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Listening to Mothers: Experiences of Mental Health Support and Insights into adapting Therapy for People with Severe or Profound Intellectual Disabilities

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Abstract

Objective: Individuals with severe or profound intellectual disabilities may be at a greater risk of developing mental health problems. Despite this, evidence suggests individuals can face difficulties in getting mental health support, and little is known about effective psychological therapies for this population. Hence, this study explored mothers' experiences of seeking mental health support for their offspring.

Method: Semi-structured interviews were conducted with six mothers of adults with severe or profound intellectual disabilities, who had sought mental health support for their offspring. Interviews were audio-recorded and analysed using Interpretative Phenomenological Analysis.

Results: The three main themes were 'A struggle to understand, Challenges to getting mental health support and A mother's approach to adapting therapy'. Mothers found it difficult to recognise signs of emotional difficulties in their offspring. However, they thought that their offspring faced discrimination when accessing services, and that professionals often lacked the knowledge and skills to work with people with severe impairments. The mothers also stressed the importance of the therapeutic relationship and the need to involve carers in therapy.

Conclusion: This study highlights the need for more appropriate mental health support for individuals with severe and profound intellectual disabilities. The findings also suggest further research is needed about adapting psychological therapies for this population.

Key words: intellectual disability, emotional difficulties, mental health, support, psychological therapy, qualitative research.

Introduction

There is evidence to suggest that individuals with intellectual disabilities are more likely to experience mental health difficulties than the general population, with a prevalence rate of 40.9% for adults (Cooper *et al.* 2007). The point prevalence rate of mental health problems in the general population is thought to be 16% (Singleton *et al.*, 2001). Within the intellectual disability population, individuals with severe or profound disabilities may be at an even greater risk of developing mental ill health (Cooper *et al.* 2007). Some of the reasons for this increased risk may include experiencing additional physical disabilities and health problems, having less access to purposeful day time activities (Jones *et al.* 1999); abuse (Lew *et al.* 2006); and experiencing a poorer quality of life and living in institutional environments (Perry and Felce 2003; The British Psychological Society 2016).

Despite high levels of mental health need amongst people with a severe or profound intellectual disability, individuals face significant obstacles to receiving appropriate support. The fact that individuals are unable to report their emotional experience means that their distress may only become apparent through behaviour such as changes in facial expression, vocalisations, self-injurious behaviour and becoming more withdrawn (The Foundation for People with Learning Disabilities 2005). Although there is growing awareness that individuals with severe impairments experience the same range of emotions as individuals without these difficulties, behaviours may not be recognised as an indication of poor emotional wellbeing and diagnostic overshadowing may occur, whereby presenting problems are ascribed to an individual's intellectual disability rather than a mental health problem (Carr

et al. 2016). Care staff, who are usually responsible for deciding whether or not to initiate referrals to mental health services, may also lack the knowledge or understanding to recognise emotional difficulties (Bates *et al.* 2004). In addition, many diagnostic measures used in clinical practice rely on proxy reports of ratings of behaviour. Therefore, mental health problems may be instead attributed to other causes such as a behavioural problem (Flynn *et al.* 2017).

People with intellectual disabilities face significant health inequalities. Mansell's report (2010), *Raising Our Sights*, described the discrimination faced by adults with severe and profound intellectual disability. This included professionals viewing these individuals as being 'too disabled' to be able to work with and having low expectations of what is possible to achieve with them. Research has shown that people with profound intellectual disabilities can face similar difficulties when accessing mental health support in particular (Chinn and Abraham 2016; The Foundation for People with Learning Disabilities 2014).

People with severe and profound intellectual disabilities rely on family or carers to seek access for help with emotional problems. Yet little is known about carer experiences of seeking support for these individuals. It would appear that only one qualitative study has explored carers' views of mental health support available for young people with profound intellectual disabilities (Phillip *et al.* 2005). Family carers said that there was an absence of specialist professional support or advice available to help with their children's emotional difficulties. Paid care staff took a different view and felt that psychological and psychiatric advice was available to them. However, they felt that the most helpful strategies were suggested by people that knew the individual well, with professionals often not having the time to devise interventions that were tailored to individual needs, due to their workload. In addition, care staff thought that professionals delivering psychosocial interventions often lack

the ability to deal with the significant communication problems of individuals with severe or profound intellectual disabilities (Phillip *et al.* 2005).

There are few evidence-based psychosocial interventions adapted to address the mental health problems of individuals with intellectual disabilities (The British Psychological Society 2016; The Scottish Government 2015), with medication as the most commonly used treatment option (Carr 2016). Even less is known about effective psychological interventions for people with more severe intellectual disabilities, and the National Institute for Health and Care Excellence (NICE) has published guidelines recommending additional research in this area (NICE 2016). Existing psychological therapy provision is not accessible for individuals with more significant impairments due to excessive cognitive and communicative demands, and there is a need for alternative methods of support to be developed.

There is limited knowledge about mental health in people with severe or profound intellectual disabilities, and how psychological interventions might be adapted for this population. Therefore, insights from people who care for individuals with severe or profound intellectual disabilities may prove helpful in this regard. This study examined the lived experience of mothers in seeking support for their offspring with severe or profound intellectual disabilities and emotional difficulties. It also sought mothers' views about making psychological interventions more accessible for individuals with a severe or profound intellectual disability.

Method

Design

This qualitative study used Interpretative Phenomenological Analysis (IPA) to explore the views of mothers of individuals with severe or profound intellectual disabilities. IPA is an approach which attempts to make sense of an individual's subjective experiences. It involves

the researcher attempting to interpret participants' experiences and how they perceive particular events in their lives (Smith *et al.* 2009).

Participants

A purposive sample of seven mothers were recruited from across Scotland through Promoting a More Inclusive Society (PAMIS), a voluntary organisation for individuals with profound and multiple intellectual disabilities and their families. Inclusion criteria were i) mothers of an individual over the age of 18 with a diagnosis of a severe or profound intellectual disability ii) had experience of seeking support for mental health difficulties faced by their offspring.

One participant's interview was not included in the analysis because her daughter had died. Hence, her experience was quite different from the other mothers. All participants have been given pseudonyms. Four of the participants were biological mothers and one had been the adoptive mother to two daughters with severe and profound intellectual disabilities since they were infants (Bernadette). The final participant had been the primary carer of an individual for the past five years (Joanne). She had taken on a maternal role and had become the main carer for this person in her own home. The term 'mothers' was used to refer to all participants in this study. The mothers lived with partners, and four participants' offspring lived at home with them, with two individuals residing in supported accommodation. Four participants' offspring attended day services part time, with one participant's daughter unable to leave her home due to physical health difficulties (Hayley). Although information about a formal diagnosis of severe or profound intellectual disability was not obtained, all participants were recruited through PAMIS, an organisation that supports individuals with profound and multiple intellectual disabilities and their families. All mothers described seeking support for their offspring's symptoms of anxiety or depression. The participants' and their offspring's

demographic information is provided in Table 1. Recruitment was carried out over a nine month period and this proved extremely challenging, even with the support of PAMIS, recruiting Scotland wide and adopting a proactive approach. Recruitment was concluded because considerable insights were obtained from the interviews that had been carried out and no further participants were forthcoming.

[Table 1 near here]

Semi-structured interview

One-to-one semi-structured interviews were conducted using a topic guide. The development of the topic guide drew on the available literature and had input from a group of mothers with children and adolescents with profound and multiple intellectual disabilities involved with the third sector organisation in Scotland, PAMIS, to ensure the relevance of the topics. In line with the IPA approach, an exploratory stance was taken by the researcher, asking open-ended questions to enable participants to talk freely and reflectively, with the aim of obtaining rich narratives. Examples of open-ended questions asked were: ‘Can you tell me about your experience of getting support?’, and ‘What was helpful/ unhelpful in the treatment of your son or daughter’s emotional difficulties?’. Due to the emotive nature of the discussion, participants were told that they could take a break or stop the interview at any point.

Procedure

This study was approved by the College of Medical, Veterinary and Life Sciences, University of Glasgow Ethics Committee. Recruitment was carried out with the support of PAMIS, whose workers identified mothers that met the eligibility criteria and provided them with the

study information sheet. The study was also advertised by PAMIS on their social media website. Interested participants were invited to contact PAMIS or the researcher directly. Three interviews were conducted face-to-face by the researcher in PAMIS offices or public buildings used by PAMIS, and three interviews were conducted over the telephone, for the convenience of mothers. Telephone interviews have been found to generate similar quality data to traditional face-to-face interview methods (Braun and Clarke 2013). Interviews lasted between 50 and 98 minutes. All participants consented to the use of anonymised quotes.

Data Analysis

Interviews were audio recorded and transcribed verbatim, with patient identifying information removed, and pseudonyms used. In line with Smith *et al.*'s (2009) recommendations, the researcher read and re-read each transcript and the audio recordings were listened to. A detailed set of notes were then created, focusing on descriptive, linguistic and conceptual interpretation of the data. The next stage in the analysis involved analysing the initial notes to identify emergent themes. Patterns and connections between emergent themes were then identified, and superordinate themes were created. Once each transcript had been analysed, patterns were examined across participant interviews.

A number of steps were taken to ensure that the process of analysis was both rigorous and transparent. Another member of the research team read two transcripts and associated emergent themes, and possible interpretations were discussed. The researcher also produced a summary of each interview to ensure the emergent themes were grounded in each participant's overall experiences, as well as reflecting the pattern of experience from across the sample as a whole. In addition, a research diary was used to support the bracketing of the researcher's preconceptions and to capture the decision making process when themes were

being generated. The researcher was a trainee clinical psychologist who had worked clinically with individuals with intellectual disabilities and had personal experience of a family member with an intellectual disability. This background provided an awareness of the challenges discussed by participants. The researcher was moved by the often reported failure of services to acknowledge and meet the needs of the participants and their offspring.

Results

The three superordinate themes and seven related subordinate themes are shown in Table 2. Each theme is discussed and illustrated with verbatim extracts from the interviews, (...) indicates that some text has been omitted, and [] brackets words that have been inserted to improve clarity.

[Table 2 near here]

A struggle to understand

The three subordinate themes are related to the challenge mothers faced in identifying their offspring's emotional difficulties and the process of trying to make sense of these difficulties.

Emotional difficulties as a hidden problem

Some mothers had difficulty recognising behavioural indicators of change in their offspring's emotional wellbeing, with Joanne suggesting that it was prior experience of her own son's emotional difficulties that made her sensitive to the signs of distress with her adoptive son. There was sometimes frustration that care staff attributed signs of emotional distress to the person's intellectual disability or a physical health problem. However, some mothers acknowledged that they also struggled to recognise signs of distress, as was apparent from

Angela's attempt to understand her daughter's behaviour when her Gran died:

...She would have suffered the loss of her gran at the time and must have been, she must have been distressed and she must have been anxious and wondering where is where is gran, but she must have, she must have experienced that loss in some way, which wouldn't necessarily manifest itself in a way that we understood. (Angela)

Angela also said that it was hard to differentiate between her daughter's behavioural expressions of anxiety and sadness.

Trying to make sense of the problem

When mothers did recognise that their offspring were distressed, they found it difficult to know what had caused their upset, as their son or daughter could not tell them. Maureen described her struggle to make sense of her daughter's distress:

I'm not really sure if it is something to do with the carers or if it is depression. I'm pretty sure it is depression because she shouts on [brother's name that passed away] all the time but there is also the fact that there is no stimulation for her there during the day either (pause) so is it just that she's being left alone so she just wants left alone do you know what I mean? ... is it this or is it that? (Maureen)

Mothers talked about making sense of their offspring's distress as being like a problem solving exercise, in which potential causes are considered, and a number of different solutions are tried out to resolve the difficulty.

Emotional consequences

Some parents expressed sadness at wanting to be able to help their child when in distress, but feeling powerless at being able to do so. Angela described the natural inclination she feels as a mother to want to relieve her child of discomfort but at the same time being unable to understand what is causing her daughter's difficulties. Maureen, felt a sense of impotence at being unable to help her child:

At the time you start getting down yourself because you feel that you can't help really so it actually starts getting you down because you feel that you've failed, you know, trying to help her (pause). (Maureen)

It was apparent during all of the interviews that this was an emotive and difficult topic for mothers to discuss.

Challenges to getting mental health support

This superordinate theme consists of four subordinate themes, concerning the barriers mothers faced when trying to gain access to adequate support for their offspring's emotional difficulties.

Concerns not taken seriously

Some mothers felt that their concerns about their son or daughters' emotional difficulties were not listened to by professionals working in intellectual disability services. Mothers appeared to make sense of this in contrasting ways. Sinead felt that professionals had poorer insight into an individual's behaviour than family members:

...my friend's emm son he's no longer with us but he emm used to, he was very depressed and emm he he used to lie with his head bent down and his mum said to me, he's like that because he's depressed Sinead, but the staff just say 'oh no he's having a nap, he's sleeping'. (Sinead)

Breda felt that a lack of service provision meant staff were reluctant to refer him for psychological help:

I think you really need to be in crisis before you would be referred on to the psychological services at that time. (Breda)

There seemed to be an overarching sense amongst mothers that care staff did not have the same level of commitment to understanding and caring for the needs of their sons and daughters as they did.

No support available

Mothers said that help or advice was not forthcoming from health and social care services for their son or daughter's emotional difficulties. Some mothers appeared to feel overwhelmed and isolated in trying to manage their offspring's difficulties, and in the context of additional family commitments or limited social support:

... 'coz I had asked my social worker, I had asked I had phoned other people and said there must be other children that have behaviours like Claire out there, how are their families coping?, I need some help, I need some advice, and ahh I couldn't get it. (Sinead)

At first sight, mothers' accounts appeared to be confusing. Whilst they said that there was no support available for their son or daughter's emotional difficulties, most did appear to have obtained mental health support from either intellectual disability or generic mental health services for their offspring. The view that no support was available may have reflected the mothers' frustration with the process of accessing services and their judgement of the available support as unhelpful or that it often arrived too late. Bernadette felt that funding

constraints meant that individuals had to reach a crisis point, where hospitalisation was required, before gaining access to treatment.

Mothers expressed anger and disappointment at the health inequalities faced by their offspring with an intellectual disability. Moreover, they felt that these disparities persisted, despite carers advocating and voicing their concerns:

You feel the health service and everybody has let you down. (Maureen)

In contrast, all mothers valued the support they received from voluntary organisations like PAMIS, with one mother describing this as a ‘lifeline’ (Angela). Useful support included suggested strategies to aid their offspring’s emotional difficulties, and peer support for parents. It is interesting that all mothers particularly valued input from PAMIS, an organisation which has specialist knowledge of individuals with severe and profound intellectual disabilities.

Lack of expertise

Mothers appeared to perceive mental health and intellectual disability services as being separate, resulting in a lack of knowledge and understanding amongst professionals.

Joanne stated that intellectual disability professionals were at a loss as how to treat her adopted son’s emotional difficulties. Angela, Sinead and Bernadette described how mental health professionals failed to have a sufficient understanding of intellectual disabilities to appreciate that an individual’s behavior may be a means of communicating their emotional difficulties. There was also a sense that most health and social care professionals lacked specialist knowledge of severe and profound intellectual disabilities. In particular, they did not know how to communicate with their sons and daughters. It appeared that mothers

thought it was not solely a lack of expertise that impacted on their offspring's care, but that many professionals were unwilling to try to understand and work with their loved ones:

...there's not enough people who understand the conditions...I think I think the fact is that a lot of people who work in learning (intellectual) disability do not have the skills for people like our our sons and daughters who have more emm who have deeper needs. (Breda)

One mother, Bernadette, said that she decided not to seek professional help for her daughter Paula's emotional difficulties, because past input for her older daughter Mary had been unhelpful. She appeared to have lost confidence in the ability of specialist mental health services to help:

I mean I suppose I didn't seek help because I didn't know what to do I didn't know what anybody could do....because I suppose I felt that there is nobody there to help her you know. (Bernadette)

Individuals discriminated against

Some mothers were angered by their son or daughter's experience of discrimination by health and social care professionals, and felt that their offspring were valued less, due to their level of intellectual disability:

I feel as if more so Paula than Mary you're just put in the rubbish bin because well Paula is physically disabled severely, she is nonverbal, she is gastrostomy fed. (Bernadette)

There appeared to be an overarching sense from mothers that professionals underestimated their offspring's level of understanding and ability, and their potential to benefit from therapies and specialist support. Some mothers saw this attitude as a barrier to

accessing support. Bernadette described the resistance she had encountered from professionals in getting support for her daughter after transitioning to adult services:

I wanted speech therapy for Mary, because Mary's speech her syntax her command of the language is still improving, it gets better every day and I asked for it and got told oh we don't improve once they're adults just maintain, and I said well sorry she is still improving.

(Bernadette)

A mother's approach to adapting therapy: Taking time to get to know each other

This superordinate theme concerns mothers' views about the strategies that clinicians can use to make therapeutic work more accessible for their offspring.

Given that mothers said professionals did not know how to communicate with their sons and daughters and underestimated their level of ability, it is unsurprising that mothers wanted professionals to spend time getting to know their offspring. Bernadette discussed the need for professionals to gain insight into her daughter Mary's distinctive use of basic speech, while other mothers expressed the importance of professionals building rapport in order to detect subtle behavioural indications of a change in mood:

...it's being able to pick up on all the wee signals from their body language from their you know from just looking at their face and saying oh that person looks quite sad today. (Breda)

Mothers often felt that their input was undervalued by professionals. However, mothers thought they could play an important role in helping professionals understand their offspring, and in assisting professionals to be able to communicate with their sons and daughters. Joanne and Breda described how they had developed meaningful ways to

communicate with their offspring, using touch and clapping of hands, and were able to gain insights from their offspring's actions:

...So I knew at this time when I was getting this hard clapping that OK you're telling me there's something really bothering you at the moment. (Joanne)

Some of the mothers described how building rapport takes time, with their son or daughter finding meeting new professionals a daunting experience:

...you know she's got to build confidence in people you know she's quite fragile that way when it comes to meeting new people she doesn't like it. (Maureen)

Maureen's statement suggests the importance of the relationship between the therapist and client, in facilitating engagement in therapy. A long-standing therapeutic relationship also enables the therapist to build up an experiential understanding of the individual.

Discussion

Although each mother's experience was unique, a number of commonalities were found across participant accounts. Mothers expressed frustration at care staff's tendency to misattribute behavioural indicators of poor emotional wellbeing to their offspring's intellectual disability or physical health problem. However, mothers acknowledged that even they struggled to recognise signs of emotional difficulties. When mothers did recognise their offspring's distress, they found it difficult to identify a cause. These findings contrasted with Phillip *et al.*'s (2005) study, in which the majority of carers were able to identify specific behavioural signs that alerted them to their offspring's emotional difficulties.

The findings in this study highlight a number of challenges for individuals with severe or profound intellectual disabilities in getting mental health support. Consistent with a

previous report, the mothers stated that they had difficulty getting professionals to take their concerns seriously regarding their offspring's emotional difficulties (The Foundation for people with learning disabilities 2014). In contrast to Phillip *et al.* (2005), where family carers reported that there was no help available for their offspring with emotional difficulties, most mothers in this study appeared to have accessed mental health support for their offspring. Yet this support was not readily accessible, and often only available in times of crisis. Moreover, the support received was not always viewed as helpful, as the mothers did not think that the professionals possessed the specialist knowledge or skills required to work effectively with their sons and daughters. However, the mothers thought it was not solely a lack of expertise that impacted on their offspring's care, but felt that many professionals were unwilling to spend time trying to understand and develop the skills to work with their offspring.

It appeared that supporting their offspring's emotional difficulties, in the absence of professional help, had an emotional impact on mothers. Mothers perceived input from PAMIS as helpful, partly due to the peer support they gained from other mothers in similar situations. Support for the carer should also be taken into account when planning improved mental health service provision for individuals with severe and profound intellectual disabilities. A family-centered approach, in which professionals support both the individual and their carer, has been shown to produce positive outcomes (Dempsey and Keen 2008).

Mothers thought they had a potentially important role in therapy, by helping professionals to understand their offspring's idiosyncratic ways of communicating their needs and emotions. Some mothers described interpreting their offspring's communication using a similar approach to intensive interaction, which involves interpreting non-verbal behaviour and using idiographic communication, such as responsive eye contact and mirroring body or

facial expressions. Intensive interaction aims to promote social interaction with people who have limited or no expressive verbal ability (Hutchison and Bodicoat 2015). There was also a view that therapists would need to take time to build up an understanding of a person and to build rapport, as individuals can find it difficult to meet and get to know new professionals. Interestingly, the mothers placed emphasis on the therapeutic relationship being important for their offspring with severe and profound disabilities, just as it has been highlighted as key to therapeutic change by individuals with mild to moderate intellectual disabilities (Pert *et al.* 2013).

Methodological Strengths and Weaknesses

A limitation of this study is the heterogeneity of the participant sample, with five of the mothers having sons or daughters with severe or profound intellectual disabilities, and one participant a primary caregiver. However, this caregiver's perspective was thought to be important as she took on a maternal role, caring for the individual in her home for 5 years. In addition, the mothers had sought professional help for their offspring at different time points, between 1-4 years ago, with one mother seeking help at the time when she was interviewed. This study has a relatively small sample size as participant recruitment proved to be challenging, with significant support from PAMIS and recruitment taking place over nine months across Scotland. A larger sample size may have afforded the authors a deeper sense of the perceptions and understandings of the broader population of mothers of people with more profound and complex needs. However, the aim of an IPA study is to report in detail from within a particular perspective about a phenomenon under study, rather than representing a population level perspective. It should be noted that the interviews produced rich, in-depth data. One reason for this was that the mothers appeared interested in sharing their experiences during the interviews. The research may have afforded an uncommon opportunity for mothers to talk openly in a confidential space about these issues.

In line with Smith *et al.* (2009), a rich transparent and contextualized analysis of the accounts of participants was provided to enable readers to evaluate transferability of these findings to other samples. However, like any qualitative study, this is contextualized piece, reflecting the experiences and views of a particular set of mothers at a particular time and in a particular place. This is a neglected group of family carers, and the study findings highlight a deep sense of disappointment with professional understanding of their perspective. There is clearly a need to build on this small exploratory study, as obtaining insight into these families' experiences has important implications for how professionals should work alongside them, to address the mental health difficulties of their offspring with profound and complex needs. Moreover, this study does not include fathers' experiences, but these are equally important and need to be explored in future work. It should also be noted that the interviews also contained a section on adapting Behavioural Activation Therapy for individuals with severe or profound intellectual disabilities. These questions were asked at the end of participant interviews and did not appear to influence the mothers' responses in the rest of the interview.

Implications for Clinical Practice

This study has implications for developing more sensitive and appropriate mental health service provision for individuals with severe and profound intellectual disabilities. Emotional difficulties are hard to identify in this population. Therefore, care staff and family carers could benefit from education and training to help them detect changes in emotional wellbeing. Behavioural techniques such as functional assessment and observation remain essential methods for clinicians to identify the function and maintaining factors of an individual's behaviours (Carr *et al* 2016). However, clinicians should also be aware that poor mental health may be an underlying cause of an individual's challenging behaviour. Mothers also felt that they faced discrimination in accessing support for their offsprings' emotional

difficulties. Health and social care staff may not have the knowledge or skills required to work with or communicate effectively with individuals with severe or profound intellectual disabilities. More specialised training is needed for professionals delivering mental health interventions to individuals with severe intellectual disabilities (NICE, 2016). An appropriate pathway of mental health support should be developed, with a dedicated number of knowledgeable professionals trained to deliver psychological help to individuals with severe and profound intellectual disabilities.

An emphasis was also placed by the mothers on a longer-term therapeutic relationship, which they thought would offer therapists an essential experiential understanding of the person in order to facilitate therapeutic work and engagement. Mothers believed that they had an important role in helping therapists to understand and communicate with individuals with more severe impairments and are crucial to supporting the delivery and implementation of therapeutic interventions. Moreover, having therapies and methods of intervention which are less reliant on speech are needed. Promising results have been found for the use of Behavioural Activation Therapy to treat depression in individuals with mild to moderate intellectual disabilities (Jahoda et al., 2017) and the pilot work included people with more severe impairments (. Support for carers should also be considered when planning mental health service provision for individuals with severe and profound intellectual disabilities.

Future research

It would be interesting to build on research including mothers' perspectives of accessing mental health support for their offspring, and to extend this research to include fathers' experiences. It may also be useful to explore mental health professionals' perspectives in

responding to the mental health needs of services users with severe and profound intellectual disabilities.

Conclusion

This study highlights mothers' commitment to supporting their offspring with emotional difficulties despite facing the considerable challenges they described. Individuals with severe and profound intellectual disabilities and emotional difficulties can have difficulty accessing mental health services, and the support available is often not suited to their needs. More appropriate and sensitive mental health service provision is needed for these individuals. These findings have clinical relevance in informing future research in establishing the effectiveness of psychological therapies for this population.

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Participant Name	Son/ Daughter Name	Son/ Daughter Age	Level of Intellectual disability	Diagnoses	Medical Conditions	Presenting Difficulties
Angela	Sarah	29	Profound	Autism Spectrum Disorder; Sensory Processing Disorder	Epilepsy	Self-injurious behaviours; sleep difficulties
Sinead	Claire	21	Profound	Cornelia de Lange Syndrome	Gastroesophageal Reflux Disease	Self-injurious behaviours; restlessness
Maureen	Hayley	30	Profound	Cerebral Palsy	Gastrointestinal Disorder and gastrostomy tube fed; non-ambulatory	Withdrawn behaviour; crying/shouting; disruptive behaviour
Breda	Mark	39	Severe	West Syndrome	Epilepsy; visual difficulties; Scoliosis	Withdrawn behaviour; not smiling; crying
Bernadette	Mary	24	Severe	Smith-Magenis Syndrome; Sensory Processing Disorder Cerebral Palsy	Hearing and visually impaired; limited mobility	Disruptive behaviour
Bernadette	Paula	20	Profound		Gastrointestinal Disorder and gastrostomy tube fed; non-ambulatory; visually impaired	Not smiling; crying
Joanne	Colin	21	Profound	Emanuel Syndrome	Epilepsy; Scoliosis; Gastroesophageal Reflux Disease; limited mobility	Withdrawn behaviour; change in appetite

Table 1. Participant and offspring demographic information

All names provided are pseudonyms.

Table 2. Superordinate and subordinate themes

Superordinate	Subordinate
A struggle to understand	Emotional difficulties as a hidden problem Trying to make sense of the problem Emotional consequences
Challenges to getting mental health support	Concerns not taken seriously No support available Lack of expertise Individuals discriminated against
A mother's approach to adapting therapy: Taking time to get to know each other	
