHD and increase SM. This exploratory study has demonstrated that visual CBI has the potential to benefit people with DD.

Bias

A further limitation was the researcher acting as the therapist and training participants on the use of the intervention. This can lead to researcher bias when developing certain elements of the intervention with participants (Kratchowill et al., 2012). To counter this bias, training participants on the use of the CBI followed the fidelity protocols designed by Jahoda et al., (2013). The intervention was implemented with high fidelity as was reported in the results (92.6-100%), with the exception of Rodney who refused to have an independent observer present.

Shaughnessy et al., (2003) advised that self-reporting may also be a source of bias, as participants who self-report may distort the data. In this study, self-reporting was considered important, as recording data helped participants develop awareness of their MHD symptoms and behaviours. To help eliminate self-report bias, supporters were required to collect data on the same target behaviours at each session, with the intention of being a secondary source of verification. However, some supporters did not consistently record the information, resulting in the researcher following up on data recording in the subsequent session. This had potential for distortion as noted by Adler (as cited in Shaughnessy et al., 2003).

Future research

This research is a developing body of work and is a contribution to current knowledge by further supporting the literature confirming that adapted CBT can be effective for people with DD (Hassiotis et al., 2013; Jahoda et al., 2005; Keeling et al., 2003; Reaven, 2011; Taylor et al., 2008; Willner, 2009). In addition to supporting the literature, the overall adaptations from the original CBT protocols have been described in the methodology chapter as recommended by Brown et al., (2011) and Grahame (2011). Previous studies seldom provided information on the specific adaptations made to Beck's (1976) original CBT model. Descriptive reporting on the adaptations enables this study to be replicated, contributing to the growing evidence supporting the use of adapted CBT for people with DD. Further replications through single case experimental research and/or controlled group designs are necessary to develop an evidence base for the use of adapted CBT as an effective treatment for persons with DD (Brown et al., 2011; Grahame, 2011; Hassiotis, et al., 2013; Scattone & Mong, 2013). Further research into specific visual adaptations will increase external validity and may offer recommendations for refinement to improve outcomes (Prout & Nowak-Drabik, 2003; Scattone & Mong, 2013; Vereenooghe & Langdon, 2013), and further understanding of the requirements needed for successful participation in visual CBT interventions.

Future research could investigate training and development of professionals and workers in applied settings. Jahoda et al., (2006) and McGillivray et al., (2008) indicated that routinely incorporating CBT strategies into service delivery could improve mental health outcomes for people with DD. Settings where visual CBI may be investigated include hospitals, supported accommodation, community day service programs, training and education services, respite centres and other locations in which people with DD are situated where staff report issues in treating or managing MHD (Bennett, 2013; Rhodes & Whatson, 2011; Weiss et al., 2009). This may in turn reduce the pressure on the currently limited specialist services.

An evaluation of cost was not part of this research. Future research could compare the costs of this intervention to other interventions. All participants had engaged in previous interventions with limited success. The National Disability Insurance Scheme (2014) will assess each eligible participant for a funding package so that the participant receives sufficient funds enabling them to access equipment and some services (not training). The amount allocated in the individualised package will be determined through a matrix of functional requirements (current and potential), cost efficiency, choice and control. If fully costed, this intervention could be considered efficacious and provide people with DD a choice in their treatment.

Implications

Policy

Improving the mental health outcomes of persons with DD goes beyond the scope of a single intervention. However, this intervention adds to the empirical evidence that psychological interventions, including adapted CBT, can be of benefit to people with DD. Such evidence can help shape specific DD policy and planning, while seeking increased funding for appropriately resourced services and interventions (Brown et al., 2011; Werner et al., 2013).

Currently, there is a commitment from the Australian Government to improve the status of people with disability, including mental health, as evidenced by the NDS, NDIS and other policies (Disability Discrimination Act, 1992; National Disability Strategy, 2010; National Disability Insurance Scheme, 2014). The NDS initiative has set the scene and will guide the responsiveness of mainstream services to be inclusive of people with disabilities, particularly in terms of the NDIS. The use of informal supports (family members, friends or community organisations) is encouraged by the NDIS. However, mainstream and disability specific services, family members, friends and community organisation report they lack training and expertise in treating or managing DD (Dowse et al., 2016; Mental Health Australia, 2017; Australian Productivity Commission, 2011; Wallace, 2014). A portable, simplified intervention such as visual CBI could be utilised by people with DD and their supporters to partially address that lack (Brown et al., 2011; Bradley et al., 2009) and increase the likelihood that supports are provided routinely and generalised in naturalistic contexts. However, to ensure that supports are provided long-term and there is sufficient workforce development in the Disability Sector, adequate training needs to be costed and sustained. For this to occur, Dowse et al., (2016) advised the NDIS will need to review funding parameters to ensure that training is included in support package for individuals. Alternatively, funding for mental health training for people with DD (and researching interventions) could be delivered via the mental health system. For this to occur, it is crucial that people with DD are identified as an ‘at risk’ group in current Mental Health Policy, which should lead to people with DD adequately represented in policy so sufficient funds and resources can be directed towards appropriate treatments. Without specific DD policy to guide the distribution of funding, resources and service provision, people with DD are likely to remain in a cycle of illness and dependency.

Practice

Several researchers, including Pridding & Proctor (2008), Rhodes & Whatson (2011), Sigan et al. (2015) and Trollor (2014) have highlighted the lack of specific professional education and training on DD for professionals and human services workers. Similarly, this study supported their findings. The development of specific DD education and training is urgently needed to improve some of the difficulties currently experienced by people with DD (Taua & Farrow, 2009). In regards to direct service delivery, it is imperative that frontline staff receive training in understanding the effects of DD, the atypical presentations; including challenging behaviour, and the effective management of MHD. Brown et al. (2011) proposed that training staff could assist with assessment, diagnosis, lead to improvement in treatment outcomes, and provide feedback on the progress of any treatment or interventions to their treatment plan. In addition, commitment is also required from organisations to provide ongoing and sustainable workforce training, with supervision and mentoring, so that systemic change occurs in service provision.

Furthermore, it is critical that professionals and staff working alongside vulnerable people, including those with DD, do so from a human rights perspective. As discussed in Chapter 4, participants expressed concern of the consequences if they could not complete the experiments, as they had previously felt pushed, coerced or punished by others when attempting to challenge or manage episodes of MHD. These statements revealed an unintentional power imbalance that can occur when working with vulnerable people (Emerson et al., 2004). In this study, participants were valued and treated as peers in line with findings in Pert et al., (2013). All attempts by participants to address the MHD were viewed from a strengths perspective, which assisted in developing trust between the researcher and the participant. This was imperative given the emotional terrain being explored by the researcher and the participants (Pert et al., 2013). Future practice, whether by staff or informal supporters, will need to employ a human rights perspective as outlined in Emerson et al., (2004) and Evans et al., (2012), along with genuine warmth and empathy to validate the participant's experience (Pert et al., 2013).

This study also supports the recommendations of Rhodes & Whatson (2011) and Sigan et al. (2015) who advocated for the development of targeted education campaigns for parents and carers as this could increase the awareness of the high incidences of MHD, in turn encouraging prompt treatment as well as providing support to families.

In terms of effective interventions, this study has demonstrated the visual CBI card system is an unobtrusive, person-centred intervention for self-management of MHD that can be easily incorporated into applied settings and everyday living contexts. The intervention is in line with current social norms of taking photographs of oneself (selfies). Most people have access to current technologies, such as mobile phones, digital cameras and computers. This allows the cards to be made with ease and inexpensively. As discussed earlier, for people who are reluctant to use hard copy cards, electronic versions of the intervention could be delivered on mobile phones or other technologies, allowing further discretion when using the intervention. Minimal training of staff is required for them to understand and support implementation of the intervention although, as recommended by Willner et al., (2013) supervision by a psychologist or other experienced therapist is recommended. With participant's consent, frontline workers or agencies within the participant's life could use the intervention for improved outcomes, as occurred with Katherine’s employer and Connor’s social inclusion program coordinator. This visual CBI could provide a consistent approach to management of MHD across the participant’s life settings. As identified, further replication of this visual CBI is required in applied settings, such as social inclusion programs, respite centres or other community setting where people with DD frequent, before evidence-based practice can be determined(Kratchowill & Levin, 2014).

Conclusion

This study adapted a well-known, highly effective treatment used in the general population to accommodate people with DD. Given the high incidences of MHD in people with ID and the limited professional assistance available for this group of people, interventions or treatments that improve quality of life are urgently needed (Brown et al., 2011; Prout & Novak-Drabik, 2003; Scattone & Mong, 2013; Vereenooghe & Langdon, 2013). The visual CBI card system is a discreet, user-friendly method that people with DD can use independently, or with assistance from their supporter. Given the positive results in this preliminary study, including an overall moderate self-management effect and generally favourable social validation reports, this intervention can continue to be researched further in a variety of applied settings.

The aim of this exploratory study was to investigate whether a visual CBI could assist people with DD to SM episodes of MHD. This intervention was not designed as a total treatment for MHD or to replace psychiatric or psychological intervention delivered in clinical settings, rather as an instrument or supplement to alleviate some of the distress caused by the symptoms of the MHD and the underlying dysfunctional thinking process, with the aim of improving quality of life. The intervention was designed as a tool for those supporting people with DD, to assist them in improving self-management. To this end, the visual CBI has demonstrated benefits for persons with DD and has the potential to do so for their families, carers and support staff. The results of this study add to the emerging evidence base that adapted CBT can be successfully used for and by people with ID experiencing MHD.

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ENDNOTE

[1] Gafurov, B. & Levin, J. (2016). Version 2.1. The single-case data-analysis ExPRT (Excel® Package of Randomization Tests). Available from https://github.com/gsborisgithub/ExPRT

[1] Microsoft Excel (2010)

APPENDICES

Appendix A. Information Sheet

Michelle Carney
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INFORMATION SHEET

Title: Visual Cognitive Behavioural Intervention: An adaptation of Cognitive Behaviour Therapy for people with intellectual disabilities and mental health difficulties

Investigators:
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Flinders University
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Supervisor(s):
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Psychiatrist in Developmental Disability Psychiatry
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Description of the study:
This study is part of the project entitled '*Visual Cognitive Behavioural Intervention: An adaptation of CBT for people with intellectual disabilities and mental health difficulties'.*

Flinders University Education department supports this project.

Purpose of the study:
The purpose of this study is to investigate the effectiveness of a visual adaptation of Cognitive Behaviour Therapy (CBT) using photographs and symbols for individuals with dual disabilities to assist them to self-manage symptoms of their mental health difficulties.

An individualised card with photographs and symbols that are meaningful to each participant will be developed to help you manage the symptoms or behaviour that you identified.

Short interviews will explore your opinions and the opinion of the supporters (parent/carer) to see how helpful the intervention was in everyday life. Discussions will be around what were the benefits of the card, what were the problems and any suggestion for improvements.

Michelle Carney, the researcher of this study will invite 6 people with an intellectual disability and mental health difficulties to take part in this 20-week study. The study will comprise of 2 weekly meetings and homework tasks to practice new skills to manage the mental health difficulty. Participants will be asked to choose a support person to assist them throughout the study.

What will I be asked to do?
Initially, you will be invited to attend an information session with the researcher to discuss the project and to see whether you are interested in being part of it. Participation in the study is voluntary. If you decide that you are interested in being involved with the study, you will meet with the researcher again and decide on the issue or problem that you would like to address and sign two consent forms. One consent form is for participation in the intervention and one for participation in the research. Both consent forms need to be signed to be part of this study.

On the consent form for participation in the intervention, you will also be asked to give permission to the researcher reading your Disability SA file to find out what has happened before, including any medication that a doctor has given you or any other things that you may have tried to help you with the problem that you want to work on now. This information will help the researcher find out what has worked and what has not worked, so that the carry card that you make will be as helpful as possible.

After that you will meet the researcher twice a week, for about an hour each time, to work on addressing the problem you identified. The researcher will meet you at different places that best suit working on the issue. That might include in the office, in your home or in community places. The researcher will measure how well the card is helping you. There will also be some activities that you will be asked to do outside the meetings with the researcher, so that you can practice the new skills that you have learned.

The researcher's supervisor will attend one of the CBT sessions to ensure that the research is being conducted correctly.

Near the end of the study you will be asked to take part in an interview to help improve the carry card. You will be asked to sign a consent form agreeing to take part in the interview at that time.

What will my supporter be asked to do?
You will be asked to choose a supporter to assist you with homework activities and getting to locations. The supporter can be a parent/carer, friend or someone you trust to help you learn this new way of managing your difficulties**.** Your supporter will make a commitment to assisting you for the 20-week project. Your supporter will be part of the twice-weekly meetings that we have and also help you with the homework tasks that included taking photographs of you practicing new skills that will help you self-manage the difficulty you have chosen to work on.
Your supporter will also be asked to sign a consent form to take part in the study as well as a confidentiality agreement. At the end of the project your supporter will also be asked to sign a consent form for taking part in an interview to help improve the card system.

What benefit will I gain from being involved in this study?
The benefit to being involved in this study is that you would have assistance in learning to self-manage an issue that you want to address that may have been causing you concern. You will develop an individual system that you can use after the study is finished.

Sharing your experiences will improve the way we assist people to manage similar issues that they may be experiencing. We are very keen to have a card system which is as useful as possible to people.

Will my information be confidential?
The researcher will take all possible steps to protect your information. Any identifying information will be removed from project documents and a pseudonym will be given. The photographs and any electronic information will be stored on a password-protected computer that only the researcher (Michelle Carney) will have access to. Any hard copy documents will be stored in a locked file.

The researcher will write and publish a thesis at the end of the study, to help other professionals learn about the carry card, but all identifying details, such as names and addresses, will be removed.

While your information is treated in the strictest confidence, the researcher is obliged to report illegal activities or seek help with you if you might hurt yourself or other people

Will I be identifiable by being involved in this study?
The information gathered will not be linked directly to you, however, your anonymity cannot be guaranteed due to the small number of people in this study.

Are there any risks or discomforts if I am involved?
There may be some discomfort as we work through some issues or problems that you want to learn how to self manage. You will have support from the researcher in managing this discomfort. Throughout the study you will learn how to manage the discomfort or issue independently through the carry card system. However, in the unlikely event that you might need assistance after hours, the contact number of emergency mental health services have provided:

Emergency Mental Health Services

Disability SA After Hours Services	8372 1414
Mental Health Emergency Hotline	13 1465
24/7 Acute Service	13 1465
Walk in Mental Health Service 7-9 Park Terrace Salisbury	7485 4300
Emergency	000

How do I agree to participate?
Participation is voluntary. You are free to withdraw from the study at any time without effect or consequences. If you decide that you want to participate in this study you would need to sign two consent forms that will be provided to you at the information session.

How will I receive feedback?
Outcomes from the project will be summarised and given to you by the investigator if you would like to see them.

What if I have any concerns or complaints?
If you have any concerns or complaints you can contact Flinders University Executive Officer of the Committee on 8201 3116 or by email human.researchethics@flinders.edu.au

or contact Families and Community Research Ethics Committee Executive Officer by phone on 08 8415 4142 or by email research@dcsi.sa.gov.au

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (6797). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix B. Information Sheet - Reader Friendly

Michelle Carney

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READER FRIENDLY PARTICIPANT INFORMATION SHEET

Title: Visual Cognitive Behavioural Intervention: An adaptation of CBT for people with intellectual disabilities and mental health difficulties

Investigators:
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Description of the study:
This study is part of the project entitled '*Visual Cognitive Behavioural Intervention: An adaptation of CBT for people with intellectual disabilities and mental health difficulties'.*

Flinders University School of Education supports this project.

Purpose of the study:

The purpose of this study is to find out if using photographs and symbols will help people with an intellectual disability and mental health difficulty to manage their difficulty better.

Michelle Carney is the researcher of this study and is inviting 6 people with an intellectual disability and mental health difficulty to be part of this study.

The 20-week study will have 2 weekly one-hour meetings that will teach you some new skills to manage your difficulty. There will also be some homework tasks for you to practice your new skills. You will be asked to choose a support person.

What will I be asked to do?
You will be invited to attend an information session with the researcher, Michelle, to talk about the study and to see whether you want to be part of it.

You get to choose if you do or don't want to be part of the study.

If you decide that you are happy to be part of the study you will sign two consent forms, one about being involved in the intervention and making a carry card, and another form for taking part in the research. Both consent forms need to be signed to be part of this study.

On the consent form for participation in the intervention, you will also be asked to give permission for Michelle to read your Disability SA file so she can find out what has happened before, including any medication that a doctor has given you or any other things that you may have tried to help you with the problem that you want to work on now. This information will help Michelle find out what has worked and what has not worked, so that the carry card that you make will be as helpful as possible

Then you will meet with Michelle again and choose the problem that you would like to learn how to manage.

After that you will meet Michelle twice a week, for about an hour each time, to learn different ways to help you.

Michelle will meet you at different places and might include in the office, in your home or in community places.

Michelle will measure how well the card is helping you.

There will also be some activities that you will do as homework, so that you can practice the new skills that you have learned.

Near the end of the project you will be asked to take part in an interview to answer some questions to help improve the card system. You will be asked to sign a consent form agreeing to take part in the interviews. A consent form agreeing to take part in the interview will be provided at that time.

Michelle's supervisor will come to one of the meeting to make sure that the project is being done properly.

What will my supporter be asked to do?
The supporter can be a parent/carer, friend or someone you trust to help you learn

this new way of managing your difficulties.

Your supporter will agree to help you for the 20-week project. Your supporter will be involved in the twice-weekly meetings and help you with the homework, including taking photographs of you practicing new skills.

Your supporter will sign a consent form agreeing to take part in the study, as well as a confidentiality agreement so that your information is kept private.

At the end of the project your supporter will also be asked to take part in an interview to help improve the card system. Your supporter will sign a consent form to take part in an interview. A consent form agreeing to take part in the interview will be provided at that time.

If I take part in the study, how will this help?
The benefit for you is that you would have help in learning how to manage a problem that may have been causing you concern.

You will develop a card system that you can use after the study is finished.

Your experiences will help the way we support other people to manage similar problems. Michelle is very keen to have a card system to help other people.

Will people know who is in this study?
Michelle will take all possible steps to protect your information. Any information that identifies you, such as your name and address, will be taken off and a pseudonym (made-up name) will be used. The photographs and any electronic information will be stored on a password-protected computer that only Michelle will have access to. Any hard copy documents will be stored in a locked file.

The researcher will write and publish a thesis at the end of the study to help other professionals learn about the carry card, but all identifying details, such as names and addresses, will be removed. However, because there are only 6 people in this study, someone might try and guess that it is you. Michelle will not tell them that it is you, so they will only be guessing and won't know for sure.

Michelle won't tell anyone anything about me?
Michelle will not tell anyone your private information, but if you tell her something that is against the law she has to report this. Also Michelle will get help with you, if she thinks you might hurt yourself or other people.

Will I feel uncomfortable?
You might feel a little uncomfortable, especially in the beginning. But you will learn new skills to manage the problem, so any uncomfortable feelings should get less and less. You will have help from Michelle to help you cope with the uncomfortable feelings and as you get better at managing you probably won't need Michelle's help.

Just in case you feel really uncomfortable after hours, such as night-time or weekends, here is a list of places you or your supporter can get help from:

<u>Emergency Mental Health Services</u>

- Disability SA After Hours Services 8372 1414

Mental Health Emergency Hotline	13 1465
24/7 Acute Service	13 1465
Walk in Mental Health Service 7-9 Park Terrace Salisbury	7485 4300
Emergency	000

How do I take part in this study?
You get to choose if you want to be part of this study. No one can make you be part of it. If you choose to be part of it you get to sign two consent forms saying that you want to be part of the study and the research. You get to keep copies of the forms. You then will meet with Michelle to find out more about the project and what type of card we will make with you.

You can stop being part of the study at any time you want to. You just need to tell Michelle. Michelle will also ask you lots of times during the study if you are happy to keep going.

How will I find out how the study went once it has finished?
At the end of the study, Michelle will ask you if you want some information about the whole study. You get to choose if you want information or not.

What if I have any concerns or complaints?
If you have any concerns or complaints you can contact Flinders University Executive Officer of the Committee on 8201 3116 or by email human.researchethics@flinders.edu.au

or contact Families and Community Research Ethics Committee Executive Officer by phone on 08 8415 4142 or by email research@dcsi.sa.gov.au

Thank you for taking the time to read this information sheet and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (6797). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix C. Consent Form for Intervention

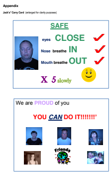
Visual Cognitive Behavioural Intervention: An adaptation of CBT for people with intellectual disabilities and mental health difficulties

Consent Form for Intervention

I, ……………………………………..(insert photo)

understand the purpose of the project is to make me a carry card

that will try to help me manage a problem that I have chosen.



Appendix

Jack's' Carry Card (enlarged for clarity purposes)

SAFE

eyes CLOSE ✓

Nose breathe IN ✓

Mouth breathe OUT ✓

X 5 slowly

We are PROUD of you

YOU CAN DO IT!!!!!!!'

Michelle Carney  from Flinders University, will help me learn how to

do this using photographs, symbols and some words.

I give Michelle permission to look in my Disability Services SA file  to see what has happened before, including any medication that may have been given or other help I may have received, to help make this card the best it can be for my difficulty.

It is  my choice to be involved in this project or not. ☑ ☒

I can stop  being involved at any time.

I agree to take part in this project

(Insert photo) Signature………………………………………. Date…………………

 Signature………………………………………. Date………………….

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (6797). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix D. Consent Form for Research

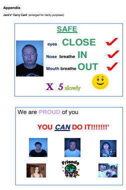
Flinders
UNIVERSITY

Visual Cognitive Behavioural Intervention: An adaptation of CBT for people with intellectual disabilities and mental health difficulties

Consent Form for Research

I, …………………………………….(insert photo)

understand the purpose of the study is to see how the carry card helped me manage a problem that I choose.



Michelle Carney  from Flinders University, will measure how

good ☑ or bad ☒ the card was at helping me manage my difficulty.

Michelle will write about it in a report to help other professionals learn about the carry card, but all personal information identifying you and your supporter will have been removed. Some people might try and guess if the person in the report is you. Michelle will not tell them it is you, so they will only be guessing.

It is  my choice to be involved in this project or not ☑ ☒

I can stop  being involved at any time.

I agree to be part of this research.

(insert photo) Signature………………………………………. Date…………………

 Signature………………………………………. Date…………………

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (6797). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Appendix E. Consent Form for Interview

Flinders
UNIVERSITY

CONSENT FORM FOR PARTICIPATION IN RESEARCH
Participant interview

Visual Cognitive Behavioural Intervention: An adaptation of CBT for people with intellectual disabilities and mental health difficulties

I …..

consent to taking part in an interview on the Visual Cognitive Behavioural Intervention study conducted by Michelle Carney from Flinders University

I agree to audio recording of my information and participation for the interview.

Michelle Carney will transcribe the interview and remove all identifying details, such as names and addresses, from the typed record

I understand that:

- I can stop being part of the project at any time and it won't affect my other services
- I don't have to answer questions
- I can ask for the recording or the interview to be stopped.

Participant's signature……………………………………Date…………………..

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Supporter's name……………………………….………………….................

Supporter's signature…………………………………..Date…………………….

Researcher's name……………………………….………………………...............

Researcher's signature…………………………………..Date…………………….

NB: Two signed copies should be obtained

Appendix F. Data Collection Sheet for Participants

DATA COLLECTION SHEET FOR PARTICIPANTS

Participant' s Name……………………………………………………………

Supporter's Name………………………………………………………………..

Date	**Behaviour**	**Self-managed**	 **Using card**
PARTICIPANT			
SUPPORTER			

Place a tick into the green box each time you ……………………………………………(behaviour). Place a tick into the blue box each time you manage your (behaviour). If you used your card to manage your behaviour put a tick in the red box

Appendix G: Master Data Sheet

Including baseline, randomisation start point, and intervention

Sessions

	BL	BL	BL	BL	BL	BL	BL	BL	BL	BL	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1.RodT							*																			
RodS																										
2.GynT									*																	
GynS																										
3.rajT						*																				
rajS																										
4.ConT								*																		
ConS																										
5.KatT										*																
KatS																										
6.NiaT					*																					
NiaS																										

	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	
1.RodT																									
RodS																									
2.GynT																									
GynS																									
3.RajT																									
RajS																									
4.ConT																									
ConS																									
5.KatT																									
KatS																									
6.NiaT																									
NiaS																									

T= target behaviour (MHD) **S**= self-managed (SM) **BL** = baseline * = randomisation start point

Name	**Randomised by start point using ExPRT (version 1.1, 2013)**	**Case number randomisation by lottery**
Niamh	5	Participant 6
Raj*	*6*	*Participant 3*
Rodney	7	Participant 1
Connor	8	Participant 4
Gyan	9	Participant 2
Katherine	10	Participant 5

*N.B. Participant 3 data were removed due to insufficient data collected by participants and/or supporter

Appendix H. Master Data Sheet for each participant

MASTER SHEET FOR…………………………………………………

Objective: for improvement in participant self-management of target behaviour

Criterion: how many times has the behaviour occurred per sessions? how many times has the self-management of behaviour occurred per session? 80% effective by week 20.

Weeks		**B**	**B**	**B**	**B**	**B**	**B**	**B**	**B**	**B**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**
Participant (Self- report)	T_B																									
	S_M																									
Supporter (Observer)	T_B																									
	S_M																									
Therapist - Observe via photographs	S_M																									

Weeks		**17**	**18**	**19**	**20**	**21**	**22**	**23**	24	**25**	**26**	**27**	**28**	**29**	**30**	**31**	**32**	**33**	**34**	**35**	**36**	**37**
Participant (Self-report)	T_B																					
	S_M																					
Supporter (Observer)	T_B																					
	S_M																					
Therapist - Observe via photographs	S_M																					

Target behaviours will be negotiated with each individual participant prior to his/her commencement in the study

B = baseline. 1-40 = total number of sessions of intervention. 1-20 = behavioural phase 21-40 = cognitive phase

T_B= Target behaviour. S_M = Self -management of behaviour

Appendix I: adapted MaGIC Fidelity Scale

Adapted MaGIC rating scale for visual CBT study

PARTICIPANT: **RATER:**	DATE:
Items are scored as present (1), absent (0), or starred items could also be scored not applicable (N/A)	
1. Coverage of session plan (i) Set out the agenda for session	
(ii) Agenda was adhered to during the session	
(iii) Good management of time	
2. Feedback (i) Asked for feedback from previous session	
(ii) Ensured that group members clearly understood and adhered to the group rules and the purpose of the session	
(iii) Asked for feedback and reactions to session	
3. Understanding (i) Conveyed understanding by rephrasing or summarizing what participant said	
(ii) Showed sensitivity by adjusting the content or style of their own communication to help participant understand	
(iii)*Welcomed participants requests for clarification	
4. Interpersonal effectiveness (i) Communicated warmth, concern and caring	
(ii) In control of the session, communicated clearly without frequent hesitations/repetitions	
(iii) Able to shift appropriately between listening and leading	
5. Engaging participants (i) Explained rationale and requirements for the different activities/elements of the session clearly	
(ii) Did not criticize, disapprove or ridicule participants behaviour	
(iii) *Responded to seemingly irrelevant interruptions in an effective yet diplomatic manner	

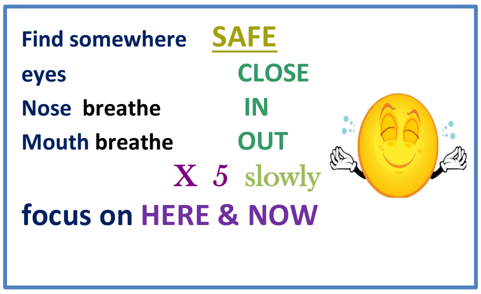
6. Accessibility of presentation (i) Discussions were pitched at a level that was understood by participant	
(ii) Materials were used appropriately	
(iii) Care was taken to pace the session at a rate that allowed participant to keep up with what was happening	
7. Focus on key cognitions (i) Elicited (or responded to) specific thoughts, assumptions, images, memories, beliefs or perceptions	
(ii) * Identified cognitions from participant's reports of their problems	
(iii) * Considered the link between elicited cognitions and affect	
8. Focus on key emotions (i) * Acknowledged the emotions of the participant in the course of the session	
(ii) * Attempted to help members manage their emotions in sessions	
(iii) * Made the link between the emotions members expressed in sessions and their particular problem	
9. Group processes (i) Encouraged a sense of responsibility and mutual respect amongst group members	**N/A for this study**
(ii) Promoted interaction between group members and encouraged participation in group activities	
(iii) Promoted an atmosphere of collaboration between therapists and group members	
10. Homework (i) Reviewed previous week's homework	
(ii) Encouraged participant to complete homework	
(iii) Asked members if they anticipated any problems with homework	

Adapted from Manualised Group Intervention Checklist Jahoda, et al., 2013

Appendix J. Examples of Niamh’s Card for Anger

Images have been edited and actors have been used to protect participant confidentiality.

NIAMH’S FIRST CARD OF ‘THINGS THAT HELP ME TO RELAX’ (reduce anger)



Find somewhere SAFE
eyes CLOSE
Nose breathe IN
Mouth breathe OUT
X 5 slowly
focus on HERE & NOW

Things that help me relax
Movies
TV
Colouring in
My Dog

The following pages demonstrate the “My Thinking” process used in the session to provide evidence of self-management.

Evidence of times I have managed my anger

27th July – went to Easter with my family

My niece and nephew didn’t get any Easter eggs from my family.

I GOT **REALLY ANGRY** = **10/10**

My unhelpful thinking– “They didn’t get any Easter eggs. This is so unfair! They are missing out!”

Helpful thinking- “They know I love them heaps”

I went to the toilet and used my card to **breathe slowly 5 times**

IT HELPED ME FEEL LESS ANGRY ↓ **5/10**

I MADE IT!!!

I had a good time with my niece and nephew.

Images have been edited and actors have been used to protect participant confidentiality.

THE MEANINGFUL PHOTOS WERE THEN PLACED ON A VISUAL CBT CARD FOR NIAMH TO CARRY AND REMIND HERSELF WITH THE EVIDENCE THAT SHE CAN SELF-MANAGE HER ANGER

Find somewhere SAFE

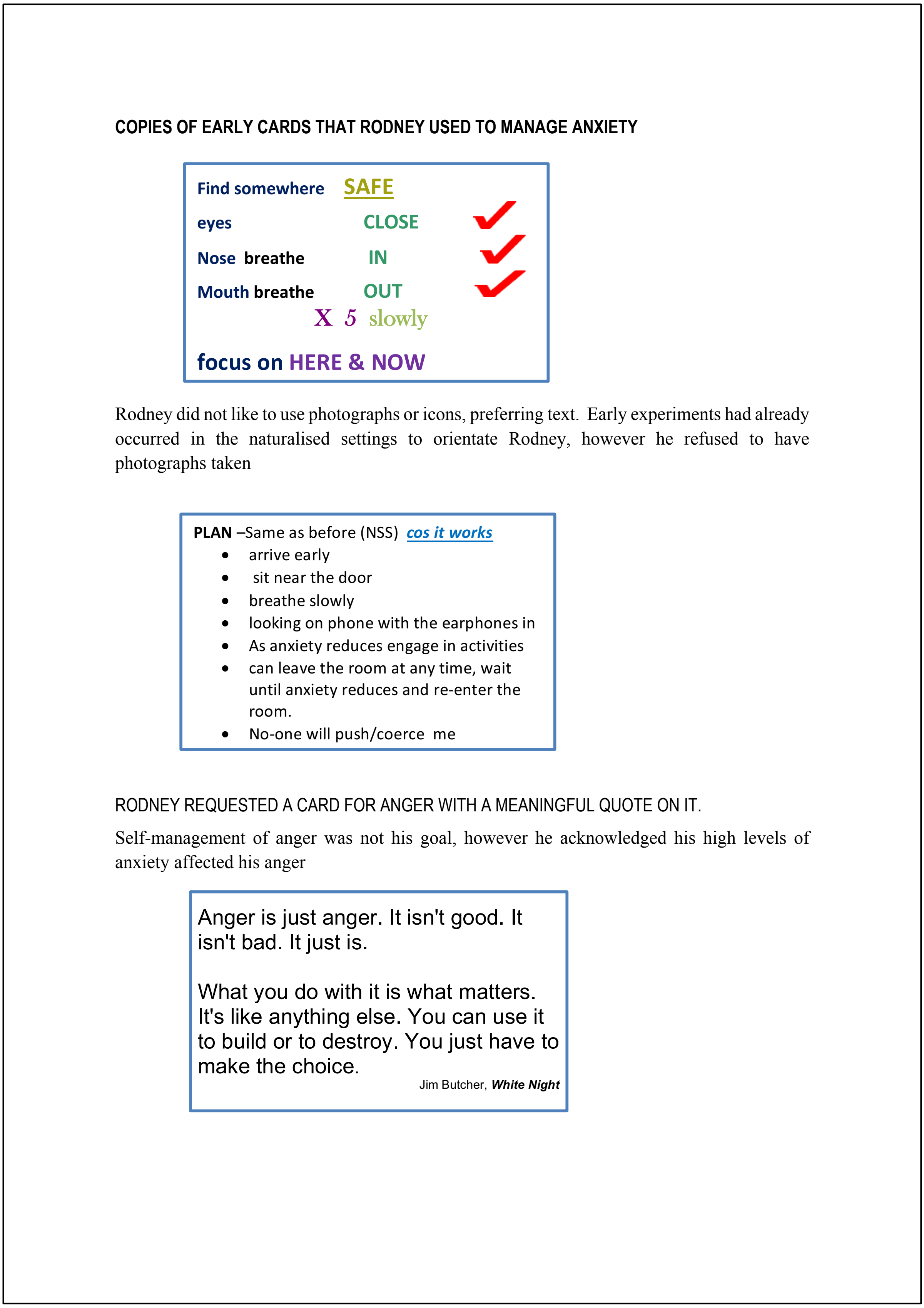
eyes CLOSE
Nose breathe IN
Mouth breathe OUT
X 5 slowly

focus on HERE & NOW

I CAN MANAGE MY ANGER =see these guys

Appendix K. Example of Rodney’s Card for Anxiety

Images have been edited and actors have been used to protect participant confidentiality.



COPIES OF EARLY CARDS THAT RODNEY USED TO MANAGE ANXIETY

Find somewhere **SAFE**

eyes **CLOSE** ✓

Nose breathe **IN** ✓

Mouth breathe **OUT** ✓

X *5* slowly

focus on HERE & NOW

Rodney did not like to use photographs or icons, preferring text. Early experiments had already occurred in the naturalised settings to orientate Rodney, however he refused to have photographs taken

PLAN –Same as before (NSS) ***cos it works***

- arrive early
- sit near the door
- breathe slowly
- looking on phone with the earphones in
- As anxiety reduces engage in activities
- can leave the room at any time, wait until anxiety reduces and re-enter the room.
- No-one will push/coerce me

RODNEY REQUESTED A CARD FOR ANGER WITH A MEANINGFUL QUOTE ON IT.

Self-management of anger was not his goal, however he acknowledged his high levels of anxiety affected his anger

Anger is just anger. It isn't good. It isn't bad. It just is.

What you do with it is what matters. It's like anything else. You can use it to build or to destroy. You just have to make the choice.

Jim Butcher, ***White Night***

Appendix L. Example of Connor's Card for Anxiety

Images have been edited and actors have been used to protect participant confidentiality.

Find somewhere SAFE
eyes CLOSE
Nose breathe IN
Mouth breathe OUT

X 5 slowly
focus on HERE & NOW

Coffee with Gary then onto see a **live band**

I took the train and **MADE** crowded **footy GAME**!!

Evidence: THE TIMES I MANAGED MY ANXIETY

Connect Up

New Friendships

As evidence of self-management increased, small icons replaced photographs. However, all photographs were retained by the participant at his home

The following pages demonstrate the “My Thinking” process used in the session to provide evidence of self-management.

Evidence of times I have self-managed

1st April - I was going to the cinemas to see London has fallen.
I was feeling anxious with the crowds

My thinking – unhelpful thinking **“it is packed”** ↑ **6/10**

Helpful thinking - **“they are going to a different movie becos** [sic] **they have kids?”** ↓ **4/10**

I did some breathing with my card ↓ **2/10**

I had a smoke ↓ **0/10**

THIS HELPED ME FEEL BETTER

Even though it was dark and I had to go up the stairs to go the back I still had

zero anxiety

A different way of thinking for self-harm

When I have unhelpful thoughts – I will think of a more helpful thought:

"I have got GOOD things in my life to look forward to:
BOWLING, FRIENDS & FAMILY, HOLIDAYS – partner.**"**

I will repeat the helpful thought **3 – 5** times

(adapted from Hassiotis et al., 2012, p.45-46)

Things I can do when I feel like I want to self-harm

Listen to music ♫

Take a **hot shower**

Talk to someone, go visit, phone, or chat online ☎

Take a **nap**

Have a **smoke** in **garden**

Exercise – get sweaty

Got for a **walk**

These icons were replaced over time with photographs of Connor engaging in the activities

Appendix M. Examples of Gyan’s Card for Anxiety (Panic Attacks)

Images have been edited and actors have been used to protect participant confidentiality.

Evidence of times I have managed my anxiety (panic attack)

11/4/16 –I was having bad memories of being yelled and hit by ** when he was a bit angry and stuff. He had been drinking alcohol and using drugs.***

My thinking – *Bad memories (thoughts and pictures) keep coming into my head.*

Unhelpful thinking

“I feel unsafe” ↑ **10/10**

I did some breathing using my card ↓ **7/10**

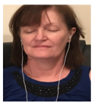
Later I spoke to Simone (staff) ↓ **7/10**

I rang Auntie Sharni. We did some breathing ↓ **5/10**

Helpful thinking – “it is hard for me, but I am *SAFE* now

Other things that I can do when I have an anxiety attack

- **breathe** with my card
- **Listen** to relaxing **music** on my phone
- look at **photos** on my phone



If I am home

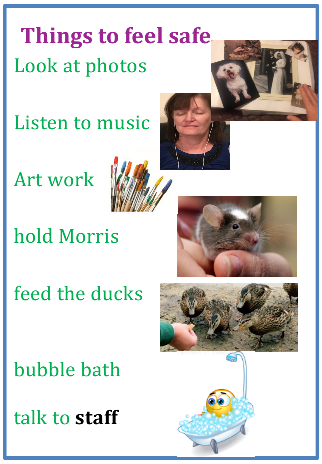
“he is so funny”

- have a **bath**
- look happy **photos**
- **Hold Morris –**
- Art work
- Talk to Simone or other staff

The meaningful photos and statements are then placed on a visual CBT card for Gyan to carry and remind herself with the evidence that she can self-manage her anxiety and panic attacks.

"it's hard for me,

but I am *SAFE* now"



Things to feel safe

Look at photos

Listen to music

Art work

hold Morris

feed the ducks

bubble bath

talk to **staff**

Appendix N. Examples of Katherine’s Card for Anger

Images have been edited and actors have been used to protect participant confidentiality.

Katherine preferred cards with colourful text rather than photographs. However, in the final few weeks she requested that some photographs be inserted.

Starting to feel angry

I’M STARTING TO FEEL ANGRY

- Heart beats start to get faster
- Hands start to make fists
- Start to think swear words in my head
- Start to think things like *“You cant tell me what to do” or “Go away”*
- Eyes roll

What can I do to manage this:

- **Quite time** reading a book or magazine
- Play a game on my phone or a computer
- **Listen to music** on IPod

Feeling aggressive

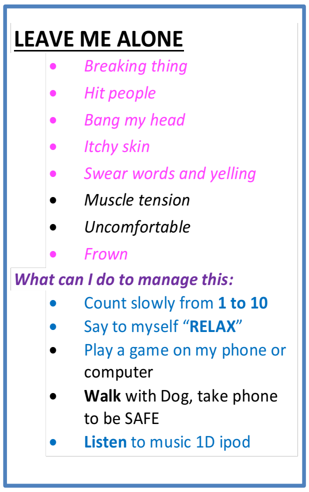
I’M FEELING AGGRESSIVE

- Feel tight Muscle tension
- Makes fists and punch hand
- Heart beating faster
- Start to get headache, pressure in the head
- Think about hurting someone
- Loud voice

What can I do to manage this:

- think “**cool down**” and **breathe**
- Look at messages from my mum
- Listen to IPod
- Type things on my computer
- Watch DVD – ‘Black Beauty’
- Watch TV horse program

Rage – leave me alone



LEAVE ME ALONE

- *Breaking thing*
- *Hit people*
- *Bang my head*
- *Itchy skin*
- *Swear words and yelling*
- *Muscle tension*
- *Uncomfortable*
- *Frown*

What can I do to manage this:

- Count slowly from **1 to 10**
- Say to myself "**RELAX**"
- Play a game on my phone or computer
- **Walk** with Dog, take phone to be SAFE
- **Listen** to music 1D ipod

Text index
Pink text depicts signs that her supporter (or others) may be able to see and advise her that her anger may be increasing. Black text depicts internal signs of anger.
Blue text depicts things she can engage in while in the community, black text depicts things she can do at home or in the workplace.

The following pages demonstrate the “My Thinking” process used in the session to provide evidence of self-management.

__Evidence of times I have managed my anger__

11/4/16 What is the problem
……………………My work trial - a man was teasing me about boys.
……………………I also got told off for talking……………………………………………………
……………………I have headache and I am missing my Mum and Dad…………….

My thinking – What are your unhelpful thoughts
“I am starting to get angry”…………………………………………………………….
……… **“I am feeling uptight cos I got told off”**………………………………………………

What are more helpful thoughts
………… “I can ignore him”……………………………………………………………………………
………….. “I will try not to talk as much”…………………………………………………………

WHAT CAN I DO TO HELP ME RELAX WHEN I AM ANGRY

- I talked to Michelle
- We rang my Mum and Dad
- I took 2 panadol and my headache started to go

IT HELPED ME FEEL BETTER!!

The meaningful statements are then placed on a visual CBT card for Katherine to carry and remind herself that she can self-manage her anger.

I want this new job – so Think

“cool down”

and Breathe slowly

I CAN DO THIS

Final card made by Katherine depicts her belief that she can manage her anger using key words from sight reading instruction. The photograph Katherine inserted was meaningful to her.

BIOGRAPHY

Michelle Carney is a Doctor of Education candidate at Flinders University, South Australia. Her Doctoral thesis is on the visual adaptation of cognitive behaviour therapy for people with intellectual disability and mental health difficulties. Michelle's research interests include intellectual disability, mental health, dual disability, social inclusion and community participation, and the National Disability Insurance Scheme. She been employed in the disability sector for twenty years, teaching independent living skills and providing social inclusion programs and recreational opportunities to people with intellectual disabilities and case management.