Adapting Cognitive Behavioural Therapy for Children with Intellectual Disabilities: Development and Feasibility Evaluation of

the Fearless Me! © Program

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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.

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ii

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Table of Contents

List of Original Publicationsvii
List of Conference Presentationsviii
List of Contributors x
Abstractxi
Definition of Key Termsxiii
Abbreviationsxv
CHAPTER 1
Introduction1
CHAPTER 2
Guidelines for the Development and Evaluation of Interventions
CHAPTER 3
A Review of Cognitive Impairments in Children with Intellectual Disabilities:
Implications for Cognitive Behaviour Therapy44
CHAPTER 4
Involvement of Parents in the Development of a Cognitive Behavioural Intervention for
Children with Intellectual Disabilities
CHAPTER 5
Potential for Children with Intellectual Disability to Engage in Cognitive Behaviour
Therapy: The Parent Perspective72
CHAPTER 6
Involving Clinicians in the Development of a Cognitive Behavioural Intervention for
Children with Intellectual Disabilities94

CHAPTER 7

Assessing the Confidence of Australian Mental Health Practitioners in Delivering
Therapy to People with Intellectual Disability104
CHAPTER 8
Adapting Cognitive Behavioural Therapy to Create the Fearless Me! ©
Program117
CHAPTER 9
Fearless Me! ©: A Feasibility Case Series of Cognitive Behavioural Therapy for
Adolescents with Intellectual Disability141
CHAPTER 10
Approaches to Evaluating Interventions157
CHAPTER 11
Pilot Evaluation of the Fearless Me! © Program for Children with Intellectual
Disabilities and Anxiety
CHAPTER 12
Discussion198
APPENDICES
Appendix A: Ethical Approval for Studies
Appendix B: Brief report published in the Journal of Intellectual Disability Research
based on the findings in Chapter 5 221
Appendix C: Fearless Me! © Treatment Manual
Appendix D: Supplementary Material for Clinician Confidence Survey

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.
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List of Conference Presentations

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- 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
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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.

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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
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- 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