Adapting Cognitive Behavioural Therapy for Children with Intellectual Disabilities: Development and Feasibility Evaluation of the *Fearless Me!* © Program

Anastasia Hronis

B Psych (Hons), M Clin Psych, AMusA, LMusA

Empirical thesis submitted to fulfil the requirements for the degree of

Doctor of Philosophy

Graduate School of Health

University of Technology Sydney, Australia

2019

Certificate of Original Authorship

I, Anastasia Hronis, declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Graduate School of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

Production Note:
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Date: 11.12.2019

Acknowledgements

I'd like to express my deep appreciation for all the people who encouraged me, supported me and guided me throughout my PhD. I am filled with gratitude.

First and foremost, I would like to express my special appreciation and thanks to my supervisors, Professor Ian Kneebone and Associate Professor Rachel Roberts. I don't think I'll ever be able to quite convey how thankful I am to you for believing in me, and supporting me every step of the way. Thank you for helping me to think big, for supporting my ideas, for the time you dedicated to me, and for helping me build my career in research and academia. It has been my aim throughout this PhD, to make the most of the experience, and you helped make this dream a reality.

I'd also like to thank my former supervisor, Dr Lynette Roberts, for her valuable input in helping shape this research and assisting me to develop the ideas for my projects. Thank you also to Alice Shires for her assistance with supervision within the university clinic, as well as to Emily Hinton who helped deliver the therapy to many of the children and families.

My gratitude extends to the entire University of Technology Sydney Graduate School of Health, and all the staff who supported me and provided me with supervision and guidance along the way. Particularly, I'd like to thank Associate Professor Toby Newton-John for his research guidance, and Dr Kris Rogers for statistical advice. Working within such a fantastic department certainly made this journey easier.

I would like to thank the James N Kirby Foundation, for graciously providing funding for us to be able to carry out this research. Without your contributions, this work would not have been possible. I'd also like to thank all the families, children and the schools who gave their time and participated in the research. It was a joy working with every one of you.

I was fortunate enough to be able to attend and share my work at a number of national and international conferences. Thank you to all the people I met along the way who encouraged me to continue with my work, and who helped guide me and provided feedback, as well as for the research collaborations we've been able to form. I look forward to what's to come.

These acknowledgements would not be complete without thanking my colleagues and friends who I have undertaken the doctoral journey alongside. Being able to share this experience with you all has been both comforting and motivating. To all my friends who supported me through life's hurdles and challenges, thank you.

Finally, I want to express my deep thanks to my family. Words can't quite convey how appreciative I am to my parents for their continuous love, help, guidance and support, not just through my PhD candidature, but my entire life. I couldn't have done any of this without you. In particular, I'd like to acknowledge my grandmother, who sadly passed away before the completion of my PhD. She would always ask me about the progress of my research, and kept a copy of every piece of work I wrote or published, despite not being able to read English. Yiayia, I know you'd be proud.

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APPENDICES

List of Original Publications

This thesis includes the following four original publications, and the publication of a treatment manual:

Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. (2019b). Potential for children with intellectual disability to engage in cognitive behaviour therapy: The parent perspective. *Journal of Intellectual Disability Research.*

Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. (2019a). Fearless Me!©: A feasibility case series of cognitive behavioral therapy for adolescents with intellectual disability. *Journal of Clinical Psychology*, *75*(6), 919-932.

Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. I. (2018). *Fearless Me! ©: Cognitive behaviour therapy for children with intellectual disability and anxiety*. University of Technology Sydney & University of Adelaide.

Hronis, A., Roberts, L., & Kneebone, I. I. (2018). Assessing the confidence of Australian mental health practitioners in delivering psychological therapy to people with Intellectual Disabilities. *Intellectual and Developmental Disabilities, 56*(3), 202-211.

Hronis, A., Roberts, L., & Kneebone, I. I. (2017). A review of cognitive impairments in children with intellectual disabilities: Implications for cognitive behaviour therapy. *British Journal of Clinical Psychology*, *56*(2), 189-207.

List of Conference Presentations

Oral Presentations

Hronis, A. (2019, November). *Cognitive Behaviour Therapy for Children with Intellectual Disability: The Fearless Me! © Program.* Oral Presentation at the Sydney Postgraduate Psychology Conference, Sydney, Australia.

Hronis, A. (2019, October). Fearless Me! *A Pilot Randomised Controlled Trial of Cognitive Behaviour Therapy for Children with Intellectual Disability and Anxiety.* Symposium at the 40th National Conference of the Australian Association for Cognitive and Behaviour Therapy, Adelaide, Australia.

Hronis, A. (2019, July). *Fearless Me!: A Pilot Randomised Controlled Trial of an Innovative Treatment Program for Children with Intellectual Disability and Anxiety.* Symposium at the 9th World Congress of Behavioural and Cognitive Therapies, Berlin, Germany.

Hronis, A. (2019, July). *Adapting Cognitive Behaviour Therapy for Children with Intellectual Disability: Development of the Fearless Me! Program.* Oral presentation at the 14th International Conference on Child and Adolescents Psychopathology, London, UK.

Hronis, A. (2018, September). *Potential for children with intellectual disability to engage in cognitive behaviour therapy: The parent perspective.* Symposium at the 2018 Australian Psychological Society Congress, Sydney, Australia.

Hronis, A. (2017, December). *Group Cognitive Behavioural Therapy for Adolescents with Intellectual Disability: The Unstoppable Me! Program*. Oral presentation at the Society for Mental Health Research Conference, Canberra, Australia.

Poster Presentations

Hronis, A. (2016, December). *The implications of cognition in children with intellectual disability for cognitive behaviour therapy: A review.* Poster presentation at the Society for Mental Heath Research Conference, Sydney, Australia.

Hronis, A. (2016, November). *Assessing the confidence of Australian mental health practitioners in delivering therapy to people with intellectual disabilities.* Poster presentation at the Australian Clinical Psychology Association Conference, Melbourne, Australia.

Invited Lectures

Hronis, A. (2018, April). *Unstoppable Me!: A Cognitive Behavioural Therapy (CBT) Program for Children with Intellectual Disability (ID).* Seminar at the University of Adelaide, Australia.

List of Contributors

Primary Supervisor	Professor Ian Kneebone Graduate School of Health University of Technology Sydney
Secondary Supervisor	Associate Professor Rachel Roberts School of Psychology The University of Adelaide
Supervisor (2016 - 2017) Researcher (2017 - 2019)	Dr Lynette Roberts Graduate School of Health University of Technology Sydney
Researcher	Dr Alice Shires Graduate School of Health University of Technology Sydney

Abstract

Introduction: Nearly half of children with an intellectual disability (ID) have comorbid mental health disorders. These problems are chronic if left untreated and can significantly impact upon future vocational, education and social opportunities. Despite this, there is a paucity of research into effective treatments for this population. Notably, one of the most supported psychological therapies, Cognitive Behaviour Therapy (CBT), remains largely uninvestigated in children with ID. The aim of this body of research was to develop and evaluate an adapted CBT program for children with mild to moderate ID and anxiety disorders.

Method: The development and evaluation of an adapted CBT program followed guidelines for complex interventions. This involved an initial review of the existing literature, to understand the neuropsychological profile of children with ID and adapt therapy according to deficits. Relevant stakeholders were also involved in the development process: clinicians were surveyed and parents of children with ID asked to provide feedback about their child's ability to engage in CBT. This led to the development of the *Fearless Me!* © cognitive behavioural therapy program, which was then evaluated for feasibility and effectiveness.

Results: The initial review of literature and feedback from relevant stakeholders informed the adaptations to CBT in order to meet the unique learning needs of children with ID. The *Fearless Me!* © program was found to be feasible and acceptable among a non-clinical sample. Within a clinical sample of anxious children, all children benefited from significant reductions in anxiety or the impact and interference anxiety had on their life, as rated by either the child or the caregiver.

Conclusion: The *Fearless Me* © program is a developmentally informed adapted CBT program, designed to fill part of the gap in evidence and resources, and to create an accessible tool for clinicians and clients to use. Preliminary research suggests that adapted CBT and the *Fearless Me!* © program shows promising results and is associated with positive changes in anxiety symptoms among children and adolescents with mild to moderate ID. The positive results of the current research support the future use of CBT and the *Fearless Me!* © program among children and adolescents with ID.

Definition of Key Terms

Anxiety Disorder: According to the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*, anxiety disorders are characterised by excessive fear, anxiety and related behavioural disturbances. Anxiety disorders differ from normative or transient fear and anxiety by being persistent, and causing clinically significant distress or impairment in social, academic, occupational or other important areas of functioning.

Borderline Intellectual Functioning: An individual with “borderline intellectual functioning” has below average cognitive ability (generally an IQ score of 70 to 80-85), however the deficit is not as severe as those with an intellectual disability (IQ score of below 70).

Cognitive Behaviour Therapy: Cognitive Behaviour Therapy is a mental health intervention based upon the combination of the principles from behavioural and cognitive psychology. Cognitive Behaviour Therapy helps an individual to change unhelpful thoughts and behaviours, improving emotional regulation. It is a relatively short term therapy which is widely practised, with extensive research demonstrating its effectiveness with a variety of mental health difficulties.

Developmental Disabilities: This refers to a range of chronic conditions which arise before adulthood. Developmental disabilities can impact language, mobility, learning, intellectual functioning and independent living, and usually last throughout a person’s lifetime. Intellectual disability is one type of developmental disability.

eHealth: eHealth, also known as “electronic health”, refers to health related services or health information which is delivered or enhanced through the internet and related technologies.

Intellectual Disability: An intellectual disability is defined as a neurodevelopmental disorder in the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*. An intellectual disability is diagnosed when an individual has significant cognitive deficits, and significant deficits in functional and adaptive skills. Cognitive deficits are established through clinical evaluation and standardized measures of intelligence, with an IQ score of below 70 (two standard deviations below the mean of 100 in the general population). Deficits in adaptive skills, mean that an individual is unable carry out age-appropriate daily life tasks. The terms “mild”, “moderate”, “severe” and “profound” have been used to describe the severity of the intellectual disability, based upon IQ scoring in conjunction with daily living skills.

Abbreviations

ASD	Autism Spectrum Disorder
CBT	Cognitive Behaviour Therapy
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
ID	Intellectual Disability
MRC	Medical Research Council
QoL	Quality of Life
RCI	Reliable Change Index
RCT	Randomized Controlled Trial
WHO	World Health Organization

Chapter 1

Introduction

Children with ID have high rates of comorbid mental health problems, yet there are few treatment options which exist for this population. The prevalence of mental illness for children with ID is estimated to be as high as 50% (Einfeld, Ellis & Emerson, 2011; Tonge & Einfeld, 2000), and children with ID show elevated rates of both externalizing and internalizing problem behaviours compared to typically developing children (Dekker, Koot, van der Ende, & Verhulst, 2002; Einfeld & Tonge, 1996). Specifically, anxiety has been reported as the most prevalent mood disorder in young people with ID (Emerson, 2003). Furthermore, it is known that when left untreated, such childhood issues can result in elevated risks for the development of psychiatric disorders later in life (Dekker & Koot, 2003; Emerson, 2003). Despite such high rates of mental illness in this population, there is a paucity of literature exploring the usefulness of psychotherapy. CBT is considered the "gold standard" when treating anxiety disorders among typically developing adults and children, however the potential for children with ID to engage in and benefit from CBT has not been evaluated systematically.

The aim of this body of research was to explore the potential usefulness of CBT for children and adolescents with ID. The first aim was to identify the ways in which CBT might be adapted to accommodate deficits in neurocognitive functioning in this population, in order to meet the unique needs of children with mild to moderate ID. Following from this, information was gathered from relevant stakeholders, including clinicians, and parents who have a child with an ID. Specifically, clinicians were surveyed regarding their confidence in working with people with ID, and parents provided their opinions about their child's ability to potentially engage in CBT. Based on the results of these studies, the *Fearless Me!* © program was developed (Hronis, Roberts, Roberts & Kneebone, 2018), a cognitive behavioural, multimodal treatment, adapted specifically for the needs of children and adolescents with ID. The *Fearless Me!* © treatment program was designed to involve face to face therapy sessions, accompanied by an online website to help children learn and practice CBT skills. Two studies evaluated the feasibility and acceptability of the *Fearless Me!* © program.

This chapter provides an introduction to the existing research exploring the mental health needs of children and adolescents with ID, and discusses some of the barriers that people with ID face when trying to access mental health treatments. The ways psychotherapy and CBT have been adapted for adults with ID is also considered. To our knowledge, CBT has not been used and evaluated amongst children with mild to moderate ID. As such, the literature pertaining to the use of CBT among adults with ID, and amongst children with other developmental disabilities is summarised, with the view to inform how CBT may be adapted and implemented amongst children with ID.

Diagnostic Criteria for Intellectual Disabilities

According to the DSM-5 (American Psychiatric Association, APA, 2013), ID is a neurodevelopmental disorder which has onset during the developmental period. It can result from a range of different aetiologies, including genetic syndromes such as Down syndrome, William's syndrome, Fragile X syndrome, and unknown causes. It involves deficits in both intellectual functioning and adaptive functioning in conceptual, social and practical domains. Deficits in adaptive functioning are identified as they result in a failure to meet developmental standards for personal independence and social responsibility (APA, 2013). Deficits in intellectual functions include reduced abilities with reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience (APA, 2013). The overall prevalence of ID is approximately 1% of the population (Maulik, Mascarenhas, Mathers, Dua & Saxena, 2011).

ID is diagnosed using both clinical assessments and standardized intelligence testing, with scores on standardized assessments required to be two standard deviations below the population mean of 100 (i.e. IQ less that 70-75). Severity of the ID is classified with the specifiers “mild”, “moderate”, “severe” or “profound”. Historically, these severity specifiers were applied on the basis of IQ scores (Black & Andreasen, 2014), with mild ID defined by IQ scores ranging from 50-55 to 70, moderate ID defined by IQ scores between 35-40 to 50-55, severe ID between 20-25 and 35-40 and profound ID identified by IQ scored less than 20-25. Those with IQ scores ranging from 71—85 are considered to be within the borderline range of intellectual functioning, which was a fifth subcategory included in the Diagnostic and Statistical Manual Fourth Edition, Text Revision (DSM-IV-TR; APA, 2000). Within the DSM-5, severity is classified on the basis of daily living skills. An individual with a mild ID can live independently with minimum support, an individual with moderate ID can live independently with moderate levels of support, an individual with severe ID requires daily assistance with self-care and safety, and an individual with profound ID requires 24-hour care. Among those diagnosed with ID, approximately 85% fall within the mild range of disability, and 10% fall within the moderate range (Black & Andreasen, 2014). IQ scores in conjunction with an assessment of adaptive functioning are used to confirm a diagnosis of ID.

The current body of research focuses primarily upon working with children with ID in the mild and moderate ranges, as well as children with borderline intellectual functioning. Clients with mild and moderate ID have been shown to have the skills considered necessary for the cognitive components of CBT, and these abilities appear to decline as verbal abilities, specifically receptive vocabulary decreases (Taylor, Lindsay & Willner, 2008).

Mental Health Disorders in Children with Intellectual Disabilities

People with ID have been identified as being at greater risk of psychopathology, due to biological, psychological and social factors. While previously it was incorrectly believed that people with ID could not experience mental illness and were unaffected adversely by stressful events due to limited cognitive capacities, it is now known that much the opposite is true (Matson, Belva, Hattier & Matson, 2012; Potter, 1965). In fact, individuals with ID are at greater risk for experiencing stress and stressful life events compared to typically developing individuals, and these stressors are associated with psychological issues (Hatton & Emerson, 2004; Hulbert-Williams & Hastings, 2008). The number of significant life events experienced by an adult with ID in the previous six months has been found to predict depression (McGillivray & McCabe, 2007). Hastings, Hatton, Taylor and Maddison (2004) found that 46.3% of individuals experienced one or more significant life event in the past 12 months, with a relationship between exposure to stressful life events, and psychiatric disorders for adults with ID. Similarly, children with ID have been found to experience a greater number and range of adverse life events compared to children without ID, with the relationship between life events and emotional disorders being robust (Hatton & Emerson, 2004).

The level of psychopathology in people with ID is high (Einfeld et al., 2006; Maughan, Collishaw & Pickles, 1999; Richards et al., 2001; Smiley, 2005; Tsiouris, Kim, Brown & Cohen, 2011; Westerhof, Beernink & Sools, 2016). Population based studies of mental health problems report large variations in prevalence, depending on methodologies used, the diagnostic assessments used, and the inclusion or exclusion of challenging behaviours as a mental health problem (Taylor & Knapp, 2013). When behavioural problems are excluded, the overall rates of mental health problems among people with ID appear to be similar to those found in the general population (Taylor & Knapp, 2013). While prevalence rates may be similar, the profiles for types of disorders do differ to those found in the general population, with rates of psychosis and affective disorders higher amongst people with ID, and personality disorders, alcohol/substance use and sleep disorders are lower amongst people with ID compared to the general population (Singleton et al., 2001; Cooper et al., 2007).

There are certain factors which make it more likely that adults and children with ID may develop mental health disorder, including have fewer resources available to help manger life stressors (Jahoda, Dagnan & Jarvie, 2006; Kerr, Lunsky & Benson, 2001). Reduced cognitive abilities in the areas of memory, problem-solving and planning, can negatively impact their capability to use psychological resources to cope with stressful events (Taylor, Lindsay & Willner, 2008; van den Hout, Arntz & Mercklebach, 2000). In addition to psychosocial factors, specific genetic conditions and abnormalities in brain development can increase the risk of developing mental health disorders (Kastner, Walsh & Fraser, 2001; Tonge & Einfeld, 2003).

Specifically, among children, population based studies have suggested that children with ID are at higher risk of developing psychiatric disorders compared to typically developing children (Dykens, 2000). A review of studies indicated that rates of comorbidity for children and adolescents with ID are between 30% to 50%, with the relative risk of mental health disorders ranging from 2.8 to 4.5 (Einfeld, Ellis & Emerson, 2011). More specifically, it has been found that conduct disorders, anxiety disorders and attention deficit hyperactivity disorder are more prevalent among children with an ID compared to those without (Emerson, 2003). Within the sample described by Emerson (2003), 9.5% of children with an ID had an emotional disorder, while 4.1% of typically developing children had an emotional disorder. Of these, the most common emotional disorder was an anxiety disorder, which 8.7% of children with ID had, compared to 3.6% of typically developing children. It is known that anxiety disorders are likely to persist if left untreated and are often unremitting into adulthood (Costello, Mustillo, Erkanli, Keeler & Anglod, 2003; Hirshfeld, Micco, Simoes & Henin, 2008; Newman, et al., 1996), thus highlighting the importance of early intervention.

Barriers to Accessing Mental Health Treatments for Children with Intellectual Disabilities

Although the need for mental health treatments to be delivered to children with ID has been identified, there are a multitude of factors which serve as barriers to people within this population accessing effective treatments. Not only are people with ID at greater risk for developing mental health problems, they additionally have very low rates of accessing mental health care services (McCarthy & Boyd, 2002; Krahn, Hammond & Turner, 2006; Michael & Richardson, 2008). In Australia, the setting for the current research, less than 10% of young people with ID and a mental illness accessed treatment over a 14-year period (Einfeld et al., 2006), in contrast to 35% of individuals in the general population who accessed treatments for mental health disorders (Slade, Johnston, Oakley Browne, Andrews & Whiteford, 2009).

There are a number of factors which may prevent people with ID accessing mental health services, such as poverty and low socio-economic status (Emerson, 2007), stigma and exclusion from services (Costello, Bouras & Davis, 2007), and the limited availability of services to assist people with ID and mental disorders (Chaplin, 2004; Wallace & Beange, 2008). Many people with ID have mental health problems that are not detected and subsequently remain untreated (Taylor, Lindsay & Willner, 2008). The presence of ID can also complicate the diagnosis of a mental illness leading to “diagnostic overshadowing”, where symptoms of comorbid mental health problems are often not recognised as separate and distinct from the ID during the assessment phase (Reiss, Levitan & Szyszko, 1982), or may be misdiagnosed as challenging behaviour within the context of the ID (Azam, Sinai & Hassiotis, 2009; Hatton & Taylor, 2005). Deficits in communication may also result in the inability of the individual to self-report symptoms and self-refer for treatment (Scott & Havercamp, 2014; Rojahn & Tasse, 1996), and assessment measures available to detect mental health problems in people with ID are not well developed (Deb, Thomas & Bright, 2001). Finally, these issues are further complicated by the fact that services of people with ID and for those with mental health problems are often separate, and have gaps in provisions for those with ID who also have mental health problems (Hatton & Taylor, 2005). Children and adolescents with ID may also lack the autonomy to engage with therapy and complete homework tasks compared to children without ID, if they are reliant on parental support. There may also be particular anxieties about being in public places which might not be cognitive distortions but relate to facing discrimination or victimisation due to their disability.

Another factor which has been identified as a key barrier to people with ID accessing and engaging in therapy, is the level of confidence practitioners feel about working with people with ID (Dagnan, Masson, Cavagin, Thwaites & Hatton, 2015; Rose, O’Brien & Rose, 2007). Australian clinicians revealed that they did not feel confident in treating clients with ID (Lennox & Chaplin, 1994), and thought that they did not have the skills to work with people with disabilities (Bouras & Holt, 2004; Rose et al., 2007; Torr et al., 2008). It is known from other areas of psychology research, that clinician confidence can have a significant impact upon the engagement of clients in therapy, and the mental health outcomes of patients (Bennun, Hahlweg, Schindler & Langlotz, 1986; Keijsers, Schaap & Hoogduin, 2000; Kingdon, Tyrer, Seivewright, Ferguson & Murphy, 1996; Ryan & Gizynski, 1971; Shaw et al., 1999). For example, Heinonen, Lindfors, Laaksonen and Knekt (2012) found that lower therapist confidence was predictive of poorer client outcomes for typically developing clients with anxiety disorders. Furthermore, retrospective evaluations have indicated that patients who improve most on mental health measures perceive their therapist to be more confident, competent and experienced (Bennum et al., 1986; Keijsers et al., 2000; Ryan & Gizynski, 1971).

In light of clinician confidence being a barrier to people with ID accessing treatments, Dagnan and colleagues (2015) developed the Therapy Confidence Scale – Intellectual Disability (TCS-ID). The measure provides a rating of confidence in relation to various key therapeutic processes. It was found that practitioners were most confident with generic counseling skills such as listening carefully to concerns presented by clients, being empathetic, and forming a therapeutic relationship when working with people with ID. However, practitioners were lowest in their self-reported ratings of the clinical components of therapy, including using assessments, explaining the results of assessments, and identifying and implementing effective therapeutic approaches with the client (Dagnan et al., 2015).

There is a positive relationship between knowledge and confidence, such that additional knowledge, often provided through training, can result in an increase in clinician confidence in working with specific populations, particular treatments and within particular contexts (see Bennett-Levy & Beedie, 2007; Beidas & Kendall, 2010 for a review). A review of the knowledge, training and attitudes towards dual diagnoses among people with ID was conducted by Werner and Stawski (2012), which indicated that specialist training resulted in enhanced knowledge, skills and confidence among varying mental health professionals. Thus addressing the mental health needs of children and adolescents with ID requires a two-fold approach;

developing and evaluating appropriately adapted interventions, while also providing clinicians with the tools to feel more confident, and competent in delivering treatments to this population.

Application of Cognitive Behavioural Therapy to Adults with Intellectual Disabilities

CBT is a well-established treatment approach supported by a large evidence base, and is considered the "gold standard" intervention for many psychopathologies, including anxiety, in childhood, adolescence and adulthood for typically developing populations (e.g. Cartwright-Hatton, Roberts, Chitsabesan, Fothergill & Harrington, 2004; Compton et al., 2004; Hofmann & Smits, 2008; Otte, 2011). A range of techniques and elements have been identified as core components of CBT (Grave & Blissett, 2004), including psychoeducation, goal setting, exposure with contingent reinforcement, coping and relaxation skills, identifying and linking thoughts with emotions, cognitive restructuring, homework, problem solving skills, mood monitoring, emotion regulation strategies and problem solving skills (e.g. Garber, Frankel & Herrington, 2016; Hirshfeld-Becker, Micco, Mazursky, Bruett & Henin, 2011; Wright, 2006). Behavioural techniques can include activity scheduling, pleasant event scheduling, graded exposure, exposure and response prevention and relaxation strategies, while the cognitive techniques available include socratic questioning, guided discovery, examining evidence, identifying cognitive errors, generating alternatives and thought change records (Wright, 2006).

Initially it was argued that people with ID are unable to engage in cognitive-based psychological therapy due to cognitive deficits (Adams & Boyd, 2010; Butz, Bowling & Bliss, 2000; Sturmey, Lott, Laud & Matson, 2005) with mental health treatments primarily involving medication and behavioural interventions (Vereenooghe & Langdon, 2013). However, research has found that adults with mild to moderate ID can correctly identify emotions in themselves and others, (Joyce, Globe & Moody, 2006; Oathamshaw & Haddock, 2006; Sams, Collins & Reynolds, 2006), can link emotions to situations (Dagnan, Chadwick & Proudlove, 2000; Joyce et al., 2006; Oathamshaw & Haddock, 2006; Reed & Clements, 1989), and can distinguish between thoughts, feelings and behaviours (Sams et al., 2006). Furthermore, Vereenooghe, Gega, Reynolds, & Langdon (2016) identified that adults with mild to moderate ID can improve in their ability to discriminate thoughts, feelings and behaviours with a single session computerized training task of CBT-related scenarios. As the ability to identify and distinguish between thoughts, emotions and behaviours is at the foundation of CBT, this research indicates that adults with ID may have the capacity to engage in the fundamental and preliminary components of CBT.

CBT is recommended for the treatment of anxiety, depression and emotional disorders in typically developing populations (APA, 2004, 2010; National Institute for Health and Clinical Excellence, NICE, 2009, 2011, 2016). The research showing that adults with ID can engage with and benefit from CBT is limited yet growing. Given that adults with mild to moderate ID have the capacity to engage in the foundational components of CBT, the need for adapting CBT for adults with ID has been addressed to tailor treatment to the unique needs of this population (Willner & Lindsay, 2016; Jahoda, Kroese & Pert, 2017). Ways to adapt CBT for the learning needs of adults with ID has been considered, with recommendations made to involve carers in the delivery of the intervention, and simplify the delivery of the therapy by using simpler language and progressing at a slower pace (Willner, 2009). Willner (2009) also proposes that the model of therapy is simplified, and the therapist adopt a more directive approach to treatment.

CBT has been evaluated as an intervention for anxiety, depression and anger issues among people with ID (Osugo & Cooper, 2016; Vereenooghe & Langdon, 2013). A meta-analysis conducted by Vereenooghe and Langdon (2013) found CBT to be at least moderately effective in the treatment of anger and depression, with greater improvements through individual therapy rather than group programs. Preliminary evidence for effective treatment of anxiety was found. In a recent study, CBT was found to significantly reduce anxiety in adults with mild to moderate ID as measured by self, informant and clinician ratings, with those with mild ID showing competence on a range a cognitive challenging skills post-treatment (Roberts & Kwan, 2018). McGillivray and Kershaw (2015) compared the effectiveness of CBT, cognitive strategies only, and behavioural strategies only in treating depressive symptoms and the negative automatic thoughts of adults with mild ID, and found long-term superiority of CBT, with behavioural strategies producing less enduring effects. Additional support for the use of cognitive based therapy among adults with ID is found in case study literature, working with people with ID and comorbid obsessive-compulsive disorder, (Klein-Tasman & Albano, 2007), post-traumatic stress disorder (Fernando & Medlicott, 2009; Lemmon & Mizes, 2002) and anorexia nervosa (Cottrell & Crisp, 1984).

Application of Cognitive Behavioural Therapy to Children with Developmental Disabilities

While research has begun to evaluate the use of CBT for adults with ID, the potential efficacy of CBT for children and adolescents with ID is significantly under researched. To our knowledge, the use of CBT for children with ID and comorbid mental health problems has not yet been explored or evaluated, thus highlighting a crucial gap in the current body of literature. To date, the existing treatments for children with mental health problems and mild ID or borderline intellectual functioning have been largely parent-training programs and social competency training interventions (Kok, van der Waa, Klip & Staal, 2016). The parenting programs focus primarily on parent-child interactions, increasing the parents' understanding of the child's behaviours, and application of behavioural techniques to reduce problem behaviours (e.g. Bagner & Eyberg, 2007; Hand, Raghallaigh, Cuppage, Coyle, & Sharry, 2012; McIntyre, 2008; Roberts, Mazzucchelli, Studman & Sanders, 2006). One such program is the Stepping Stones Triple P parenting program, based on positive parenting strategies (Sanders, Mazzucchelli & Studman, 2004). It is specifically designed for parents of children with developmental disabilities, with the view to manage behaviour problems and developmental issues common in children with disabilities. Overall, such interventions show a tendency towards reduced problem behaviours, however the focus is on externalizing issues rather than internalizing problems such as anxiety and depression. Considering CBT has been useful for adults with ID and mood disorders, the potential of CBT for children with ID experiencing comorbid mood disorders warrants exploration.

To our knowledge, research has not yet been conducted to evaluate the effectiveness of CBT for children with ID and comorbid mental health disorders, specifically internalizing emotional disorders. There has however, been a substantial body of research which has explored the use of CBT for children was other developmental disabilities, such as Autism Spectrum Disorder (ASD). As children with ASD have unique social and emotional needs, CBT requires adaptations to these needs in order to be as effective as possible. Randomized controlled trials (RCTs) of CBT adapted specifically for children with high functioning ASD have demonstrated large reductions in anxiety symptoms (Storch et al., 2013; Wood et al., 2009). A systematic review and meta-analysis of CBT for children and adolescents with high functioning ASD indicated that CBT demonstrates robust efficacy in reducing anxiety symptoms for this population (Ung, Selles, Small & Storch, 2015).

As children with high functioning ASD present with inherent developmental features which may compromise the efficacy of traditional CBT, researchers and clinicians have identified the ways in which CBT may need to be adapted to meet the needs of children within this population. Beebe and Risi (2003) suggested adjustment of the developmental level to reflect the child's ability, as well as involving parents and carers through therapy, and extending treatment by number of sessions and overall session duration. The use of role-plays and visuals have been identified as important during treatment, along with the incorporation of in vivo practice to aide the generalization of skills (Anderson & Morris, 2006; Moree & Davis, 2010). A review of the use of adapted CBT when working with children with high functioning ASD and heightened anxiety, identified four primary modification trends: the use of exposure hierarchies adapted specifically for developmental disorders; the use of concrete, visual materials or aides; the incorporation of child specific interests; and the incorporation of parents in therapy (Moree & Davis, 2010).

From the identification of the necessary adaptations to therapy, have come programs specifically designed to meet the needs of children with ASD. For example, the "Cool Kids" Program (Lyneham, Abbot, Wignall & Rapee, 2003), which was originally developed for anxious children without a developmental disability, was adapted for children with high functioning ASD and found to be effective in reducing anxiety in this population (Chalfant, Rapee & Carroll, 2007). Adaptations were made to the program to account for the learning style of children with high functioning ASD, including extending the program over a longer period of time, the additional use of visual aides and structured worksheets, the simplification of information during cognitive activities and the use of concrete exercises to place less emphasis on children's communication skills. Overall the authors note that the Cool Kids program was implemented with flexibility to allow for the individual differences of each child.

Additionally, Ratcliffe, Wong, Dossetor and Hayes (2014) developed the "Emotion Based Social Skills Training Program" (EBSST), a manualised social-emotional intervention designed to improve the emotional competence of school-aged children with ASD. The program was trialed with children with ASD (Ratcliffe et al., 2014), and has since also been adapted and used among children with ASD and ID (Ratcliffe, 2011).

Overall, this research is promising as it has shown that CBT and cognitive-based therapies can be adapted to meet the needs of children with developmental disabilities, namely ASD. This can be done by identifying the unique features of the disorder which may impact negatively upon therapy, and determining the appropriate adaptations required to accommodate for these. Given the prevalence of mental health problems among children with ID, it is imperative that researchers begin to explore how CBT can be adapted for the needs of this population.

Current Research

To date, there has been a paucity of research examining mental health treatments for children and adolescents with ID, as rates of comorbid illness remain high and rates of access to treatments are low. There is a clear need for the development and evaluation of effective interventions for this population, which clinicians feel confident in delivering. In an attempt to start to fill this gap in the literature, the current body of research aimed to create and evaluate a CBT program, specifically adapted for the needs of children with ID and anxiety disorders.

The first part of this research set out to understand the ways in which the neurocognitive deficits present for children with ID may impact on therapy (Chapter 3; Hronis, Roberts & Kneebone, 2017). A narrative review was conducted to address three key questions: 1) what are the neuropsychological deficits present for children and adolescents with mild to moderate ID?; 2) what are the implications of such deficits on CBT?; and 3) in what ways can therapy be adapted to meet the unique needs of children with ID? These questions were explored specifically in relation to the neuropsychological domains of attention, learning and memory, language and reading, working memory, and executive functioning. A narrative review was conducted rather than a systematic review, in order to collate adaptations to therapy across a number of neurocognitive domains to inform practice, rather than answer a specific research question.

The next phase of the research aimed to gather feedback from parents who have a child with ID, as to how their child may be able to effectively engage in CBT (Chapter 5; Hronis, Roberts, Roberts & Kneebone, 2019a). Specifically, the research aimed to explore how parents thought the process of CBT could be best adapted to the needs of their children, the role which parents saw themselves playing through this process and any challenges they anticipated. As very little research has explored how children with ID can benefit from CBT, and no studies to our knowledge have previously investigated the parent perspective of the potential of CBT for children with ID, this research was exploratory and no hypotheses were generated as to the outcomes. A mixed method of qualitative and quantitative data collection was adopted to allow for a more in-depth understanding.

Following from this, the researchers aimed to explore the confidence of Australian clinicians in providing therapy to people with ID (Chapter 7; Hronis, Roberts & Kneebone, 2018). Clinicians have been found to have low confidence when treating people with ID (Dagnan et al., 2015), however this has not been specifically explored within an Australian sample. The study aimed to extend upon the research of Dagnan and colleagues (2015) using the Therapy Confidence Scale – Intellectual Disabilities (TCS-ID; Dagnan et al., 2015) to gather self-reports about the confidence of clinicians in relation to various components of therapy, and identify factors that may be associated with increased confidence in working with this population. Clinicians were asked about their confidence working with people with ID in general, not specific to working with children with ID, as there is no current established evidence base specific to using psychotherapy with children with ID.

After reviewing the literature and having gathered feedback from relevant stakeholders, a CBT program called *Fearless Me!* © was designed and developed (Chapter 8; Hronis, Roberts, Roberts & Kneebone, 2018). The *Fearless Me!* © program has been specifically adapted to the neuropsychological deficits and unique needs of children with ID, and aims to reduce anxiety within this population. It is a multi-modal program, combining face-to-face therapy sessions with an online website allowing additional practice of CBT skills. The *Fearless Me!* © program breaks down the elements of CBT, specifically the process of challenging thoughts and cognitions, and attempts to provide children with opportunities to practice these skills in a fun and engaging way. The feasibility and acceptability of the *Fearless Me!* © program was first evaluated in a cohort of 21 female high-school students, who had mild ID, moderate ID, or intellectual functioning within the borderline range (Chapter 9; Hronis, Roberts, Roberts & Kneebone, 2019b). The program was delivered in group format (two groups). A case series approach was adopted when examining the results, as not all children who participated had elevated levels of anxiety. The program was found to be feasible and acceptable, and reductions in anxiety were seen for some of the participants.

To further evaluate the *Fearless Me!* © program, a pilot RCT was planned to evaluate the effectiveness of the program among children with clinical or subclinical levels of anxiety, administered in a one to one format (Chapter 11). This involved children completing ten face-to-face therapy sessions with a parent present, as well as using the online program to practice CBT skills. Children who participated were randomized to either the intervention group or a waitlist control group. Due to difficulties with recruitment and thus a small sample size, a case series analysis was conducted with the results for each individual child examined.

Conclusion

Therapists and clinicians must be prepared to make appropriate adjustments to therapy when working with people with ID, in order to compensate for deficits in cognitive functioning. As such, evidence-based methods of doing so are crucial to appropriately and ethically guide clinical practice. In conducting the research detailed above, it is hoped that CBT can effectively be adapted for children with mild to moderate ID and anxiety, and produce positive changes in mood for this population. If successful, this can consequently broaden the potential therapies which clinicians can use when working with this population, improving their overall access to effective treatments.

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Chapter 2

Guidelines for the Development and Evaluation of Interventions

As discussed in Chapter 1, children with ID have high rates of anxiety. CBT, which is the gold standard therapy for typically developing children experiencing anxiety, has not been tested and evaluated within this population. CBT in its current form may not be appropriate or effective for children with ID, particularly on account of their experiencing a range of neuropsychological deficits such as difficulties with reasoning, problem solving, planning, abstract thinking, judgment and learning from experiences (American Psychiatric Association, 2013). It is therefore necessary to adapt CBT, by considering how these deficits can be accommodated for in therapy. To our knowledge, CBT has not been adapted for the unique learning needs of children with ID and systematically evaluated. Given the demonstrated benefits of CBT in other populations such as adults with ID, it was therefore the aim of this research to design, develop and evaluate an adapted CBT intervention, specifically for children with ID. The framework for developing complex interventions proposed by the Medical Research Council (Craig et al., 2008), was used to inform the process of developing and evaluating this intervention. In addition, guidelines for developing and evaluating eHealth (also know as “electronic health”) and online interventions were also used, specifically the roadmap proposed by the Center for eHealth Research and Disease Management (CeHRes; van Gemert-Pijnen et al., 2011) on account of our use of contemporary practice in CBT that takes advantage of this media. Both these frameworks and the ways in which they informed the current body of research are explained below.

Medical Research Council Framework for Developing and Evaluating Complex Interventions

The process of developing and evaluating an intervention can be complex and multifaceted. Guidelines such as those by the MRC (Craig et al., 2008) have been developed to guide researchers through the various stages. First proposed in 2000 and revised in 2008, the MRC framework identifies a number of key components in the process of development through to implementation (see Figure 1). These best practice guidelines emphasise the importance of developing interventions systematically, using the best available evidence and theoretical foundations to inform development. This is followed by a phased approach to evaluation, starting with pilot studies before moving to definitive evaluations (Craig et al., 2008). It is noted in the guidelines, that these phases may not necessarily follow a linear or cyclical sequence. The guidelines further advise that the reporting of results and progress is not an isolated component, but one which should be included in each phase of the development and evaluation process outlined in Figure 1. These results should be disseminated as widely as possible, with further research to assist and monitor the process of implementation (Craig et al., 2008).

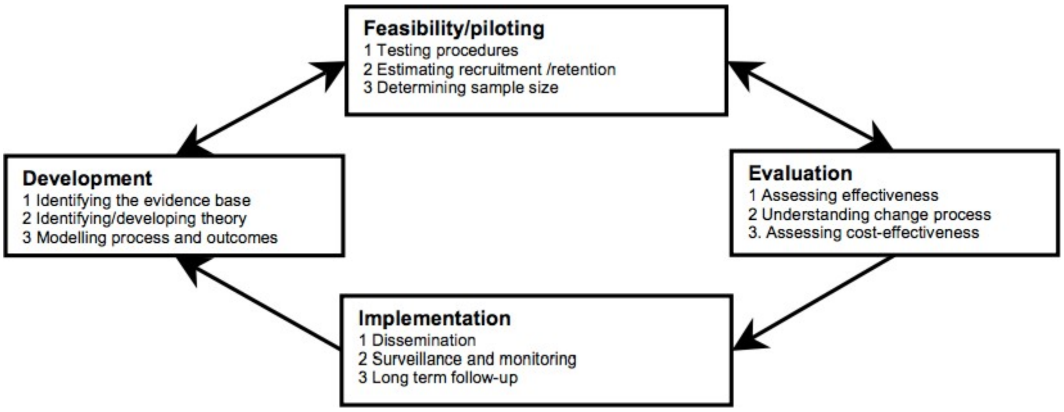

Figure 1. Elements of the development and evaluation process within the Medical Research Council Framework for Developing and Evaluating Complex Interventions. From “Developing

and evaluating complex interventions: the new Medical Research Council guidance”, by Craig et al., 2008, *BMJ,* 337, a1655.

Center for eHealth Research and Disease Management Roadmap for Developing Interventions

eHealth and online interventions are rapidly growing, and guidelines to inform and guide researchers in the development and evaluation of such interventions is crucial. eHealth refers to health services or information which are delivered or enhanced though the internet and related technologies (Stuti, Adam, Herman & Bernard, 2010). The Center for eHealth Research and Disease Management (CeHRes) has created a roadmap offering a holistic approach to eHealth developments, uptake and impact (van Gemert-Pijnen et al., 2011). The roadmap serves as a practical guide for developers, researchers and policy makers, to help plan, coordinate and execute the development process of technologies within health, as well as being a tool for decision making about the use of eHealth technologies (van Gemert-Pijnen et al., 2011). This is an important framework to consider, as it has as explicit focus on the fit between the use of technologies and the content being delivered, which not all frameworks include (Kelders, Pots, Oskam, Bohlmeijer & van Gemert-Pijnen, 2013). The six working principles within the CeHRes framework are depicted in Figure 2 below.

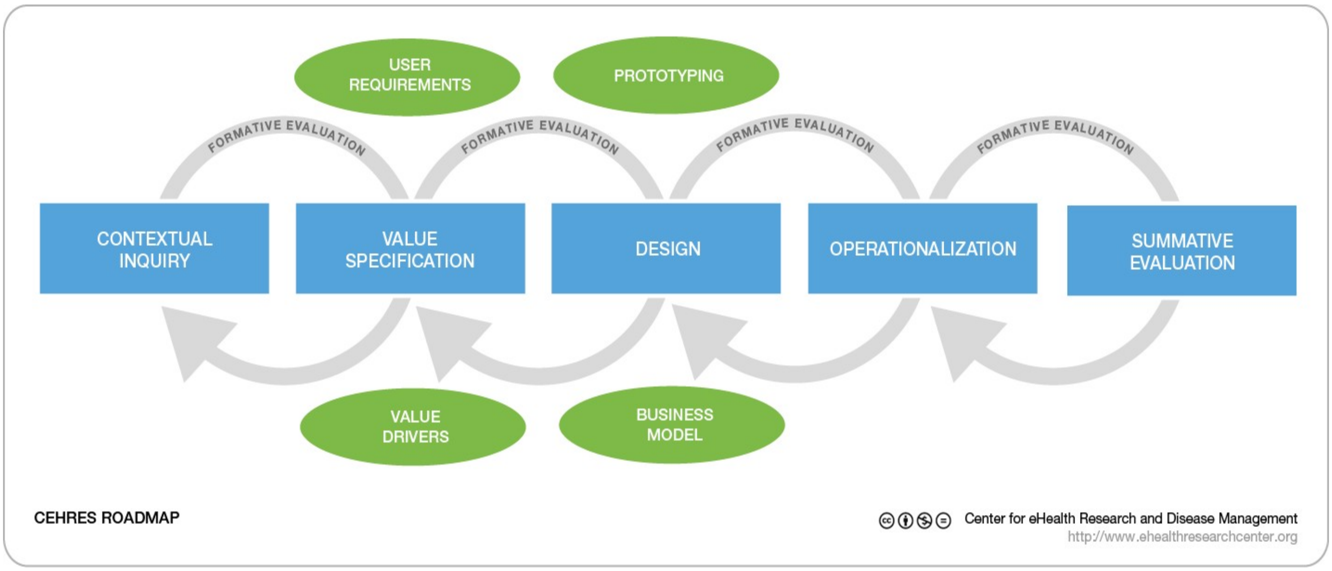

Figure 2. CeHRes Roadmap for the development of eHealth technologies. From "A holistic framework to improve the uptake and impact of eHealth technologies", by van Gemert-Pijen et al., 2001, *Journal of Medical Internet Research, 13*(4), e111.

Firstly, the CeHRes roadmap emphasizes the requirement for eHealth technologies to be designed according to the needs of its users, and encourages the involvement of stakeholders in the development process. Stakeholder involvement should span the full developmental process, beginning from the initial contextual inquiry and ending with the evaluation. Secondly, the CeHRes roadmap highlights the importance of continuous evaluation cycles, with development being an iterative, flexible and dynamic process. The third principle is that of development being intertwined with implementation. The roadmap emphasizes the need for implementation to be taken into account from the beginning, with potential implementation issues (e.g. limited resources, time constraints, financial restrictions, inadequate skills etc.) identified and accounted for in later stages. The fourth principle in the roadmap, is that of considering the changes which eHealth technologies produce within health care processes, and the catalyst effect which is inherent to eHealth technology developments. The roadmap's fifth principle is that eHealth technologies should involve persuasive design techniques. This is to ensure that technologies are matched with the needs of the user, and the utilization of technology capacities to enhance behaviour change. The sixth and final principle of the CeHRes roadmap, is that eHealth technology developments require advanced methods to assess the overall impact on health care, considering benefits and drawbacks relating to ethics, risks, performance, finances and adherence. The authors of the framework acknowledge that clinical trials and RCTs are often used to evaluate the impact of eHealth technologies, but suggest mixed method designs (i.e. both qualitative and quantitative designs) may better measure the impact of eHealth technologies.

The process of development, evaluation and implementation proposed by the CeHRes roadmap, holds many similarities to other guidelines for digital and eHealth intervention development. It is widely recommended that a user-centered approach be included in the intervention development process (Esser & Goossens, 2009; Hamid & Sarmad, 2008; Kaufman, Roberts, Merrill, Lai & Bakken, 2006). Similarly, the use of stakeholders is widely recommended to allow intervention developers to build a deep understanding of the psychosocial context of potential users (Catwell & Sheikh, 2009; Yardley, Morrison, Bradbury & Muller, 2015; Yusof, Kuljis, Papazafeiropoulou & Stergioulas, 2008). Furthermore, continued evaluation throughout the development process, using multiple methodologies has also been identified as integral (Catwell & Sheikh, 2009; Yardley et al., 2015; van der Meijden, Tange, Troost & Hasman, 2003).

Application of the Recommended Guidelines to the Current Research

The planned research to adapt and evaluate a CBT program for children with ID, and the subsequent development of the *Fearless Me!* © program (Hronis, Roberts, Roberts & Kneebone, 2018), followed both the MRC guidelines for complex intervention (Craig et al.,

2008) and the CeHRes roadmap for eHealth interventions (van Gemert-Pijnen et al., 2011). As the MRC guidelines emphasise that interventions be grounded in theory, using the best available evidence, the initial phase of the research involved identifying an existing evidence base, albeit limited. This involved conducting a review of literature to understand the neuropsychological deficits that children with ID experience and the impact of these upon therapy processes, to ensure that subsequent research was theoretically grounded (Chapter 3; Hronis, Roberts & Kneebone, 2017).

Both the MRC guidelines and CeHRes roadmap encourage that when the existing literature is limited in the initial development phase, interviews with stakeholders should be conducted to gather further information (Craig et al., 2008; van Gemert-Pijnen et al., 2011). The current body of research involved stakeholder feedback both at the start of the development process, and then throughout the evaluations of the program. Parents of children with intellectual disabilities were initially asked for feedback as to their child's capacity to engage with a CBT program (Chapter 5; Hronis, Roberts, Roberts & Kneebone, 2019b) and clinicians were surveyed to understand attitudes to working with people with ID (Chapter 7; Hronis, Roberts & Kneebone, 2018). In addition, feedback was gathered from the children who participated in a feasibility evaluation of the *Fearless Me!* © program delivered as a group (Chapter 9; Hronis, Roberts, Roberts & Kneebone, 2019a). This ensures a user-centred approach in designing and evaluating the *Fearless Me!* © program, to ensure the treatment and its delivery is matched with the needs of the users.

Both guidelines recommend that before undertaking substantial evaluations, the treatment should first be developed to a point where it can be piloted. This suggestion was followed within the current body of research, as the feasibility of the *Fearless Me!* © program was first evaluated among two groups of adolescents with mild to moderate intellectual disabilities (Chapter 9; Hronis, Roberts, Roberts & Kneebone, 2019a). The aim of this study was to explore the ability of children to engage with the CBT concepts and the related technology, rather than explore the clinical impact upon anxiety, and thus not all of the participants had elevated levels of anxiety when they began the program. Following this feasibility trial, *Fearless Me!* © was evaluated amongst children with subclinical and clinical levels of anxiety in a one-to-one setting (Chapter 11). This was done to ensure the program was able to produce significant reductions in anxiety before investing resources into a large scale trial.

Stage 1 of the Development Process

The next chapter (Chapter 3) describes the process of reviewing the existing literature, in order to understand the neuropsychological deficits that children with mild to moderate ID experience. This was deemed an important first step in the development of the intervention, in order to gain a comprehensive understanding of these deficits and how they may impact upon delivering CBT. It is also consistent with MRC guidelines and the CeHRes roadmap which recommend initial steps using best available existing evidence and theoretical foundations to inform intervention development. The review paper allows for recommendations to be made about how CBT can be adapted to accommodate for the unique needs of children with ID.

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Chapter 3

A Review of Cognitive Impairments in Children with Intellectual Disabilities: Implications for Cognitive Behaviour Therapy

This chapter was previously published:

Hronis, A., Roberts, L., & Kneebone, I. I. (2017). A review of cognitive impairments in chidlren with intellectual disabilities: Implications for cognitive behaviour therapy. *British Journal of Clinical Psychology*, *56*(2), 189-207.

Statement of Authorship

Title of Paper	A review of cognitive impairments in children with intellectual disabilities: Implications for cognitive behaviour therapy.	
Publication Status	☒ Published	☐ Accepted for publication
	☐ Submitted for publication	☐ Unpublished and unsubmitted work written in manuscript style
Publication Details	Hronis, A., Roberts, L., & Kneebone, I. I. (2017). A review of cognitive impairments in chidlren with intellectual disabilities: Implications for cognitive behaviour therapy. *British Journal of Clinical Psychology*, *56*(2), 189-207.	

Principal Author

Name of Principal Author (Candidate)	Anastasia Hronis		
Contribution to the Paper	Responsible for the development and design of the research project, conducting the literature review, collating the results, data analysis and writing of the paper in collaboration with my supervisors. Served as the corresponding author and was responsible for the submission, revisions and responses to journal reviewers.		
Overall percentage (%)	80%		
Signature	Production Note: Signature removed prior to publication.	Date	21.10.2019

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Dr Lynette Roberts		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (10%)		
Signature	Production Note: Signature removed prior to publication.	Date	10.12.2019

Name of Co-Author	Prof Ian Kneebone		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (10%)		
Signature	Production Note: Signature removed prior to publication.	Date	09.12.2019

British Journal of Clinical Psychology (2017), 56, 189–207
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A review of cognitive impairments in children with intellectual disabilities: Implications for cognitive behaviour therapy

Anastasia Hronis*, Lynette Roberts and Ian I. Kneebone
Discipline of Clinical Psychology, Graduate School of Health, University of Technology Sydney, New South Wales, Australia

Objective. Nearly half of children with intellectual disability (ID) have comorbid affective disorders. These problems are chronic if left untreated and can significantly impact upon future vocational, educational, and social opportunities. Despite this, there is a paucity of research into effective treatments for this population. Notably, one of the most supported of psychological therapies, cognitive behaviour therapy (CBT), remains largely uninvestigated in children with ID. The current review considers the neuropsychological profile of children and adolescents with mild to moderate ID, with a view to informing how CBT might best be adapted for children and adolescents with ID.

Method. Narrative review of literature considering the neuropsychological profiles of children and adolescents with ID, with specific focus upon attention, memory, learning, executive functioning, and communication. Studies were identified through SCOPUS, PsycINFO, and PubMed databases, using combinations of the key words 'intellectual disability', 'learning disability', 'neuropsychology', 'attention', 'learning', 'memory', 'executive function', 'language', and 'reading'.

Results. Children with ID have significant deficits in attention, learning, memory, executive functions, and language. These deficits are likely to have a negative impact upon engagement in CBT. Suggestions for adapting therapy to accommodate these wide ranging deficits are proposed.

Conclusions. There are multiple cognitive factors which need to be considered when modifying CBT for children who have ID. Furthermore, research is required to test whether CBT so modified is effective in this population.

Practitioner points

Clinical implications

- Effective ways of providing cognitive behavioural therapy (CBT) to children with intellectual disability (ID) is unclear. This study provides a framework of potential adaptations for clinical practice
- As rates of mental illness for children with intellectual disability are high, and rates of treatment provision low, it is hoped that the recommendations provided in this study will encourage more mental health practitioners to provide CBT to children with ID.

**Correspondence should be addressed to Anastasia Hronis, Discipline of Clinical Psychology, Graduate School of Health, University of Technology Sydney, 15 Broadway, Ultimo, NSW 2007, Australia (email: anastasia.hronis-1@uts.edu.au).*

DOI:10.1111/bjc.12133

Limitations

- These recommendations are based only upon neuropsychological literature. Trialling the effectiveness of an adapted form of CBT for children and adolescents with ID is required.
- There are varying causes of intellectual disability, with differences in cognitive profiles. The utility of the recommendations made here may vary according to specific aetiologies.

Hronis, A., Roberts, L., & Kneebone, I. I. (2017). A review of cognitive impairments in chidlren with intellectual disabilities: Implications for cognitive behaviour therapy. *British Journal of Clinical Psychology*, 56(2), 189-207.

Chapter 4

Involvement of Parents in the Development of a Cognitive Behavioural Intervention for Children with Intellectual Disabilities

The narrative review in Chapter 3 identified the barriers to CBT that children with ID may experience due to neuropsychological deficits, and adaptations to therapy which can accommodate for their unique learning needs (Hronis, Roberts & Kneebone, 2017). Through the review, impaired cognitive functions such as attention, memory, executive functioning and language and communication deficits were identified to have potential negative impacts upon therapy, and thus adaptations to treatment were suggested to accommodate for these deficits. This review was an important first step in understanding the barriers and learning needs of children with ID when accessing psychological treatment, and followed MRC and CeHReS guidelines on grounding the development of interventions in theory (Craig et al., 2008). Following the guidelines on intervention development, the next phase in adapting a CBT program for children with ID was to gather feedback from relevant stakeholders.

Parents and carers often play a crucial role in a child's psychological development and treatment, and therefore are important stakeholders to consider when developing interventions for children. While the existing literature provides information as to the neuropsychological deficits present from neurocognitive testing, it is important to gather feedback from parents and carers, who are able to comment and provide insight from a practical, "real-life" perspective. A consideration of patients' preferences, actions, clinical state and circumstances allows for interventions to be developed which best match the needs of the user (Cook, Schwarzt & Kaslow, 2017; Haynes, Devereaux & Guyatt, 2002). The recent emphasis on family-centred practice for interventions for children, recognises that parent-therapist collaboration in planning and evaluating interventions is key, and operates based on the principle that parents know their child best (Hanna & Rodgers, 2002; Keen, 2007; Rosenbaum, King, Law, Kind & Evans, 1998).

Underlying the collaboration between parents and therapists is the belief that shared-decision making in program planning and service delivery, results in outcomes in therapy which are more meaningful and relevant to the child and family (Hanna & Rodgers, 2002; Wallen & Doyle, 1996). The four principles driving the implementation of family-centred services are 1) the understanding that the family, not the professional, is the constant in the child's life, 2) the family is in the best position to determine the needs of of the child, 3) the child is helped when help is also provided to the family, and 4) family collaboration, shared decision making and affirmation of the families' strengths should be emphasized. In line with this framework, a review of family-centred approaches for children with a disability found positive outcomes relating to parent satisfaction with the intervention, parental empowerment and self-efficacy (Dempsey & Keen, 2006; Dunst, 2002; Duwa, Wells, & Lalinde, 1993).

Parents and carers have been identified as integral to the development of interventions, as well as the process of therapy in other disability populations, notably ASD. The reasoning behind involving parents in treatment is that it may enhance the benefit of the therapy for the children, change the parents' attitude towards their child's problem and their own efficacy in managing it, as well as having a positive impact on the behaviour of the parents who may involuntarily elicit anxiety in their children through reinforcement and modeling (Barrett, Rapee, Dadds & Ryan, 1996). When adapting CBT for adolescents with ASD, parent and family involvement has been identified as an essential element of the treatment program (White et al., 2010). A program which was developed for selective eating in youths with ASD incorporated existing literature with the feedback from a stakeholder advisory board, including a range of health and mental health professions, as well as parents for children with ASD and self-advocate adults with ASD (Kuschner et al., 2017). In addition, an RCT of CBT for anxiety among children with ASD found superior treatment outcomes for the group which included parental involvement, when compared to child-only treatment (Sofronoff, Attwood & Hinton, 2005). Furthermore, parents who were involved in the treatment process also felt more competent and empowered in assisting their child. Among typically developing children, CBT is an effective treatment for anxious youths with or without active parental involvement, however treatment gains continue from the end of treatment until the 1-year follow-up for those with active parental involvement, while those without active parental involvement merely maintain treatment gains (Manassis et al., 2014).

Given the importance of involving stakeholders, clients and caregivers in the development, planning and evaluation of complex interventions, and the guidelines which recommend stakeholder involvement, parents of children with ID were deemed to be important in the process of adapting CBT for children with ID. Chapter 5 aimed to gather feedback from parents and carers who had a child with ID, about their perspectives on how CBT could be used as an intervention with their child. A qualitative design was used to explore the subjective experiences of parents and carers. When developing evidence-based interventions, the American Psychological Association Presidential Task Force on Evidence-Based Practice (2006) endorse multiple research designs as contributing to evidence-based practices, with some research designs better suited to address different questions. Such designs include clinical observations, qualitative research, systematic case studies, single-case experimental designs, public health and ethnographic research, process studies, effectiveness research, randomized controlled trials and meta-analyses. Qualitative methodologies are often found to be useful during the initial stages of research in order to provide understanding of an issue when little previous research is available, and to describe the subjective, lived experiences of people (American Psychological Association Presidential Task Force, 2006; Palinkas, 2014). Given that caregiver perspectives on CBT for children with ID have not previously been explored, it was decided that a qualitative evaluation would provide the most relevant and useful information to guide the development of an intervention.

The following study (Chapter 5) aimed to gather perspectives about the use of CBT from parents and carers of children with borderline, mild or moderate ID, aged ten years to seventeen years. Specifically, the study aimed to understand whether parents and carers believe their child would be able to engage in the processes of CBT (i.e. identifying, distinguishing between, and linking thoughts, feelings and behaviours), the challenges they may anticipate, and any adaptations they may suggest in order for therapists to incorporate into sessions. The information gathered from carers in conjunction with the outcomes of the literature review, were used to inform the development of an adapted CBT program.

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Chapter 5

Potential for Children with Intellectual Disability to Engage in Cognitive Behaviour Therapy: The Parent Perspective

This chapter was published as a brief report. The full report is included in Chapter 5, and the published brief report is included in the appendices (see Appendix B):

Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. I. (2019). Potential for children with Intellectual Disability to engage in Cognitive Behaviour Therapy: The parent perspective. *Journal of Intellectual Disability Research.*

Introduction

Children with Intellectual Disability (ID) are reported to have higher rates of mental illness than children without ID, with the prevalence estimated to be up to 50% (Einfeld, Ellis & Emerson, 2011; Tonge & Einfeld, 2000). Due to deficits in intellectual functioning, treatments for children with ID have largely involved behavioural interventions and use of medications (Vereenooghe & Langdon, 2013). Recently however, the potential use of Cognitive Behaviour Therapy (CBT) for people with ID and comorbid psychopathology has been explored, and has been found to be an effective treatment option for adults with ID and depression, anxiety and anger issues (e.g. Hassiotis et al., 2013; Osugo & Cooper, 2016; Roberts & Kwan, 2018; Vereenooghe & Langdon, 2013).

CBT has been established as the gold standard psychological intervention for many childhood psychopathologies for children without ID (e.g. Cartwright-Hatton, Roberts, Chitsabesan, Fothergill & Harrington, 2004; Compton et al., 2004). At the foundation of CBT is the ability to identify and link thoughts, emotions and behaviours, before then challenging cognitions and making behavioural changes. Research has shown that adults with ID are able to correctly identify emotions in themselves and others (Joyce, Globe & Moody, 2006; Oathamshaw & Haddock 2006; Sams, Collins & Reynolds, 2006), link emotions to situations (Dagnan et al., 2000; Joyce et al., 2006; Oathamshaw & Haddock 2006; Reed & Clements 1989), and distinguish between thoughts, feelings and behaviours (Sams et al., 2006). To our knowledge, similar research has not been conducted examining whether children with mild to moderate ID are also able to do so. It has been proposed that CBT should be considered as a treatment option for children with ID, provided the necessary adaptations are made to accommodate neuropsychological deficits in the domains of attention, learning, memory, executive functioning and language (Hronis, Roberts & Kneebone, 2017).

As little research to date has explored how children with ID can benefit from CBT, the aim of the current study was to gather perspectives from parents who have children with ID as to how their child may be able to effectively engage in treatment. Specifically, the research aimed to explore how parents thought the process of CBT could be best adapted to the needs of their children, the role which parents saw themselves playing through this process and any challenges they anticipated. As no studies to our knowledge have previously investigated the parent perspective of the potential of CBT for children with ID, this study was exploratory and no hypotheses were generated as to the outcomes. A mixed method of qualitative and quantitative data collection was adopted to allow for a more in-depth understanding of the perspectives of parents.

Method

Procedure

This research was approved by the university ethics committee (Ethics Approval Number: 2015000482-54). Participants were recruited via online advertising through professional mental health organisations, disability organisations and social media. The study was advertised as seeking parents and carers of children with a mild to moderate ID, aged 10 to 17. Participants were informed that they would be asked to respond to questions online about how their child thinks and feels, in order to inform research developments in the area of mental health and wellbeing for children with ID. All participants consented to participating prior to completing the study. The survey was disseminated online using Qualtrics® (2016) survey software. The survey was distributed online as carers of children with ID have limited time, competing demands and elevated levels of stress (Hastings & Beck 2004), and as such conducting face-to-face individual sessions was thought to be an added unnecessary burden.

Measures

Participants responded to quantitative measures and also provided qualitative responses to open-ended questions. Quantitative measures used were the Emotions Development Questionnaire – Parent Form (EDQ-P; Wong, Heriot & Lopes, 2009), and questions to assess parent's self-reported ability to identify their child's emotional state, and their child's ability to engage in the therapeutic processes of CBT (i.e. identifying and linking thoughts, feelings and behaviours, identifying unhelpful thoughts and cognitive challenging).

Emotions Development Questionnaire – Parent Form (EDQ-P; Wong et al,. 2009)

The EDQ-P was developed to assess emotional competence in children with Autism Spectrum Disorder (ASD). It assesses emotional understanding, theory of mind, emotion regulation and emotion-coaching skills (Ratcliffe, Wong, Dossetor & Hayes, 2014). The EDQ-P is completed by parents of school-aged children with ASD and with or without ID, and has been used in trials providing intervention to children with comorbid ASD and ID (Ratcliffe et al., 2014). It consists of 29 items rated on a five point Likert scale from "Never" = 1 to "Always = 5" with a sixth option of "Don't Know". The ratings on the EDQ-P are added to produce a single total score of emotional competence, with "Don't Know" responses excluded from the final score. The EDQ-P has been found to have excellent internal consistency ($\alpha = .91$; Ratcliffe et al., 2014). In the current sample, internal consistency was also high (α =0.92).

Parent Report of Child's Ability to Engage in CBT

Parents were asked to respond to questions which assessed their child's ability to engage in the basic components of CBT. Participants read information about CBT and then rated whether their child would be able to express their feelings, articulate their thoughts, describe their actions and make the link between thoughts, feelings and behaviours. Responses to these questions were rated on a five point Likert scale (1 = Strongly Disagree, 2 = Disagree, 3 = Undecided, 4 = Agree, 5 = Strongly Agree). Furthermore, parents were prompted to respond “Yes/No” to the question of whether their child would be able to participate in CBT with assistance.

In addition, parents were asked to rate how often they know if their child is feeling happy, sad, angry and anxious/worried. They rated this on a five-point Likert rating scale (1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Almost Always).

Open-Ended Questions

Participants were provided with information about the basic components of CBT and how the therapy works, illustrated by a brief case example. The information highlighted the need to identify and link thoughts, feelings and behaviours as part of CBT. Following this, parents and carers were asked to respond to the following open-ended questions:

1. Given the information provided, what do you think your child with Intellectual Disability may find challenging about the above process?
2. Are you able to suggest any ways in which we might be able to make this process easier for them?
3. Do you have any recommendations for how we may be able to transfer this process from a therapy session into a real world situation?
4. What sort of role could you see yourself playing if your child were to engage in such a therapy?
5. Would you be able to support your child engaging in such a therapy? How would you do that?

6. Are there any factors which would encourage you/discourage you from engaging in such a therapy?
7. Do you have any other comments you think we might find helpful?

Data Analysis

Descriptive statistics for quantitative data were calculated. To analyze the qualitative data, a thematic analysis was conducted using an inductive method of identifying themes (Braun & Clarke, 2006). This method was chosen as this is the first study to our knowledge to examine the perspectives of parents for CBT for children with ID. In this method no specific theoretical framework is used to select salient themes, but rather themes are closely connected to the raw data. All responses to all questions were collated and coded together. The data was read and participant responses were coded. Two independent researchers read all of the individual responses, and noted potential ideas and codes. These were then discussed and codes were collated into themes. Lastly, a selection of extracts was identified to illustrate key themes generated from the analysis procedure.

Results

Participants

Participants who responded to the survey were parents of children residing in Australia between the ages of 10 to 17 who had a mild or moderate ID, or IQ within the borderline range. Thirty parents of children with ID responded to the questionnaire, however nine of these responses were removed as the children did not meet the age and disability inclusion criteria (i.e. children were younger than ten, or had a severe ID). Thus the data reported in this study is based on a final sample of 21 participants.

The average age of the children was 13.33 (*SD* = 2.58), ranging from 10 to 17 years of age. Based upon parent reports, 23% (*n* = 5) of children fell within the mild ID range, 33% (*n* = 7) within the moderate ID range, 10% (*n* = 2) were on the border of mild to moderate ID, 5% (*n* = 1) fell within the borderline range, and 29% (*n* = 6) were unspecified. In addition to ID, parents commonly reported comorbid diagnoses of Autism Spectrum Disorder (67%; *n* = 14), Attention Deficit Hyperactivity Disorder (57%; *n* = 12) and Learning Disorder (33%; *n* = 7) (full list of comorbid diagnoses provided in Table 1). The average age at which the child was diagnosed with ID according to parent reports was 6.1 years of age (*SD* = 4.19).

Table 1. Rate of comorbid diagnoses in the sample.

Diagnosis	***n***	**%**
Autism Spectrum Disorder	14	67
Attention Deficit Hyperactivity Disorder	12	57
Specific Learning Disorder	7	33
Anxiety	6	29
Oppositional Defiant Disorder	3	14
Depression	2	10
Auditory Processing Disorder	1	5
Cerebral Palsy	1	5
Epilepsy	1	5
Robertsonian Translocation	1	5
Sensory Processing Disorder	1	5

Quantitative Data

Parents were asked to rate whether they could tell if their child was happy, sad, angry and anxious/worried. The majority of participants reported that they could often or almost always tell when their child was sad (16 of 21 participants; 76%), angry (16 participants; 76%) and happy (15 participants; 72%), while less than half (10 participants; 48%) could often or almost always tell when their child was anxious or worried.

One third of respondents agreed that their child is able to describe their emotional state, while one third disagreed/strongly disagreed and 24% were undecided (Figure 1). Fourteen percent agreed that their child is able to articulate their thoughts, while 43% disagreed/strongly disagreed and one third were undecided. Twenty-four percent agreed their child can describe their actions, however 33% disagreed/strongly disagreed and one third were undecided. Finally, only 10% of the sample agreed that their child would be able to link thoughts, feelings and behaviours, while 19% were undecided and over half (62%) disagreed/strongly disagreed. Overall however, 16 of the 21 participants (76%) agreed that their child with ID would be able to participate in CBT with assistance.

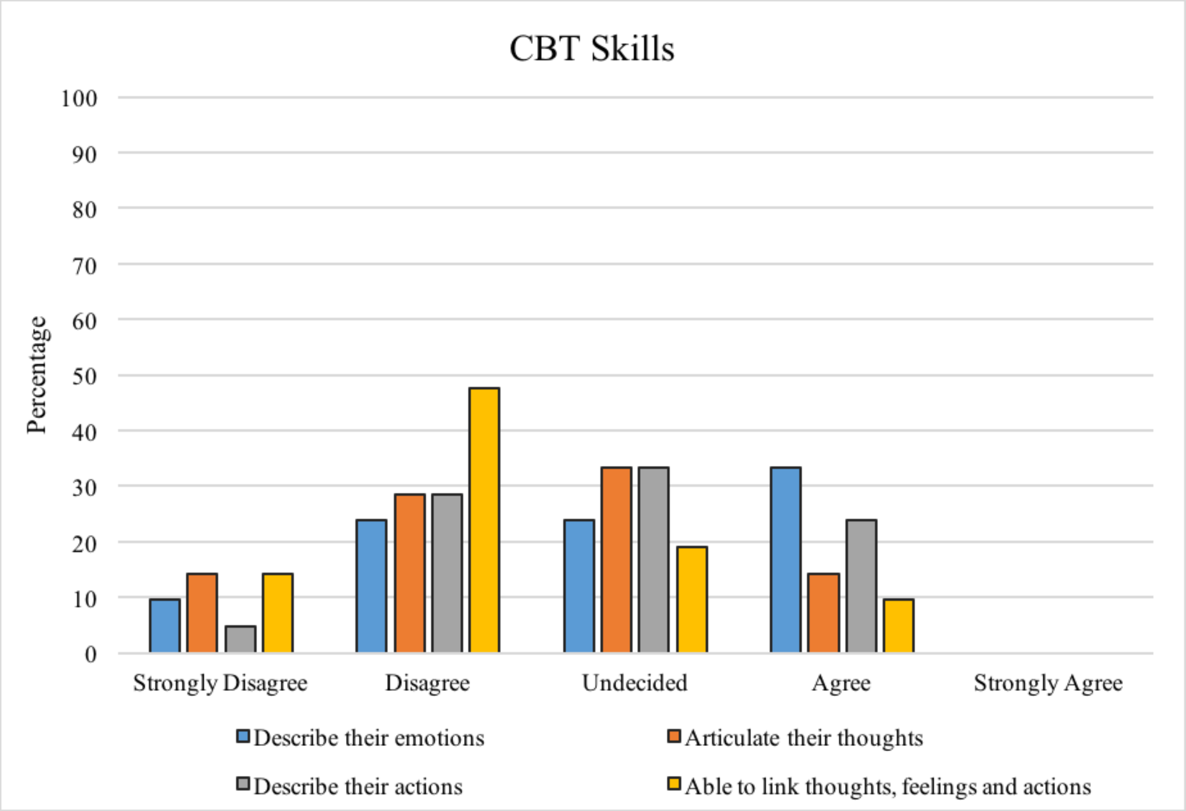

Figure 1. Parents rating of child’s ability for CBT skills.

Seventeen parents completed the EDQ-P, with scores ranging from 80 to 168 out of a total 200 (higher scores indicate greater emotional understanding, theory of mind, emotion regulation and emotion-coaching skills). The average score on the EDQ-P was 108.1 (*SD* = 19.9). This indicates a range of level of functioning with respect to emotional development within the sample.

Qualitative Data

The responses to open-ended questions provided by participants were organised into five themes: 1) emotional attunement, 2) role of the parent/carer, 3) role of the therapist, 4) anticipated obstacles, and 5) suggested adaptations to therapy.

Emotional Attunement

Parents provided responses which reflected the degree to which they consider they were able to identify and recognise varying emotional states for their child, as well as understand factors which may influence their child's emotional state. Parents were asked specifically how they knew their child's emotional state for the emotions "happy", "sad", "angry" and "anxious/worried".

It was found that the following were indicators of a child's emotions for the parents:

- Body language (e.g. trembling hands, stillness etc.);
- Facial expression (e.g. smiling, laughing, frowning, eyes wide open etc.);
- Behaviours (e.g. walking away, refusal to engage in tasks, self-harm, throws objects etc.);

- Verbal expression of emotions (e.g. stating the emotion they are feeling, verbal aggression, screaming, squealing etc.);
- Increased or decreased social interactions (e.g. talkative, hugging, sitting alone, talking less etc.)

Role of the Parent/Carer

Parents noted ways in which they thought they could assist and facilitate the process of their child receiving psychological intervention. Overall, the ways of assisting their child in therapy involved providing both practical and emotional supports.

Some participants made reference to taking on the role of the "therapist/teacher" outside of therapy sessions to help facilitate practices of skills and continue progress at home. As one participant noted *"I would become the teacher for the therapy and reaffirm therapy at home"*. Another wrote that they would be *"learning from the therapist and continuing therapy at home"*. Emphasis was placed on parents helping their child generalise the use of CBT strategies outside of the therapy session. Participants commented that they would *"help with homework if needed"*, *"reinforce (skills) at home"* and *"remind her what to do outside of sessions."*.

The emotional support that parents felt they could provide to their child throughout therapy largely involved encouragement to participate in the exercises and engage with the therapist. This was reflected in the responses for participants who suggested that they would *"support by just being there to encourage"* and as one participant stated, *"help them in the session open up to the psychologist"*. Practical support involved parents *"sit(ting) in on sessions"* and *"taking notes and helping with practice"*.

Some parents also noted that their knowledge of their child's communication patterns, as well as knowledge of their individual strengths and weaknesses, was an important factor for them to communicate to a psychologist to facilitate the intervention process. One participant wrote that *"Knowing her cues I can "interpret" with her and (the) therapist"*. Another commented that they would assist to *"establish a vocabulary ... both therapists and my daughter understand"*.

Role of the Therapist

In addition to the role the parent may play, participants noted that there were factors specific to the role of the psychologist which were important to consider. Some participants commented that the therapist's knowledge and experience in working with children with ID was important, and that finding a therapist who was experienced in providing intervention to this population would encourage them to engage in treatment. As one participant wrote, it would encourage them to participate in therapy *"if the therapist was understanding of the disabilities my son has and had experience working with them"*. Similarly, it was expressed that a therapist's lack of knowledge about working with children with ID would discourage proceeding with therapy, i.e. "*if the therapist did not know how to effectively work with the disabilities my son has"*.

It was also noted that part of the therapist's role would be to understand the strengths and weaknesses of the child, and adapt therapy for their needs. This is reflected in the comment of one participant who wrote that *"the approach taken to engage a child needs to be carefully thought out prior to engagement to reduce the likelihood of shutdown during therapy"*. Qualities of the therapist's manner and style were also specified as being important, such as being *"respectful", "willing to work with intellectual disability (many in our experience do not)",* and developing a good therapeutic relationship with the child.

Anticipated Obstacles

Participants identified a range of factors which may serve as obstacles to their child participating in therapy and being able to make effective use of the CBT skills. These obstacles were grouped into four categories; child-specific factors, clinical obstacles, parent-specific factors and practical obstacles.

The child-specific factor which respondents commented may be an obstacle was reduced flexibility in processes relating to thoughts and emotions. Participants stated that their child *"can be very rigid"* and *"a literal person so won't generalise".* One parent was concerned about their child *"not being able to move past (a) feeling*", and another noted that a challenge for their child would be *"knowing the difference between thinking something and it not necessarily being true".*

The difficulty for a child with ID to identify and express thoughts and emotions was also described by multiple participants as an anticipated obstacle to the treatment. Participants wrote that the challenges would be *"understanding the exact feeling he is feeling"*, *"(he) doesn't understand what his moods are", "she has trouble getting the right word out to explain her feelings"* and *"knowing the emotions she feels and being able to express that/tell us".* One participant stated that *"feeling, and being able to explain the feelings, are very different things".* Confusion of emotions was also reported by one parent who wrote that *"he can't tell me what he is thinking about, and he often insists that he is happy when he's very angry".*

In addition to child-specific factors, clinical elements of the intervention itself were noted as being potential barriers in the therapy process. Specifically, parents questioned whether CBT may be too complex for their child, noting that the difficulties would be *"finding the link between thoughts, actions and feelings"*. One participant commented that it *"seems like too many steps in the process to be able to link the thoughts, feelings, actions"*, while another wrote that *"making the links between thoughts, feelings behaviours would be difficult. She could do each of those three elements independently but perhaps hard to link."*

Other clinical obstacles identified were previous experiences of therapy where limited progress was made, as well as the attitude of the parents towards psychological intervention. Some parents commented that they had tried psychological interventions in the past without significant improvements, reporting *"10 years of therapy and not much has changed"*, *"not much has worked and I feel he doesn't retain information well"* and *"we have tried behaviour management"*. One parent also stated that they would discontinue therapy if they found *"it was upsetting my child too much"*.

Practical obstacles which were reported by parents included time constraints, cost of the therapy, the location where the therapy would take place, and the difficulty of finding a clinician. Some parents were concerned that they would be required to travel far distances for the therapy, while another participant noted that for children with sensory difficulties, *"noises, lights, smells, feel of materials etc"* within the therapy room were important considerations. One participant stated that *"finding a clinician willing to work with intellectual disability"* was an obstacle and that their daughter was previously *"denied cognitive therapy for her anxiety because she has an intellectual disability"*.

Suggested Adaptations to Therapy

Parents were specifically prompted in the survey to list ways in which they thought the process of CBT and psychological therapy could be made easier for their child. The responses from parents were organised into the following categories: providing instructions, prompts and cues, checking understanding, practicing skills, emotion training and support networks. Table 2 summarises the suggested adaptations proposed by the respondents.

Table 2. Proposed adaptations to CBT by parents of children with ID.

Adaptations	Specific suggestions from parents
Providing Instructions	• Provide explicit instructions • Break instructions into small steps • Use stories to explain concepts and to provide examples • Use videos to explain and teach *"Teaching in baby steps"* *"Make it as simple as possible"*
Prompts and Cues	• Use of visual cues • Colour coded charts as prompts and reminders *"Make a chart of feelings and thoughts so they can visualise them"* *"Behavioural cues to "lock in" lessons"*
Check Understanding	• Confirm the child has understood before progressing to the next step

	"Making sure he understands how to do it before moving onto the next thing"
Practicing Skills	• Repeat each step multiple times • Repeat practices of skills • Practice with multiple examples *"Getting him to show you"* *"Practice in therapy sessions and then practice outside of sessions"*
Emotion Training	• Additional time to be spent on establishing an awareness and understanding of different emotional states *"Teaching children to recognise feelings in the body that occur when getting close to a meltdown"*
Support Network	• Have teachers involved in the treatment process • Have parents involved throughout treatment

Discussion

To our knowledge this is the first study to explore the carer perspective as to how children with ID can benefit from CBT. The aim of the study was to gather perspectives from parents who have children with ID as to how their child may be able to engage in the process of CBT. Overall, the results from the survey indicate that parents believe their child may be able to benefit from CBT with assistance from carers and the therapist, provided that therapy is adapted for the specific needs of the child and that barriers to treatment are considered and managed.

Although approximately 42% of parents did not think that their child would be able to identify their thoughts, and more than half indicated that they did not think their child could link thoughts, feelings and behaviours, three quarters agreed that their child could participate in CBT with assistance. This level of agreement is promising given that the sample comprised of parents whose children had a wide range of variation in emotional development as apparent on the EDQ-P. It is important to note that the aim of a CBT treatment approach is to teach individuals the skills of identifying and linking thoughts, feelings and actions. Thus while parents acknowledge that their child may not be able to to do that at present, they are hopeful and optimistic that their child *could* learn the skills of doing so through CBT treatment.

Parents provided suggestions as to how CBT could be adapted for the specific needs of their child with ID. These suggested adaptations were largely in line with the proposed framework suggested by Hronis, Roberts and Kneebone (2017) based upon a review of the literature. Adaptations relating to simplifying teaching, using engaging materials to teach concepts, hands-on practice and support from parents were proposed by both the current sample and the previous review. It is important that future trials which investigate the effectiveness and efficacy of CBT for children with ID incorporate such adaptations.

The anticipated barriers to treatment and treatment progress reported by parents are particularly important to note. A number of respondents stated that the ability of their child to identify and express thoughts and feelings would be a significant treatment obstacle. This must be taken into consideration when using CBT with children with ID, and additional time should be spent consolidating the difference between thoughts, feelings and behaviours, and helping children to recognise these three elements within themselves. As thoughts, feelings and behaviours are the foundation of CBT, it is crucial that therapists spend adequate time establishing these concepts with children. Additional important obstacles were previous interventions which were of little benefit, and the difficulty of finding a psychologist with the knowledge and experience required to work with ID populations. Young people with ID and a mental illness have been found to have lower rates of access to treatment than the typically developing population (Einfeld et al., 2006; Slade, Johnston, Oakley Browne, Andrews & Whiteford, 2009), and clinician knowledge, confidence and experience has been noted as an obstacle to people with ID accessing mental health services (Dagnan et al., 2014; Hronis, Roberts & Kneebone, 2018; Rose, O'Brien & Rose, 2007). Thus while it is important to develop and adapt CBT treatments for children with ID, it is equally as important to train clinicians in how to deliver adapted CBT programs.

Comments which indicated that parents were willing to support their child, both practically and emotionally, throughout the process of therapy were encouraging. Many parents described taking an active role in their child’s treatment, including helping with homework tasks, taking notes and facilitating communication between child and therapist. This is positive as it is consistent with literature stating that parental involvement is beneficial for treatment outcomes for CBT with children (Mendlowitz et al., 1999; Wood, McLeod, Piacentini & Sigman, 2009).

A limitation of the current study is that on account of the recruitment strategy, parents who responded to the questionnaire may be more open to the idea of therapy for their child, providing a possible bias in the sample. Furthermore, some participants provided very brief qualitative responses, and due to the nature of the online questionnaire there was not the opportunity to ask for further information or clarification. Overall, the current study shows promise for the use of CBT for children and adolescents with ID and mental health disorders. Future research should focus on experimental studies which explore whether children with ID can identify, distinguish between and link thoughts, feelings and behaviours, as has been shown for adults with ID. In addition, research trials are needed to evaluate the efficacy of adapted CBT for children with ID and different mental health conditions, while considering and incorporating the feedback provided by parents and carers.

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Chapter 6

Involving Clinicians in the Development of a Cognitive Behavioural Intervention for Children with Intellectual Disabilities

The importance of involving stakeholders in the development of complex interventions has been highlighted by numerous frameworks, including the MRC guidelines (Craig et al., 2008), and the Center for eHealth Research and Disease Management roadmap (CeHRes; van Gemert-Pijnen et al., 2011) as discussed in Chapter 2. Best practice involves gathering feedback and insights from multiple stakeholders, including caregivers, professionals and patients (Shaw, 2002) in order to develop a deep understanding of stakeholder needs (Catwell & Sheikh, 2009). This is important, as if an intervention does not meet the needs of stakeholders, it is possible that the uptake of the intervention will not be maximised. Stakeholder feedback is important to gather, not just at one particular stage of the intervention development, but throughout the initial development, piloting of the intervention, and evaluation of the effectiveness and implementation of the intervention (Entwistle, Renfrew, Yearley, Forrester & Lamont, 1998; Lowes et al., 2011; TwoCan Associates, 2009). Both lay and professional stakeholders are seen as important and complementary in this process, bringing expertise by experience as well as expertise by profession (Faulkner & Thomas, 2002; Lowes et al., 2011). Chapter 5 described the feedback provided by parents of children with ID about whether they thought their child could participate and benefit from adapted CBT (Hronis, Roberts, Roberts & Kneebone, 2019). Parents were able to identify a range of obstacles which may prevent their child from engaging in therapy, as well as provide suggestions as to how therapy may be adapted to accommodate their child's needs.

Another group of stakeholders who are integral to the intervention development, are clinicians who provide therapy services. Gathering feedback from clinicians is important in adapting CBT for children with ID, as to our knowledge, there is no current existing evidence examining the effect of CBT of children with ID and anxiety disorders. In the absence of an existing evidence base to guide clinicians in an evidence-based practice model (Sackett, 2000), practice is used to inform research in a "practice-based evidence" model (Barkham & Mellor-Clark, 2003; Kazdin, 2008). This process invites clinicians to share their experiences and expertise, as a means of guiding and informing the development of interventions.

The involvement of a range of stakeholders, including professionals and clinicians, has been demonstrated as best practice in developing complex interventions at all stages of the development process. Lambert, Greaves, Farrand, Haase and Taylor (2017) developed a web-based intervention to promote physical activity in people with depression. Their development process involved not only patient and public involvement, but additional consultation with experts in the field. Professionals with expertise in behaviour change, physical activity and mental health were involved in the development and feedback process of the first version of the intervention. Similarly, another study sought the qualitative feedback of clinical staff members providing an intervention for anxiety (Curran et al., 2012). The qualitative evaluation aimed to explore the facilitators and barriers to implementing and sustaining the treatment program, with the view to maximize implementation success and minimize obstacles. There are many more examples of the involvement of professional stakeholders invited to provide advice and feedback on clinical issues and treatment developments. These include professionals providing feedback about clinical pathways to stepped care management of anxiety and depression in the context of cancer (Shaw et al., 2016) and a toolkit designed to enhance caregiver participation in community-based child mental health services (Haine-

Schlagel, Mechammil & Brookman-Frazee, 2017). Professional stakeholders have also been involved in the development of a list of behaviours and cognitions to define and guide responsible consumption of gambling (Hing, Russell & Hronis, 2017) and the blending of face-to-face and online therapy sessions in psychotherapy for depression (Titzler, Saruhanjan, Berking, Riper & Ebert, 2018). Involving professionals and clinicians in developing interventions allows for an in-depth understanding of their needs, and of the facilitators and barriers which may be present based on first hand experiences.

Considering the role of clinicians is particularly relevant and important to the ID population. In Australia, less than 10% of young people with ID and a mental illness accessed treatment over a 14-year period (Einfeld et al., 2006), in contrast to 35% of the general population who accessed mental health treatments (Slade et al., 2009). One of the potential barriers to people with ID accessing effective mental health care has been identified as a lack of training and confidence amongst mental health professionals when working with this population (Edward, Lennox & White, 2007; Phillips, Morrison & Davis, 2004; Torr et al., 2008; Jess et al., 2008). It is known that the confidence of therapists plays a crucial role in the success of therapy in people without ID (Bennun, Hahlwek, Schindler & Langoltz, 1986; Heinonen, Lindfors, Laaksonen & Knekt, 2012; Keijsers, Schaap & Hoogduin, 2000; Shaw et al., 1999), and has a significant impact upon the engagement of clients and their mental health outcomes (Bennun et al., 1986; Keijsers et al., 2000; Shaw et al., 1999). Lower therapist confidence is also predictive of poorer client outcomes for those with anxiety disorders in typically developing populations (Heinonen et al., 2012). Furthermore, retrospective evaluations from clients indicate that patients who improve most, perceive their therapists as more confident, competent and experienced (Bennun, et al., 1986; Keijsers et al., 2000).

There is limited research examining the confidence of clinicians when working specifically with people with ID or developmental disabilities. Dagnan, Mason, Cavagin, Thwaites and Hatton (2014) examined the confidence of clinicians in the UK in working with people with ID. It was found that the elements of interventions which clinicians were most confident with, were "generic" therapy and counselling skills such as providing empathy, actively listening and forming therapeutic relationships. Clinicians were least confident with specific clinical elements of the therapy process. This included using appropriate assessment measures, identifying appropriate treatments, and the implementation of such interventions. These findings highlight the lack of evidence-based resources available to clinicians when working with individuals with ID, as well as the need for additional training and research in this area.

The perceived importance of a clinician's confidence and understanding of ID was also reflected in the responses that were provided by parents who gave feedback about their child's ability to engage with CBT (Hronis, Roberts, Roberts & Kneebone, 2019; Chapter 5). Carers identified that a therapist's knowledge and experience in working with children who have ID was important, as well as the therapist's ability to adapt the intervention for the needs of the child. Parents report that these factors would encourage them to engage in treatment, while a lack of knowledge in working with children with ID would discourage proceeding with therapy. The emphasis which parents placed on the role of the therapist is important, given that it is parents and carers who are often responsible for seeking treatment for children with ID, taking them to sessions, and assisting with the implementation of skills outside of sessions.

As the research by Dagnan and colleagues (2014) indicated that clinicians who are not specialists in working with people with ID have limited confidence when delivering treatments to people with ID, this needs to be given consideration during the development process of a clinical intervention. This involves understanding the learning needs of clinicians, and their perspectives as to what would facilitate their ability to provide treatment to this population. The confidence of clinicians when working with people with ID in Australia has not been examined, and further research is needed to understand the barriers which may prevent therapists providing effective treatments to people with ID, and explore how these barriers can be overcome. Parents endorse the delivery of CBT to their children with ID (Hronis, Roberts, Roberts & Kneebone, 2019; Chapter 5), however this is not sufficient if clinicians are not confident or willing to provide such treatments. Furthermore, it is unfair to expect therapists to confidently deliver effective treatments to children with ID, when the evidence base is almost non-existent.

The following chapter (Chapter 7) describes research which aimed to identify how confident Australian clinicians are when working therapeutically with people with ID, and identify factors that may be associated with increased confidence. It also aimed to understand the needs of clinicians, and whether additional training and resources such as treatment manuals, would help improve their confidence. Given that there is not an established body of evidence for using psychotherapy among children with ID, the survey was not designed to be specific to children with ID, but rather asked clinicians about their experiences working with people with ID in general, capturing data regarding both adults and children. A detailed explanation of this research and the findings is provided in Chapter 7.

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Chapter 7

Assessing the Confidence of Australian Mental Health Practitioners in Delivering Therapy to People with Intellectual Disability

This chapter was previously published:

Hronis, A., Roberts, L., & Kneebone, I. I. (2018). Assessing the confidence of Australian mental health practitioners in delivering psychological therapy to people with Intellectual Disabilities. *Intellectual and Developmental Disabilities, 56*(3), 202-211.

Statement of Authorship

Title of Paper	Assessing the Confidence of Australian Mental Health Practitioners in Delivering Therapy to People With Intellectual Disability	
Publication Status	☒ Published	☐ Accepted for publication
	☐ Submitted for publication	☐ Unpublished and unsubmitted work written in manuscript style
Publication Details	Hronis, A., Roberts, L., & Kneebone, I. (2018). Assessing the confidence of Australian mental health practitioners in delivering therapy to people with Intellectual Disability. *Intellectual and Developmental Disabilities*, *56*(3), 202-211.	

Principal Author

Name of Principal Author (Candidate)	Anastasia Hronis		
Contribution to the Paper	Responsible for the development, collecting the data, data analysis and writing of the paper in collaboration with my supervisors. Served as the corresponding author and was responsible for the submission, revisions and responses to journal reviewers.		
Overall percentage (%)	80%		
Signature	Production Note: Signature removed prior to publication.	Date	21.10.2019

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	Dr Lynette Roberts		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (10%)		
Signature	Production Note: Signature removed prior to publication.	Date	10.12.2019

Name of Co-Author	Prof Ian Kneebone		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (10%)		
Signature	Production Note: Signature removed prior to publication.	Date	09.12.2019

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES
2018, Vol. 56, No. 3, 202–211

DOI: 10.1352/1934-9556-56.3.202

Assessing the Confidence of Australian Mental Health Practitioners in Delivering Therapy to People With Intellectual Disability

Anastasia Hronis, Lynette Roberts, and Ian Kneebone

Abstract

Research supports the use of psychological therapies among people with mild to moderate intellectual disability (ID). One barrier to people with ID accessing psychological treatments is the confidence of mental health practitioners. This article explores the confidence of Australian clinicians in providing therapy to people with ID. One hundred and fifty-two psychologists and counselors in Australia completed a survey exploring self-reported confidence when working with clients who have ID and mental health difficulties. Clinicians were most confident with generic counseling skills, but less confident with elements of assessments and interventions. The use of treatment protocols was endorsed as helpful particularly among those with low confidence. This highlights the need for dissemination of treatment guides and training to help increase clinician confidence.

Key Words: *intellectual disability; counselors; confidence; counselling skills; therapy; psychologists*

Hronis, A., Roberts, L., & Kneebone, I. I. (2018). Assessing the confidence of Australian mental health practitioners in delivering psychological therapy to people with Intellectual Disabilities. *Intellectual and Developmental Disabilities*, 56(3), 202-211.

Chapter 8

Adapting Cognitive Behavioural Therapy to Create the *Fearless Me!* © Program

CBT in its traditional form is talking intense and highly cognitive, and thus not suitable for children with ID. It has been recognised that adaptations need to be made to CBT interventions for this, in order to accommodate for their cognitive deficits (Chapter 3; Hronis, Roberts & Kneebone, 2017). To develop an adapted CBT program for children with ID and anxiety, the relevant literature was reviewed to understand the modifications that would be necessary. As recommended best practice for the development of interventions, feedback was also gathered from parents of children with ID (Chapter 5; Hronis, Roberts, Roberts & Kneebone, 2019), and from clinicians (Hronis, Roberts, & Kneebone, 2018). Collectively, this research confirmed how standard CBT may not meet the unique needs of children with mild to moderate ID, and subsequently leading to the development of the *Fearless Me!* © program (Hronis, Roberts, Roberts & Kneebone, 2018). The following sections provide a description of the program including the target audience for the intervention, content covered in the program, mode of delivery, and an explanation of the adaptions to made to CBT.

Target Audience

Fearless Me! © (Hronis, Roberts, Roberts & Kneebone, 2018) has been specifically designed for children and adolescents with mild to moderate intellectual disabilities, or intellectual functioning within the borderline range, aged approximately eight years and older. This target audience was selected as CBT is fundamentally more suited for individuals with higher cognitive capacity (Hronis et al, 2017). It is likely that children and adolescents with severe and profound ID would not have the cognitive capacity or verbal abilities to engage effectively in a cognitive based therapy.

Content of the Program

CBT is a complex therapy with a number of core cognitive and behavioural components, including psychoeducation, goal setting, exposure, coping and relaxation skills, cognitive restructuring, mood monitoring and homework (e.g., Garber, Frankel & Herrington, 2016; Hirshfeld-Becker, Micco, Mazursky, Bruett, & Henin, 2011; Wright, 2006). The *Fearless Me!* © program (Hronis, Roberts, Roberts & Kneebone, 2018) includes all these main components of standard CBT for anxiety. *Fearless Me!* © contains the core behavioural technique of graded exposure combined with positive reinforcements. Coping and relaxation strategies are also incorporated in the program, including deep breathing, progressive muscle relaxation, positive coping statements, and imagery of a safe place. The core cognitive techniques of CBT are included in the *Fearless Me!* © program, which are the identification of cognitive errors and irrational thoughts, examining evidence and generating alternative, helpful thoughts.

Delivery of the Program

Fearless Me! © is a multi-modal intervention, combining traditional face-to-face therapy sessions with an online website. The *Fearless Me!* © program has been designed to be delivered over ten face-to-face sessions, between 30-50 minutes per session. It is recommended that the program be delivered by a psychologist or mental health clinician who has been trained in CBT. There is a treatment manual available for clinicians to follow (Hronis, Roberts, Roberts & Kneebone, 2018; see Appendix C). The therapy sessions involve talking with the therapist about the given content for the session, as well as using the website to practice the skills and complete the online activities. The website has not been designed as a stand-alone treatment, but rather as an adjunct to face-to-face sessions. Children and their carers are able to access the website between sessions, and are encouraged to do the online activities as part of their homework. The website is also accessible to the families, once children complete the program, allowing them to continue to have resources available to practice the skills they have learnt.

Program Structure

The *Fearless Me!* © program was designed as a ten session CBT program. The overall structure of the program is described in detail in the *Fearless Me!* © manual (Hronis, Roberts, Roberts & Kneebone, 2018; see Appendix C). The structure is outlined in Table 1. While the manual guides what the clinician should cover in each session, it is noted that there is flexibility within the cognitive component of the intervention (sessions five through nine). The manual indicates that session nine can be used to continue consolidating the cognitive challenging skills from sessions five to eight, if the clinicians believes that further work on this is needed. Otherwise, an alternate session plan is provided which the clinician can follow if the child has progressed through the cognitive challenging.

Table 1. Session structure of *Fearless Me!* ©.

Session	Content of Session	Homework
Session 1	• Introduction to the program • Psychoeducation about anxiety, including where it is experienced in the body • Identification of the child’s fears. • Introduction to the thermometer rating scale	None
Session 2	• Review of anxiety psychoeducation • Introduce Module 1, “Keep Calm”, and orient children to the website	• Practice “Balloon Breathing” and “Safe Place”

	• Teaching and practice of "Balloon Breathing" (i.e. deep breathing) • Teaching and practice of "Safe Place" imagery	
Session 3	• Review "Balloon Breathing" and "Safe Place" • Teaching and practice of "Squeeze and Relax" (i.e. progressive muscle relaxation)	• Practice "Squeeze and Relax"
Session 4	• Review of relaxation strategies • Introduction to "Facing Fears" module • Watch "Brave Ben" video and discuss • Develop exposure hierarchy with the child	• Watch Brave Ben again at home • Do the first steps of the exposure hierarchy and monitor progress on the website
Session 5	• Review progress with exposure • Identification of thoughts, feelings and behaviours • Collaboratively create a list of examples of feelings, behaviours and thoughts • Introduce Module 2, "Stop and Think" • Practice some examples from the activity "Think, Feel, Do" on the website	• Continue with exposure hierarchy steps • Practice "Think, Feel, Do" on the website
Session 6	• Review progress with exposure • Review identification of thoughts, feelings and behaviours	• Continue with exposure hierarchy steps

	• Introduce the concept of unhelpful thoughts and "worry thoughts" • Exemplify that in the same situation, we can have different thoughts. • Practice the "Thought Catching" activity in Module 2	• Practice "Thought Catching" on the website
Session 7	• Review progress with exposure • Review identification of thoughts, feelings and behaviours, and catching worry thoughts • Practice further catching worry thoughts • Introduce the concept of "check the facts" • Practice the "Detective Thinking" activity in Module 2	• Continue with exposure hierarchy steps • Practice "Detective Thinking" on the website
Session 8	• Review progress with exposure • Review "Detective Thinking" • Practice further the "Detective Thinking activity in Module 2 • Practice applying the "Detective Thinking" to situations specific to the child	• Continue with exposure hierarchy steps • Practice "Detective Thinking" on the website
Session 9	• Review "Detective Thinking" homework • Application of exposure hierarchies to other fears • Development of positive self-statements	• Practice using positive self-statements • Practice "Detective Thinking" on the website

Session 10	- Review of relaxation skills, cognitive challenging, and exposure hierarchies	None

Therapy Adaptations Incorporated in the Fearless Me! © Program

The following section describes the many ways in which standard CBT has been adapted for the unique needs of children with ID. It is important to note that children with ID present with a spectrum of difficulties which range in severity, and the cognitive development of a child can vary significantly from one individual to another (Everall, Bostik & Paulson, 2005; Hronis et al., 2017; Schrodt & Fitzgerald, 1987). Furthermore, cognitive abilities also vary given the age of a child, and CBT requires adaptation according to developmental level (Garber et al., 2016; Grave & Blissett, 2004). Therefore, the clinician delivering *Fearless Me!* © is encouraged to adjust and adapt the program as required for the individual child they are working with, based upon their developmental level and neuropsychological profile.

An explanation of the ways in which CBT was adapted to create the *Fearless Me!* © is described in detail below. These adaptations, along with their benefits, are summarised in Table 2.

Table 2. Adaptations to CBT in the *Fearless Me!* © program.

Adaptation to CBT	Benefit of Adaptation
Multi-modal program	Using multiple modalities in therapy, such as talking, worksheets, drawing, watching videos and completing activities on the *Fearless Me!* © website promotes engagement, and helps to sustain attention.
Interactive, game-like activities	Using interactive games helps children generalise the skills, while providing a fun and engaging platform to facilitate learning.
Instructional videos	Videos provide additional engaging teaching material. To model the skills being taught they use both avatars as well as real people, to model the skills being taught. The relaxation videos can also be used to guide the practice of skills in between sessions.
Use of images and animated characters	The images function as a means of further engaging children with the program. They are also used as visual aides to help children remember key phrases and skills, accommodating for learning and memory deficits. The images also help facilitate communication between the child and therapist, particularly important for children who have limited expressive language and reading abilities.
Immediate feedback	Immediate feedback for the activities on the website allows children to learn whether they completed activities

	correctly or incorrectly. This immediate feedback facilitates learning and reduces the working memory load.
Jargon avoided	Jargon terminology is avoided and instead replaced with simple, key phrases which are repeated throughout the program. This supports communication of the relevant concepts.
Text to speech function	This enables children who have limited reading and language abilities to navigate the website and complete activities, without being required to read.
Short, simple sentences	Short, simple sentences are used to simplify written text, in order to accommodate for reading difficulties. The therapist is also encouraged to use short, simple sentences when communicating verbally, as a means of accommodating for receptive language difficulties.
Repetition of key phrases	Key phrases are repeatedly used throughout the program, accommodating for deficits in learning and memory.
One activity at a time	One activity is presented at a time, with minimal switching between tasks and content, reducing the load on working memory and executive functions.
Reduced session length	Sessions are reduced to 30-45 minutes to assist with sustained attention. Alternatively, a break is included during the session to help maintain attention.
Consistent session structure	Sessions being with a review of the previous content and homework, followed by new content, and a final review of

	the session. A consistent structure reduces the executive functioning load for the child.
Accessibility of website from home	Children can access the *Fearless Me!* © website in between sessions, which allows for further practice and the generalization of skills to different contexts and environments, other than the therapy room.

Use of Technology

In order to accommodate for neuropsychological deficits in attention, learning, executive functioning, language, communication and working memory, it has been recommended that therapeutic activities should be as engaging as possible for children with ID (Hronis et al., 2017). Using a variety of modalities within therapy is a way of adapting CBT to accommodate for the needs of children with ID. This can include talking with the therapist, drawing, colouring, initiating role plays and the use of computers, videos and other game-like tasks. (Cunningham et al.,2009; Grave & Blissett, 2004; Sauter, Heyne & Westenberg, 2009; Spence et al., 2008; Stallard, 2005). Stimulating materials involving colours and pictures can assist children with ID to focus on specific tasks (Raggi & Chronis, 2006). This literature was taken into consideration when developing the *Fearless Me!* © program, and as a result, it involves a range of modalities, including talking with the clinician, completing worksheets in sessions, interactive and game-like activities to complete on the website, and videos to explain concepts and practice skills. Specifically, an online website was created as an adjunct to face-to-face, in person therapy sessions. The role of the website is to assist children in their learning and practice of the relevant therapy skills, in a fun and engaging way.

The use of technology has been recognised and evaluated when working with people with intellectual and learning disabilities. A meta-analysis found that technology is "fairly effective" when used in interventions among people with ID, and holds considerable potential, though further research and evaluation is needed (Wehmeyer, Palmer, Smith, Davies & Stock, 2008). To date, technologies have been used more in education settings and for teaching purposes among those with ID, rather than as a means of facilitating psychological interventions. A computer-based intervention to teach sight-words to students with moderate ID was found to be effective (Coleman, Hurley & Cihak, 2012), and virtual reality has been found useful in helping people learn independent living skills, social skills and communication skills (Standen & Brown, 2005; 2006). Only recently has the potential for technology to facilitate therapy for individuals with ID been explored. A randomised controlled trial found computer-assisted CBT to be effective for reducing anxiety among adults with mild to moderate ID, when compared to a treatment-as-usual waitlist control group (Cooney, Jackman, Coyle & O'Reilly, 2017). The researchers delivered the computer-based therapy as a computer game. The game simplifies core CBT concepts into social stories, to facilitate learning and understanding. Participants played the game alongside a clinical psychologist over seven weekly sessions, each lasting approximately one hour. This study is a novel treatment approach for providing psychological intervention to those with ID, and overcomes some of the barriers preventing people with ID accessing mental health care. In a similar way, the *Fearless Me!* © program aims to provide an accessible treatment, by overcoming some of the existing obstacles for children with ID receiving psychological interventions.

The *Fearless Me!* © website has three modules, which closely follows the structure of the ten face-to-face therapy sessions (see Figure 1). The first module, called "Keep Calm", aims to teach children relaxation strategies. The *Fearless Me!* © website has videos which explain and show children how to do deep breathing (called “Balloon Breathing), and progressive muscle relaxation (called “Squeeze and Relax”). These videos can be used as initial teaching materials, as well as resources that children can use at home to practice the strategies. The second module, “Stop and Think”, targets the cognitive components of CBT. Cognitive restructuring has been broken into three sub-concepts, and there is an interactive activity on the website to facilitate the learning of each of these: 1) identifying and distinguishing between thoughts, emotions and behaviours (called “Think, Feel, Do”); 2) identifying unhelpful and irrational thoughts (called “Thought Catching”) and 3) challenging unhelpful cognitions (called “Detective Thinking”. The third module, “Facing Fears”, focuses on graded exposure to feared stimuli, and uses a video about “Brave Ben” to explain the rationale for exposure, as well as a log where children can record their steps.

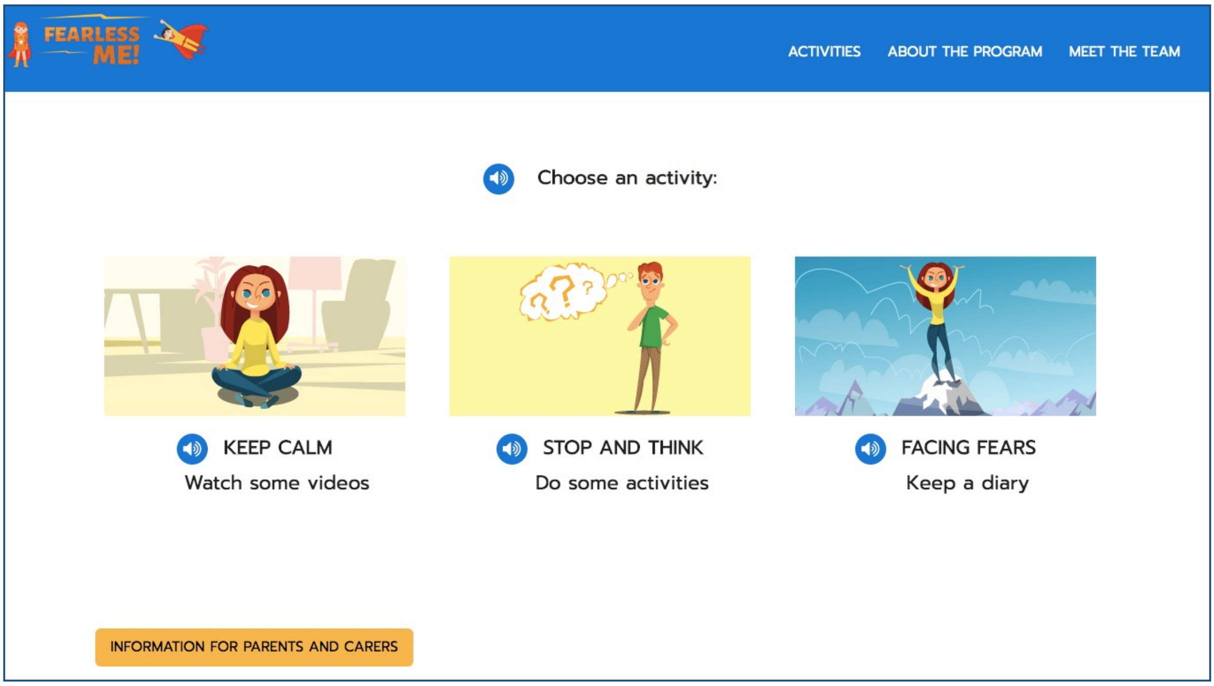


Figure 1. Three modules within the *Fearless Me!* © website

Use of Colours and Images

The *Fearless Me!* © website, utilises colours and images specifically created for the program, to help engage children and sustain their attention (Figure 1). There is a combination of both male and female characters on the website, to accommodate relatability to both genders. These animated characters were designed with the intent to appeal to children and adolescents aged 8-18 with an intellectual delay. The characters in the online activities not only describe situations aimed to be relatable for the children completing the program, but are also visually created to look like adolescents.

As children with ID often show delays in language development, speech production, syntax, and vocabulary (Facon, Facon-Bollengier & Grubar, 2002; Mervis & John, 2008; Roberts, Price & Malkin, 2007; Ypsilanti & Grouios, 2008), images are also used to facilitate the communication between the child and therapist. For example, faces representing various emotions are integrated into the cognitive restructuring activities to assist with communication and learning. As suggested by Beail & Jahoda (2012), thought bubbles are used as visual aids to represent cognitions on the *Fearless Me!* © website (Figure 1). Children also learn the phrase "Stop and Think" as part of the cognitive restructuring process, which is symbolised by a red stop sign.

One of the images which was designed for the program is the graphic of a thermometer, used to represent levels of anxiety (see Figure 2). Children are introduced to the thermometer rating scale during the first therapy session, and it is referred to consistently throughout the program. Children use the thermometer to rate their level of worry or anxiety on a given day, or after completing a step on the exposure hierarchy. The thermometer incorporates text, a graphic, and colours, with different colours used to represent different levels of anxiety. The thermometer on the website is interactive, as the internal bar of the thermometer rises, given the level of anxiety a child feels. In this way, the thermometer serves as an engaging tool to facilitate learning and understanding.

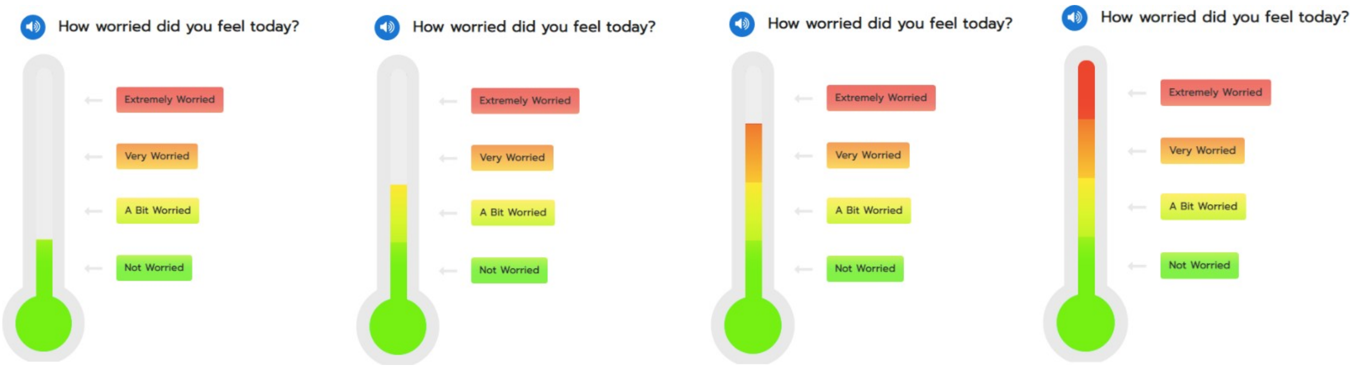


Figure 2. The thermometer rating scale serves as an interactive tool for children to rate their level of anxiety on the *Fearless Me!* © website.

Adapting Teaching Methods and Modalities

To accommodate for deficits in working memory, learning, attention and executive functioning, a range of teaching materials and modalities are used in the *Fearless Me!* © program. These include both implicit and explicit learning processes, such as talking with the therapist, completing worksheets, role plays and using the website in sessions and at home. The CBT skills are applied to the individual child's own fears and worries, as well as those of other children in order to practice generalising the skills being taught. To accommodate for learning and memory deficits, immediate feedback should be provided to children when completing an activity (Hronis et al., 2017). When using the *Fearless Me!* © website, children are shown if they have chosen a correct or incorrect answer while completing cognitive restructuring activities. Clinicians are encouraged to also verbally provide feedback when interacting with the child, as well as to frequently check the child's understanding, and repeat and master skills before moving on to the next topic.

Videos are used on the *Fearless Me!* © website to teach skills, and also as a means of children practicing skills at home. One specific character in the program, called “Brave Ben” (see Figure 3), is used in a video to explain the rationale for gradual exposure to feared stimuli and situations. In the educational video, Ben has a fear of heights, however his school class is going on an excursion to climb the Sydney Harbour Bridge. In the vignette, Ben would like to go on the excursion with his friends, however, his avoidance of heights is maintaining his phobia. Exposure to feared situations via hierarchies is explained, and Ben is shown to work “step by step” to overcome his fear of heights through graded exposure. Ben completes steps such as walking out onto a balcony, climbing up a ladder, going to the highest level of a tall building, climbing a mountain with his dad and going on a ferris wheel ride. By completing these steps and receiving rewards for the completed steps, Ben is able to overcome his fear of heights and join his classmates on their excursion. The video is designed to be visually engaging for children, and relatable in story. The video voice-over is a male, adolescent sounding voice. Short, clear, simple sentences are used, and jargon such as “hierarchies” is avoided, instead using the phrase “step by step” to explain graded exposure.

Figure 3. The “Brave Ben” video is used to explain hierarchies of exposure to feared stimuli.

Additional videos were created to explain specific relaxation techniques (Figure 4), including deep breathing (called "Balloon Breathing" in the program), and progressive muscle relaxation (called "Squeeze and Relax" in the program). Once again, the use of jargon terms has been avoided, and the relaxation techniques have been given short, simple and easy to remember names. As with "Brave Ben", the videos are designed to be visually engaging and involve a combination of animated characters and real-life recordings of one of the researchers practicing the relaxation exercises. The videos use a female, adolescent sounding voice-over and short, clear, simple sentences. The rate of speech is deliberately slow to accommodate for potential delays in processing speed. The videos can be used to initially teach a skill or concept, but can also be used as practice materials at home. This facilitates learning and memory processes by providing concrete practice materials.

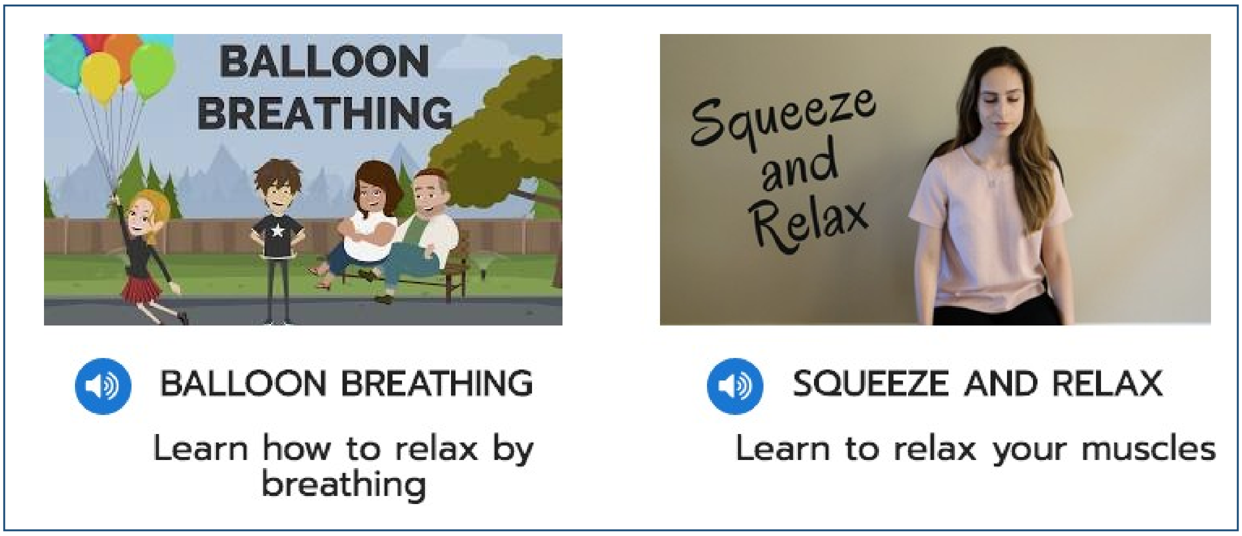


Figure 4. Videos used in the "Keep Calm" module to teach relaxation strategies.

Adaptations to Language and Communication

In the literature review conducted, language and communication barriers were identified as potential obstacles to therapy (Hronis et al., Roberts & Kneebone, 2017). As reading difficulties have been found to effect up to 67% of children with ID (Koritsas & Iacono, 2011), the *Fearless Me!* © website contains a "text-to-speech function" on all web pages, and for all exercises. Children are able to press the sound icon, as depicted in Figures 1 and 4, and the related text will be read to them. The inclusion of the text-to-speech function, also means that children are not reliant on an adult or therapist to read the text on the screen, but rather can independently navigate the website and complete the activities.

The need for written information to be easily accessible and understood for those with ID has been recently recognised (Chinn & Homeyard, 2017). Thus, where text is used on the *Fearless Me!* © website, it is written in an "Easy Reading" format with high frequency words and connectives (Karreman, van der Geest, & Buursink, 2007; Mastropieri & Scruggs, 1992). Easy Reading text aims to clearly and concisely convey information, while catering for a broad ability level (Department of Health, 2010). Guidelines suggest that the main, important ideas be conveyed using a combination of words and images, with the accompanying pictures placed next to the text with clear links between them. On the *Fearless Me!* © website, many graphics are used to accompany short, simple text, as is exemplified in Figures 1 and 4.

It is also recommended that jargon and complicated words be avoided where possible, with an explanation of specific terms provided the first time they appear (Department of Health, 2010). This recommendation is adhered to within the *Fearless Me!* © program. The primary focus of the treatment is to reduce anxiety in children with ID, and as such, "anxiety" and "worry" are defined, explained and discussed in the very first therapy session. Furthermore, additional complex terms and jargon are avoided, and replaced with simpler alternatives. For example, rather than referring to "cognitive distortions", the *Fearless Me!* © program uses the phrase "worry thoughts", and works to help children "catch" their "worry thoughts". Sentences are short and simple, generally containing one concept, and are repeated throughout, to assist and accommodate for reading, language and memory impairments (Gathercole, Lamont & Alloway, 2006). These adjustments are not only applied to the written the text in the *Fearless Me!* © program, but the clinician administering the intervention is also advised to adjust their communication style using short, simple sentences without jargon (see the treatment manual in Appendix C for recommendations to clinicians).

Figure 5 shows a snapshot of the *Fearless Me!* © website, and provides an example of the ways in which the language and communication adaptations outlined above have been incorporated into the program. A short, simple, clear sentence is used as part of a vignette in a cognitive challenging exercise. The sentence avoids jargon, and uses the phrase "Stop and Think", which is easy to recall and repeated many times throughout the program. The combination of graphics and text enables children to understand the sentence regardless of reading abilities, and uses visual aids to assist with reading, learnings and memory.

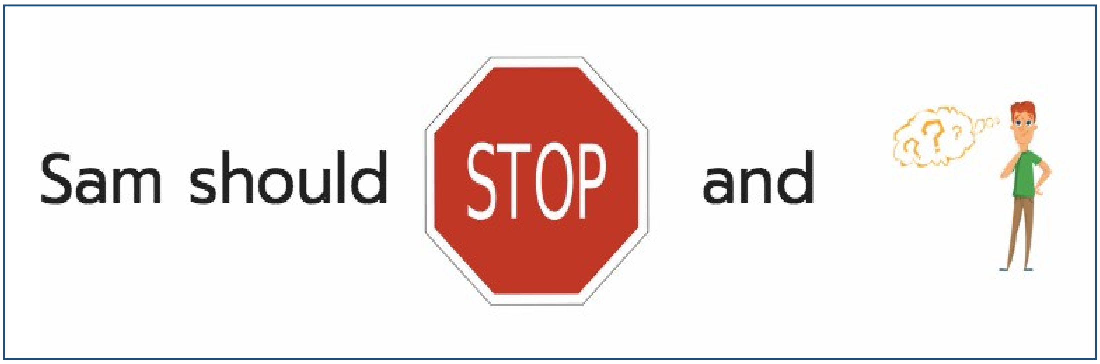

Sam should STOP and

Figure 5. "Stop and Think" is used within the cognitive challenging module of the *Fearless Me!* © website.

Adaptations to Session Structure

Within the *Fearless Me!* © program, adaptations to session structure and length are incorporated to accommodate for learning needs. Children with ID are found to have impairments in the domains of executive functioning, selective attention, divided attention and sustained attention (Hronis et al., 2017). Therefore, sessions are typically shorter (between 30-45 minutes,) or incorporate a break to assist with maintaining attention. To also assist with attentional and executive function deficits, one task or activity is presented at a time, and switching between different tasks with different concepts is kept to a minimum. To facilitate engagement however, the same task is repeated using a variety of modalities. For example, when teaching the relaxation technique “Squeeze and Relax”, the therapist may do the following: 1) explain the technique to the child, 2) watch the ‘Squeeze and Relax” instructional video with the child, 3) practice “Squeeze and Relax” along with the video with the child, 4) practice without the aide of the video, and 5) the therapist might ask the child to role-play as a “teacher” and teach the therapist or parent how to do the exercise. In this way, engagement is maintained through the varied modalities and a combination of implicit and explicit teaching strategies, but the topic and content is kept consistent.

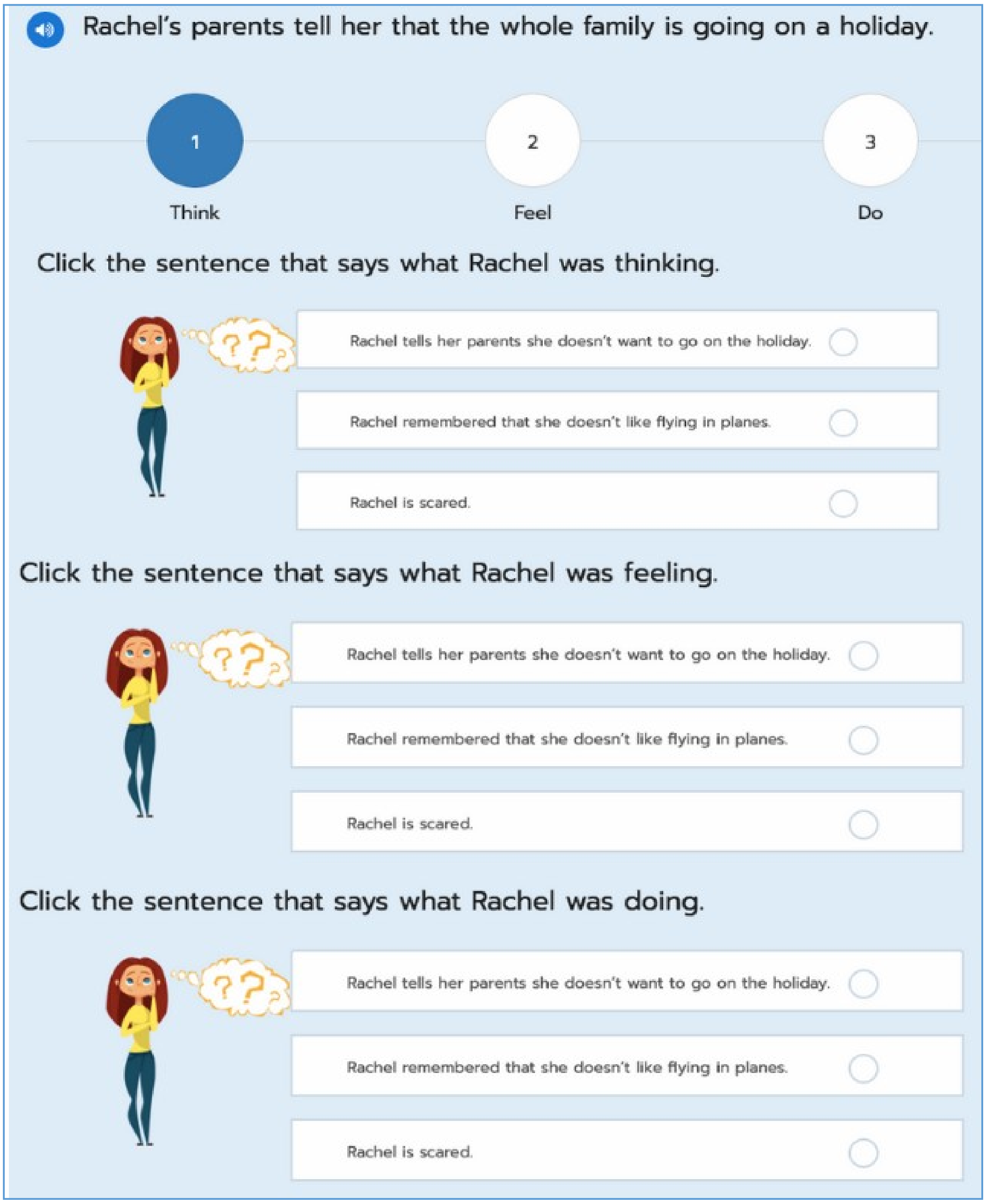
To further accommodate executive functioning deficits, it is recommended that a consistent structure to sessions be maintained throughout the *Fearless Me!* © intervention. Each session, therefore, begins with a review of the content from the previous week, along with homework. Content is covered during the middle part of the session, followed by a review of the session and homework for the week ahead.

Adjusting Task Complexity

One of the key features of the *Fearless Me!* © program, is the way in which it simplifies the complex concept of challenging cognitive distortions. The cognitive complexity of CBT is a large reason as to why children and adolescents with ID have been excluded from receiving this type of therapy (Adams & Boyd, 2010; Butz, Bowling & Bliss, 2000; Sturmey, Lott, Laud

& Matson, 2005). *Fearless Me!* © helps break down cognitive challenging into its simplest form. The cognitive behavioural model works on the assumption that our thoughts, emotions and behaviours are all linked and impact one another. However, being able to understand and apply this model assumes that an individual can firstly identify their thoughts, feelings and behaviours, distinguish between them, and then further challenge and change them. If an individual is unable to identify their thoughts, and how these may differ from emotions or behaviours, then teaching cognitive challenging is likely to be ineffective.

Fearless Me! © first teaches children to identify emotions, identify behaviours and identify thoughts (see Appendix C for Session 5 in the treatment manual). The therapist and child work together to generate various emotions the child may know, and various actions or behaviours. The therapist then introduces the concept of a thought, and thoughts being both true and untrue, and together the therapist and child brainstorm various thoughts. Children practice distinguishing between these in the online activity "Think, Feel, Do" (Figure 6). Short vignettes are provided, where the child is required to identify the character's thought, emotion and behaviour from three options. Immediate feedback as to whether the selected answer is correct or incorrect is provided on the website when this activity is being completed.



Rachel's parents tell her that the whole family is going on a holiday.

Click the sentence that says what Rachel was thinking.

Rachel tells her parents she doesn't want to go on the holiday. ○

Rachel remembered that she doesn't like flying in planes. ○

Rachel is scared. ○

Click the sentence that says what Rachel was feeling.

Rachel tells her parents she doesn't want to go on the holiday. ○

Rachel remembered that she doesn't like flying in planes. ○

Rachel is scared. ○

Click the sentence that says what Rachel was doing.

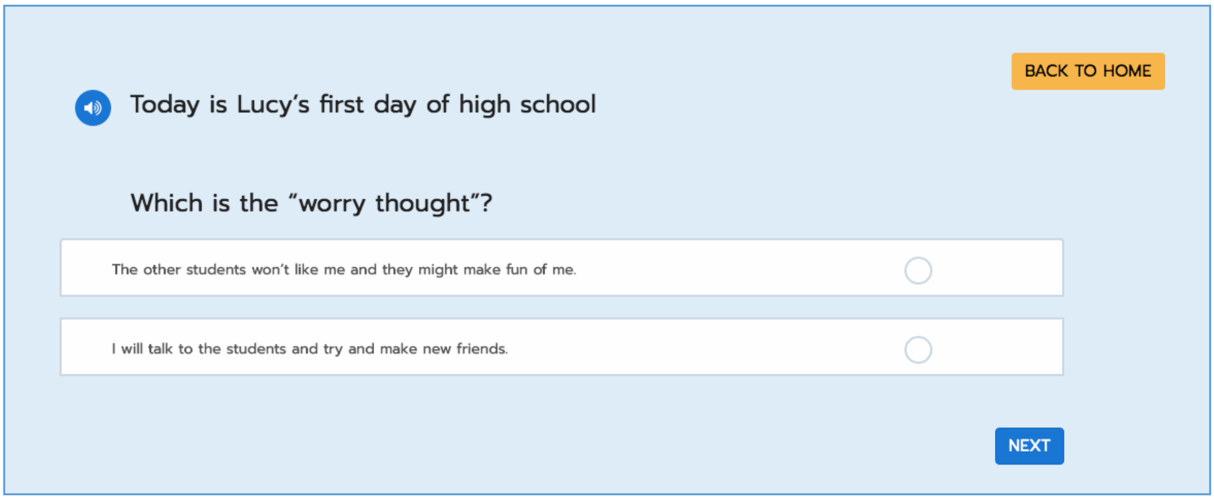
Rachel tells her parents she doesn't want to go on the holiday. ○

Rachel remembered that she doesn't like flying in planes. ○

Rachel is scared. ○

Figure 6. "Think, Feel, Do" activity on the *Fearless Me!* © website helps children identify and distinguish between thoughts, emotions and actions.

Children next work on identifying their unhelpful, worry thoughts and then practice the "Thought Catching" activity on the website (see Figure 7). Finally, children learn to challenge their "worry thoughts", and practice doing so using the "Detective Thinking" activity. Through the cognitive components of the program, the phrase "Stop and Think" (see Figure 5) is repeatedly used to prompt children to catch their unhelpful, irrational thoughts and challenge them.



Today is Lucy's first day of high school

Which is the "worry thought"?

The other students won't like me and they might make fun of me. ○

I will talk to the students and try and make new friends. ○

Figure 7. The "Thought Catching" activity helps children practice identifying unhelpful thoughts.

Conclusion

Fearless Me! © was developed based upon literature and feedback from stakeholders informing adaptations to CBT. The program aims to accommodate for deficits in the areas of learning, attention, memory, communication, reading and executive functioning, and the impacts that these deficits may have upon therapy. The following chapter described the preliminary evaluation of *Fearless Me!* ©, which was conducted to evaluate the feasibility and accessibility of the program among adolescents with ID.

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Chapter 9

Fearless Me! ©: A Feasibility Case Series of Cognitive Behavioral Therapy for Adolescents with Intellectual Disability

This chapter was previously published:

Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. (2019). *Fearless Me!* ©: A feasibility case series of cognitive behavioral therapy for adolescents with intellectual disability. *Journal of Clinical Psychology*, *75*(6), 919-932.

Supplemental material published online is included in Appendix D.

Statement of Authorship

Title of Paper	*Fearless Me!* ©: A feasibility case series of cognitive behavioral therapy for adolescents with intellectual disability	
Publication Status	☒ Published	☐ Accepted for publication
	☐ Submitted for publication	☐ Unpublished and unsubmitted work written in manuscript style
Publication Details	Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. (2019). *Fearless Me!* ©: A feasibility case series of cognitive behavioral therapy for adolescents with intellectual disability. *Journal of Clinical Psychology*, *75*(6), 919-932.	

Principal Author

Name of Principal Author (Candidate)	Anastasia Hronis		
Contribution to the Paper	Responsible for the research idea development, delivering the intervetion, collecting the data, data analysis and writing of the paper in collaboration with my supervisors. Served as the corresponding author and was responsible for the submission, revisions and responses to journal reviewers.		
Overall percentage (%)	80%		
Signature	Production Note: Signature removed prior to publication.	Date	21.10.2019

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	A/Prof Rachel Roberts		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (6.7%)		
Signature	Production Note: Signature removed prior to publication.	Date	09.12.2019

Name of Co-Author	Dr Lynette Roberts		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (6.7%)		
Signature	Production Note: Signature removed prior to publication.	Date	10.12.2019

Name of Co-Author	Prof Ian Kneebone		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (6.7%)		
Signature	Production Note: Signature removed prior to publication.	Date	09.12.2019

Received: 2 March 2018 | Revised: 26 October 2018 | Accepted: 6 November 2018

DOI: 10.1002/jclp.22741

RESEARCH ARTICLE

WILEY

Fearless Me!©: A feasibility case series of cognitive behavioral therapy for adolescents with intellectual disability

Anastasia Hronis[1] | Rachel Roberts[2] | Lynette Roberts[1] | Ian Kneebone[1]

[1]Discipline of Clinical Psychology, Graduate School of Health, University of Technology Sydney, Ultimo, NSW, Australia

[2]School of Psychology, Faculty of Health and Medical Sciences, The University of Adelaide, Adelaide, SA, Australia

Correspondence
Anastasia Hronis, Discipline of Clinical Psychology, Graduate School of Health, University of Technology Sydney, PO Box 123, Broadway, Ultimo, NSW 2007, Australia.
Email: Anastasia.Hronis@uts.edu.au

Funding information
James N. Kirby Foundation

Abstract

Objective: This study evaluated the feasibility of the *Fearless Me!* program, an online cognitive behavioral therapy (CBT) program for children with intellectual disability (ID) and anxiety.

Method: Twenty-one adolescents with mild to moderate ID participated in ten sessions of the therapist-assisted *Fearless Me!* program, combining face-to-face group sessions and an online component. A case series design was adopted to assess anxiety symptoms at baseline, throughout intervention, and postintervention. Feasibility of the measures, intervention, and trial design were considered.

Results: The measures were appropriate and sensitive to changes in anxiety, whereas the need for attention to factors influencing parent's completion of them was identified. Reliable Change Index and visual analyses of results indicated reductions in anxiety, particularly for older adolescents with heightened levels of anxiety at baseline.

Conclusions: This is one of the first CBT programs for adolescents with ID, and provides preliminary evidence of adapted CBT as a feasible treatment.

KEYWORDS

child and adolescent anxiety disorders, child and adolescent mood disorders, cognitive behavioral therapy, intellectual disability, online therapy

Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. (2019). Fearless Me! ©: A feasibility case series of cognitive behavioral therapy for adolescents with intellectual disability. *Journal of Clinical Psychology*, 75(6), 919-932.

Chapter 10

Approaches to Evaluating Interventions

Chapter 9 described the initial feasibility evaluation that was conducted of the *Fearless Me!* © program (Hronis, Roberts, Roberts & Kneebone, 2019). Consistent with the Medical Research Council guidelines for the development and evaluation of complex interventions (Craig et al., 2008) the evaluation evaluated the feasibility and acceptability of the program. A feasibility study aims to evaluate "whether something can be done, should we proceed with it, and if so, how." (Eldridge et al., 2016, p. 1). Feasibility studies aim to answer key questions about whether some elements of a future trial are possible. The feasibility study in Chapter 9 aimed to answer the key question of whether children with ID could understand the concepts of CBT and engage with the therapy program developed to implement treatment. The results indicated that CBT and the *Fearless Me!* © treatment program are acceptable and feasible among this population.

Feasibility studies have an important role to play in the evaluation of interventions. They are a necessary, cost-effective step in the evaluation process, as they can provide important methodological information about the design and planning of a trial (Blatch-Jones, Pek, Kirkpatrick, & Ashton-Key, 2018). Conducting full-scale trials requires significant time, resources and funding, and thus it is important to assess and examine the feasibility, design and methodology of a treatment before conducting such trials. In this way, feasibility and pilot studies can help avoid methodological design flaws and reduce the burden of research waste (Blatch-Jones, Pek, Kirkpatrick, & Ashton-Key, 2018). In the case of the feasibility evaluation conducted in Chapter 9, it was important to first establish that children with ID had the cognitive capacity and ability to learn and engage with the concepts of CBT, before administering the treatment on a wider-scale, and engaging with a clinically vulnerable population with heightened anxiety.

The study in Chapter 9 assessed the feasibility of the *Fearless Me!* © program, but did not prioritise assessing its impact on anxiety with a clinical population. The next step within the process of evaluation according to MRC guidelines (Craig et al., 2008) was therefore to conduct a preliminary investigation into the efficacy of CBT and the *Fearless Me!* © treatment among a cohort of children and adolescents with clinical/subclinical levels of anxiety. This investigation was originally designed to be conducted as a pilot randomized controlled trial (RCT), and was registered with the Australian New Zealand Clinical Trials Registry (Registration Number: ACTRN12619000434190). According to the National Health and Medical Research Council guidelines for levels of evidence supporting the use of an intervention, an RCT is considered as Level II evidence (National Health and Medical Research Council, 2009). Within the hierarchy of evidence, the RCT is considered to provide reliable evidence about the efficacy of an intervention, as it minimizes the risk of confounding variables which may influence the data (Akobeng, 2005). The results which are generated by RCTs are therefore likely to be a closer indication of the true effects of the treatment, as randomization eliminates bias, compared to findings produced by other research methodologies (Evans, 2003).

RCTs are the most rigorous way of determining whether a cause-effect relationship exists between an intervention and treatment outcomes, however there are a number of barriers and limitations which can interfere with the successful completion of an RCT. RCTs generally require significant resources, time and funds. Difficulties with randomization or recruitment may also arise, and strong patient preferences may limit recruitment and randomization.

Recruitment is an additional difficulty when the research involves overly selective inclusion criteria, or when recruitment is from a relatively small population (Nichol, Bailey, Cooper & POLAR, 2010; Sibbald & Roland, 1998). Without a sufficient sample size, conclusions as to the effect of the intervention are unable to be made.

The following chapter (Chapter 11) aimed to report on a pilot RCT to evaluate the *Fearless Me!* © CBT treatment program (Hronis, Roberts, Roberts & Kneebone, 2018), and its effect in reducing anxiety among children with ID. There were key differences between the feasibility evaluation (Chapter 9) and the planned pilot RCT, based upon the outcomes from the feasibility study. The pilot RCT aimed to recruit a sample of children and adolescents who had either subclinical or clinical levels of anxiety, while the feasibility evaluation did not. As the feasibility study aimed to confirm that the children could engage with the CBT concepts and materials, the planned pilot RCT aimed to evaluate the impact of the program specifically on anxiety. Therefore, children who were recruited were required to have subclinical or clinical levels of anxiety. In addition, the treatment was delivered in a group format in the feasibility evaluation, while treatment in the pilot RCT evaluation was delivered on an individual basis. It was observed from the feasibility evaluation, that due to differences in neuropsychological profiles, some adolescents progressed faster than others, and that additional support was required during the groups to ensure all children were able to follow the pace of the content. Finally, parents were required to attend most therapy sessions in the pilot RCT, while parents and carers had a very small role in the feasibility trial. This was so that parents might support the intervention by learning and understanding the therapy tools and techniques, and assist with practice and homework outside of sessions.

While the evaluation was initially planned to be a pilot RCT, due to difficulties with recruitment and limited resources, the study was only able to report analyses on a single case basis. The research was advertised as a pilot RCT and participants were at first informed it was a randomized trial with a wait list control group, but that the participants in the control group would receive the treatment after the 12 week waiting period. The study was not funded and therefore limited in resources which could be accessed (i.e. funding for advertising, to have clinicians see participants etc.). Many participants who enquired did not meet the inclusion criteria (i.e. they had another developmental disability such as ASD, but did not have an ID, they were outside of the required age range, they were nonverbal). For others, location was a barrier and they were unable to find the time in their schedule and their child's schedule to travel to the university for sessions.

The trial involved children and adolescents between the ages of eight to 17 years of age completing the *Fearless Me* © program. This involved a pre-intervention assessment, ten face-to-face therapy sessions, use of the *Fearless Me!* © website to assist therapy in session and at home, and a post-intervention assessment. In total, approximately 150 hours of therapy and assessments were conducted, half of which were delivered by the primary researcher and doctoral candidate. The results of the treatment are discussed, with implications and directions for future research considered.

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Chapter 11

Pilot Evaluation of the *Fearless Me!* © Program for Children with Intellectual Disabilities and Anxiety

This chapter has been prepared for publication.

Statement of Authorship

Title of Paper	Evaluation of the *Fearless Me!* © Program for Children with Intellectual Disabilities and Anxiety.	
Publication Status	☐ Published	☐ Accepted for publication
	☐ Submitted for publication	☒ Unpublished and unsubmitted work written in manuscript style

Principal Author

Name of Principal Author (Candidate)	Anastasia Hronis		
Contribution to the Paper	Responsible for the research idea development, delivering the intervention, collecting the data, data analysis and writing of the manuscript in collaboration with my supervisors.		
Overall percentage (%)	80%		
Signature	Production Note: Signature removed prior to publication.	Date	21.10.2019

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	A/Prof Rachel Roberts		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (6.7%)		
Signature	Production Note: Signature removed prior to publication.	Date	09.12.2019

Name of Co-Author	Dr Lynette Roberts		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (6.7%)		
Signature	Production Note: Signature removed prior to publication.	Date	10.12.2019

Name of Co-Author	Prof Ian Kneebone		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (6.7%)		
Signature	Production Note: Signature removed prior to publication.	Date	09.12.2019

Chapter 11

Pilot Evaluation of the Fearless Me! © Program for Children with Intellectual Disabilities and Anxiety

Introduction

The treatment of mental health conditions among children with ID is an area which to date has been largely overlooked in the literature. The prevalence of mental illness for children with ID is estimated to be as high as 50% (Einfeld, Ellis & Emerson, 2011; Tonge & Einfeld, 2000) and children with ID show elevated rates of both internalizing and externalizing problem behaviours compared to typically developing children (Dekker, Koot, van der Ende, & Verhulst, 2002; Einfeld & Tonge, 1996). Specifically, anxiety has been reported as the most prevalent mood disorder in young people with ID (Emerson, 2003). Furthermore, when left untreated, childhood mental health issues can result in elevated risks for the development of mental health disorders later in life. (Dekker et al., 2003; Emerson, 2003).

Historically, treatments for the mental health conditions of people with ID have involved medication and/or behavioural interventions (Vereenooghe & Langdon, 2013). It was argued that people with ID were unable to engage in cognitive-based therapies because of cognitive deficits (Adams & Boyd, 2010; Butz, Bowling & Bliss, 2000; Sturmey, Lott, Laud & Matson 2005). Research has found however, that adults with mild to moderate ID are capable of engaging in the cognitive components of Cognitive Behavioural Therapy (CBT; see Dagnan, Chadwick, & Proudlove, 2000; Joyce, Globe & Moody, 2006; Oathamshaw & Haddock, 2006; Sams, Collins, & Reynolds, 2006), and when CBT is adapted for the needs of adults with ID, the therapy is effective in reducing anxiety, depression and anger (Osugo & Cooper, 2016; Vereenooghe & Langdon, 2013).

While CBT is considered the “gold standard” when treating mood disorders among typically developing adults and children (e.g., Cartwright-Hatton, Roberts, Chitsabesan, Fothergill & Harrington, 2004; Compton et al., 2004), and the need for adapting CBT for adults with ID has been addressed, the potential for children with ID to engage in and benefit from CBT has not been systematically evaluated. A review of the neuropsychological deficits that are present for children with ID (Hronis, Roberts & Kneebone, 2017), identified ways in which CBT could be adapted for the unique learning needs of this population. In combination with stakeholder involvement, including feedback from parents of children with ID (Hronis, Roberts, Roberts & Kneebone, 2019b) and Australian clinicians (Hronis, Roberts & Kneebone, 2018), the *Fearless Me!* © treatment program was developed (Hronis et al., 2019b).

Fearless Me! © (Hronis, Roberts, Roberts & Kneebone, 2018) is a multimodal CBT intervention for children with anxiety concerns, specifically adapted to accommodate for the unique needs of children with ID. It involves face to face sessions with a psychologist, as well as an online website which children and their parents can access at home and use to practice CBT skills. The *Fearless Me!* © program aims to break down the elements of the CBT into their simplest form. There are three modules which children work through: “Keep Calm” which teaches relaxation strategies, “Stop and Think” which helps children identify and challenge anxious thoughts, and “Facing Fears” which focuses on behavioural changes and exposure. The use of technology and online programs in therapy has been found to be beneficial when working with people with ID, particularly to facilitate engagement, homework practice and the teaching of skills and techniques (Bendelin et al., 2011; Vereenooghe., Gega., Reynolds, & Langdon, 2017). In addition to this, the website has engaging visuals and illustrations, along with videos to help children understand concepts and practice relaxation techniques. The feasibility and acceptability of the *Fearless Me!* © program have been evaluated when delivered in a group setting (Hronis, Roberts, Roberts & Kneebone, 2019a). Twenty-one female adolescents with mild to moderate ID, or intellectual functioning in the borderline range, completed the program. Not all of the participants had elevated levels of anxiety prior to completing the program, however the program was found to be feasible and reductions in anxiety were found for some of those who did have initially heightened anxiety.

Current Study

The current study aimed to build upon an initial feasibility evaluation of the *Fearless Me!* © program (Hronis, Roberts, Roberts & Kneebone, 2018) by evaluating it in a population with significant anxiety symptoms. It was predicted that children with ID and significant anxiety would have reduced anxiety following completion of the intervention. There were three key differences between the current study and the initial feasibility evaluation. In the feasibility study of the *Fearless Me!* © program, the intervention was delivered to participants in two groups. Due to the heterogeneity in the cognitive functioning of children with ID (Hronis et al., 2017), and the experience in the feasibility trial it was determined the treatment in the current study be delivered to children individually. Another key difference between this study and the feasibility trial, was that all children in the current study were required to have clinical or subclinical levels of anxiety, in order to determine the effect of the treatment on mood. Finally, parents were required to be actively involved and attend sessions, in order to facilitate homework completion, compared to the feasibility evaluation where parents were not actively engaged in the program.

This evaluation was originally designed to be a pilot RCT and was registered with the Australian and New Zealand Clinical Trials Registry (Registration No:

ACTRN12619000434190). Due to difficulties with recruitment and limited resources, the study was able to only report analyses on a single case basis. The research was advertised as a pilot RCT and participants were at first informed it was a randomized trial with a wait list control group, but that the participants in the control group would receive the treatment after the 12 week waiting period. The study was not funded and therefore limited in resources which could be accessed (i.e. funding for advertising, to have clinicians see participants etc.). Many participants who enquired did not meet the inclusion criteria (i.e. they had another developmental disability such as ASD, but did not have an ID, they were outside of the required age range, they were nonverbal). For others, location was a barrier and they were unable to find the time in their schedule and their child's schedule to travel to the university for sessions. Given that to our knowledge, this is the first evaluation of CBT for children with ID and anxiety, it was deemed appropriate to report on a single case basis.

While the evaluation was initially planned to be a pilot RCT, due to difficulties with recruitment and limited resources, the study was only able to report analyses on a single case basis. The research was advertised as a pilot RCT and participants were at first informed it was a randomized trial with a wait list control group, but that the participants in the control group would receive the treatment after the 12 week waiting period. The study was not funded and therefore limited in resources which could be accessed (i.e. funding for advertising, to have clinicians see participants etc.). Many participants who enquired did not meet the inclusion criteria (i.e. they had another developmental disability such as ASD, but did not have an ID, they were outside of the required age range, they were nonverbal). For others, location was a barrier and they were unable to find the time in their schedule and their child's schedule to travel to the university for sessions.

Method

Participants

The participants were nine children, aged between 8 and 17 at the time of enrollment in the study. All children and adolescents had either a mild ID, moderate ID, or intellectual functioning in the borderline range. The participants were consecutively referred for the study for treatment of anxiety. Patients were deemed to be eligible if they met the following criteria: (1) mild/moderate/borderline ID, (2) aged between 8 and 18, (3) scored above 20 on the Screen for Child Related Anxiety Disorders (SCARED; Birmaher et al., 1999), (4) were not actively suicidal or engaging in significant self harm behaviours, (5) had access at home to a computer or tablet, and (6) had a parent/carer who was able to attend each session. Parents were required to confirm ID by providing a letter or assessment report by a doctor or psychologist.

Outcome Measures

Measures were administered to both the children and parents. These are described in detail below.

Child Measures

The child measures administered were the Kaufman Brief Intelligence test, Second Edition (KBIT-2; Kaufman & Kaufman, 2004), Spence Children's Anxiety Scale – Child Report (SCAS-C; Spence, 1998), the Strengths and Difficulties Questionnaire – Child Report (SDQ-C) emotional problems and peer relationship problems subscales (Goodman, 1997), and a measure of Subjective Units of Distress Scale (SUDS; Wolpe, 1969). The measures which were completed by the children were done so with the assistance of the treating psychologist. The psychologist would read the questions aloud for the child, and the child was provided with an A4 laminated sheet with different responses to the questions. The child could verbally respond, or point to the answers, and the psychologist recorded their responses.

Kaufmann Brief Intelligence Test Second Edition (KBIT-2; Kaufman et al., 2004)

The KBIT-2 is a brief measure of intelligence, often used as a screening assessment, that takes approximately 20 minutes to complete and can be used with individuals aged four through to 90 years. The KBIT-2 provides a measure of verbal and nonverbal intelligence. The verbal intelligence quotient is comprised of a verbal knowledge task and a riddles task. The nonverbal intelligence quotient is based upon matrices. The verbal and nonverbal scores produce an IQ composite, which has a mean of 100 and standard deviation of 15.

Subjective Units of Distress Scale (SUDS)

A Subjective Units of Distress/Discomfort Scale was adapted from Wolpe (1969) which originally used a 0-100 scale. SUDS have been shown to be a valid measure of distress (e.g., Kaplan & Smith, 1995), and have been used with smaller scales when working with children in order to simplify the child's decision-making process (Kendall et al., 2005). The current study asked participants to respond to the prompt "How worried do you feel today?" on a four-point rating scale, (1 = Not Worried, 2=A Bit Worried, 3 = Very Worried, 4 = Extremely Worried). The ratings of anxiety were shown alongside an image of an anxiety thermometer which is recommended when working with children (Kendall et al., 2005). This measure was also used in the initial feasibility trial of the *Fearless Me!* © program (Hronis et al,, 2019a).

Spence Children's Anxiety Scale – Child Report (SCAS-C; Spence, 1998)

Participants completed the SCAS-C (Spence, 1998), a 44 item self-rated measure of how often a child experiences anxiety symptoms. Responses are rated using a 4-point Likert scale (0 = Never, 1 = Sometimes, 2 = Often, 3 = Always). For some children who did not understand the word “often”, this was substituted with “a lot”. There are six positively worded filler items which are not included in the scoring process. The SCAS consists of six subscales which reflect DSM-IV anxiety disorders; separation anxiety, social phobia, obsessive compulsive, panic/agoraphobia, physical injury fears and generalized anxiety. The total score is calculated by adding 38 of the 44 total items (maximum total score = 114), with higher scores reflecting greater anxiety.

The SCAS-C is widely used and there is research to support it having good psychometric properties. The SCAS-C has very high internal reliability (α=.87-.94; Brown-Jacobsen, Wallance & Whiteside, 2011; Spence 1998; Spence, Barrett & Turner, 2003). The construct validity of the measure and factor structure have been confirmed within Australian samples (Spence, 1998; Spence et al., 2003). The SCAS has also been found to have good convergent validity, and has been compared to other established scales of child anxiety. There are strong correlations between the total SCAS score and the SCARED (Birmaher et al., 1999), ranging from r = .85-.89 (Essau, Muris & Ederer, 2002; Muris, Merckelbach, Ollendick, King & Bogie, 2002; Zhao, Xing & Wang, 2012). Intercorrelations are also strong between the SCAS and the Revised Measure of Children’s Manifest Anxiety (RCMAS; Reynolds & Richmond, 1978) with a correlation of r = .71 (Spence, 1998).

Strengths and Difficulties Questionnaire – Child Report (SDQ-C; Goodman, 1997)

The Strengths and Difficulties Questionnaire – Child report (SDQ-C) is a brief measure of emotional and behavioural functioning in children and adolescents. There are 25 items in the SDQ-C relating to specific strengths and difficulties faced by the child. Items are rated on a three-point scale (0 = Not True 1 = Somewhat True, 2 = Certainly True). The 25 items make five subscales of five items each; emotional problems, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviour. The scores of the first four subscales (i.e. not the prosocial behaviour subscale) are summed to produce a Total Difficulties score. In this study, only the emotional problems and peer relationship problem subscales were administered, in order to reduce the task length and cognitive load. The emotional problems and peer relationship problem subscales were chosen as they were deemed to be the most relevant to anxiety. Scores are categorized as falling within the "normal", borderline" or "abnormal" ranges.

The SDQ has been shown to have acceptable levels of test-retest reliability in typically developing populations (Goodman, 1999), and so discriminate well between community-based and clinic-based samples of children (Goodman 1999; Goodman, Meltzer & Bailey, 1998). The SDQ-C has been evaluated amongst adolescents with ID, and it was found that the internal consistency of the SDQ subscales was equivalent for children who did and did not have ID (α=.71 for children with ID; Emerson, 2005). Furthermore, there was no evidence of response bias among children with ID, and the degree of correspondence between child self-reported difficulties and parent reports was modest, but equivalent for children with and without an ID (Emerson, 2005).

Parent Measures

The measures completed by the parents were a demographics questionnaire, the Screen for Child Anxiety Related Emotional Disorders (SCARED; Birmaher et al., 1999), Spence Children's Anxiety Scale – Parent Report (SCAS-P; Nauta et al., 2004), Strengths and

Difficulties Questionnaire- Parent Report (SDQ-P; Goodman, 1997), Children's Anxiety Life Interference Scale (CALIS; Lyneham et al., 2013), and Emotions Development Questionnaire – Parent Form (EDQ-P; Wong, Heriot & Lopes, 2009).

Demographic Questionnaire

Parents were asked to complete a questionnaire providing demographic information. This included their child's date of birth, sex, current school grade, cultural background, primary language spoken at home, and the conditions which their child has been diagnosed with. Parents were also asked to state whether their child had received any previous therapy or interventions for mood difficulties, as well as the type of therapy if known, the duration of the therapy and the frequency at which it was provided. Finally, parents provided information about the fears and worries their child has, things or situations which make their child feel anxious or they want to avoid, and some potential goals for their child in completing the program.

Screen for Child Anxiety Related Emotional Disorders (SCARED; Birmaher et al., 1999).

The SCARED (Birmaher et al., 1999) was completed by parents and used as a screen for clinical or subclinical anxiety. This is a 38 item parent-reported measure of their child's anxiety. There are five anxiety subscales: generalized anxiety, panic disorder, separation anxiety, social anxiety and school anxiety/refusal. All 38 items are scored to produce a Total score. Scores which are equal to or above 25 are considered to indicate elevated levels of anxiety. In this study, we included children who had a SCARED score of 20 or over, as we were aiming to include children with both clinical and subclinical levels of anxiety. Overall, the SCARED has been shown to have good internal consistency and discriminant validity (both between anxiety and depressive disorders, and between anxiety disorders (Birmaher et al., 1999).

Spence Children's Anxiety Scale – Parent Report (SCAS-P; Nauta et al., 2004)

Parents of the children participating in the study completed the SCAS-P (Nauta et al., 2004), a 38-item parent-report measure of child anxiety. Parents indicated on a 4-point Likert scale (0 = Never, 1 = Sometimes, 2 = Often, 3 = Always) how applicable the statements and feelings would be to their child. As with the SCAS-C, there are six subscales which reflect DSM-IV anxiety disorders; separation anxiety, social phobia, obsessive compulsive, panic/agoraphobia, physical injury fears and generalized anxiety. The total score is calculated by adding each of the items, producing a maximum score of 114. The SCAS-P excludes the six positive filler items in the SCAS-C, but otherwise contains the same 38 items, but worded so that parents report about their child (e.g. "I worry about things" on the SCAS-C; and "My child worries about things" on the SCAS-P). The internal reliability of the SCAS-P has been found to be consistently high with internal reliability ranging from α = .86 - .93 for the full scale total score (Li, Delvecchio, Riso, Nie, & Lis, 2016; Nauta et al., 2004).

Strengths and Difficulties Questionnaire- Parent Report (SDQ-P; Goodman, 1997)

The SDQ-P is a brief measure of emotional and behavioural functioning in children and adolescents (Goodman, 1997). There are 25 items in the SDQ-P relating to specific strengths and difficulties faced by the child. Items are rated on a three-point scale (0 = Not True 1 = Somewhat True, 2 = Certainly True). The 25 items make five subscales of five items each. These subscales are; emotional problems, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviour. The scores of the first four subscales (i.e. not the prosocial behaviour subscale) are summed to produce a Total Difficulties score. As reported above, the SDQ has been evaluated within a learning disorders population, and has been found to be a robust measure for this group (Emerson, 2005). It is recommended for use for children and young people with mild ID, but not severe/profound ID (Emerson, 2005; Law & Wolpert, 2014). Given that the children in the current sample did not have severe or profound ID, it was considered to be an appropriate tool.

Children's Anxiety Life Interference Scale – Parent Report (CALIS; Lyneham et al., 2013)

The CALIS (Lyneham et al., 2013) is a measure of life interference and impairment associated with childhood anxiety. The parent report is designed to measure life interference and impairment experienced by the child from the parental point of view, as well as the interference experienced by the parent in their own life. The parent report consists of 16 items, each item rated on a five point Likert scale (0 = not at all; 1 = only a little; 2 = sometimes; 3 = quite a lot; 4 = a great deal). Total scores are obtained by the addition of the responses. The CALIS has been found to have good internal consistency among a sample of typically developing children ($\alpha = .90$ for mother reports and $\alpha = .88$ for father reports), with moderate to high re-test reliability, good convergent and divergent validity and sensitivity to treatment change (Lyneham et al., 2013).

Emotions Development Questionnaire – Parent Form (EDQ-P; Wong, Heriot & Lopes, 2009)

The EDQ-P (Wong, Heriot & Lopes, 2009) is a parent-reported measure developed to assess emotional competence in children with Autism Spectrum Disorder (ASD). It assesses emotional understanding, theory of mind, emotion regulation and emotion-coaching skills (Ratcliffe, Wong, Dossetor & Hayes, 2014). The EDQ-P is completed by parents of school-aged children with ASD and with or without ID, and has been used in trials providing intervention to children with comorbid ASD and ID (Ratcliffe et al., 2014). The EDQ-P consists of 40 items which are rated on a five-point Likert scale from “Never” = 1 to “Always = 5” with a sixth option of “Don’t Know”. The ratings are added to produce a total score of emotional competence, with “Don’t Know” responses excluded from the final score. Higher scores indicate better emotional competence and skills, with a maximum total score of 200. The measure yields a maximum score of The EDQ-P has excellent internal consistency (α = .91; Ratcliffe et al., 2014).

Procedure

The current research study was approved by the university ethics committee (Approval No: ETH18-2384). Advertisements were circulated via disability organisations, schools that supported children with learning needs, social media and professional psychology membership bodies. The advertisement called for children with ID between the ages of eight to 18 to participate in a 12-week therapy program for anxiety. The advertisement also provided an outline as to what CBT is and how the therapy program worked. Parents of children with ID contacted the lead researcher (AH) via phone or email to express interest. The parents were then screened over the phone as to whether their child was within the required age range, had verbal abilities, and was not currently actively suicidal or engaging in significant self-harm behaviours. After speaking with the lead research over the phone, parents were emailed the SCARED questionnaire (Birmaher et al., 1999), to screen for clinical or subclinical levels of anxiety in their child. They were also sent the information sheet and consent forms to read, and were able to ask the researcher questions about the study. Following the completion of the SCARED, all parents were contacted, and those with a score above 20 were offered a place in the study, while others were referred to alternate services as appropriate.

All sessions were held at the University of Technology Sydney Psychology Clinic. Sessions were conducted by either the lead researcher (AH) or a provisionally registered psychologist completing the Master of Clinical Psychology training program. Parents attended the initial assessment session with their child. Children were provided with an "easy read" information sheet, and parents provided consent to participate on behalf of the children. Limits to confidentiality were explained to both parents and children at the start of the initial session. Parents were then asked to leave the room and complete the following questionnaires: SCAS-P, CALIS, SDQ-P and EDQ-P. The child and psychologist completed the following assessment measures: KBIT-2, SCAS-C, SUDS and SDQ. The initial session ran for approximately 60-90 minutes.

Children then attended a subsequent ten therapy sessions. One parent/carer was asked to be available to be present in the therapy room for the therapy sessions. The clinician and the child worked through the therapy program outlined in the *Fearless Me!* © manual (Hronis, Roberts, Roberts & Kneebone, 2018; Appendix C). Children were provided with homework tasks to complete with the assistance of parents/carers at the end of each session. The final assessment session involved a repetition of the initial assessment measures, excluding the KBIT-2.

Treatment

Fearless Me! © (Hronis, Roberts, Roberts & Kneebone, 2018) is a ten-session, manualised CBT program with adaptations specific to accommodate the unique needs of children with ID. It involves face-to-face therapy sessions, as well as an online website which allows children to learn and practice CBT skills. Use of the website was incorporated into each face-to-face therapy session. Homework was set at the end of each session to practice skills using the website. Therapy sessions were held weekly to fortnightly, and lasted between 30-50 minutes, depending on the topic and the child. An overview of the treatment sessions is described in Table 1.

Table 1. Overview of *Fearless Me!* © therapy sessions.

Session	Content of session
Session 1	Psychoeducation provided about anxiety and symptoms in the body; introduction to the thermometer rating scale; identification of feared stimuli.
Session 2	Deep breathing (called “Balloon Breathing”) and safe place taught as relaxation strategies.
Session 3	Progressive Muscle Relaxation (called “Squeeze and Relax”) taught; review of relaxation strategies.
Session 4	Rationale for exposure provided using “Brave Ben” video; exposure hierarchy developed.
Session 5	Introduction to differentiating thoughts, feelings and behaviours; “Think Feel Do” task on the website.
Session 6	Identifying worry thoughts; “Thought Catching” exercise on the website.
Sessions 7 & 8	Challenging unhelpful thoughts; “Detective Thinking” exercise on the website.
Session 9	Optional continuation of cognitive challenging skills OR developing hierarchies and positive coping statements.
Session 10	Review of treatment and skills.

Data Analysis

In line with the original intention to conduct an RCT, comparisons between treatment and waitlist groups using ANCOVA analyses were planned. As recruitment was insufficient to conduct these analyses a case evaluation approach was used. The Reliable Change Index (RCI; Jacobson & Truax, 1991) was employed to calculate whether significant changes were evident for each participant. The RCI indicates whether an individual change score (i.e., the difference between a child's pre-intervention and post-intervention score is statistically significantly greater that what may occur due to random error (Guhn, Forer & Zumbo, 2014; Jacobson & Truax, 1991). The formula for reliable change is calculated using participants' difference scores and the standard error of the measure (SE), where the formula is:

$$\mathrm{RCI} = (x - x\ )/\mathrm{SE}, \text{ where } \mathrm{SE},= \mathrm{SD}\ 1 - r$$

If the RCI is greater than +/−1.96, the difference is reliable as a change of that size would not be expected from the unreliability of the measure (Jacobson & Truax, 1991).

Results

Nine children completed the program, including the pre and post assessment sessions. Three children enrolled but were unable to complete the program. One did not complete due to time constraints, one due to travel distance, another completed all therapy sessions but did not return for the final assessment. In total, approximately 150 hours of therapy and assessments were conducted, half of which were delivered by the doctoral candidate (AH), and the other half which were conducted by a provisionally registered psychologist completing the Master of Clinical Psychology training program.

The individual changes for the nine participants on measures of anxiety, anxiety interference and strengths and difficulties are outlined below. No children had significant changes on the EDQ-P or SDQ-P, and therefore these measures are not reported for each of the individual children. Changes in SUDS scores are not provided in the results, as they appeared to have little sensitivity to change, with the majority of children consistently reporting the lowest level of anxiety at each session.

A summary of the participant demographic information of the nine children who completed is included in Table 2, including gender, cultural background, primary language spoken at home, and comorbid diagnoses.

Table 2. Relevant demographic and diagnostic information

Demographic Variable	N
Gender	
Male	5
Female	4
Cultural background	
Australian	5
Indian	3
European	1
Primary Language Spoke at Home	
English	8
Russian	1
Comorbid diagnoses	
Autism Spectrum Disorder	4
Cerebral Palsy	4

Attention Deficit Hyperactivity Disorder	2
Epilepsy	1
Depression	1
Down Syndrome	1
Rare genetic condition	1

Participant 1 (P1)

P1 was a 17 year 1-month old female, with moderate ID and Down Syndrome. Her mother reported that P1 had received psychological intervention “on and off” over the past few years. P1 and her mother reported that her main fears and anxieties were cockroaches, the dark, crossing the road and loud noises. On the SCARED, P1 scored 20. On the KBIT-2, P1 scored 63 for verbal IQ, 44 for non-verbal IQ and 52 for composite score.

Significant reductions in anxiety were found for P1 on the SCAS-P total score (RCI = 2.81), and for the SCAS-C total score (RCI = 2.27). There was no significant reduction in anxiety life interference on the CALIS total score (RCI = 1.13). On the child reported SDQ emotional problems subscale, P1 initially scored in the borderline range, and this remained so at the end of treatment. P1’s initial score on the peer problems subscale of the SDQ was in the borderline range and reduced to the normal range at the end of the treatment.

Participant 2 (P2)

P2 was a 12 year 10-month old male, with an ID and comorbid ASD. He was also reported to have mild cerebral palsy affecting his motor skills. His father reported that he had received no previous intervention for mood concerns. P2’s main fears were related to social situations, such as attending parties, greeting other people and playing with friends. He was also reported to become anxious when plans were changed. On the SCARED, P2 scored 27. On the KBIT-2, P2 scored 60 for verbal IQ, 52 for non-verbal IQ and 51 for composite score.

Significant reductions in anxiety were found for P2 on the SCAS-P total score (RCI = 2.81). The SCAS-C at pre-treatment was not completed due to non-compliance, and therefore a change score was unable to be calculated. There was no significant reduction in anxiety life interference on the CALIS total score (RCI = 0.38). On the child reported SDQ emotional problems subscale, P2 initially scored in the abnormal range, and this had reduced to the normal range at the end of the treatment. P2's initial score on the peer problems subscale of the SDQ was in the normal range and remained so at the end of the treatment.

Participant 3 (P3)

P3 was a 17 year 7-month old male at the time of enrolment into the program, with ID and severe cerebral palsy. He has previously had psychological intervention, though his parents were unable to recall the frequency of the sessions or the type of therapy used. P3 was reported to experience general worry and "think too far into the future". On the SCARED, P3 scored 35. On the KBIT-2, P3 scored 85 for verbal IQ, 64 for non-verbal IQ and 71 for composite score.

Significant reductions in anxiety for P3 were found for the SCAS-P total score (RCI = 2.34) and for the SCAS-C total score (RCI = 3.64). There was a significant reduction in anxiety life interference on the CALIS total score (RCI = 3.38). On the child reported SDQ emotional problems subscale, P3 initially scored in the borderline range, and this had reduced to the normal range at the end of the treatment. P3's initial score on the peer problems subscale of the SDQ was in the normal range and remained so at the end of the treatment.

Participant 4 (P4)

P4 was a 17 year 7-month old female at the time of enrolment into the program, with ID, severe cerebral palsy, spastic dystonia and visual impairments. She was the twin sister of P3. P4's mother reported that she had received intervention for mood concerns which lasted for three months, though was unable to recall the frequency of the sessions or who provided the sessions. P4 was reported to feel anxious in new situations and when in new surroundings, particularly if she is without parents or a sibling. She also experienced anxiety talking to new people and friends, and was nervous to ask for help or assistance. During the program, P4 enrolled in a school camp which she had not attended before, and was very anxious about attending. On the SCARED, P4 scored 35. On the KBIT-2, P4 scored 61 for verbal IQ, 40 for non-verbal IQ and 45 for composite score.

No significant reductions in anxiety were found for P4 on the SCAS-P total score (RCI = -0.94). Significant reductions in anxiety were however found for the SCAS-C total score (RCI = 5.67). There was no significant reduction in anxiety life interference on the CALIS total score (RCI = 1.13). On the child reported SDQ emotional problems subscale, P4 initially scored in the normal range, and this remained so at the end of the program. P4's initial score on the peer problems subscale of the SDQ was in the normal range and remained so at the end of the treatment.

Participant 5 (P5)

P5 was a 15-year 8-month old male, with an ID and comorbid ASD. His mother reported a history of childhood anxiety and depression. The primary language spoken at home was Russian, though P5 was able to speak fluent English in the session and attended an English speaking school. He has previously taken antidepressant medication, and had weekly sessions with a psychologist for two months, though his mother reported little improvement. P5's main fears and worries were related to changes in routine and structure, new situations, tests and school work, someone "getting angry" with him and loud noises. On the SCARED, P5 scored 46. On the KBIT-2, P5 scored 58 for verbal IQ, 81 for non-verbal IQ and 65 for composite score.

No significant reductions in anxiety were found for P5 on the SCAS-P total score (RCI = 1.14). Significant reductions in anxiety were however found for the SCAS-C total score (RCI = 2.12). There was no significant reduction in anxiety life interference on the CALIS total score (RCI = 1.13). On the child reported SDQ emotional problems subscale, P5 initially scored in the borderline range, and this increased to the abnormal range by the end of the program. P5's initial score on the peer problems subscale of the SDQ was in the abnormal range and this reduced to the borderline range by the end of the treatment.

Participant 6 (P6)

P6 was an 8 year 8-month old male, with ID and comorbid ASD. He had not previously received any intervention for anxiety or other mood disorders. P6 experienced claustrophobia and was scared of being in the car for too long with the window rolled up, elevators and small rooms. On the SCARED, P6 scored 39. On the KBIT-2, P6 scored 81 for verbal IQ, 69 for non-verbal IQ and 71 for composite score.

Significant reductions in anxiety were found for P6 on the SCAS-P total score (RCI = 4.92) and the SCAS-C total score (RCI = 4.55). There was no significant reduction in anxiety life interference on the CALIS total score (RCI = 1.32). On the child reported SDQ emotional problems subscale, P6 initially scored in the normal range, and this remain so at the end of treatment. P6's initial score on the peer problems subscale of the SDQ was initially in the normal range and remained so at the end of the treatment.

Participant 7 (P7)

P7 was a 15 years 1-month old female, with ID and rare genetic condition. Her mother a reported a history of anxiety and weekly to fortnight sessions with a psychologist approximately three years' prior, spanning for almost one and a half years. P7 was reported to experience very distressing nightmares which have resulted in a fear of the dark. Her mother also reported that P7 would experience general worry about the future. On the SCARED, P7 scored 40. On the KBIT-2, P7 scored 75 for verbal IQ, 75 for non-verbal IQ and 71 for composite score.

No significant reductions in anxiety were found for P7 on the SCAS-P total score (RCI = 0.00). Reductions in anxiety were found for the SCAS-C total score, but this was not significant (RCI = 1.52). There was a significant reduction in anxiety life interference on the CALIS total score (RCI = 3.01). On the child reported SDQ emotional problems subscale, P7 initially scored in the normal range, and this remain so at the end of treatment. P7's initial score on the peer problems subscale of the SDQ was initially in the normal range and remained so at the end of the treatment.

Participant 8 (P8)

P8 was a 16 year 11-month old male with an ID and comorbid ASD and ADHD. His general practitioner had also diagnosed him with anxiety, and he had received psychological intervention on four occasions, over a four-week period in the previous year. P8 was fearful of loud and unexpected noises such as thunder, fireworks. He was also scared of dogs and cockroaches, and would become anxious about being late and changes in routine. On the SCARED, P8 scored 43. On the KBIT-2, P8 scored 40 for verbal IQ, 40 for non-verbal IQ and 40 for composite score.

No significant reductions in anxiety were found for P8 on the SCAS-P total score (RCI = -0.47) or on the SCAS-P total score (RCI = 0.61). There was a significant reduction in anxiety life interference on the CALIS total score (RCI = 2.07). On the child reported SDQ emotional problems subscale, P8 initially scored in the abnormal range, and this had reduced to the borderline range at the end of the treatment. P8's initial score on the peer problems subscale of the SDQ was initially in the normal range and remained so at the end of the treatment.

Participant 9 (P9)

P9 was a 9 year 10-month old female with diagnosed ID, ASD, Epilepsy and Cerebral Palsy. Her mother reported P9 as fearful of storms, rain, and losing her mother. On the SCARED, P4 scored 38. On the KBIT-2, P9 scored 65 for verbal IQ, 78 for non-verbal IQ and 71 for composite score.

No significant reductions in anxiety were found for P9 on the SCAS-P total score (RCI = 0.23). Significant reductions in anxiety were however found for the SCAS-C total score (RCI = 4.55). There was no significant reduction in anxiety life interference on the CALIS total score

(RCI = 0.19). On the child reported SDQ emotional problems subscale, P9 initially scored in the normal range and remained so at the end of the treatment. P9's initial score on the peer problems subscale was in the abnormal range, and this had reduced to the normal range at the end of treatment.

The following spaghetti graphs depict the changes in self reported anxiety (Figure 1), parent reported anxiety (Figure 2) and anxiety life interference (Figure 3) for the nine participants.

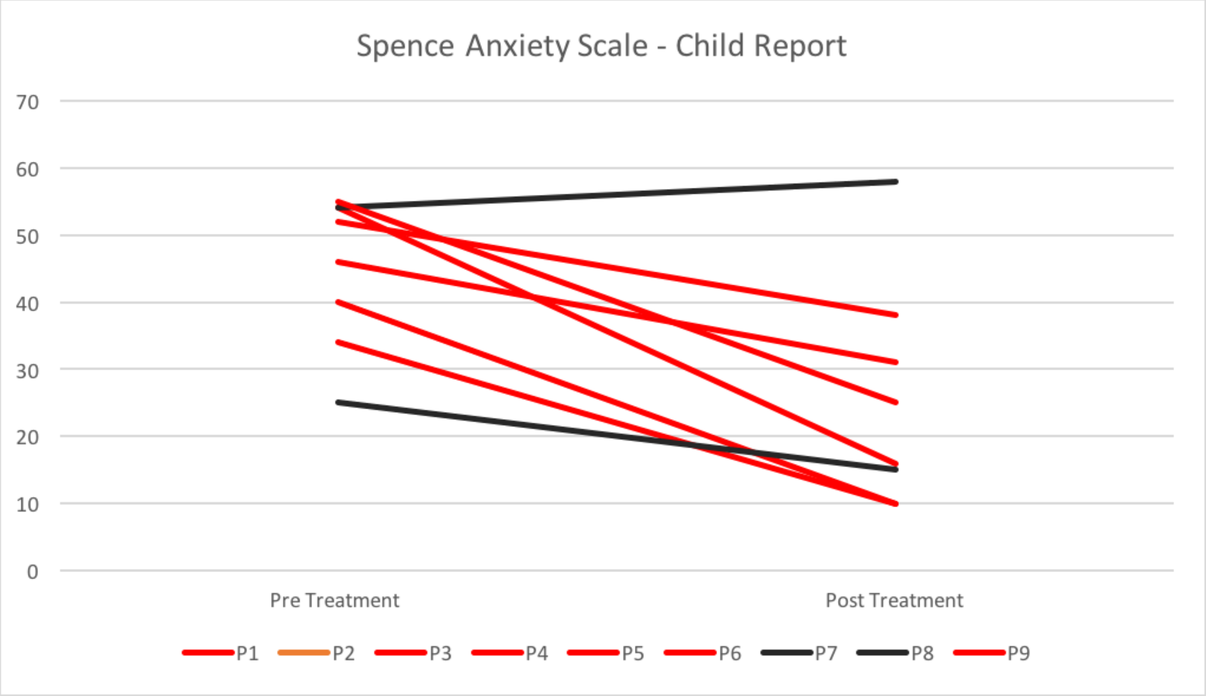

Figure 1. Changes in anxiety on the Spence Anxiety Scale – Child Report.

Note: red lines indicate significant change using the RCI.

Note: data is missing for P2.

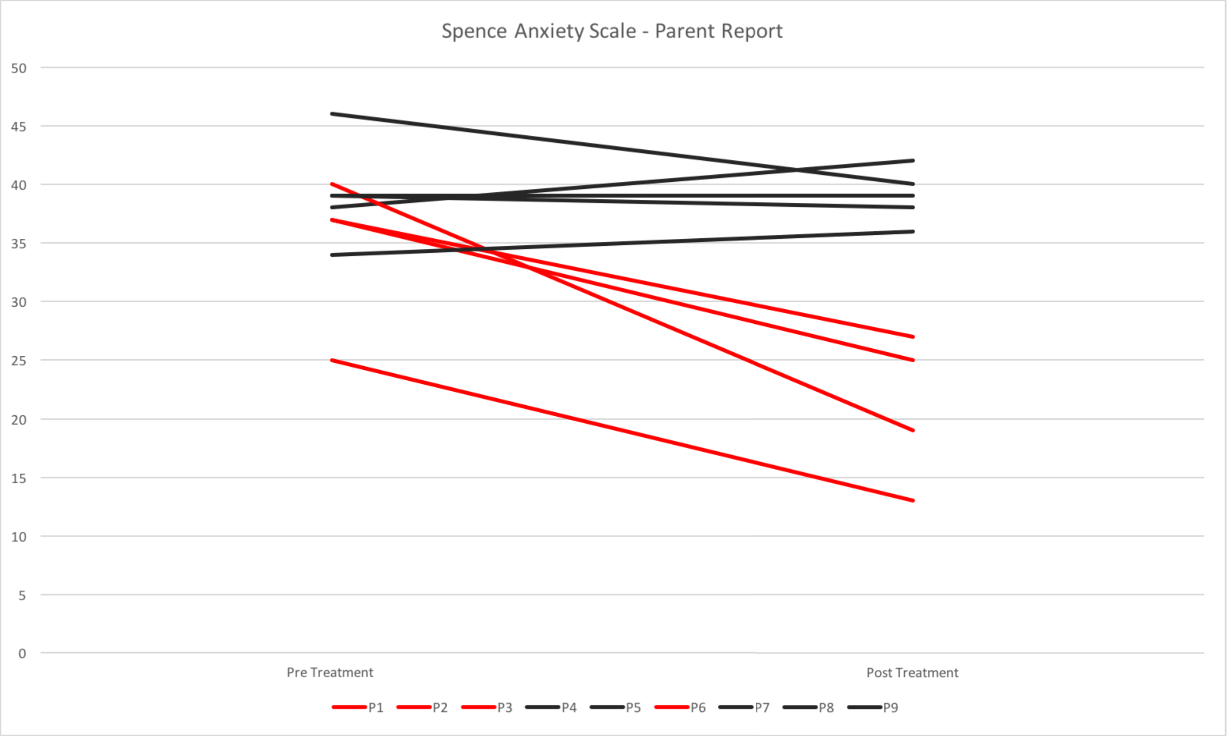

Figure 2. Changes in anxiety on the Spence Anxiety Scale – Parent Report.

Note: red lines indicate significant change using the RCI.

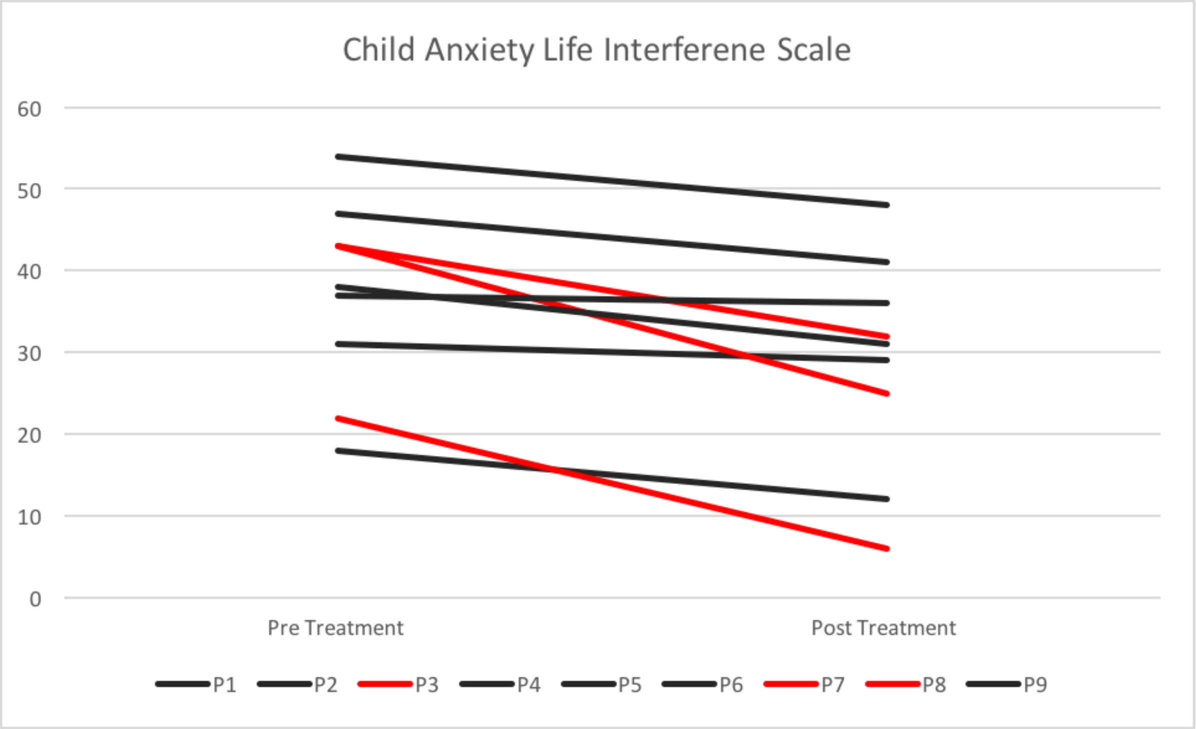

Figure 3. Changes on the Child Anxiety Life Interference Scale.

Note: red lines indicate significant change using the RCI.

Discussion

This study aimed to evaluate the impact of *Fearless Me ©,* a CBT intervention for children with ID and anxiety via RCT. Recruitment and resource issues meant it was only possible to consider individual case changes. It was hypothesized that the intervention would reduce anxiety for children who participated, and this was supported by the results. All children had significant reductions on at least one measure of anxiety or anxiety life interference. Seven children had significant reductions in anxiety on the self-reported measure of anxiety, four children had significant reductions in anxiety based upon the parent measure of anxiety, and three children had significant reductions on the measure of anxiety life interference. Some children also had reductions in the self-reported emotional and peer subscales of the SDQ. Only one child (P5) self-reported an increase in SDQ scores on one subscale. There were no significant reductions on the EDQ-P or SDQ-P.

To our knowledge, this study is the first to consider the use of CBT for anxiety in children with ID. The results of this study indicate that CBT shows promise for use with children and adolescents with mild to moderate ID, when adapted for their learning needs. A strength of the current study was that parents were involved for the majority of the client sessions, and actively assisted children with completion of homework tasks outside of sessions. The active involvement of parents also enabled data to be collected from both the child and parents, unlike in the initial feasibility trial (Hronis, Roberts, Roberts & Kneebone, 2019a) where parents were not involved and there was very low rate of completion of parental report measures.

There were a number of limitations to the research. Primarily a pilot RCT was not able to be conducted due to low recruitment and resource issues. The small population from which to recruit was a relevant and practical barrier to the research, as 3% of the population of Australia (including both adults and children) are estimated to have an ID (Australian Institute of Health and Welfare, 2008). As a result of the practical limitations to recruitment, the *Fearless Me!* © program was instead evaluated by single case reliable change analysis. While this level of analysis does not hold the same position as an RCTs within the evidence hierarchy, it is acknowledged it remains important for hypothesis generation and can lay the groundwork for controlled trials (Burns, Rohrich & Chung, 2011). Case series evaluations have been identified as particularly useful when a condition is uncommon (Parab & Bhalerao, 2010), and can produce the first evidence for the effectiveness of a new therapy (Nakamura, Igarashi, Ito & Jensen, 2014). A further limitation to the current trial is that the majority of the measures used have not been validated within ID populations. They may not be valid, reliable or sensitive to change among children with ID. That said, the current and previous feasibility evaluation (Hronis, Roberts, Roberts & Kneebone, 2019a) do provide, albeit limited evidence of this. It should also be acknowledged the sample of children in the study may potentially be biased to those families who are open to seeking psychological treatment for their child. Finally, the therapists delivering the treatment were not blind to treatment conditions when completing the outcome assessment measures with the children.

Overall, despite it's limitations, this evaluation provides a sound basis for continued investigation and research into the use of the *Fearless Me!* © program for children with ID and anxiety issues. A fully powered RCT should be undertaken. The current research also indicates the possibility for children with ID to be able to engage in more cognitive based therapies such as CBT, and encourages research to be conducted into the use of CBT for other emotional and mental health disorders within this population.

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Chapter 12

Discussion

Thesis Overview

The overall aim of this research was to develop and evaluate an adapted CBT intervention for children with mild to moderate ID and anxiety. The research aims were achieved through five sequential studies. First, a narrative literature review was conducted to understand the neuropsychological deficits of children with mild to moderate ID, the impact these deficits may have on therapy, and the adaptations to therapy which could accommodate for such deficits (Chapter 3; Hronis, Roberts & Kneebone, 2017). Following this, parents of children with ID were asked to provide their perspectives around their child's potential to engage in a cognitive based therapy such as CBT (Chapter 5; Hronis, Roberts, Roberts & Kneebone, 2019b). Next, clinicians were surveyed to understand attitudes around working with people with ID (Chapter 7; Hronis, Roberts & Kneebone, 2018). On this basis, an adapted CBT program was developed, called *Fearless Me!* © (Chapter 8; Hronis, Roberts, Roberts & Kneebone, 2018), and feasibility was evaluated in a non-clinical (Chapter 9; Hronis, Roberts, Roberts & Kneebone, 2019a) and clinical sample (Chapter 11). Overall, the studies demonstrated that *Fearless Me!* ©, a modified CBT program, is feasible, acceptable and potentially effective in reducing anxiety when delivered to children with mild to moderate ID, or borderline intellectual functioning, aged between 8 to 17 years of age. The results suggest that children with ID do have the cognitive capabilities to engage with cognitive based therapies such as CBT, provided that therapy is adapted to meet their unique learning needs. This chapter summarises the key findings of each study, the theoretical and practical implications of the research, the strengths and limitations of the methodology, and future research directions.

Review of Thesis Findings

Study 1 – A review of cognitive impairments in children with intellectual disabilities: Implications for cognitive behaviour therapy

The aim of this study was to conduct a narrative review of the pertinent literature on the neuropsychological profiles of children with mild to moderate ID, and propose a developmentally informed framework for effectively adapting and implementing CBT among children with ID (Chapter 3; Hronis et al., 2017). The review considered studies which addressed the neuropsychological domains of attention, working memory, learning, executive functioning, language and reading. For each domain, the cognitive profile of children with ID was identified, the impact of the deficits upon CBT were considered, and adaptations to accommodate for such deficits in therapy were proposed. The study concluded that while children with ID do have deficits which would impact upon the process and effectiveness of CBT, modifications to CBT to compensate for these, and allow for their participant for them potentially benefit from one of the most empirically supported of psychological therapies.

Study 2 – Potential for children with Intellectual Disability to engage in Cognitive Behaviour Therapy: The parent perspective

The aim of this study was to gather the opinions of parents and carers of children with ID, as to whether they thought CBT could be useful for their child, what challenges they anticipated, and how these might be overcome (Chapter 5; Hronis et al., 2019b). A mixed qualitative and quantitative methodology was employed. Twenty-one parents/carers of children aged 10 to 17 responded to an online questionnaire. Parents were provided with information about the basic components of CBT and its proposed mechanism of action, and then asked to respond to open-ended questions. Quantitative data collected pertained to questions on a five point Likert scale as to their child's ability to identify and describe thoughts, feelings and behaviours.

From the qualitative data analysis, five themes emerged: *Emotional Attunement* (i.e. parent's understanding and recognition of their child's emotions), *Role of the Therapist* (i.e. ways in which the therapist could engage with the child to facilitate the intervention), *Role of the Parent* (i.e. ways in which the parents could engage in the therapy process), *Anticipated Obstacles* (i.e. what parents believe could get in the way of the therapy), and *Suggested Adaptations for Therapy* (i.e. how CBT can best be adapted to suit the specific needs of children with ID). The suggested adaptations to therapy were similar to those proposed from the narrative literature review. The majority of parents agreed that their child would be able to engage in CBT with assistance. Overall, the study indicated promise for the use of CBT for children and adolescents with ID and mental health disorders. The majority of parents believed that CBT is an intervention which children with ID could engage in, provided that the therapy and therapist adapted it to suit the child's needs. This further supports the future evaluation of CBT as an intervention for children with comorbid ID and mental health disorders.

Study 3 – Assessing the confidence of Australian mental health practitioners in delivering therapy to people with Intellectual Disability

Study 3 (Chapter 7; Hronis, Roberts & Kneebone, 2018) aimed to evaluate the confidence of Australian clinicians in providing therapy to people with ID, as clinician confidence has been identified as one barrier to people with ID accessing psychological services (Dagnan, Masson, Cavagin, Thwaites & Hatton, 2015; Rose, O'Brien & Rose, 2007). An online questionnaire was distributed including the Therapy Confidence Scale – Intellectual Disabilities (TCS-ID; Dagnan et al., 2015), which assesses confidence for various therapeutic processes such as building rapport, explaining procedures, and identifying appropriate treatment approaches. The questionnaire also assessed knowledge of existing treatment guides and protocols, and participants were asked to rate if they thought using treatment guides with clients with ID would improve the quality of their therapy and increase their confidence when providing treatment.

The survey was completed by 152 psychologists and counselors working in Australia. Overall, clinicians were most confident with generic counselling skills when working with clients with ID, including being empathic, listening to client concerns and working with caregivers. Clinicians were least confident with the clinical components of treatment, such as using assessments, explaining assessment results, identifying effective therapeutic approaches and implementing interventions. The majority of participants identified that using treatment guides would result in better therapy and greater confidence, particularly among those with low rating of confidence on the TCS-ID. The study findings highlight the need for greater research in the area of treatments for people with ID, and the needs for dissemination of treatments guides to help clinicians confidently select and implement interventions.

Study 4 – *Fearless Me!* ©: A feasibility case series of cognitive behavioural therapy for adolescents with Intellectual Disability

The aim of this study was to evaluate the feasibility of the *Fearless Me!* © therapy program (Hronis, Roberts, Roberts & Kneebone, 2018), an adapted CBT intervention for children with mild to moderate ID (Chapter 9; Hronis et al., 2019a). It was hypothesised that the intervention would be feasible and acceptable, given that it had been designed specifically for the needs of children and adolescents with mild to moderate ID. Furthermore, it was predicted that *Fearless Me!* © would contribute to reductions of anxiety for those participants with heightened levels of anxiety before the treatment. Twenty-one girls aged 12–18 years participated in the program. All adolescents had ID in the mild to moderate range, except one participant who was within the borderline range of intellectual functioning. The treatment was delivered to participants at their school, in two pre-assigned classes. There were ten sessions over a period of six weeks. This involved twenty hours to therapy in total, all of which was delivered by the primary researcher and doctoral candidate.

The results of the study indicate that overall, the *Fearless Me!* © program is appropriate, feasible and acceptable among adolescents with mild to moderate ID, with good uptake and engagement. Teacher measures of anxiety on the School Anxiety Scale-Teacher Report (SAS-TR; Lyneham, Street, Abbott, & Rapee, 2008), indicated that the majority of participants who had elevated levels of anxiety prior to the program had either significant reductions in anxiety, or reductions which placed them within the non-elevated range of anxiety. A limitation of this work was the low completion rate of data from parents, and the limited involvement of parents in the program, likely explaining the highly limited adherence to homework. Given the established feasibility of the program, it was recommended that *Fearless Me!* © be administered in a clinical population, with revisions to support parents' active involvement in treatment.

Study 5 –Evaluation of the *Fearless Me!* © Program for Children with Intellectual Disability and Anxiety

The final study (Chapter 11) aimed to build upon the feasibility evaluation of the *Fearless Me!* © program via a pilot RCT evaluating the effectiveness of *Fearless Me!* © in reducing anxiety for children and adolescents with ID. Nine children, aged between 8 and 17, participated in the treatment. They had mild or moderate ID, or intellectual functioning in the borderline range, and either clinical or sub-clinical levels of anxiety. Treatment was delivered in a one to one format, with parents present for most sessions. The program involved an initial assessment session, followed by ten therapy sessions, and a post therapy assessment session. This involved approximately 150 hours of therapy and assessments, approximately half of which were delivered by the primary researcher and doctoral candidate.

While the study was originally designed as a pilot RCT, due to issues with recruitment and limited resources, individual cases were evaluated using the Reliable Change Index (RCI; Jacobson & Truax, 1991) to calculate changes for each participant. The results indicated that all children had significant reductions on at least one measure of anxiety/anxiety interference (i.e. either child reported anxiety, parents reported anxiety, or parents reported anxiety life interference). The case series supports the use of adapted CBT and the *Fearless Me!* © program, as interventions which can be used to treat anxiety disorders among children with ID. It is hoped that this research supports the future use of cognitive based therapies for children with ID.

Reflections on the Implementation of the Program

Overall it appeared that the participants enjoyed the program, found the online website to be engaging, and benefited from the strategies taught to reduce anxiety. Anecdotal reports from the parents and children in the feasibility school evaluation and the pilot individual therapy evaluation support this. In particular, it seemed the animations and titles of the exercises facilitated children remembering the strategies to use (i.e. renaming progressive muscle relaxation to “Squeeze and Relax”, the story of “Brave Ben” to explain the purpose of exposure hierarchies etc.). It was noted from the school feasibility program that children with moderate ID had more difficulty understanding the concepts than those with mild OD or IQ in the borderline range, as could be expected. Children with moderate ID required more time to consolidate the cognitive component of the program, which is why the flexible session nine was added into the final case series evaluation. From the facilitator's perspective, the program structure was easy to follow, however was easier to apply in the individual therapy context rather than a group of 10 participants, despite having disability support teachers involved. The lack of parental involvement in the school program was also noted to be a significant barrier to homework completion. Future groups, whether in a school setting or clinic, would benefit from being smaller in size (approximately 5 participants), with parents present.

Implications of the Research

The current body of research supports and adds to the existing literature on CBT for people with ID. As CBT has been adapted for adults with ID and children with other developmental disabilities (see Chapter 1 for a review), the current research indicated that it can also be used amongst children and adolescents with ID. There are several practical implications of this program of research. Most important is support that CBT is a treatment which can feasibly be delivered to children with ID. This counters skepticism about the ability of people with ID to engage in cognitive based therapies such as CBT one of the most empirically supported psychological therapies. While research had shown that this has been possible for adults with ID (e.g. Hassiotis et al., 2013; Osugo & Cooper, 2016; Vereenooghe & Langdon, 2013), previously there was no research to the author's knowledge, showing that the same was possible for children with ID. To date, the main interventions which have been used amongst children with ID and comorbid mental health disorders, have been behavioural interventions or medications. The program of research reported here provides evidence that CBT is an additional treatment option which can be considered when deciding upon interventions to implement with a child with ID and anxiety. This also opens the potential for other psychological interventions with cognitive components, to be adapted, trialed and evaluated amongst children with ID, such as Acceptance and Commitment Therapy, Mindfulness Integrated Cognitive Behaviour Therapy, and Dialectical Behaviour Therapy, as has been used amongst typically developing children (e.g. Groves, Backer, van den Bosch & Miller, 2012; Halliburton & Cooper, 2015; Swain, Hancock, Dixon & Bowman, 2015). This may further widen the scope of potential treatment options for children and adolescents with ID.

Another significant implication of the current research is linked to the development of the *Fearless Me!* © treatment manual and website. The feedback provided by clinicians indicated that they did not feel confident working clinically with clients with ID, and that treatment protocol, manuals and resources would assist them to deliver better therapy, more confidently (Hronis, Roberts & Kneebone, 2018). As clinician confidence has been one of the barriers identified to people with ID not accessing psychological treatments, it is hoped that the development of the *Fearless Me!* © resources will help clinicians feel more confident to deliver CBT to children with ID, and hopefully reduce one of the barriers to treatment. In this way, the current research shows the potential to expand access to treatment for children with ID. The website is also available for children and their families to use on an ongoing basis, allowing for them to consolidate and review the skills they have learnt during therapy.

Primary Strengths and Limitations of the Research

First and foremost, to our knowledge, this program of research is the first of its kind. It supports CBT *can* be used with children and adolescents with ID, potentially bridging the gap between clinical needs and service availability. A particular strength of the research is that the development and evaluation of *Fearless Me!* © followed standard frameworks for the development and evaluation of complex interventions and e-Health treatments (as per Chapter

2). A rigorous process of evaluation, involving existing literature, multiple stakeholders and continuous feedback was employed, to ensure that the needs of the participants were being met as adequately as possible. All elements of the development and evaluation process outlined within the Medical Research Council Framework (MRC; Craig et al., 2008), including development, feasibility/piloting, evaluation and implementation, were utilized. The development of *Fearless Me!* © was theoretically informed by the existing neuropsychological literature, along with the feedback of various stakeholders. Consistent with the Medical Research Council recommendations (Craig et al., 2008), feasibility of the program was established before an evaluation within a clinical sample. This ensures a cost-effective approach to evaluation and can inform directions for methodology and design before conducting a larger RCT.

Another strength of this research was the output which was produced, in the form of a treatment manual (Hronis, Roberts, Roberts & Kneebone, 2018) and website (www.fearlessme.com.au). The development of these resources addresses one of the barriers identified to people with ID accessing treatments and can hopefully increase the confidence of clinicians (Dagnan et al., 2015; Hronis, Roberts, Kneebone, 2018). There is evidence to suggest that following treatment manuals and protocols produces better outcomes for patients, while the tendency by psychologists not to implement empirically supported practices results in therapist drift (Waller, 2009). Importantly, the clinicians involved in providing feedback as part of the current research highly endorsed the concept of treatment manuals and guides when working with people with ID, which hopefully might support a higher uptake.

Another strength of this research was that feedback and data was consistently collected from various stakeholders throughout the development and evaluation phases of the research.

This included the involvement of children with ID, parents of children with ID, clinicians and teachers. In the initial feasibility evaluation, data was collected from both participating children and the classroom teacher (Hronis et al., 2019a). Data collection from parents was also attempted at this phase, however with little success due to not having direct contact with caregivers. In the case series evaluation of *Fearless Me!* © among the clinically anxious sample of children with ID*,* data was collected from the children and adolescents as well as their parents. The collection of data from multiple sources allows for a range of feedback to ensure that the program is most adequately meeting the needs of the target population, with best practice involving the collection of data from parents, teachers and children.

There were a number of limitations to the current body of research. Firstly, the measures of anxiety which were administered and used as the primary measures to determine effectiveness have not been validated amongst children and adolescents with ID. These include the Spence Children's Anxiety Scale Child Report and Parent Report (Spence, 1998; Nauta et al., 2004). Furthermore, there was no formal assessment of the cognitive functioning or literacy skills of the adolescents who participated in the feasibility school evaluation, but rather information was gathered based upon the school reports, meaning that differences according to literacy skills or IQ could not be explored. Secondly, it is noted that the sample of children and parents who participated in the evaluations may have been biased. It is possible that parents who enrolled their child in the case series evaluation were more open to the concept of cognitive and psychological therapy. It would be important for future studies to determine whether similar results were gained within a community sample. Thirdly, the studies conducted were of limited sample sizes due to limited resources and difficulties with recruitment. While these initial trials provide promising outcomes, this may impact the degree to which the results can be generalized to other children with ID. Larger scale RCT evaluations are required.

Another limitation to the current research was the impact that a manualised program may have had on clinical outcomes for children completing the *Fearless Me* © program. While manusalised programs were endorsed by clinicians when surveyed about their needs for additional resources, it is likely that these in practice would be implemented with some degree of flexibility, regarding number of sessions, how much content was covered each session, frequency of sessions etc. It is recommended in the narrative review (Hronis, Roberts & Kneebone, 2017) that these factors all be adjusted to suit the individual learning needs of a child, given the spectrum of difficulties that a child with ID can present with. The therapy was delivered over ten weeks however it is likely that some children may have benefited further from the program being delivered over additional sessions or a longer period of time. Additionally, long term follow-up of the participants after receiving the treatment has not been conducted, and thus information about whether the positive effects of the treatment are sustained is unclear. There was no formal attempt to gather feedback from the school feasibility program as to how the young people felt about the acceptability of the intervention, but this was rather based on anecdotal evidence. The participants in this study were also all female, as the school was an all female school, meaning that data was not collected from males and thus it is not possible to tell if there may have been differences in acceptability or feasibility for males. A stable baseline was not able to be established for all the participants in the school group feasibility study as the program was run as a group and had a fixed start date, which has an impact on attributing the findings to the treatment as opposed to regression towards the mean. Finally, there were no treatment fidelity checks included for the preliminary feasibility and pilot evaluations, which future evaluations should include.

Future Research Directions

The current body of research is important as it has provided an initial contribution to the literature on using CBT with children who have ID. However, there is significant scope to build upon the research, given the promising results. There are several possible directions for future research. Given the establishment of the feasibility of the *Fearless Me!* © program, and the case series results supporting its ability to reduce anxiety among children with ID, it is recommended that the next phase of research continues with the planned pilot RCT in order to establish recruitment and retention rates, outcome measure validity and reliability, effect sizes and power calculations to run a fully powered RCT. It is recommended that through this evaluation, feedback is gathered from the parents and children themselves in order to ascertain the elements of the program which they found most/least useful and enjoyable, and to gather views as to how the program could be further improved. Further research should also be undertaken to examine the effectiveness of the program when run with clinical populations in group settings while still incorporating parental involvement. Delivering the program in schools would be a cost-effective and efficient means of providing the *Fearless Me!* © treatment to children with ID.

There is also scope for adapted CBT to be trialed for children with ID and comorbid mental health disorders, other than anxiety. For many other mood disorders such as depression, post traumatic stress disorder, and obsessive compulsive disorder, there is solid evidence to support the use of CBT in typically developing children (David, Cristea & Hofmass, 2018). In the same way that CBT was adapted the trialed for children with ID and anxiety, it is recommended that CBT be adapted and trialed for children with ID and other mental health conditions. Furthermore, the current research exemplifies that children with ID can engage in and benefit from cognitive based therapies, and as mentioned above, there may be potential for future work adapting other third-wave cognitive behavioural therapies for children with ID such as Acceptance and Commitment Therapy, Mindfulness-Integrated Cognitive Behaviour Therapy, and Dialectical Behaviour Therapy. This may further widen the scope of potential treatment options for people and children with ID. Further evaluations would be enhanced with measures which are validated for children and adolescents with ID, as many of the measures used in the current research have not yet been validated amongst children with ID.

Given that clinicians in Australia report limited confidence when working with people and children with ID, there is also future scope to assess whether the provision of a treatment guide and program such as *Fearless Me!* © increases confidence. The treatment manual is hypothesized to meet the needs of clinicians who endorsed the availability of manuals and treatment guides (Hronis, Roberts & Kneebone, 2018). A lack of training for practitioners, and a lack of specialized services for people with ID have been identified as barriers to the accessibility of health and mental health services (Buckles, Luckasson & Keefe, 2013; Michael 2008). Mental health clinicians often view themselves as having inadequate training in working with people with mental disorder and ID (National & NSW Councils for Intellectual Disability, 2011; Werner & Stawski, 2012). Future research could consider the best means of training clinicians in adapting CBT for children and adolescents with ID.

In addition, future research may benefit from considering the inclusion of specific interventions for parents within the *Fearless Me!* © program. Parents of children with ID are more likely to experience reduced wellbeing compared to parents of typically developing children (Hastings & Beck, 2004). Developing and delivering effective psychosocial interventions to reduce distress for parents whose children have ID is critical due to the long term impact parents distress can have on the family system (Hastings, 2002; Resch, Benz &

Elliott, 2012). MiCBT for carers of children with developmental disabilities has preliminary evidence indicating its potential to reduce psychological distress (Osborn et al., 2018). Incorporating parent only sessions, or online modules which are aimed to reduce parental distress utilizing MiCBT may be beneficial to the child, carer and family system. Furthermore, targeting systematic factors contributing to anxiety and parenting strategies may in turn have a reciprocal relationship upon child behaviour and anxiety (Crnic, Neece, McIntyre, Blacher & Baker, 2017).

Conclusions

To our knowledge, this body of research is the first of it's kind. CBT has been shown to be effective for children without ID, and adults with ID, however had not previously been trialed amongst children with ID. The *Fearless Me* © program is a developmentally informed adapted CBT program, designed to fill part of the gap in evidence and resources, and to create an accessible tool for clinicians and clients to use. The positive results of the current research in understanding how to adapt CBT for the needs of children with ID, and the reductions in anxiety for children with ID exhibited, support the future use of CBT and the *Fearless Me!* © program among children and adolescents with ID.

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APPENDIX A

Ethical Approval for Studies

UTS

20th October, 2017

Dear Ms Hronis,

Re: “Assessing the Cognitive Functions of Children with Intellectual Disability” UTS HREC REF NO. 2015000482-32

Thank you for submitting your proposed research protocol amendment to the **"Program Approval: Low Risk Research MPsych (Clinical) Program Graduate School of Health"** which has been granted approval by the UTS Human Research Ethics Expedited Review Committee to review low risk research within the Discipline of Clinical Psychology. I am pleased to inform you that the requested amendment for the above project has been approved.

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact me at David.Berle@uts.edu.au.

Yours sincerely,

Production Note:
Signature removed
prior to publication.

Dr David Berle
Program Ethics Coordinator (Discipline of Clinical Psychology)
University of Technology Sydney

Ethics Approval UTS HREC REF NO. 2015000482-21

Robert Brockman <Robert.Brockman@uts.edu.au>

Tue 17/11/2015 13:03

To: Lynette Roberts <Lynette.Roberts@uts.edu.au>; Anastasia Hronis <Anastasia.Hronis@student.uts.edu.au>;

Dear Applicant/s,

Thank you for submitting your research project for internal ethical review under the "**Program Approval: Low Risk Research MPsych (Clinical) Program Graduate School of Health**" which has been granted approval by the UTS Human Research Ethics Expedited Review Committee to review low risk research within the Discipline of Clinical Psychology. I am pleased to inform you that program ethics approval is now granted for your research titled **"Assessing the confidence of Australian mental health practitioners in delivering therapy to people with intellectual disabilities"** with the following conditions:

1. That the title is changed to "Mental Health Practitioners".

Your approval number is **UTS HREC REF NO. 2015000482-21.** Approval will be for a period of two (2) years from the date of this correspondence. After this period has lapsed, approval will automatically cease unless an extension has been sought and approved in writing.

You should consider this your official letter of approval. If you require a hardcopy please contact Robert Brockman (Robert.Brockman@uts.edu.au).

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact me at Robert.Brockman@uts.edu.au.

Yours sincerely,

Dr Robert Brockman
Lecturer & Clinic Supervisor
Graduate School of Health | **University of Technology, Sydney**
Level 4, Building 7
67 Thomas St, Ultimo NSW 2007 (PO Box 123)
T +61 2 9514 1448 **F**+61 2 9514 8300
E Robert.Brockman@uts.edu.au **W** clinicalpsychology.uts.edu.au

Think. Change. Do

20th October, 2017

Dear Ms Hronis,

Re: "Can children with intellectual disability engage in cognitive behavior therapy? The parent perspective" UTS HREC REF NO. 2015000482-54

Thank you for submitting your proposed research protocol amendment to the **"Program Approval: Low Risk Research MPsych (Clinical) Program Graduate School of Health"** which has been granted approval by the UTS Human Research Ethics Expedited Review Committee to review low risk research within the Discipline of Clinical Psychology. I am pleased to inform you that the requested amendment for the above project has been approved.

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact me at David.Berle@uts.edu.au.

Yours sincerely,

Production Note:

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prior to publication.

Dr David Berle
Program Ethics Coordinator (Discipline of Clinical Psychology)
University of Technology Sydney

HREC Approval Granted - ETH18-2384

Research.Ethics@uts.edu.au

Wed 21/11/2018 2:09 PM

To: Ian Kneebone <Ian.Kneebone@uts.edu.au>; Anastasia Hronis <Anastasia.Hronis@uts.edu.au>; Senali Panditaratne <Senali.Panditaratne@student.uts.edu.au>; Lynette Roberts <Lynette.Roberts@uts.edu.au>; Research Ethics <research.ethics@uts.edu.au>

Dear Applicant

Thank you for your response to the Committee's comments for your project titled, "Fearless Me!: A Pilot Randomised Controlled Trial (RCT) of an Innovative Treatment Program for Children with Intellectual Disability and Anxiety". The Committee agreed that this application now meets the requirements of the National Statement on Ethical Conduct in Human Research (2007) and has been approved on that basis. You are therefore authorised to commence activities as outlined in your application on the condition that the screening script is provided to the HREC prior to the commencement of the study.

You are reminded that this letter constitutes ethics approval only. This research project must also be undertaken in accordance with all UTS policies and guidelines including the Research Management Policy (http://www.gsu.uts.edu.au/policies/research-management-policy.html).

Your approval number is UTS HREC REF NO. ETH18-2384.

Approval will be for a period of five (5) years from the date of this correspondence subject to the submission of annual progress reports.

The following standard conditions apply to your approval:

- Your approval number must be included in all participant material and advertisements. Any advertisements on Staff Connect without an approval number will be removed.

- The Principal Investigator will immediately report anything that might warrant review of ethical approval of the project to the Ethics Secretariat (Research.Ethics@uts.edu.au).

- The Principal Investigator will notify the UTS HREC of any event that requires a modification to the protocol or other project documents, and submit any required amendments prior to implementation. Instructions can be found at https://staff.uts.edu.au/topichub/Pages/Researching/Research%20Ethics%20and%20Integrity/Human%20research%20ethics/Post-approval/post-approval.aspx#tab2.

- The Principal Investigator will promptly report adverse events to the Ethics Secretariat (Research.Ethics@uts.edu.au). An adverse event is any event (anticipated or otherwise) that has a negative impact on participants, researchers or the reputation of the University. Adverse events can also include privacy breaches, loss of data and damage to property.

- The Principal Investigator will report to the UTS HREC annually and notify the HREC when the project is completed at all sites. The Principal Investigator will notify the UTS HREC of any plan to extend the duration of the project past the approval period listed above through the progress report.

- The Principal Investigator will obtain any additional approvals or authorisations as required (e.g. from other ethics committees, collaborating institutions, supporting organisations).

- The Principal Investigator will notify the UTS HREC of his or her inability to continue as Principal Investigator including the name of and contact information for a replacement.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval. If you require a hardcopy please contact Research.Ethics@uts.edu.au.

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact Research.Ethics@uts.edu.au.

Yours sincerely,

Dr Tim Luckett
(Acting) Chairperson
UTS Human Research Ethics Committee
C/- Research & Innovation Office
University of Technology, Sydney
E: Research.Ethics@uts.edu.au

REF: E38

APPENDIX B

Brief report published in the Journal of Intellectual Disability Research based on the findings in Chapter 5

Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. I. (2019). Potential for children with Intellectual Disability to engage in Cognitive Behaviour Therapy: The parent perspective. *Journal of Intellectual Disability Research.*

Statement of Authorship

Title of Paper	Potential for children with Intellectual Disability to engage in Cognitive Behaviour Therapy: The parent perspective.	
Publication Status	☒ Published	☐ Accepted for publication
	☐ Submitted for publication	☐ Unpublished and unsubmitted work written in manuscript style
Publication Details	Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. I. (2019). Potential for children with Intellectual Disability to engage in Cognitive Behaviour Therapy: The parent perspective. *Journal of Intellectual Disability Research.*	

Principal Author

Name of Principal Author (Candidate)	Anastasia Hronis		
Contribution to the Paper	Responsible for the development, collecting the data, data analysis and writing of the paper in collaboration with my supervisors. Served as the corresponding author and was responsible for the submission, revisions and responses to journal reviewers.		
Overall percentage (%)	80%		
Signature	Production Note: Signature removed prior to publication.	Date	21.10.2019

Co-Author Contributions

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate in include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of Co-Author	A/Prof Rachel Roberts		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (6.7%)		
Signature	Production Note: Signature removed prior to publication.	Date	09.12.2019

Name of Co-Author	Dr Lynette Roberts		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (6.7%)		
Signature	Production Note: Signature removed prior to publication.	Date	10.12.2019

Name of Co-Author	Prof Ian Kneebone		
Contribution to the Paper	Contributed to the conceptualisation of the research, interpretation of the results and revision of manuscripts. (6.7%)		
Signature	Production Note: Signature removed prior to publication.	Date	09.12.2019

Journal of Intellectual Disability Research doi: 10.1111/jir.12694

Brief Report

Potential for children with intellectual disability to engage in cognitive behaviour therapy: the parent perspective

A. Hronis,[1] **R. Roberts,**[2] **L. Roberts**[1] **& I. Kneebone**[1]

1 *Graduate School of Health, University of Technology Sydney, Ultimo, Australia*
2 *The University of Adelaide, Adelaide, Australia*

Abstract

Background This study aimed to obtain the opinions of parents and carers of children with intellectual disability (ID) as to whether cognitive behaviour therapy (CBT) could be useful for their children.
Methods A mixed qualitative and quantitative method was employed. Twenty-one carers of children aged 10 to 17 having borderline to moderate intellectual functioning responded to an online questionnaire. Participants were provided with information about CBT and asked to respond to open-ended questions. Quantitative data pertained to questions about their child's ability to identify and describe thoughts, feelings and behaviours. Thematic analysis of responses was conducted using an inductive method of identifying themes from the qualitative data collected.
Results Five themes emerged from the qualitative analysis: *Emotional Attunement* (i.e. parent's understanding and recognition of their child's emotions), *Role of the Therapist* (i.e. ways therapists could facilitate the intervention), *Role of the Parent* (i.e. ways parents could engage in the therapy process), *Anticipated Obstacles* (i.e. what may get in the way of the therapy) and *Suggested Adaptations for Therapy* (i.e. how CBT can be adapted to suit the needs of children with ID). Seventy-six per cent agreed that their child would be able to engage in CBT with assistance.
Conclusions The majority of parents believed that CBT is an intervention that children with ID could engage in, provided the therapy is adapted, and the therapist accommodates their needs.

Keywords children, cognitive behaviour therapy, intellectual disability, learning disability

Background

Up to 50% of children with intellectual disability (ID) have a comorbid mental illness (Einfeld et al. 2011; Tonge & Einfeld 2000). Because of deficits in intellectual functioning, treatments have largely involved behavioural interventions and use of medications (Vereenooghe & Langdon 2013). Recently, cognitive behaviour therapy (CBT) has been identified as an effective treatment for adults with mild to moderate ID and comorbid depression, anxiety and anger (e.g. Hassiotis et al. 2013; Osugo & Cooper 2016; Roberts & Kwan 2018; Vereenooghe & Langdon 2013). While similar trials have not been conducted among children with ID, CBT could be a treatment option for children with ID, provided adaptations are made (Hronis et al. 2017).

Correspondence: Ms Anastasia Hronis, Discipline of Clinical Psychology, Graduate School of Health, University of Technology Sydney, PO BOX 123, Broadway NSW 2007, AUSTRALIA. (e-mail: anastasia.hronis@uts.edu.au)

Neuropsychological deficits for children with ID have been identified in learning, memory, attention, executive functions and language. The impact on therapy and adaptations for therapy has been proposed specific to CBT (see Hronis et al. 2017).

Cognitive behaviour therapy is the gold standard intervention for many psychopathologies for children without ID (e.g. Cartwright-Hatton et al. 2004; Compton et al. 2004). At the foundation of CBT is the identification and linking of thoughts, emotions and behaviours, which adults with ID can do (Dagnan et al. 2000; Joyce et al. 2006; Oathamshaw & Haddock 2006; Sams et al. 2006). To our knowledge, this has not been evaluated among children with mild to moderate ID. Parents play a crucial role in the therapy process for children with and without developmental disabilities (Manassis et al. 2014; White et al. 2010). Involving parents is in line with family-centred practices for interventions for children, recognising that parent-therapist collaboration in planning and evaluating interventions is key, and based on the principle that parents know their child best (Hanna & Rodgers, 2002; Rosenbaum et al. 1998).

The aim of this study was to gather the opinions of parents who have children with ID about CBT. The researchers set out to understand if parents who have children with ID believe their child could engage in the process of CBT and factors associated with this. As to our knowledge, no research has previously investigated this, the study was exploratory.

Method

Procedure

This research was approved by the University Ethics Committee (approval number: 2015000482–54). Participants were recruited via online advertising through mental health organisations and social media. The study was advertised as seeking parents/carers of children with a mild to moderate ID, aged 10 to 17, to respond to questions online about how their child thinks and feels.

Measures

Parent report of child's ability to engage in CBT

Participants read information about CBT and rated their child's ability to express feelings, articulate thoughts, describe actions and link thoughts, feelings and behaviours. Parents rated on a 5-point Likert scale how often they know if their child is feeling happy, sad, angry and anxious/worried.

Emotions development questionnaire – parent form (Wong et al. 2009)

The Emotions Development Questionnaire – Parent Form (EDQ-P) assesses emotional understanding, emotional and behavioural regulation, theory of mind and problem solving in children with autism spectrum disorder, with or without ID (Ratcliffe et al. 2014). Quantitative data were used to supplement qualitative data to describe the emotional development of the sample. It has 29 items rated on a 5-point Likert scale, added to produce a total score. The EDQ-P has excellent internal consistency (α = .91; Ratcliffe et al. 2014), and was high in the current sample (α = 0.92). Higher scores indicate greater emotional understanding.

Open-ended questions

Participants were provided with information about the components of CBT, illustrated by a case example (Data S1), and responded to open-ended questions about their child's potential to engage in CBT (Data S2).

Data analysis

Descriptive statistics for quantitative data were calculated. Thematic analysis was used to analyze the qualitative data. This involved initial prolonged engagement with the data via repeated readings, coding of responses by two independent researchers and codes then collated into themes (Braun & Clarke, 2006).

Results

Participants

Participants were 21 parents/carers of children in Australia between the ages of 10 and 17 with a mild or moderate ID or borderline intellectual functioning. The average age was 13.33 (SD = 2.58). Based upon parent reports, 23% had mild ID, 33% had moderate ID, 10% were on the border of mild to moderate ID, 5% had borderline intellectual functioning and 29%

were unspecified. Comorbid diagnoses are reported in Table 1.

Quantitative data

Most participants reported they could often or almost always tell when their child was sad (76%), angry (76%) and happy (72%). 48% could often or almost always tell when their child was anxious or worried.

One third agreed that their child can describe their emotional state, while one third disagreed/strongly disagreed, and 24% were undecided (Figure 1). Fourteen per cent agreed their child can articulate their thoughts, while 43% disagreed/strongly disagreed, and one third were undecided. Twenty-four per cent agreed their child can describe their actions, however 33% disagreed/strongly disagreed, and one third were undecided. Finally, only 10% agreed that their child could link thoughts, feelings and behaviours, while 19% were undecided and over half (62%) disagreed/strongly disagreed. Overall, 76% agreed that their child would be able to participate in CBT with assistance.

Seventeen parents completed the EDQ-P, with scores ranging from 80 to 168 out of 200 (M = 108.1; SD = 19.9), indicating a range of emotional development within the sample.

Qualitative data

Length of responses ranged from a few words, to multiple sentences and were organised into five themes: (1) emotional attunement, (2) role of the parent/carer, (3) role of the therapist, (4) anticipated obstacles and (5) suggested adaptations to therapy.

Table 1 Rate of comorbid diagnoses in the sample

Diagnosis	*n*	%
Autism spectrum disorder	14	67
Attention deficit hyperactivity disorder	12	57
Specific learning disorder	7	33
Anxiety	6	29
Oppositional defiant disorder	3	14
Depression	2	10
Auditory processing disorder	1	5
Cerebral palsy	1	5
Epilepsy	1	5
Robertsonian translocation	1	5
Sensory processing disorder	1	5

Emotional attunement

Responses reflected parents' ability to recognise emotional states in their child. Indicators of a child's emotions reported were body language, facial expressions, behaviours, verbal expressions of the emotion and increased or decreased social interactions.

Role of the parent/carer

Participants referenced taking on the role of the therapist outside of sessions, to help practice and generalise using strategies, as participants stated "I would become the teacher for the therapy and reaffirm therapy at home" and "help with homework". Parents acknowledged they could provide practical support by "sit[ting] in on sessions" and "taking notes". Emotional support they could provide involved encouragement to participate.

Role of the therapist

Therapist's knowledge and experience working with children with ID were identified as important. One participant wrote, it would help "if the therapist was understanding of the disabilities my son has and had experience working with them". Parents wanted therapists to understand the strengths and weaknesses of their child and adapt therapy, as one parent stated "the approach taken to engage a child needs to be carefully thought out prior to engagement to reduce the likelihood of shutdown during therapy".

Anticipated obstacles

The difficulty of identifying and expressing thoughts and emotions was identified. Parents questioned whether CBT may be too complex with "too many steps in the process". Rigid thinking was a potential obstacle, as one participant stated their child is "a literal person so won't generalise". Practical obstacles included time constraints, cost of therapy, geographical restrictions and the difficulty of "finding a clinician willing to work with intellectual disability".

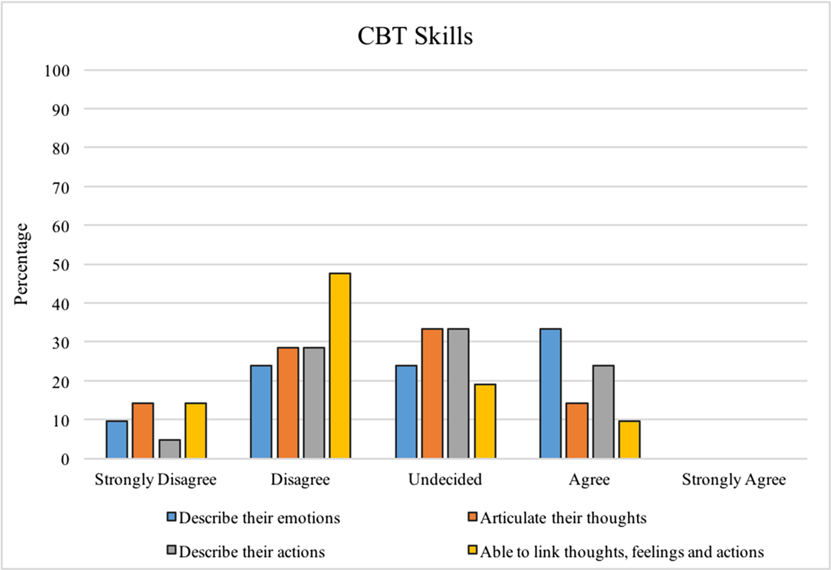

Figure 1. Parents rating of child's ability for CBT skills. CBT, cognitive behavioural therapy [Colour figure can be viewed at wileyonlinelibrary.com]

Suggested adaptations to therapy

Parents suggested how CBT could be adapted for their child's needs (Table 2).

Discussion

The involvement of stakeholders is in line with patient-centred care best practices (Epstein & Street,

Table 2 Proposed adaptations to CBT by parents of children with ID

Adaptations	Specific suggestions from parents
Providing instructions	•Provide explicit instructions •Break instructions into small steps •Use stories to explain concepts and to provide examples •Use videos to explain and teach "Teaching in baby steps" "Make it as simple as possible"
Prompts and cues	•Use of visual cues •Colour coded charts as prompts and reminders "Make a chart of feelings and thoughts so they can visualise them" "Behavioural cues to "lock in" lessons"
Check understanding	•Confirm the child has understood before progressing to the next step "Making sure he understands how to do it before moving onto the next thing"
Practicing skills	•Repeat each step multiple times •Repeat practices of skills •Practice with multiple examples "Getting him to show you" "Practice in therapy sessions and then practice outside of sessions"
Emotion training	•Additional time to be spent on establishing an awareness and understanding of different emotional states "Teaching children to recognise feelings in the body that occur when getting close to a meltdown"
Support network	•Have teachers involved in the treatment process •Have parents involved throughout treatment

2011). To our knowledge, this is the first study exploring the carer perspective about how children with ID can engage in CBT. The results indicate that parents believe their child may benefit from CBT with assistance, provided therapy is adapted for their needs and barriers to treatment are managed. Although more than half of participants did not think their child could link thoughts, feelings and behaviours, three quarters agreed their child could participate in CBT with assistance. This is promising, because while parents acknowledge their child may not currently have those skills, they are hopeful their child could learn them. Parents provided suggestions on adapting CBT, which were consistent with those suggested by Hronis, Roberts and Kneebone (2017). Furthermore, parents were willing to take an active role in treatment, which is beneficial for CBT outcomes (Mendlowitz et al., 1999; Wood et al., 2009).

A limitation was that parents who responded may be more open to therapy, providing a possible biassed sample. Furthermore, the sample size was small, and some participants provided brief responses. Because of the nature of the online questionnaire, there was no opportunity to question further. Additionally, formal measures of intellectual and adaptive functioning were not used to confirm diagnoses. Nonetheless, the findings show promise for the use of CBT for children and adolescents with ID and mental health disorders. The results hold important practice implications and can contribute to the development and piloting of adapted CBT programmes for children with ID. Future research should focus on experimental studies exploring whether children with ID can make links between thoughts, feelings and behaviours and research trials evaluating the efficacy of adapted CBT for children with ID.

Conflict of Interest

The authors have declared that no conflict of interests exists.

Source of Funding

No external funding was received for the research reported in the paper.

Ethical Approval

This research was approved by the University Ethics Committee and undertaken with the understanding and written consent of each participant.

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Accepted 15 September 2019

Supporting Information

Additional Supporting Information may be found online in the supporting information tab for this article.

Data S1 Supporting information

Data S2 Supporting information

APPENDIX C

Fearless Me! © Treatment Manual

Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. I. (2018). *Fearless Me! ©: Cognitive Behaviour Therapy for Children with Intellectual Disability and Anxiety*. University of Technology Sydney & University of Adelaide.

Fearless Me!

Cognitive Behaviour Therapy for Children and Adolescents with Intellectual Disability and Anxiety

Anastasia Hronis, Rachel Roberts, Lynette Roberts, Ian Kneebone

Table of Contents

About the Authors

Professor Ian Kneebone

Head of Discipline (Clinical Psychology), Clinical Psychology

Professor Kneebone has over 20 years' experience in applied practice, teaching, training, policy and research in clinical psychology. He has worked as a Rehabilitation Counsellor for Bedford, SA and CRS Australia and as Programme Area Leader of a head injury service. He has also worked as a Clinical Psychologist in community mental health and with older people in a physical rehabilitation setting (Health Department of Western Australia). He worked at Consultant level, for the NHS (National Health Service of Great Britain and Northern Ireland) in physical rehabilitation and neuro rehabilitation settings in Surrey, the UK for sixteen years. He has consistently achieved funding for his research in rehabilitation and has published numerous papers in peer-reviewed journals. These include journals with the highest ranking in this research area. Professor Kneebone is a Visiting Professor at the University of Surrey.

Anastasia Hronis

BPsyc (Hons I), M Clin Psych, AMusA, LMusA

Anastasia is a registered psychologist and clinical psychology registrar. The Fearless Me! program was developed as part of her Doctor of Philosophy (PhD) degree at the University of Technology Sydney. Anastasia's doctoral research looks specifically at how Cognitive Behaviour Therapy (CBT) can be adapted to suit the needs of children and adolescents with intellectual disabilities.

Anastasia also works clinically with children, adolescents and adults experiencing mental health concerns, and combines a strong interest and background for research into her clinical work. She is also passionate about working with adults with chronic mood disorders and interpersonal difficulties. In addition, Anastasia has published research in the area of problem gambling.

Associate Professor Rachel Roberts
BA(Hons), MPsych (Clinical), PhD

Rachel Roberts is an Associate Professor at the University of Adelaide and a clinical psychologist with extensive experience working with children with a range of developmental disabilities including intellectual disability, and their families. She teaches in the Master of Psychology (Clinical) and (Health) programs, and conducts research in the areas of clinical psychology, health psychology and neuropsychology. She has received grants and funding for much of her research, and has published numerous papers in high-ranking peer-reviewed journals.

Dr Lynette Roberts
B. Psych (Hons.), Masters of Clinical Psychology; PhD

Dr Lynette Roberts is a practising Clinical Psychologist and was a Lecturer and Early Career Researcher at UTS from 2015-2017. She is passionate about her lab's work on improving mental health treatments for vulnerable populations, including children, adolescents and adults with intellectual disabilities, and their carers. Her lab's focus on mental health included investigating novel treatments for depression, including the use of probiotics (good bacteria). She has a particular interest in women's health, working clinically with women with perinatal anxiety and depression. She is currently an Honorary Associate in the Graduate School of Health, UTS.

The Unstoppable Me! website was funded by the following grant: L Roberts, "Unstoppable Me: An iPad anxiety program for children with intellectual disability", $20,581 from the James N Kirby Foundation 2016-2017.

About the Program

The *Fearless Me!* program is a Cognitive Behaviour Therapy (CBT) treatment program which has been specifically adapted for children with intellectual disabilities and anxiety. It was developed in recognition that children and adolescents with intellectual disabilities experience very high rates of mental illness, yet there are very few psychotherapy treatment programs available which cater for the unique needs of children with intellectual disabilities.

Children can sometimes fall into patterns of thinking which are unhelpful. They may think negative and unhelpful thoughts such as “I’m not good at this”, “this is too hard”, “my friends will laugh at me”, “I can’t do it” etc. These types of thoughts can lead children to feel sad, worried, scared or anxious. As a result, children may avoid particular tasks, situations and activities. In this case, the role of the clinician within a CBT framework is to help children link what they think, to how it makes them feel and to what actions they take. Therapists may help children learn ways to “catch” their thoughts, check whether their thoughts are helpful and realistic, and challenge unhelpful/unrealistic thoughts. Some adults will automatically challenge their own thoughts, but children with an intellectual disability may need to be taught these skills.

Fearless Me! is a multimodal treatment approach, in that it involves both face to face therapy sessions, as well as an online component. A multimodal approach is used as a means of breaking down the CBT skills in a way that can hopefully be engaging and fun for children with disabilities. This manual provides information on how to use and deliver the components of both the online program and the content for face-to-face sessions. It is recommended that before using the online program, clinicians access the material themselves and explore the various online modules.

It is important to keep in mind that this treatment manual has been developed as a guide for therapy. As with any intervention, it is crucial to adapt the treatment and therapy process to suit the needs of the individual. This is particularly important when working with children with developmental delays and unique needs. More on how to adapt therapy for children with developmental and intellectual disabilities can be found on page 11.

Who is the Fearless Me! program for?

The *Fearless Me!* program was designed to be used with children and adolescents who have mild to moderate intellectual disabilities, or intellectual abilities in the borderline range, aged from approximately eight years to eighteen years of age. It is designed to assist children with subclinical or clinical anxiety concerns.

How do sessions work?

Outlined in this manual is a ten session treatment program, to be delivered after a comprehensive assessment has been conducted. It is recommended that each session run for approximately 45-60 minutes, and involve both teaching and practicing skills. While the treatment manual has ten session plans provided, it is at the clinician’s discretion to adapt this however best appropriate for the client.

The aim of the program is to break down the skills of CBT in a way that can be understood and used by children with intellectual disabilities. In particular, there is additional focus on the cognitive components of CBT. It is recommended that both practical and online components be used in most sessions to help facilitate the child's engagement in the therapy process. Therefore, it is important that the clinician have access to a computer or electronic device during the sessions, or that the child bring an electronic device with them to sessions (i.e. laptop, tablet or iPad. Using a mobile phone to access the online site is not recommended).

We highly recommend having a carer or parent present for all sessions. We have found that having a carer involved in the treatment is beneficial to the progress of therapy, as they are able to provide valuable clinical information as part of the assessment, can provide relevant examples of times when the child has felt anxious, and can learn the skills as part of the program to facilitate practice and generalisation of skills outside of therapy sessions.

As is typical within a CBT treatment program, sessions involve homework tasks for children to do between session. These involve a combination of exposure exercises, use of relaxation skills, and practice of cognitive skills. This is where parents/carers may be able to assist with a child's progress outside of therapy sessions.

Group vs Individual Therapy

The *Fearless Me!* program has been designed to be an intervention which can either be delivered in an individual or group setting. Throughout the treatment manual you will note that there are options for adaptations, based on whether the program is being delivered in an individual or group setting.

For both individual therapy and groups, we recommend having a carer or parent present for all sessions. In addition, group therapy programs may benefit from having two group facilitators. Group sizes are likely to vary according to the level of disability of the children in the group and clinical judgement should be used to determine group size (i.e. groups of children with mild intellectual disabilities may be larger than groups predominately comprised of children with moderate intellectual disabilities).

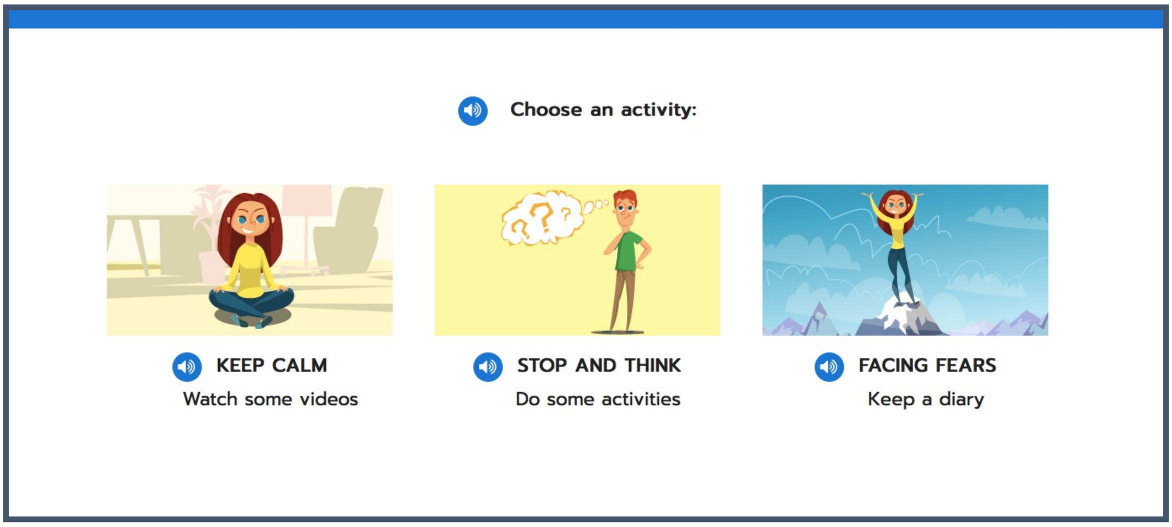
Optional Session 9

In the treatment manual, you will note that Session 9 had been identified as optional content to teach. This has been designed in this way as we recognise that some children may require additional teaching of previous steps and content, before being able to move onto the next steps. Thus the content of Session 9 does not need to be delivered if a child requires additional time to be spent on the other components of the program.

Components of the Online *Fearless Me!* program

The Fearless Me! online program consists of three modules:

1. Keep Calm
2. Stop and Think
3. Facing Fears



Module 1 - Keep Calm

Keep Calm teaches children relaxation strategies. Videos have been created which teach children paced breathing (*Balloon Breathing*) and progressive muscle relaxation (*Squeeze and Relax*).

Balloon Breathing

Heightened anxiety often results in breathing become quick and shallow. Shallow over-breathing can prolong the symptoms of anxiety and make the experience worse. Balloon Breathing teaches children how to use a relaxed breathing pattern to help them feel calmer by breathing in through their nose and out through their mouth. The image of blowing up a balloon is used to help with the exercise.

Squeeze and Relax

Squeeze and Relax is a variation of progressive muscle relaxation. The video takes children through the process of tensing and then relaxing particular muscles in their body while noticing the difference in the feeling.

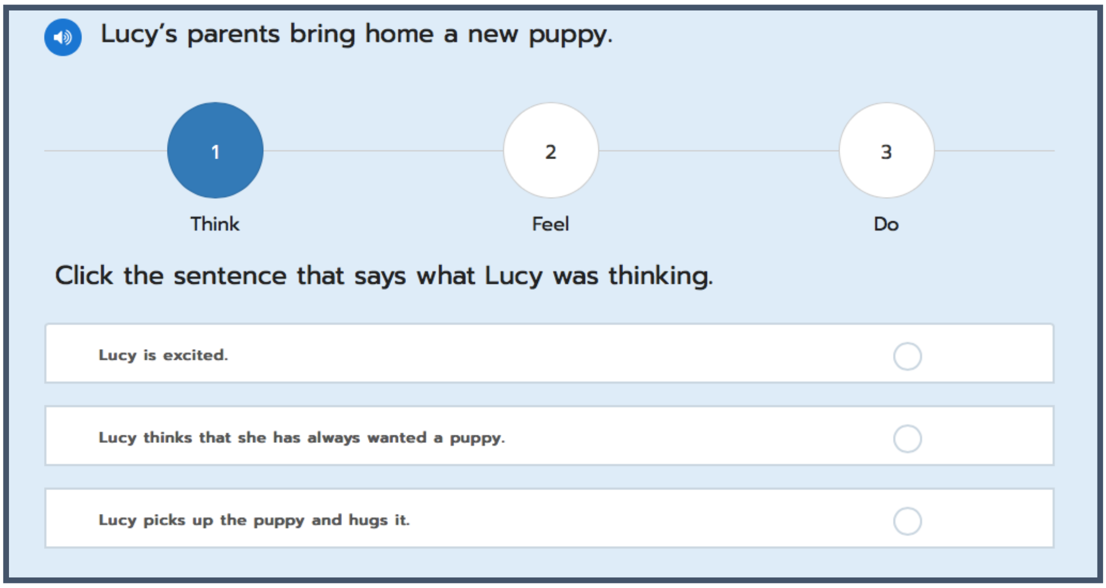
Module 2 – Stop and Think

This module focusses on the cognitive components of the CBT treatment. The aim of the module is to help children build the skills of identifying thoughts, recognising unhelpful thoughts and challenging unhelpful thoughts. There are three activities in this module: *Think Feel Do, Thought Catching* and *Detective Thinking.*

Think Feel Do

This activity first helps children learn the difference between their thoughts, their feelings and their actions. In this activity, they will read/hear brief scenarios about another child. They will have to identify what the person was thinking, what they were feeling, and what they were doing. Practicing this is the first step, as it is important children can tell the difference between their feelings, their thoughts and their actions.

See the example below:



Lucy's parents bring home a new puppy.

Click the sentence that says what Lucy was thinking.

Lucy is excited. ○

Lucy thinks that she has always wanted a puppy. ○

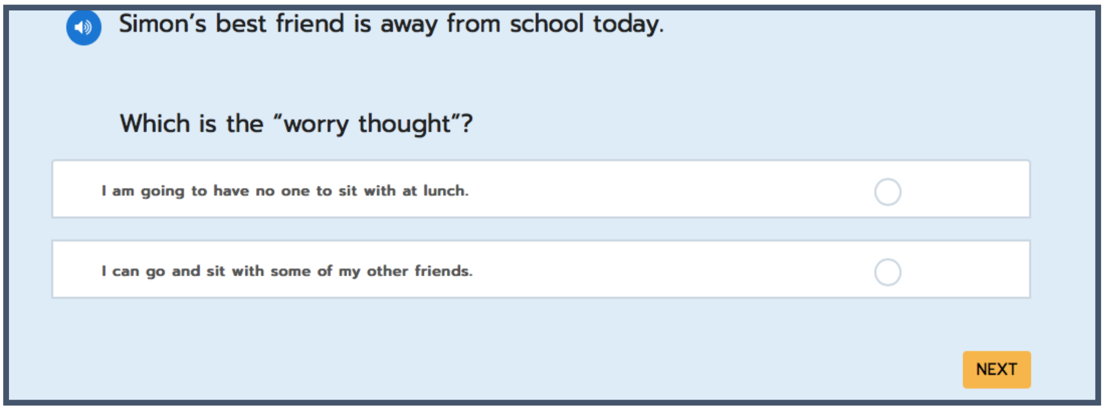
Lucy picks up the puppy and hugs it. ○

In this example the answers are:
Thought → "Lucy thinks that she has always wanted a puppy"
Feeling → "Lucy is excited"
Doing → "Lucy picks up the puppy and hugs it.

Thought Catching

This activity helps children to learn that unhelpful thoughts can lead to feeling stressed, worried, anxious or sad. The task requires them to read/listen to two different thoughts and choose, or "catch", the worry thought.

See the example below:



Simon's best friend is away from school today.

Which is the "worry thought"?

I am going to have no one to sit with at lunch. ○

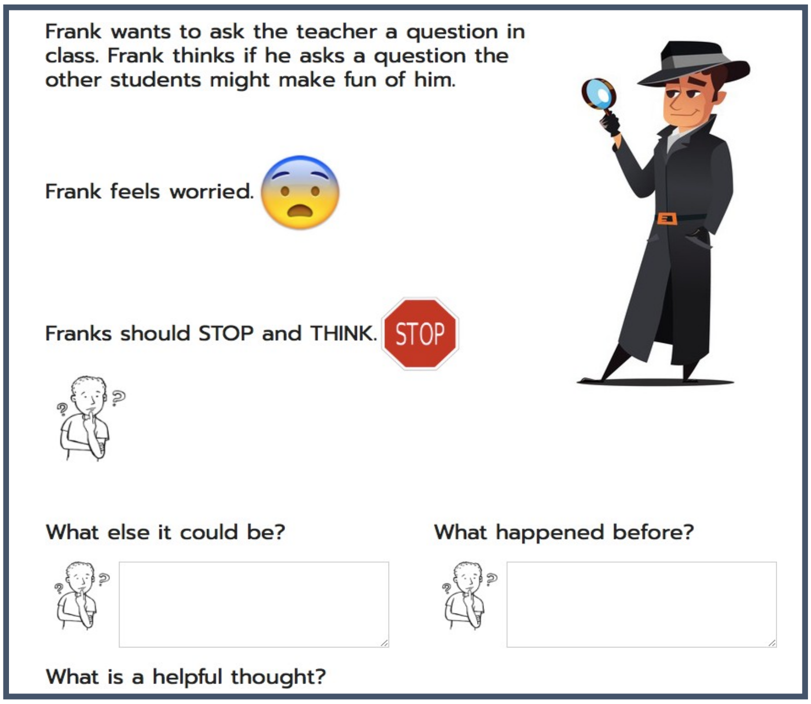
I can go and sit with some of my other friends. ○

In the example above, the "worry" thought is "I am going to have no one to sit with at lunch". Thinking this would make a child feel more worried than thinking "I can go and sit with some of my other friends". This exercise helps children build the ability to "catch" the worrisome or unhelpful thoughts they may think.

Detective Thinking

Once children can identify their thoughts (by practicing *Think Feel Do*) and can catch their worry thoughts (by practicing *Thought Catching*) they can next move onto Detective Thinking.

Detective Thinking involves children challenging their unhelpful thoughts. They practice being a "detective" and finding more helpful thoughts. Children do this by asking "What else can it be?", "What happened before?" and "What is a helpful thought?". See the example below:



Frank wants to ask the teacher a question in class. Frank thinks if he asks a question the other students might make fun of him.

Frank feels worried.

Franks should STOP and THINK.

What else it could be?

What happened before?

What is a helpful thought?

In the example above, children are encouraged to challenge the thought "Frank thinks if he asks a question the other students might make fun of him".

Children are encouraged to question what else could happen (i.e. maybe the other children won't laugh and make fun) and what happened before? (i.e. last time someone asked a question the other students did not laugh and make fun).
By doing this, children can come to choose a more helpful thought such as "If I ask the teacher a question she can help me and maybe other students too".

Module 3 – Facing Fears

This module focuses on the behavioural component of CBT. As is common with subclinical and clinical anxiety, avoidance of the feared stimuli is usually a key factor in maintaining the anxiety. This module therefore focuses on graded exposure, and working in small steps to achieve a goal.

This module includes a video called *Brave Ben* which explains how we can work step by step to reach a goal. Children can create their own steps and goals in the activity *Facing Your Fears*.

Facing Your Fears

In this activity, children choose something which they usually avoid or are scared of. Together with parents, a teacher or psychologist, they can develop a list of components which are related to their fear. These activities are then put in order from least anxiety provoking to most anxiety provoking. Children start with the least anxiety provoking task, and receive a reward when they complete it. By working through these steps children are able to eventually face the fear at the top of their list.

For example, a child who becomes anxious in social situations may avoid going to parties. To work up to being able to attend a party, they may start by having a conversation with a friend at school, then saying hello to a student they do not know, then inviting one friend over to their house, then going over to a friend's house, and finally going to a party.

It is important that each step is repeated multiple times. It is also important that steps are gradual. The steps for one child will be different for another child.

Working with Children with Intellectual Disability

As has been outlined in the previous sections, this program is an adapted Cognitive Behaviour Therapy (CBT) treatment. In the past, clinicians have placed greater emphasis on behavioural and pharmacological interventions for people with intellectual disabilities. This program aims to make use of both behavioural and cognitive strategies to help children and adolescents with anxiety.

Consideration of a child’s cognitive, social and emotional development is crucial prior to undertaking therapy and these factors should be examined during the initial assessment. Children with intellectual disabilities have cognitive deficits and as such, the therapy and therapist must adapt to meet the needs of the child. Neurocognitive deficits exist in the areas of attention, memory, learning, working memory, executive functions and language and reading. It is thus these factors which are likely to have an additional impact on the therapy process and needed to be accommodated and adapted for.

The authors of the *Fearless Me!* program have conducted a review into the research looking at the neurocognitive deficits of children with intellectual disabilities, the implications these may have for therapy, and suggested adaptations to therapy (Hronis, Roberts & Kneebone, 2017)[1]. The table below is taken from the review paper and is included to help clinicians and facilitators understand the ways in which they may consider additional adaptations to therapy to suit the needs of the individual child they are working with.

Table of adaptations to CBT for children with intellectual disabilities according to neurocognitive domain. From Hronis, Roberts and Kneebone (2017).

Domain	**Therapy Adaptations**
Attention	• Shorter, more frequent sessions • Include breaks • Reduce task length by dividing into smaller units • Engage children with a variety of modalities, colours and pictures • Positively reinforce attention • Minimal distractions in therapy room • Begin with “person oriented” tasks before moving to “task oriented” exercises
Working Memory	• Use short, simple, subject-verb-object sentences • Present material verbally and visually • Use memory aids such as visual prompts

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[1] Hronis, A., Roberts, L., & Kneebone, I. I. (2017). A review of cognitive impairments in children with intellectual disabilities: Implications for cognitive behaviour therapy. *British Journal of Clinical Psychology*, *56*(2), 189-207.

	• Present one task/activity at a time • Present information numerous times/ repeat tasks
Learning and Memory	• Engage in implicit learning processes (e.g. role play, hands-on activities) • Reality-based teaching; learn via “doing” • Teach via modelling, using “thinking out loud” when modelling • Frequently check understanding • Master skills before moving on • Practice and repeat skills • Provide immediate feedback • Record sessions or provide written summaries to the child and caregiver • Children encouraged to write events from the week to facilitate recall • Involve carers/parents to facilitate memory and recall
Executive Functions	• Therapist should plan and structure the sessions • Try to maintain a set structure to sessions • Use a visual schedule outlining session structure • Minimise switching between tasks • Target mental flexibility problem solving and decision making throughout therapy • Redirect uninhibited responses • Establish rules for therapy
Language and Reading	• Child should be facing therapist • Visual aids can assist communication • Use pictures/drawings to facilitate understanding, placed next to text with a clear link between text and image • Use ‘Easy Reading” format for text • High frequency connectives are more effective for ID (e.g. “and”) • Divide text into bullet points • Bold to emphasise main points • Avoid jargon • Define new terms where necessary • Sentences as short as possible (maximum 15 words) • Good contrast between colour of text and page • Sentences consisting a single concept • Words fewer than three syllables

Program Outline

Session 1 – Introduction & Psychoeducation
Session 2 – Balloon Breathing & Safe Place
Session 3 – PMR and Review Relaxation

Session 4 – Facing Fears: Goals & Hierarchy Development

Session 5 – Identify Thoughts, Feelings and Behaviours
Session 6 – Catching Unhelpful Thoughts
Session 7 – Check the Facts
Session 8 – Check the Facts

Session 9 – Linking Helpful Thoughts to Exposure Hierarchies (Optional)

Session 10 – Review of Skills

Session 1: Introduction & Psychoeducation

Introductions

- Psychologist Introduces self and role
- Name tags for everyone (if delivered in group setting)

Confidentiality

- Explain confidentiality. Emphasise working as a team (child, psychologist, carer/parents, teacher etc).
- If delivered in group format, explain that we do not discuss about what other people say outside of group.

What this program is about

- Psychoeducation around anxiety
- Normalise anxiety experience

What are my fears?

Everyone has different fears and worries, and things that make them feel anxious.

- Hand out – things that make me anxious. Circle what applies to you. Go through these one by one. Draw in the blank space any other fears/worries.

What does anxiety feel like?

Imagine that you have to do something that you circled. Imagine you have to give a speech, or go to the doctor, or spend the night away from mum and dad.
Close your eyes. Where can you feel the anxiety in your body?

- Activity: colour/draw in where you feel anxiety in the body. What do these feel like? Butterflies, heart racing, tension etc?

Thermometer

One way we can tell how anxious we feel is by using this thermometer to help us.
If we don't feel a lot of anxiety, then we are low on the thermometer. If we feel a bit of anxiety, we are in the middle. If we feel a lot of anxiety, we are at the top!

Resources

- Name Tag stickers (for group delivery)
- Activity Sheet 1: what are my fears?
- Activity Sheet 2: where do I feel anxiety in my body?
- Activity Sheet 3: thermometer rating scale

Session 2: Balloon Breathing and Safe Place

Review anxiety psychoeducation from previous week.

<u>Balloon Breathing</u>

Often when we feel anxious or scared, we start to breathe really fast. If we breathe fast, this makes our heart beat faster. This can make us feel even MORE anxious than we already are!

One way we can help ourselves feel more calm, is to do some balloon breathing. Balloon breathing helps us to take slower and deeper breaths. When we do Balloon Breathing we imagine that we have a balloon inside of us. When we breathe in through our nose, we blow up the balloon. When we breathe out through our mouth, we let the air out of the balloon.

Practice Balloon Breathing with video first, then without.

<u>Safe Place</u>

Another thing we can do when we feel scared or worried, is imagine a place that we call our Safe Place. When we imagine our safe place, nothing can hurt us or upset us. We are 100% safe. This is where we can go to feel calm. But it's not a real place. We just go there in our mind.

Activity: Imagine the safe place.
Ask children to close their eyes and imagine the safe place.
Use prompts:

- *Where are you?*
- *What can you see/hear/smell around you?*
- *You can take anything you want to your safe place that you like. What will you take?*

Activity: drawing the safe place and the things that are there with them.

<u>Homework</u>

Practice Balloon Breathing with the video. Practice imagining your safe place and describe it to carers/parents/siblings.

<u>Resources</u>

- *Fearless Me!:* Balloon Breathing video
- Blank paper for Safe Place
- Materials to draw with

Session 3: Progressive Muscle Relaxation and Review Relaxation

Review of Balloon Breathing and Safe Place exercises from last week.
Check in on homework practice and use of relaxation skills.

Practice Balloon Breathing and imagining Safe Place again.

Squeeze and Relax – Progressive Muscle Relaxation
Teach Progressive Muscle Relaxation using the “Squeeze and Relax” video.
Have children practice while watching the video (eyes open first time, eyes closed after repeated practices)

Activity: practice the squeeze and relax exercise with video.

Review times when children could use their relaxation strategies. Refer back to their initial activity where they indicated the situations that make them feel worried or anxious. Explain using relaxation strategies in these situations to help.

Homework
Practice Squeeze and Relax and teach a family member how to do it using the video.
Continued practice of the relaxation strategies.

Resources
- *Fearless Me!:* Squeeze and Relax video

Session 4: Facing Fears – Goals & Hierarchy Development

Review and practice relaxation strategies (balloon breathing; safe place; squeeze and relax). Check in on homework practice and use of relaxation skills.

Facing Fears

Sometimes when we have to do something which is seems scary or hard, it helps to break it down into small steps.

Activity: Watch the Brave Ben video.

Q/ What did Ben learn from doing all those steps?
Q/ What can we learn from the video about Brave Ben?

Highlight how Brave Ben was able to conquer his fear of heights by going "step by step".

Rewards

Q/ What did Brave Ben get after he did every step? (A: reward)

Develop a list of potential rewards.

Developing Own Hierarchy

Develop hierarchy/steps for something they are fearful of doing. Refer back to information from parents/carers and what they identified as anxiety provoking from session 1.

For each step on the hierarchy, add in rewards.

(If there is additional time, can work on developing a second hierarchy)

Use *Fearless Me!* online program to develop exposure hierarchy steps.

Homework

- Watch Brave Ben video again at home.
- Try to do the steps at the bottom of the exposure hierarchy and monitor progress using the website.

Resources

- *Fearless Me!* Brave Ben video
- Activity Sheet 4: Facing Fears Worksheet

Session 5: Identify Thoughts, Feelings & Behaviours

Review homework to take steps on exposure hierarchy.

Identifying Thoughts, Feelings and Behaviours
Activity: using blank paper of a whiteboard, develop a list of all the emotions/feelings the children know. Once children are unable to identify additional emotions spontaneously, prompt them for more (e.g. *What about anger? Have you ever felt angry?)*

Practice making the link between feelings and situations as a group. Have children tell you a time they remember they felt the main emotions (anger, sadness, anxiety, happiness).

Activity: develop a list of behaviours i.e. “things that we can do”.
Start this with some examples
e.g. *Running is something I can do. Jumping is something I can do. Writing is something I can do.*

Thoughts
Thinking is when we talk to ourselves in our mind/head. Everyone thinks. We can think about different things. Our thoughts are like an internal voice.
I can think all different things. I can think things which are true and I can think things which are not true. For example, I can think, that this table is brown and that is true. I can think that your hair is pink, but that is not true!
Can you tell me something you can think which is true?
Can you tell me something you can thinks which is not true?

Activity: Use the *Fearless Me!* website and orient parent and child to the Module titled “Stop and Think”. Practice together the activity titled “Think, Feel, Do”, which asks children to practice identifying thoughts, feelings and behaviours.

Homework
- Practice Think, Feel, Do activity

Resources
- Whiteboard/blank paper
- *Fearless Me!* activity: Think, Feel, Do.
- Continue with exposure hierarchy steps

Session 6: Catching Unhelpful Thoughts

Review homework activity to practice Think, Feel, Do activity. Review progress on exposure hierarchy.

Practice “Think, Feel, Do” again in session to clarify child’s progress and in what areas they may be having difficulty and require further focused intervention. Consolidate this before moving onto next step of unhelpful thoughts.

Helpful vs Unhelpful Thoughts

Some of the things we think can be helpful. Our thoughts can help us. Our thoughts can help us do things that are important. Our thoughts can help us do things even if they are a bit scary or make us feel worried.
We might think “I can do this!” to help ourselves do something.

Some other thoughts are not so helpful. We might think things like “I can’t do this” or “this is too hard”. These thoughts don’t help us.

Some thoughts might make us feel even more worried!

Provide the following relevant examples:

1. Situation: school test.
   Unhelpful thoughts: I can’t do this it is too hard.
   Q/ How do you think someone would feel if they thought this?
   Helpful thoughts: I will try my best even if it is hard.
   Q/ How do you think someone would feel if they thought this?
2. Situation: starting a new school
   Unhelpful thought: no one will like me.
   Q/ How do you think someone would feel if they thought this?
   Helpful thoughts: I have made new friends before so I will be able to do it again.
   Q/ How do you think someone would feel if they thought this?

(Children can draw the above situations to help facilitate the discussion and examples)

Resources

- Blank paper
- *Fearless Me!* “Thought Catching” computer exercise

Homework

- *Fearless Me!* “Thought Catching” computer exercise
- Continue with exposure hierarchy steps

Session 7 & 8: Check the Facts

Review homework to practice "Thought Catching" and exposure hierarchy progress.

Practice "Thought Catching" again in session to clarify child's progress and in what areas they may be having difficulty and require further focused intervention. Consolidate this before moving onto next step of unhelpful thoughts.

Check the Facts
Explain what a fact is. Recap how thoughts can be true or untrue.
Explain detective thinking means looking for the facts of a situation.
After we check the facts, we can come up with a more helpful thought.

Go through examples as a group.

Jessica is going to a new school and thinks she won't make any friends.
Jessica should stop and think. What are the facts? What happened before? Is thinking think way helpful?

Examples:
A friend walks past and does not say hello. You think they do not like you.
Stop and think. What are the facts? What else could it be? Is thinking this way helpful?

You have a test to do. You think you will do badly.
Stop and think. What are the facts? What happened before? Is thinking this way helpful?

You catch a train and worry that you will get lost.
Stop and think. What are the facts? What happened before? Is thinking this way helpful?

You have the grand final netball game but are worried the team won't win.
Stop and think. What are the facts? What happened before? Is thinking this way helpful?

You are learning to ride a bike but think you will never be able to do it.
Stop and think. What are the facts? What happened before? Is thinking this way helpful?

Activity: "Detective Thinking" computer exercise.

Resources
- *Fearless Me!* "Detective Thinking" computer exercise

Homework
- *Fearless Me!* "Detective Thinking" computer exercise
- Continue with exposure hierarchy steps

Session 9: Linking Helpful Thoughts to Exposure Hierarchies (Optional)

(Note: this session can either be used to continue and consolidate the cognitive skills from sessions 5-8, or can be delivered according to the session plan below)

Review homework to practice “Detective Thinking” and exposure hierarchy progress.

<u>Activity</u>

Practice developing exposure hierarchies for a specific concern a friend may have, to help them face their fear.

- Fear of making new friends
- Fear of catching the train alone
- Fear of spiders
- Fear of the dark
- Fear of hospitals

<u>Positive Self Statements</u>

Development of a list of helpful statements children can tell themselves and use to encourage themselves when feeling anxious or engaging in exposure hierarchies. Children can draw/write these to facilitate the process.

<u>Resources</u>

- Blank paper

<u>Homework</u>

- Continue with exposure hierarchy steps
- *Fearless Me!* “Detective Thinking” computer exercise

Session 10: Review of Skills

Review of Skills

- Balloon Breathing
- Safe Place
- Squeeze and Relax
- Hierarchies – going step by step to face our fears
- Helpful vs unhelpful thoughts
- Check the facts

Practice each of the relaxation skills.

Practice applying “Thought Catching” and “Detective Thinking” to a personal situation.

Discussion with parents/caregivers around progress and provide referral options for further intervention where required.

Certificate for completion of the course.

Resources

- Certificate for completion of the course
- *Fearless Me!* activities on website

ADDITIONAL RESOURCES

Fearless Me!

Helping young people with intellectual disabilities overcome anxiety

PARENT/CARER INFORMATION BOOKLET

Fearless Me! is an anxiety treatment program designed specifically for children and adolescents with an intellectual disability.

The *Fearless Me!* program explores the ways in which children think, feel and behave. The aim of the program is to help the children overcome their fears and worries, and help them to live a full and happy life.

This booklet aims to serve as a guide to parents and carers of children with an intellectual disability who are using the *Fearless Me!* program. This booklet explains each of the sections of the online program and why they are important to the overall intervention.

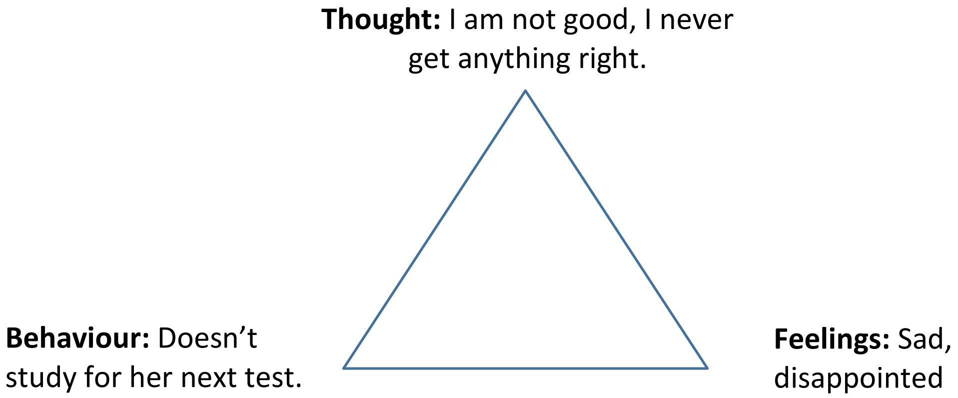
About Cognitive Behaviour Therapy (CBT)

The *Fearless Me!* program is based upon a very well researched therapy called Cognitive Behaviour Therapy, which has evidence to suggest that it can be effective for children with mood and anxiety disorders.

Children can sometimes fall into patterns of thinking which are unhelpful. They may think things such as “I’m not good at this”, “this is too hard”, “my friends will laugh at me”, “I can’t do it” etc. These types of thoughts can lead children to feel sad, worried, scared or anxious. As a result, children may avoid doing some tasks and activities.

Psychologists help children link what they think, to how it makes them feel and to what actions they take. That is, they think their thoughts, feelings and behaviours. Psychologists may help children lean ways to “catch” their thoughts, “check” whether their thoughts are helpful and realistic, and challenge unhelpful/unrealistic thoughts. Adults often automatically challenge their own thoughts, but children with an intellectual disability may need to be taught these skills.

The following is an example relating to a student “Emily” who failed a school spelling test.



Emily had the thought “I am not good, I never get anything right”. Thought challenging would involve looking at the evidence against this thought.
e.g. I passed my spelling test the last time. Just because I failed one test, does not mean I am not good. I am good at math and did well in my math test. I’m good at many things.

Helping children to challenge their unhelpful thoughts is a key component of CBT. There is a lot of research showing that CBT can help children face their fears, overcome their anxiety, increase their self-esteem, improve their mood and support their overall wellbeing. It is one of the main therapies that psychologists use.

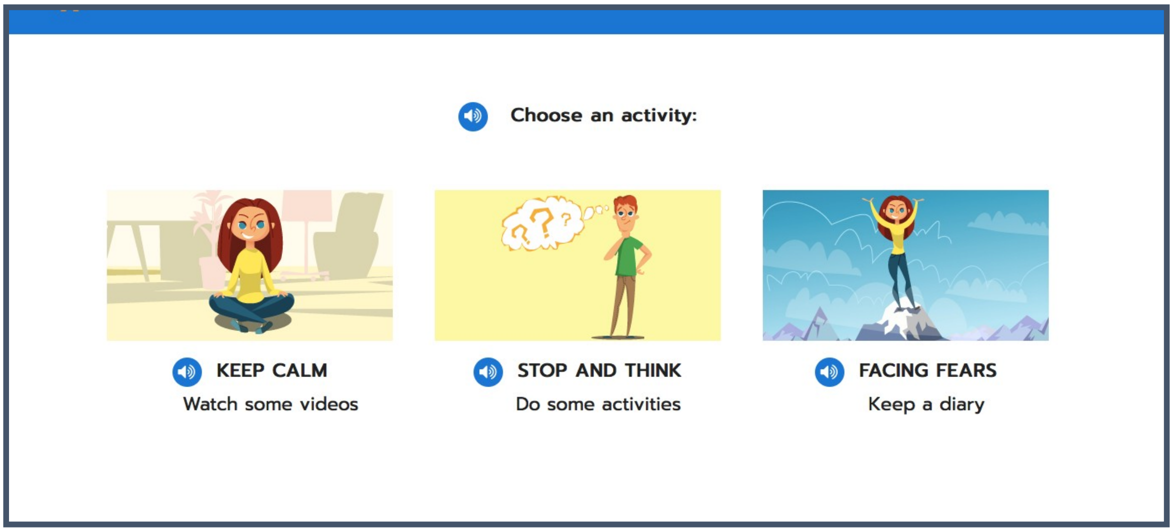
CBT also involves working with children to help them to face their fears. Children who often feel anxious or worried may avoid some activities and situations. CBT helps children to work step by step in a gradual way to face their fears.

How *Fearless Me!* Works

The *Fearless Me!* program targets the way children <u>think,</u> and the <u>actions</u> they take to improve their mood and reduce anxiety.

The *Fearless Me!* program consists of three modules:

1. Keep Calm
2. Stop and Think
3. Facing Fears



Below is an explanation of each of the modules and activities in the *Fearless Me!* program.

Module 1 - Keep Calm

Keep Calm teaches children relaxation strategies. Here children are able to watch videos and practice some relaxation. The two relaxation strategies taught are *Balloon Breathing* and *Squeeze and Relax.*

Balloon Breathing

Often when we feel stressed or anxious, our breathing becomes quick and shallow. Shallow over-breathing can prolong the symptoms of anxiety and make the experience worse. Balloon Breathing teaches children how to use a relaxed breathing pattern to help them feel calmer. Children are taught to breathe in through the nose and out through their mouth. The image of blowing up a balloon is used to help with the exercise.

Squeeze and Relax

Squeeze and Relax is a variation of Progressive Muscle Relaxation (PMR). When we are stressed or anxious, we often tense the muscles in our body. PMR works by asking people to tense particular muscles in their body and then relax them, while noticing the difference in the feeling.

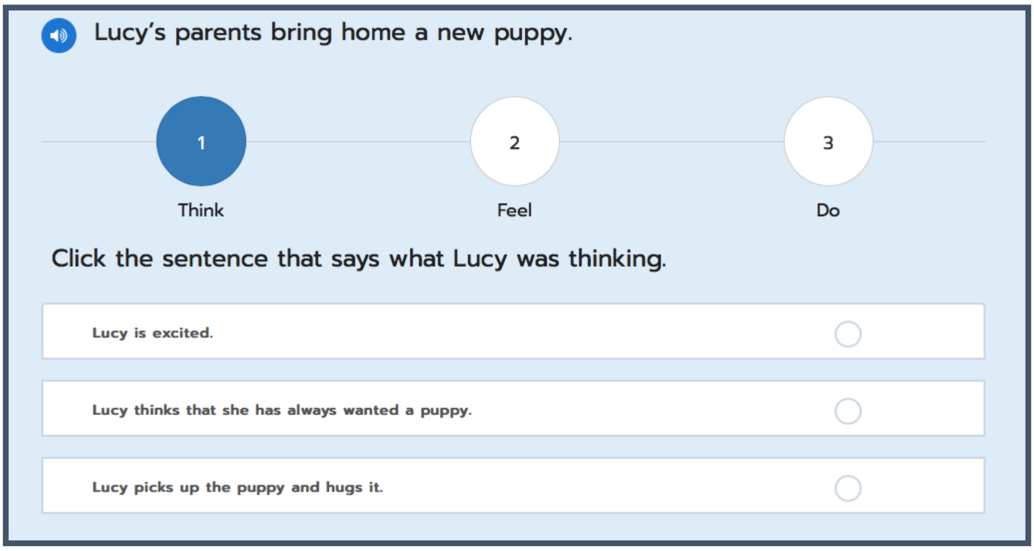
Module 2 – Stop and Think

This module is all about helping children identify and challenge their thoughts. This is a key component in CBT. There are three activities in this module: *Think Feel Do, Thought Catching* and *Detective Thinking.*

Think Feel Do

This activity first helps children learn the difference between their thoughts, their feelings and their actions. In this activity, they will read/hear brief scenarios about another child. They will have to identify what the person was thinking, what they were feeling, and what they were doing. Practicing this is the first step, as it is important children can tell the difference between their feelings, their thoughts and their actions.

See the example below:



Lucy's parents bring home a new puppy.

Click the sentence that says what Lucy was thinking.

Lucy is excited. ○

Lucy thinks that she has always wanted a puppy. ○

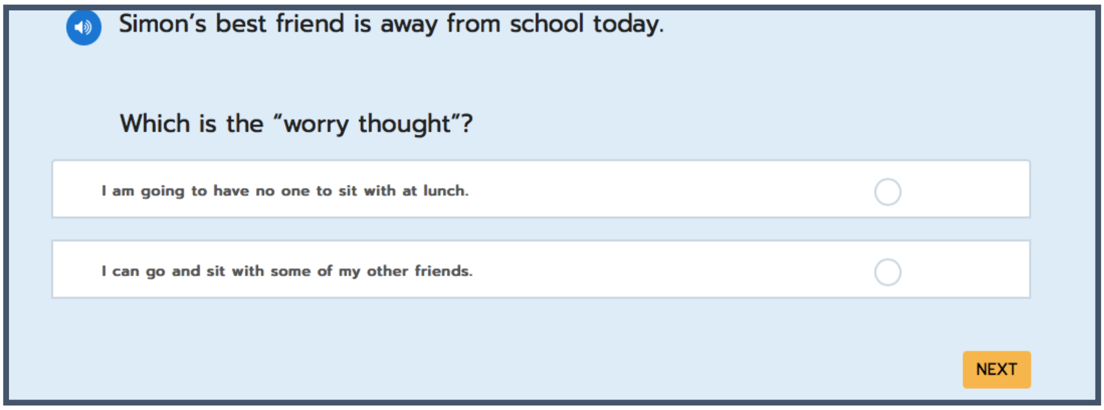
Lucy picks up the puppy and hugs it. ○

In this example the answers are:
Thought → "Lucy thinks that she has always wanted a puppy"
Feeling → "Lucy is excited"
Doing → "Lucy picks up the puppy and hugs it.

Thought Catching

This activity helps children to learn that unhelpful thoughts can lead to us feeling stressed, worried, anxious or sad. The task requires them to read/listen to two different thoughts and choose, or "catch", the worry thought.

See the example below:



Simon's best friend is away from school today.

Which is the "worry thought"?

I am going to have no one to sit with at lunch. ○

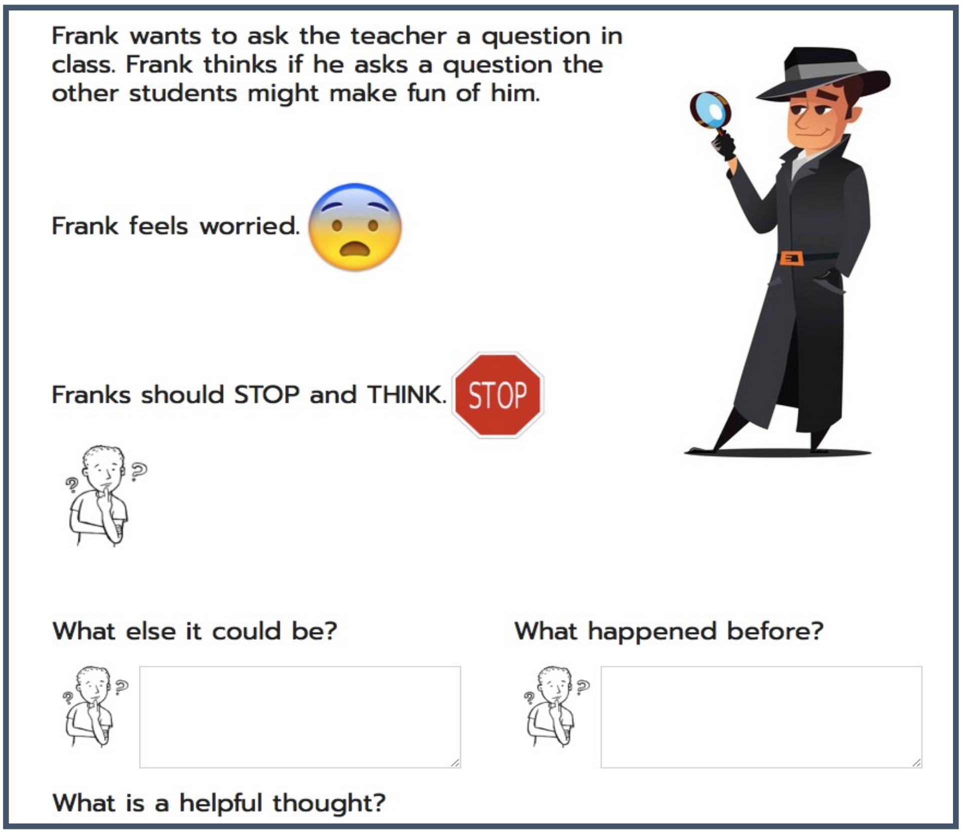
I can go and sit with some of my other friends. ○

In the example above, the "worry" thought is "I am going to have no one to sit with at lunch". Thinking this would make a child feel more worried than thinking "I can go and sit with some of my other friends". This exercises helps children build the ability to "catch" the worry thoughts they may think.

Detective Thinking

Once children can identify their thoughts (by practicing *Think Feel Do*) and can catch their worry thoughts (by practicing *Thought Catching*) they can next move onto Detective Thinking.

Detective Thinking involves children challenging their worry thoughts. They practice being a "detective" and finding more helpful thoughts. Children do this by asking "What else can it be?", "What happened before?" and "What is a helpful thought?". See the example below:



Frank wants to ask the teacher a question in class. Frank thinks if he asks a question the other students might make fun of him.

Frank feels worried.

Franks should STOP and THINK.

What else it could be?

What happened before?

What is a helpful thought?

In the example above, children are encouraged to challenge the thought "Frank thinks if he asks a question the other students might make fun of him".

Children are encouraged to question what else could happen (i.e. maybe the other children won't laugh and make fun) and what happened before? (i.e. last time someone asked a question the other students did not laugh and make fun).
By doing this, children can come to choose a more helpful thought such as "If I ask the teacher a question she can help me and maybe other students too".

Module 3 – Facing Fears

This module is all about helping children face their fears. Often when children feel anxious or worried about something, they do not want to do it and will avoid doing so. This module involves working in small steps to achieve a goal.

This module includes a video called *Brave Ben* which explains how we can work step by step to reach a goal. Children can create their own steps and goals in the activity *Facing Your Fears*.

Facing Your Fears

In this activity, children choose something which they usually avoid or are scared of. Together with parents, a teacher or psychologist, they can develop a list of things which are related to their fear. These activities are then put in order from least anxiety provoking to most anxiety provoking. Children start with the least anxiety provoking task, and receive a reward when they do it. By working through these steps children are able to eventually face the fear at the top of their list.

For example, a child who becomes anxious in social situation may avoid going to parties. To work up to being able to attend a party, they may start by having a conversation with a friend at school, then saying hello to a student they do not know, then inviting one friend over to their house, then going over to a friend's house, and finally going to a party.

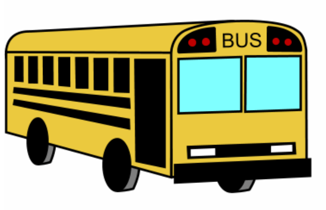
It is important that each step is repeated multiple times. It is also important that steps are gradual. The steps for one child will be different for another child.

Activity Sheet 1:
Circle what makes you feel anxious, worried or scared:


Giving a presentation


Going to the dentist


Feeling sick

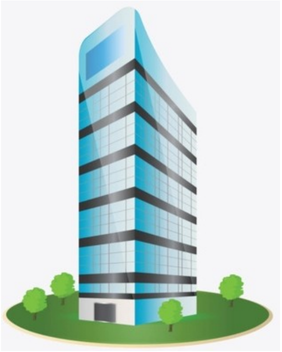


Catching the bus

Being away from my parents


Seeing the doctor


Dogs


High places


What my friends think of me


School work

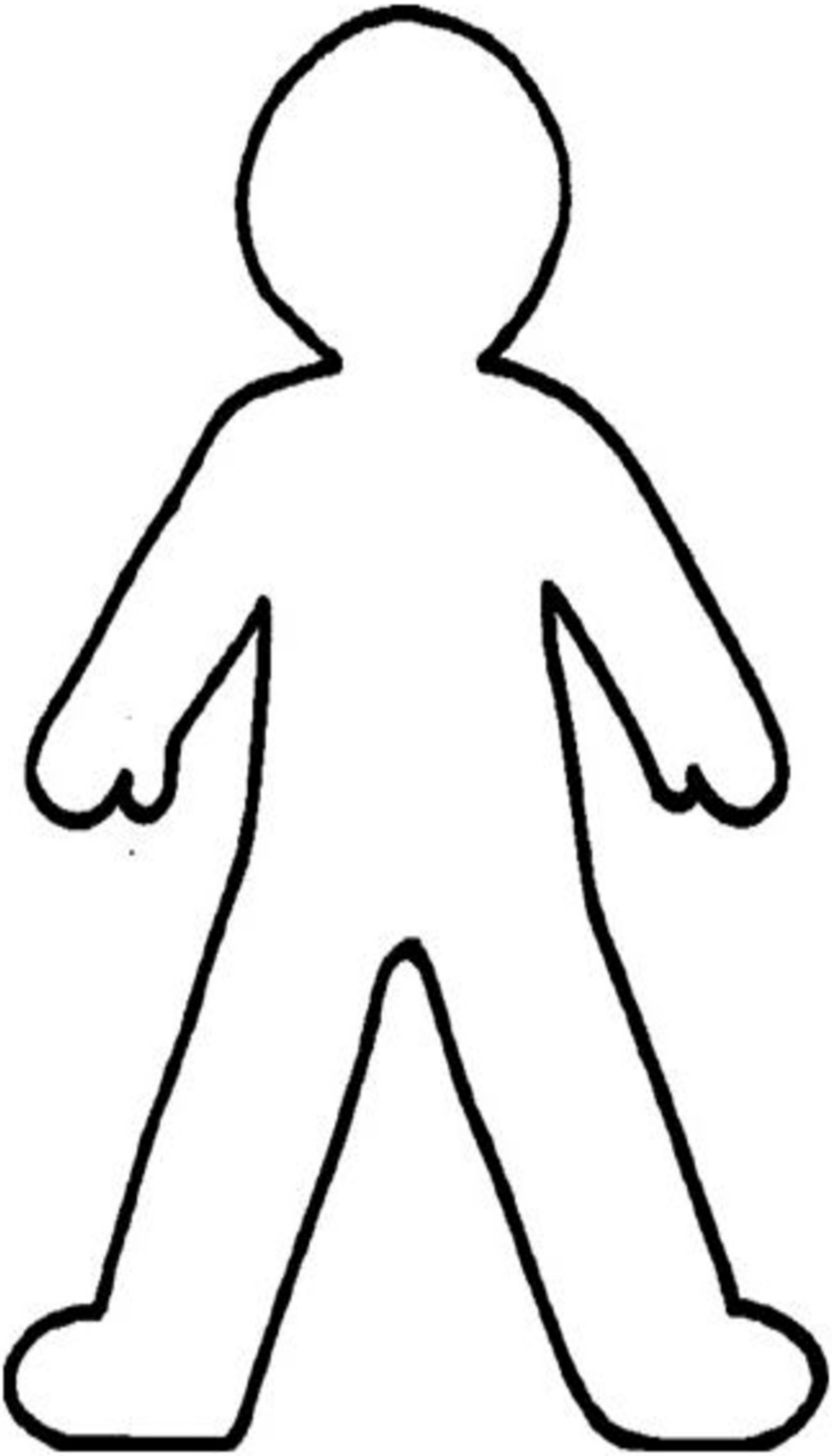

The dark

Going to school

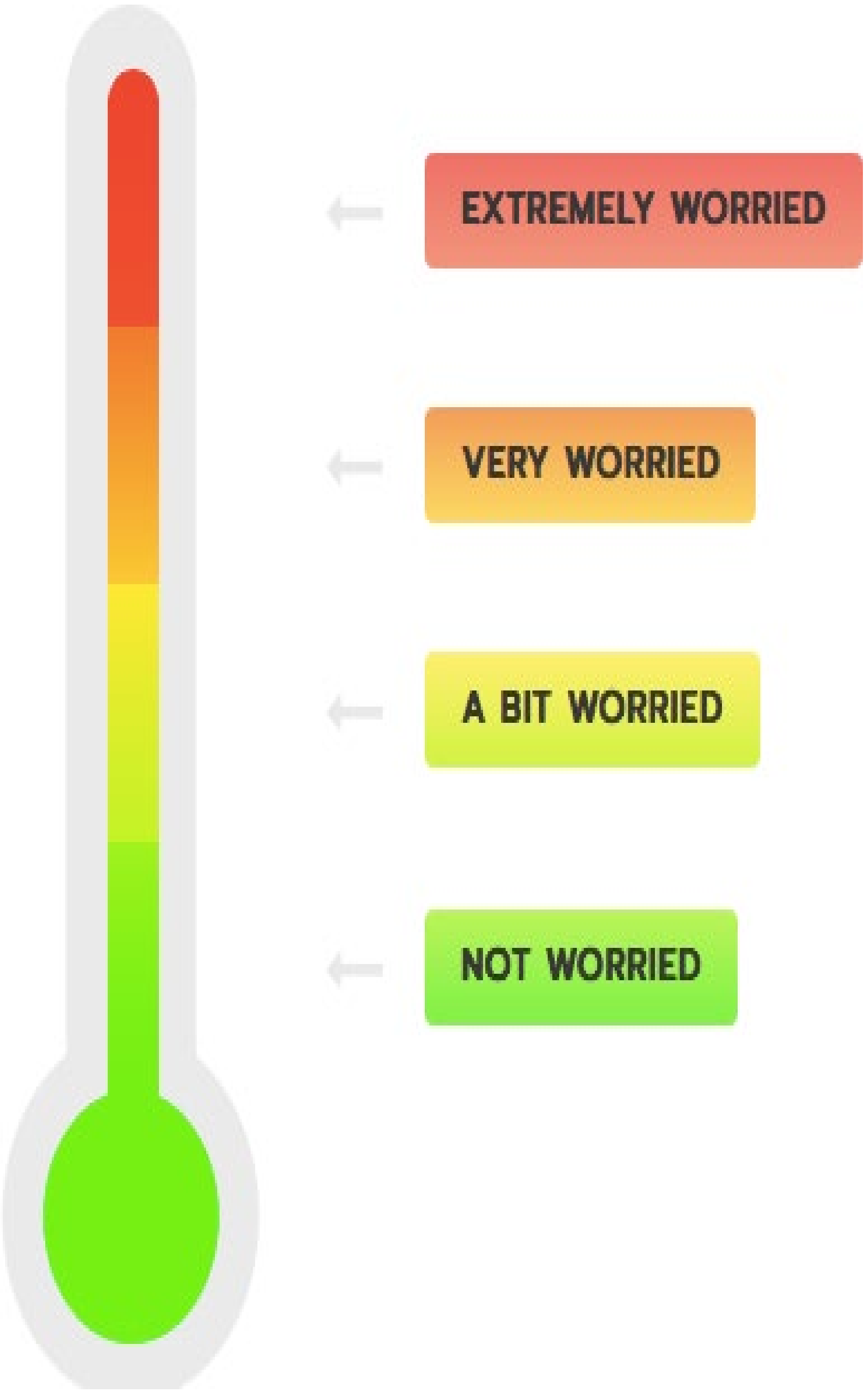

Spiders

Something else?

Activity Sheet 2:
Draw in where you feel anxiety in your body.



Activity Sheet 3:
Draw or write what makes you worried.



Activity Sheet 4:

STEP BY STEP

STEP	REWARD
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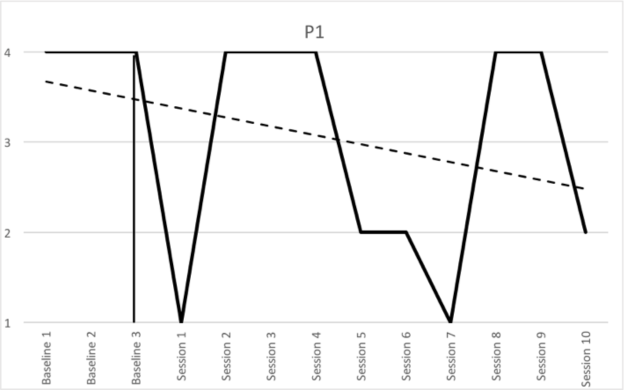
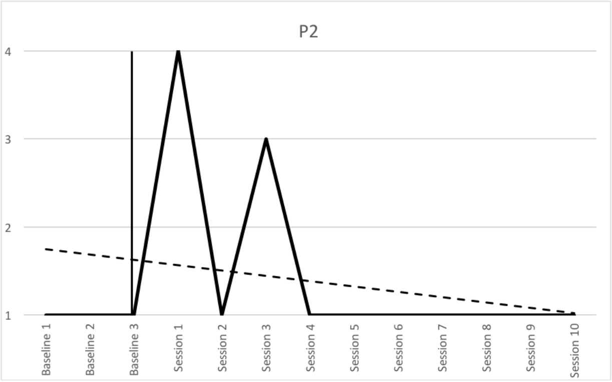
2.	
3.	
4.	
5.	

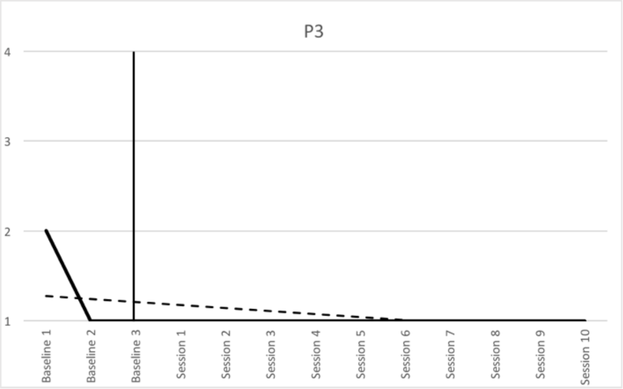
APPENDIX D

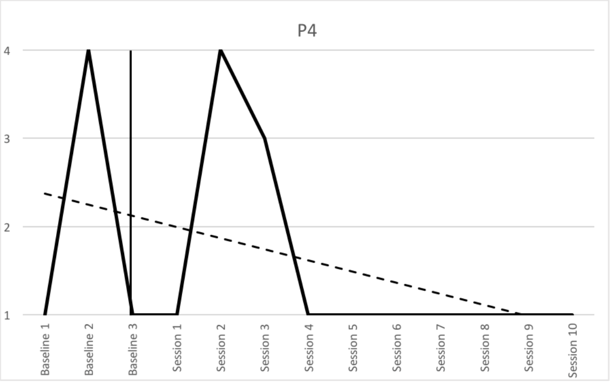
Supplementary Material for Clinician Confidence Survey

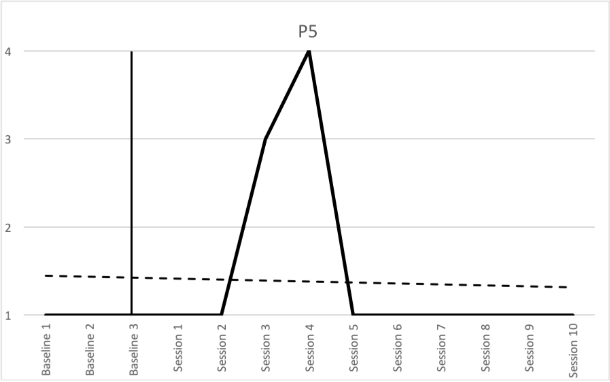
Supplementary File 1.

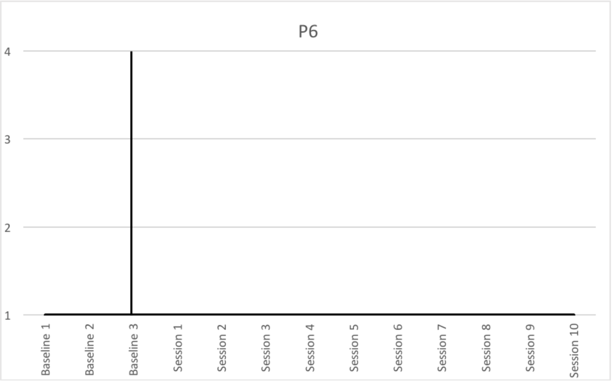


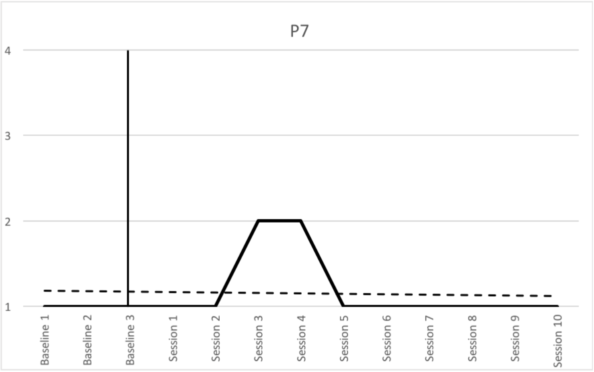


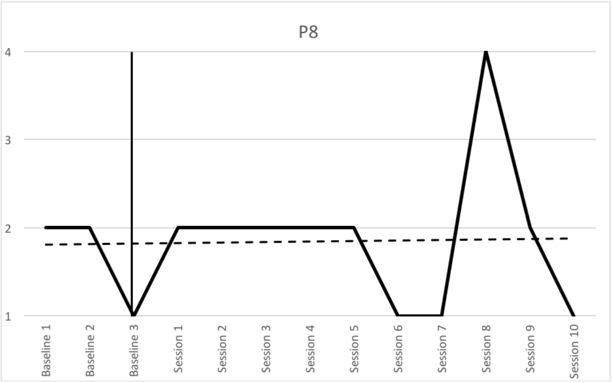


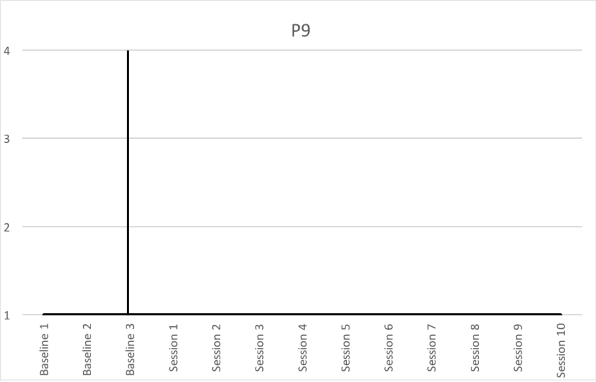








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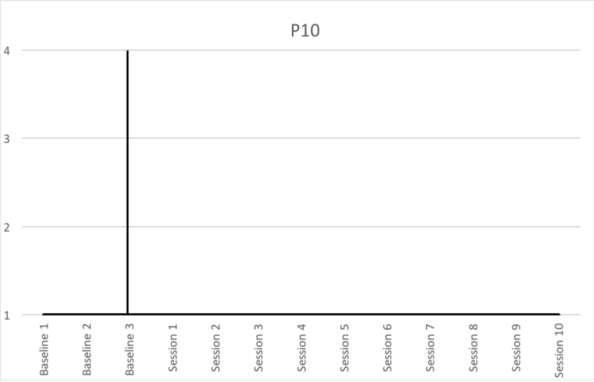
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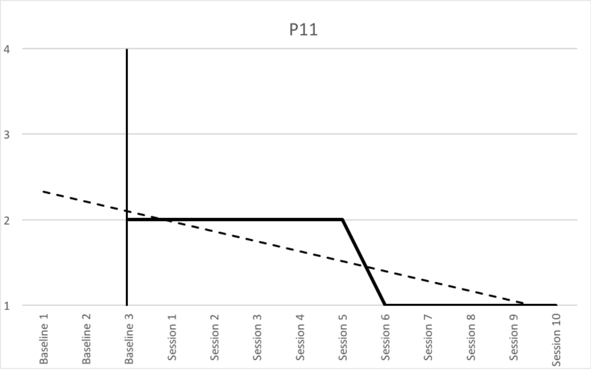
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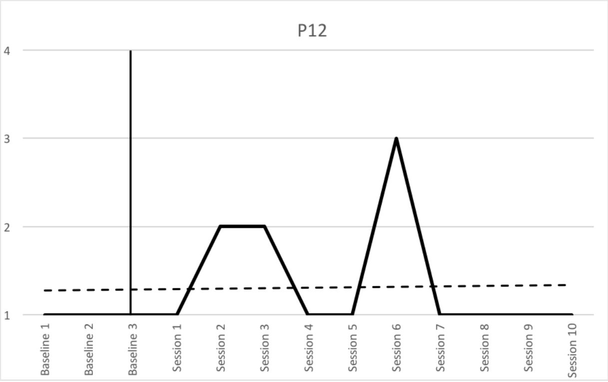
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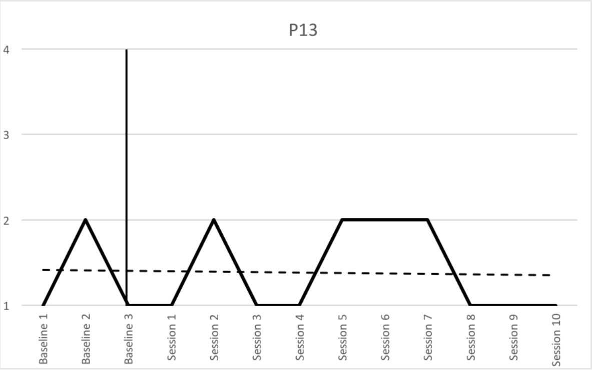
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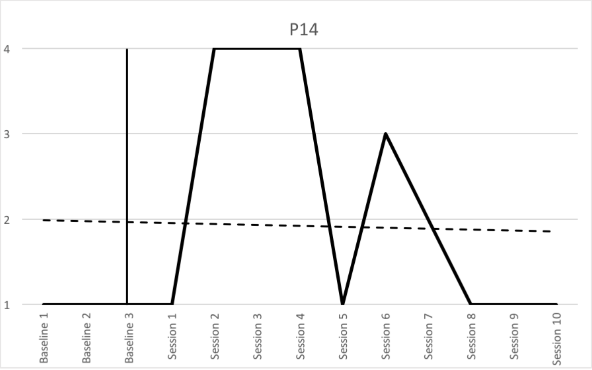
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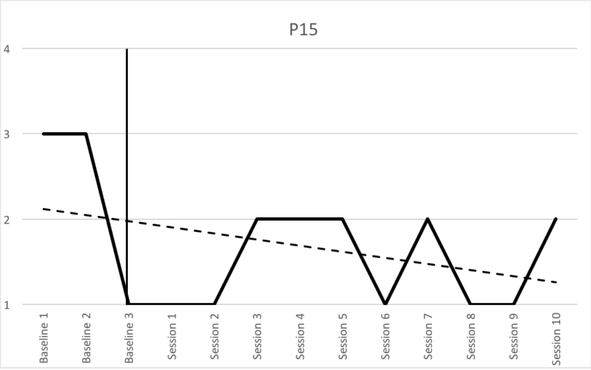
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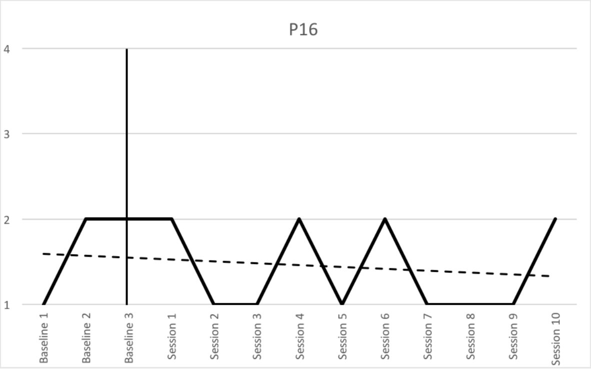
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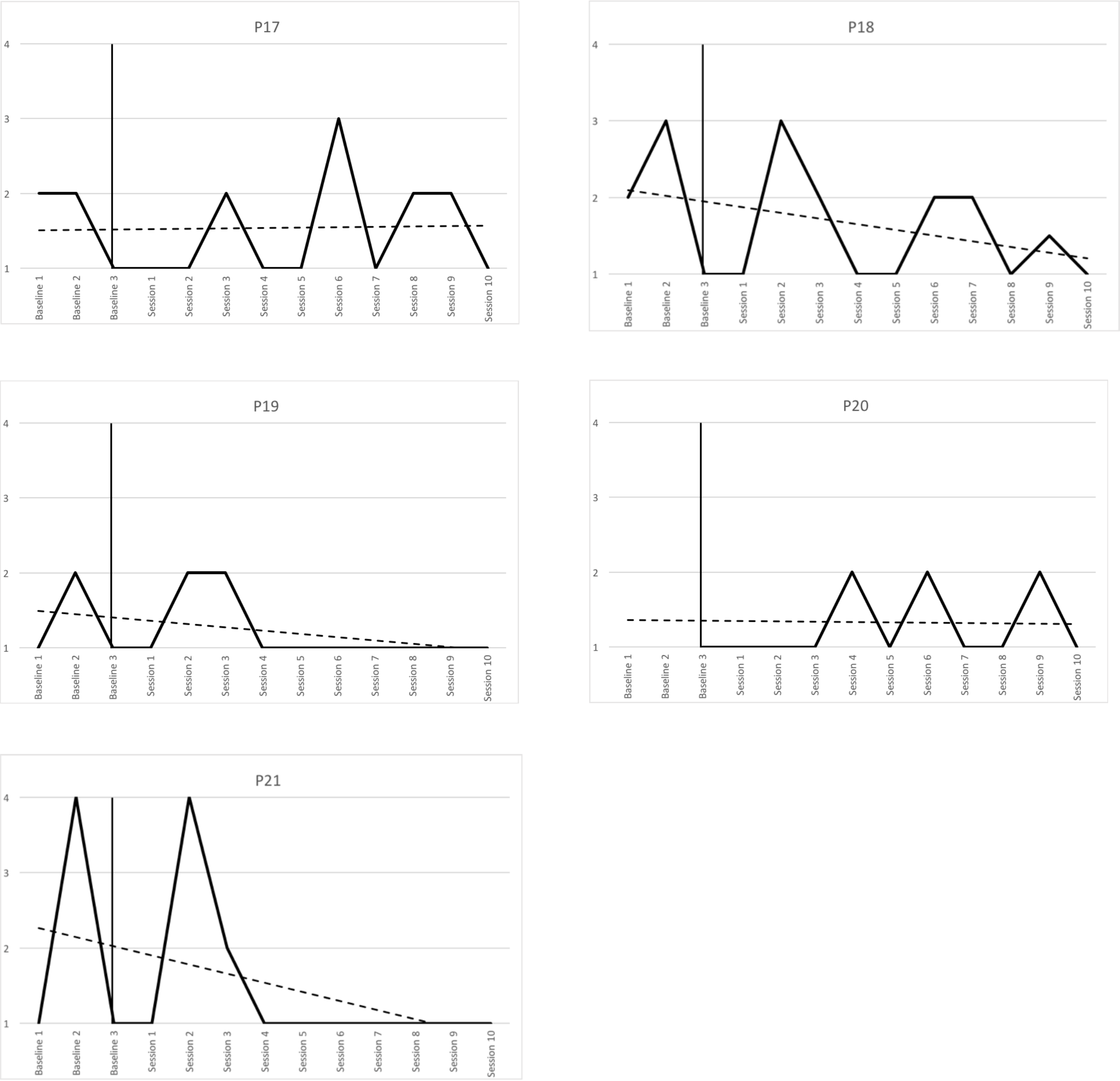

Graphs of Subjective Units of Distress (SUDS) for each participant.