

Participant experiences of *Fearless Me!* ©: Cognitive behaviour therapy for anxiety in children with intellectual disabilities

Senali Panditaratne¹ · Anastasia Hronis¹ · Rachel Roberts² · Ian Kneebone¹

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Abstract

Research shows that almost half of children with intellectual disabilities (ID) experience mental ill-health at any given time point. However, traditional cognitive behaviour therapy (CBT) may not be appropriate for children with ID due to the cognitive deficits associated with their diagnosis. The *Fearless Me!* © CBT program for anxiety is adapted to accommodate the cognitive abilities of children with ID. The aim of the current study was to provide the first qualitative evaluation of the *Fearless Me!* © program by exploring participant experiences. Eight mother—child dyads were interviewed using a semi-structured protocol. The responses were transcribed and analysed using thematic analysis. Identified codes and themes were cross-checked with an independent researcher and discrepancies were resolved. Parents found the program to be positive and useful for acquiring knowledge. They commented on features of the program, significance of inter- and intra-personal factors and whether the program suited the capability of their child. They also discussed features of treatment outcomes. The qualitative results highlighted that experiences of the program varied. Themes identified included those relating to barriers and facilitators to participation and treatment-related change. The themes provide guidance for program revisions and can inform future delivery of the *Fearless Me!* © program.

Keywords Fearless Me · Adapted · Cognitive behaviour therapy · Qualitative · Children · Intellectual Disability

It is well established that children with Intellectual Disability (ID) experience comorbid mental health concerns, to a greater than their same aged peers without disabilities (Einfeld et al., 2006; Wallander et al., 2006). Thirty to fifty percent of children and adolescents with ID experience mental ill-health at any given time point (Einfeld et al., 2011). A systematic review and meta-analysis found that 5.4% of children with ID experience one or more anxiety disorders (Maïano et al., 2018). Furthermore, experiencing anxiety was predictive of children with ID exhibiting challenging behaviours (Rzepecka et al., 2011). Also, children with ID who experience high levels of emotional disturbance often experience distress well into young adulthood (Einfeld et al., 2006). As such, it is clear that developing effective therapies

for mental health concerns in children with ID is a worthwhile undertaking.

Children with ID experience significant deficits in areas of intellectual and adaptive functioning which often exclude them from receiving cognitive-based interventions (American Psychiatric Association, 2013). Specifically, they often struggle with reasoning, problem solving, planning and abstract thinking (Hronis et al., 2017). Children with ID may also fail to meet certain developmental and socio-cultural expectations normal for their age group, such as communication and social participation (American Psychiatric Association, 2013). Hence children with ID need suitable psychological therapies to account for these social and cognitive deficits..

Cognitive behavior therapy (CBT) is the gold standard for the treatment of anxiety disorders and emotional disturbance in typically developing children (Compton et al., 2004). It is also efficacious in treating anxiety disorders in children with Autism Spectrum Disorders (Hunsche & Kerns, 2019; van Steensel & Bögels, 2015) however, has not been evaluated for children with ID (Taylor et al., 2008). Key features of CBT interventions involve understanding

Anastasia Hronis anastasia.hronis@uts.edu.au

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- Discipline of Psychology, Graduate School of Health, University of Technology Sydney, Sydney, New South Wales, Australia
- School of Psychology, University of Adelaide, Adelaide, South Australia, Australia



the link between thoughts, feelings and behaviours and addressing unhelpful cognitions and behaviours through disputation and experiments (Tolin, 2016). Children with ID may struggle to engage with CBT programs (Hronis et al., 2017) as their deficits appear to contribute to difficulties in discriminating between thoughts, feelings and behaviours (Sams et al., 2006). As such, adaptations to the delivery of therapy should be considered. Parents of children with ID and comorbid anxiety, also support adapting CBT to suit their child's abilities. They have suggested changes such as breaking instructions into smaller steps, using visual cues and involving parents in the treatment (Hronis et al., 2020). To meet the need for adapted CBT for children with ID and anxiety, the Fearless Me! © CBT program was developed (Hronis et al., 2018a, b. A pilot study evaluated the feasibility of the program and found the potential for reliable reductions in anxiety in adolescents with ID, as a result of the intervention (Hronis et al., 2019).

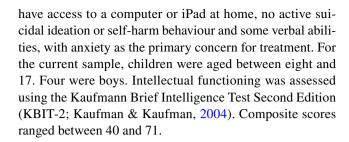
A case series was conducted to quantitatively evaluate the effect of the *Fearless Me!* © program on reducing anxiety in children with ID (Hronis et al., in preparation). Qualitative evaluation is another valuable form of assessing a program as it collects highly detailed information regarding client experiences, contextual factors that may affect treatment outcomes, unintended treatment effects and significance of treatment effects (Patton, 2002). While quantitative data identifies the existence or absence of treatment effects, qualitative data attempts to explain why the treatment effects occurred (Patton, 2002). This is valuable information for developing a program and evaluating its merit, value and worth (Mertens & Wilson, 2012).

The current study was a qualitative evaluation of the Fearless Me! © (Hronis et al., 2018a, b, 2022) program. It aimed to evaluate the user experience by providing an explorative overview of: (i) the participant experience of the intervention and (ii) the participant experience of treatment-related change. In addition, the current study aimed to identify areas for improvement of the program. Due to the exploratory nature of the study, there were no hypotheses or expected outcomes.

Method

Participants

Participants were recruited from the families enrolled in completing the *Fearless Me!* © CBT program and consisted of 8 mother–child dyads. Inclusion and exclusion criteria were those that applied to the case series evaluation Hronis et al. (in preparation). Children were required to be within the ages of eight and 18, have a diagnosis of mild or moderate ID or intellectual functioning in the borderline range,



Procedure

The study received HREC approval from the University of Technology Sydney Human Research Ethics Committee (ETH18-2384). Children completed 10 treatment sessions of the Fearless Me! © program before taking part in the qualitative evaluation with their parents. The Fearless Me! © program is an adapted CBT program designed for children with mild to moderate intellectual disabilities. Program development followed the framework for developing complex interventions proposed by the Medical Research Council (Craig et al., 2008) and the roadmap proposed by Center for eHealth Research and Disease Management (CeHRes; van Gemert-Pijnen et al., 2011) for developing and evaluating eHealth and online interventions. This involved a review of literature about how CBT could be adapted to meet the needs of children with ID (Hronis et al., 2017), collecting parent perspectives (Hronis et al., 2020), assessing the confidence of clinicians (Hronis et al., 2018a, b), and conducting a feasibility pilot (Hronis et al., 2019).

The The Fearless Me! © program consists of ten face-to-face sessions and an online program which breaks the elements of CBT into their simplest form and provides participants the opportunity to practice CBT skills through a range of exercises. Each session involves teaching material and use of the online program. Exercises on the website are provided for homework. The program teaches relaxation strategies, identifying and challenging unhelpful/irrational thoughts, and developing and implementing exposure hierarchies.

Interviews wer held at a university psychology clinic. An independent researcher initially interviewed a parent of the child participant. They were asked about their experiences of the program and those of their child's. The child was then interviewed about their experiences. Their parent was present for this interview. The interviews were video recorded, transcribed, and then de-identified transcripts were subject to analysis.

Data Analysis

Data analysis was conducted using Nvivo12 Pro (QRS International Pty. Ltd., 2018). Each interview was transcribed, resulting in a sample of eight transcripts to be included in a thematic analysis (Braun & Clarke, 2006). The resulting



themes and subthemes were repeatedly read and scrutinised by one of the research team who was blind to the outcomes of the case series study. A second, independent researcher reviewed the themes and subthemes to ensure the participants' understandings were not lost and to validate the themes identified. Agreement on the themes was reached by discussion with the independent reviewer.

Results

The results of the thematic analysis identified four themes and 14 subthemes (Table 1) which will be discussed further below. It was noted that the data reached saturation.

Theme 1: Reflections on Features of the Program

Throughout the interviews, parents made reference to various features and elements of the *Fearless Me!* © program. These included the timing of sessions and specific tasks required. Three subthemes highlight the program features: helpful aspects, structure and parental role.

Subtheme 1: Finding Aspects of the Program Helpful or Likeable

Overall, parents reported that completing the intervention was a positive experience, with no parent describing the intervention as a negative experience.

"Thanks for the invite. It's brilliant it's brilliant." (R10's mother)

"It's all been pretty positive." (R1's mother)

Responses regarding specific activities highlighted that the children responded differently to each of the tasks. Some participants liked and engaged well with *Detective Thinking*, whereas some parents stated their child struggled with it. Similarly, some parents reported *Progressive Muscle Relaxation* was not helpful or liked by their child, but some enjoyed it the most.

"She doesn't wanna do the tense and relax, tense and relax, she's not interested in that." (R1's mother) "So the squeeze and relax was really good for her, cos she, she can remember like it's, it's simple for her to remember all those motions." (R16's mother).

Subtheme 2: Structure of the Program

Parents commented on how the sessions were structured and their frequency. Weekly sessions was considered a possible barrier to engaging with the program. Firstly, because it required commitment from parents, and secondly, because children tended to easily forget skills so much was covered in a session. To address this, one parent suggested delivering the intervention in three-week blocks, with a week break in between. The considered this would give their child time to consolidate learning through practice and homework.

"It was more of a commitment than I anticipated... but when it came to being every single week like she's got, like a lot of kids with intellectual disabilities, she's got other various things on after school on different days." (R1's mother)

Parents also commented on the standardised nature of the intervention and made suggestions to alter the program.

Table 1 Themes and subthemes following the thematic analysis

| Themes | Subthemes |
|---|--|
| 1. Reflections on features of the program | 1.1 Finding the program helpful or likeable |
| | 1.2 Structure of the Program |
| | 1.3 Parental role |
| 2. Interpersonal vs intrapersonal factors affecting participation | 2.1 Child/adolescent fears and anxieties |
| | 2.2 Relationship with the therapist |
| | 2.3 Intrinsic child characteristics |
| 3. Catering to the abilities of child/adolescent | 3.1 Parent beliefs of program matching or mismatching |
| | 3.2 Complexity of language used in the program |
| | 3.3 Consideration of communication abilities |
| | 3.4 Level of child/adolescents' understanding |
| | 3.5 Sufficient time for comprehension |
| 4. Characteristics of treatment outcomes | 4.1 Parental expectations of change for child/adolescent |
| | 4.2 Learning of skills and information |
| | 4.3 Treatment related changes |



"Maybe changing it sometimes on the run, to tailor it a little bit to the person." (R16's mother)

Subtheme 3: Parental Role

Parents were asked about their perceptions of their role in their child's engagement with the program. All parents agreed that their role was to support their child going through the intervention. Most parents believed this was achieved by practicing and following up the new skills at home.

"To basically put into practice during the week what we had done the week before. So that she could use it otherwise there's no point in her coming." (R16's mother)

However, some parents faced challenges when trying to assist their children with practicing skills, due to their child's reticence to take direction from them.

"I uhh, faced this challenge with them, I don't know if it's the teenage years...they don't take it seriously." (R5's mother)

"But my personal challenge in that was that A does not like me to be teacher, so I had to delegate practicing this to friends, to his speech therapist." (R8's mother)

All parents felt that they were happy with their role and would not have been able to be involved in further ways due to other commitments.

"That's what I can do with my role with my life...I don't see any way I could push myself more." (R4's mother)

Theme 2: Interpersonal vs Intrapersonal Factors Affecting Participation

Subtheme 1: Child/Adolescent Fears and Anxieties

A variety of fears, anxiety with different levels of impact on families, was identified across all participants. Some children were anxious about socialising with their peers and some were fearful of insects. One child also presented with anxiety around sleep due to nightmares and some children were anxious about the weather.

"[R16's] got the anxiety and fears about certain things that are kind of quite crippling in our household... She's petrified of rain, so she won't go to sleep at night if it's raining, and she asks people all day, constantly if it's going to rain and she constantly checks the weather." (R16's mother)

The nature of their child's fear(s) was identified as a possible barrier to engaging with the program by some parents. One parent stated that the complexity of her child's fears made it difficult to treat.

"With [R8], he doesn't speak about fears and it's kind of hidden inside...if they were obvious fears, 'I'm afraid of ...' that would be immediate kind of response and he would got it quicker." (R8's mother)

Another parent stated that what her child fears, limits her willingness to leave home and attend sessions.

"Now today she didn't want to come, and she came to know it's raining, she didn't want to get out because she's scared she's going to get sick." (R6's mother)

Subtheme 2: Relationship with the Therapist

Almost all parents commented on the relationship between their child and the *Fearless Me!* © therapist, being a strong therapeutic alliance. Their responses highlighted that the therapist's ability to understand the child/adolescent was a facilitator for treatment engagement and change.

"She likes, you know, even the way [therapist] is able to explain everything to her." (R10's mother) "You know what, him and [therapist] are a perfect fit, I think it really makes a difference." (R9's mother)

Subtheme 3: Intrinsic Child Characteristics

Parents identified intrinsic features of their child, which promoted their active participation in the program. Two parents stated that their child's development stage was important. They felt that their children were "mature" and "ready" to be taught the skills of the intervention and able to practice them.

"Part of it I definitely feel is from his growth, mental growth...He's quite mature now." (R4's mother) "He is ready for these things, couple years ago he wasn't, I think at his age he's ready...So he's open and he's ready to listen, so he will benefit regardless because he's ready for it." (R9's mother)

The notion of success, achievement and control being motivating factors was also brought up by some parents. One of the program's tasks was to develop "step ladders" to face their fears, and a tangible reward was set to be delivered following the completion of each step. However, parents stated that their children were motivated to engage in the skills learnt, more due to the feelings of achievement when completing a step, rather than any predetermined reward.



"It's just the sense of achievement with her that's enough, so she yeah so she ended up staying in the bed and she was really proud of herself." (R16's mother)

Interestingly, the theme of program features was also found to be related to intrinsic child characteristics. Parents stated that the tasks were designed in a way that motivated their children or provided them with a sense of control.

"Because he feels that he is in control of something and like you know, he has sort of found some solutions to some of his anxieties, like how he can tackle them." (R5's mother)

Theme 3: Catering to the Abilities of Child/ Adolescent

Parent responses indicated whether the *Fearless Me!* © program was suitable, or not, given the abilities of their child.

Subtheme 1: Parent beliefs of Matching or Mismatching

Parents provided conflicting reports about the tasks matching their child's abilities. Some parents felt that overall the sessions and tasks were suitable, but then highlighted specific ways in which some activities were too complex.

"Some of the program I thought was umm a little bit complicated for her." (R16's mother)

"Online activities, for her it's a little bit frustrating because of her vision yeah she yeah, she, her concentration and things like that, she can't concentrate for a long time." (R6's mother)

One parent felt the program fully matched the abilities of her child, without any components being too complex.

"I think his ability to sit down, focus, understand and with his intellect abilities, the program suits him." (R9's mother)

Subtheme 2: Complexity of Language Used in the Program

When exploring why the program may not have matched the child/adolescents abilities, parents often commented on the level of language used. The most common comment around the language of the program was that it was too verbal, and demanded higher verbal skills than those the children had. Many believed the sentences were too long, included too many colloquialisms and the materials were too verbal rather than visual.

"You have to look at her as somebody, like English is almost her second." (R1's mother)

"Because he's language deficient, it was hard on him." (R4's mother)

"I think there was a little bit too much of verbal information for him." (R8's mother)

This was seen to be a barrier to their child's ability to participate in the program. To manage this, parents suggested seeking external assistance.

"Have an input from some, somebody who is in the language field or who has dealt with children on the spectrum in terms of the language to use." (R4's mother)

They also suggested changing the language:

"So you need a lot more visuals as opposed, and a lot less words...It's like just very short sentences, the least amount of words you can use as possible... the English could be a lot simpler." (R1's mother)

Subtheme 3: Consideration of Communication Abilities

Parents have described varying levels of communication between themselves and their child. They also noted that their children would not be able to effectively communicate their intended responses, hence the therapist would not be receiving accurate representations of the child's understanding.

"He has a magic phrase which is "sort of, yes and no, sometimes" it means that he is avoiding the question." (R8's mother)

"When she's been asked a question about "would you like that again?" her default answer is always yes... You're not really getting a true response to something because she will always say "yes"." (R1's mother)

Subtheme 4: Level of child/adolescents' understanding

The concept of the child/adolescent lacking understanding or comprehension of the tasks was mentioned with frequently in parent responses.

"Concepts like detective, uhh, for you and I detective is something clear, but detective, what the heck is detective?...It's a concept it has to be taught." (R8's mother).

"The video of the child climbing up the stair, they were not for [R4's] abilities because he doesn't care whether somebody climbs a mountain...because it's like beyond his comprehension." (R4's mother)

Lack of understanding was also identified as a possible barrier to engagement for one child.

"To really engage in such things you need full comprehension of why you are doing this, but because he



doesn't even recognise he has anxiety, for him it's uh a tricky thing really." (R8's mother)

Furthermore, parent responses about lack of understanding were associated with comments about the language of the program being too complex.

"Some of the things they were saying to her, I'm thinking "gosh, she isn't gonna have a clue what that means", you know?" (R1's mother)

However, some parents did note their child was able to understand components of the intervention, indicating that comprehension can serve as a facilitator for engagement and treatment related change.

"Yeah I mean she had quite good comprehension, you know when it was all nutted out, yeah I think so yes she did." (R1's mother)

"It's uh, been rewarding because they've been expressing themselves well with [therapist] and are able to understand it's anxiety and they can help, and they can overcome it." (R6's mother)

Subtheme 5: Sufficient time for Comprehension

Parents made reference to the need for time for new skills to be understood and practiced.

"I think I'm going to have to give it some time to be able to uhh yeah see how it is uhh, how if, there is any changes." (R6's mother)

"With him every new skill, it takes a lot of time to sink in... So yeah I guess we have not yet fully experienced the umm the results of the treatment, I think it's still yet to come." (R8's mother)

Theme 4: Characteristics of Treatment Outcomes

Due to the evaluative nature of the current study, parents were asked for evidence of changes in their child's experience of anxiety and/or fears.

Subtheme 1: Parental Expectations of Child/Adolescent for Change

Most parents hoped to see some change, however were not expecting to see major changes in their child's presenting concerns.

"I certainly was not expecting there to be... you know, that she was going to suddenly going to turn around and be a completely fearless, compliant teenager." (R1's mother)

"Of course I wish that you know, he just did the programs and suddenly became you know, a fear free indi-

vidual but umm yeah, I also realised it's probably not possible because re-wiring of the brain takes time." (R8's mother)

Subtheme 2: Learning of Skills and Information

Both parents and children/adolescents noted that they had acquired new skills and information throughout the intervention, which may explain changes seen in the children.

"It felt good coming here and expressing myself and learning stuff along, long the way." (R5)

"He learnt that he can actually break down the problem into parts and uh realise that, there are worry thoughts that are not helpful." (R8's mother)

"What we have learn there, we'll carry it on as part of our daily life." (R4's mother)

Subtheme 3: Treatment related Changes

Participant responses regarding treatment related change were varied and were associated with some of the factors described above. Some parents saw changes specific to the fears of their children.

"One of her biggest fears was addressing the cockroaches ... we ended up putting a cockroach in a washed-out ice-cream container to show [therapist], so you know she made leaps and bounds." (R1's mother) "We were making quite a lot of progress...it was raining in the night, and she didn't get out of bed, she stayed in bed and she used the things she's learned in the program...She would start doing her balloon breathing and squeeze and relax and then she'd start saying "it's only rain, it's for the flowers" you know, so trying to do that thought challenging you know?" (R16's mother)

Some parents also noticed changes in the domain of emotion regulation.

"She's settling herself down a lot better now." (R10's mother)

"The biggest thing we have noticed is, he is labelling his emotions and he is talking more about it." (R4's mother)

Most of the parental reflections about seeing change in their children, were associated with use of the skills taught in the *Fearless Me!* © program.

Suggestions

During the interviews, parents provided suggestions for program improvements, most of which were associated with



Table 2 Parent suggestions for program revisions sorted by associated themes

| Associated Theme | Suggestions |
|----------------------------|--|
| 1.3 Parent Role | "So I didn't know that I was going to be sitting in all of the sessions. Maybe that's something you should tell all the parents [before they start]." (R1's mother) |
| | "I would have liked a little bit more interaction [with the therapist] umm like you know, probably after the session for me to know what they were doing in session." (R6's mother) |
| 3.2 Complexity of Language | "If you get on the umm Down Syndrome Association website, so there is a whole thing called easy readerI would get the fearless me website completely changed into that readable English thing." (R1's mother) |
| | "A lot more visuals so if [therapist]'s, if she's saying, "remember in week 3, we did this?" it's like she needs a laminated sheet of paper to say, to bring the person back" (R1's mother) |
| | "So if you're saying, "did you find that useful?" "Yes." "Would you like to do that again?", "Yes" so you know so everything is always a yes. But if you, you need to give a few different choices for her to pick one." (R1's mother) |
| 3.5 Adequate time | "You need a lot bigger gap [when asking questions] to elicit a response from somebody like her" (R1's mother) |
| | "You have to wait, cos if you, you're talking to somebody and they're not responding to you and you continue talking to them, they're not able to process the first sentence." (R1's mother) |
| | "I think it's important that on the week, on the new week, that you just summarise cos sometimes you don't quite grasp it and you're a bit lost." (R10's mother) |
| | "I think all also just checking her understanding sometimes because sometimes she's and it just takes a lot of time. You just gotta take a lot of time and explain it and double check she knows what's going on." (R16's mother) |
| Uncoded | "I just thought that if [R8] had an opportunity to teach what he was taught to another child, then I think I he will probably owe ithe would comprehend the skill better." (R8's mother) |
| | "Probably there's some apps or something like that with accessible tools he's not so much into a piece of paper to go through, he most likely wouldn't use that, but if it was on a phone he might usethe prompts to remember what to do when he has anxiety." (R5's mother) |

the four themes. However, there were some suggestions that were not coded within the themes, which would be beneficial to inform program revisions. These are listed in Table 2.

Discussion

The aim of the current study was to explore the participant experiences of the *Fearless Me!* © program (Hronis et al., 2022). The outcomes and findings are intended to be used alongside the outcomes of the case series study (Hronis et al., in preparation) to provide a mixed methods evaluation of the *Fearless Me!* © program.

Overall, the results showed that participants found the intervention to be positive, and were grateful that a suitable intervention to address anxiety was available. Parents made reflected on features of the program, how the components were received by themselves and their children, the program's structure and the parent's role.

One theme highlighted the influence of inter- and intrapersonal factors on the children's experience of the program. Parents commented on intrinsic factors such as their child's maturity and subsequent readiness to engage, and the nature of their child's fears. Parents also emphasised the importance of the relationship between their child and the *Fearless Me!* © therapist. There were mixed reports of the program being able to match the abilities of a child. These included the

complexity of the program's language, communication difficulties, lack of understanding of program components and not having sufficient time to comprehend what was taught.

The contribution of the program to changes in anxiety was also explored. Parent's had realistic expectations for change, and some did identify evidence of change in anxiety whilst also noticing changes in emotion regulation. Some parents stated that they saw no change in anxiety, however they identified that new knowledge or skills had been learnt.

Implications

The resulting themes, identified within participant responses, were recognised as barriers or challenges to program participation and treatment-related change. They also identified factors that were facilitators, such as therapist relationship and some program tasks suiting child abilities. These barriers and facilitators may provide guidance for the revision and future delivery of the program.

One potential barrier may have been the program not suiting certain abilities of the participants. The implication of this is to either tailor the program to individual needs, or continue with delivering a manualised treatment. However, the decision to individualise or manualise becomes difficult with those with ID. Children with ID have common deficits in areas such as language comprehension (Sams et al., 2006), which were also noted in



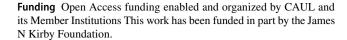
the participants of the *Fearless Me!* © program. However, within an area of deficit, each child had a different level of ability, possibly making it difficult to create a standardised program that caters for all needs. Additionally, there seems to be no difference in treatment outcomes between manual-based and individualised CBT (Ghaderi, 2006), but therapist flexibility in adapting the program to child needs may promote child engagement (Chu & Kendall, 2009). As the child-therapist relationship was identified as a facilitator in the current study, the program might allow more space for therapist flexibility, whilst continuing to deliver a manualised treatment.

Another implication is the level of assessment undertaken to determine participant eligibility prior to commencing intervention. The themes identified indicate that greater assessment of child and parent capacity may be required. For example, one parent mentioned that her child struggled using the website to complete activities due to problems with her vision. Although interventions have found success incorporating the use of computers for children with ID (Alcalde et al., 1998; Choi et al., 2012), the Fearless Me! © program may benefit from assessing a potential participant's computer literacy. Parental role and the dynamic between parent and child/adolescent was also found to be a possible barrier. This could be due to parents experiencing conflicting commitments or carer burden (Cadman et al., 2012), which could limit their ability to practice newly learnt skills out of session. Additionally, some parents noted that their child was not likely to take on their suggestions, or communicate their experiences to them. As such, it may be beneficial to assess the capacity of the parent-child relationship to support the child's engagement in the program.

Conclusion

Overall, the exploration of participant experiences of the *Fearless Me!* © program highlighted possible facilitators and barriers to engagement and treatment related change, which may inform program revisions. These revisions could include greater flexibility to accommodate for the different levels of ability in each participant. It is also worth considering that when working with a child/adolescent with ID and their parent, a more thorough assessment may be needed to determine their eligibility to participate. Despite finding areas of improvement, there were program features which promoted treatment related change, and the program would benefit from retaining these facilitators.

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Data Availability Statement The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations Authors have abided by the by the Ethical Principles of Psychologists and Code of Conduct as set out by the BABCP and Australian Psychology Society (APS).

Ethical Approval Ethical approval was granted by the University of Technology Sydney Ethics Committee (ETH18-2384).

Informed Consent Informed consent was obtained from all individual participants and their parents/legal guardians in the study.

Conflicts of Interest None.

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References

- Alcalde, C., Navarro, J. I., Marchena, E., & Ruiz, G. (1998). Acquisition of basic concepts by children with intellectual disabilities using a computer-assisted learning approach. *Psychological Reports*, 82, 1051–1056. https://doi.org/10.2466/PR0.82.3. 1051-1056
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed.). Author.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77–101. https://doi.org/10. 1191/1478088706qp063oa
- Cadman, T., Eklund, H., Howley, D., Hayward, H., Clarke, H., Findon, J., & Glaser, K. (2012). Caregiver burden as people with autism spectrum disorder and attention-deficit/hyperactivity disorder transition into adolescence and adulthood in the United Kingdom. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51, 879–888. https://doi.org/10.1016/j.jaac.2012.06.017
- Choi, K.-S., Wong, P.-K., & Chung, W.-Y. (2012). Using computer-assisted method to teach children with intellectual disabilities handwashing skills. *Disability and Rehabilitation: Assistive Technology*, 7, 507–516. https://doi.org/10.3109/17483107.2011. 652998
- Chu, B. C., & Kendall, P. C. (2009). Therapist responsiveness to child engagement: Flexibility within manual-based CBT for anxious youth. *Journal of Clinical Psychology*, 65, 736–754. https://doi. org/10.1002/jclp.20582
- Compton, S. N., March, J. S., Brent, D., Albano, A. M., Weersing, V. R., & Curry, J. (2004). Cognitive-behavioral psychotherapy for



- anxiety and depressive disorders in children and adolescents: An evidence-based medicine review. *Journal of the American Academy of Child & Adolescent Psychiatry*, 43, 930–959. https://doi.org/10.1097/01.chi.0000127589.57468.bf
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: The new Medical Research Council guidance. *BMJ*, 337, a1655. https://doi.org/10.1136/bmj.a1655
- Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual and Developmental Disability*, 36, 137–143. https://doi.org/10.1080/13668250.2011. 572548
- Einfeld, S. L., Piccinin, A. M., Mackinnon, A., Hofer, S. M., Taffe, J., Gray, K. M., . . . Tonge, B. J. (2006). Psychopathology in young people with intellectual disability. *Journal of the American Medical Association*, 296, 1981-1989. https://doi.org/10.1001/jama. 296.16.1981
- Ghaderi, A. (2006). Does individualization matter? A randomized trial of standardized (focused) versus individualized (broad) cognitive behavior therapy for bulimia nervosa. *Behaviour Research and Therapy*, 44, 273–288. https://doi.org/10.1016/j.brat.2005.02.004
- Gobrial, E., & Raghavan, R. (2012). Prevalence of anxiety disorder in children and young people with intellectual disabilities and autism. Advances in Mental Health and Intellectual Disabilities, 6, 130–140. https://doi.org/10.1108/20441281211227193
- 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, 189–207. https://doi.org/10.1111/bjc.12133
- Hronis, A., Roberts, L., & Kneebone, I. (2018a). Assessing the confidence of Australian mental health practitioners in delivering theray to people with intellectual disabilities. *Intellectual and Developmental Disabilities*, 56(3), 202–211. https://doi.org/10.1352/1934-9556-56.3.202
- Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. I. (2018b). Fearless Me!©: Cognitive behaviour therapy for children with intellectual disability and anxiety. University of Technology Sydney & University of Adelaide.
- Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. I. (2019). Fearless Me!©: A feasibility case series of cognitive behavioral therapy for adolescents with intellectual disability. *Journal of Clinical Psychology*, 75, 919–932. https://doi.org/10.1002/jclp.22741
- Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. I. (2020). Potential for children with intellectual disability to engage in cognitive behaviour therapy: The parent perspective. *Journal of Intellectual Disability Research*, 64, 62–67. https://doi.org/10.1111/jir.12694
- Hronis, A., Roberts, R., Roberts, L., & Kneebone, I. (2022). Cognitive Behavioural Therapy for children and adolescents with intellectual disability and anxiety: a therapist manual. *Discov Psychol*, 2, 24. https://doi.org/10.1007/s44202-021-00017-z
- Hronis, A., Roberts, R., Roberts, L., Shires, A., & Kneebone, I. I. (in preparation). A case series evaluation of Fearless Me!©: Cognitive behavioural therapy for anxiety in adolescents and children with intellectual disability. University of Technology Sydney & University of Adelaide.
- Hunsche, M. C., & Kerns, C. M. (2019). Update on the effectiveness of psychotherapy for anxiety disorders in children and adolescents

- with ASD. *Bulletin of the Menninger Clinic*, *83*, 326–352. https://doi.org/10.1521/bumc.2019.83.3.326
- Kaufman, A. S., & Kaufman, N. L. (2004). Kaufman Brief Intelligence Test (2nd ed.). Pearson Inc.
- Maïano, C., Coutu, S., Tracey, D., Bouchard, S., Lepage, G., Morin, A. J. S., & Moullec, G. (2018). Prevalence of anxiety and depressive disorders among youth with intellectual disabilities: A systematic review and meta-analysis. *Journal of Affective Disorders*, 236, 230–242. https://doi.org/10.1016/j.jad.2018.04.029
- Mertens, D. M., & Wilson, A. T. (2012). Introduction to evaluation: Defining terms and ethical considerations. In D. M. Mertens & A. T. Wilson (Eds.), *Program evaluation theory and practice: A comprehensive guide* (pp. 3–32). The Guilford Press.
- Morgan, D. L. (2017). *Integrating qualitative and quantitative methods: A pragmatic approach*. SAGE Publications Inc.
- Patton, M. Q. (2002). Qualitative research and evaluation methods (3rd ed.). Sage Publications.
- NVivo 12 Pro. QSR International Pty. Ltd. (2018). *Qualitative solutions for research software*. Australia. Available from: https://www.qsrinternational.com/nvivo/home. Accessed in August 2019
- Rzepecka, H., McKenzie, K., McClure, I., & Murphy, S. (2011). Sleep, anxiety and challenging behaviour in children with intellectual disability and/or autism spectrum disorder. Research in Developmental Disabilities, 32, 2758–2766. https://doi.org/10.1016/j. ridd.2011.05.034
- Sams, K., Collins, S., & Reynolds, S. (2006). Cognitive therapy abilities in people with learning disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19, 25–33. https://doi.org/ 10.1111/j.1468-3148.2006.00303.x
- Scriven, M. (1991). Prose and cons about goal-free evaluation. Evaluation Practice, 12, 55–62. https://doi.org/10.1177/109821409101200108
- Taylor, J. L., Lindsay, W. R., & Willner, P. (2008). CBT for people with intellectual disabilities: Emerging evidence, cognitive ability and IQ effects. *Behavioural and Cognitive Psychotherapy*, 36, 723–733. https://doi.org/10.1017/S1352465808004906
- Tolin, D. F. (2016). Doing CBT: A comprehensive guide to working with behaviors, thoughts, and emotions. Guilford Press.
- van Gemert-Pijnen, J. E., Nijland, N., van Limburg, M., Ossebaard, H. C., Kelders, S. M., Eysenbach, G., & Seydel, E. R. (2011). A holistic framework to improve the uptake 101 and impact of eHealth technologies. *Journal of Medical Internet Research*, 13(4), e111. https://doi.org/10.2196/jmir.1672
- van Steensel, F. J. A., & Bögels, S. M. (2015). Cbt for anxiety disorders in children with and without autism spectrum disorders. *Journal* of Consulting and Clinical Psychology, 83, 512–523. https://doi. org/10.1037/a0039108
- Wallander, J. L., Dekker, M. C., & Koot, H. M. (2006). Risk factors for psychopathology in children with intellectual disability: A prospective longitudinal population-based study. *Journal of Intellectual Disability Research*, 50, 259–268. https://doi.org/10.1111/j. 1365-2788.2005.00792.x

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