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Experiences and needs of mothers concerning their involvement in the life and care of their adult sons with mild intellectual disabilities and autism spectrum disorders who display challenging behaviour and live in residential facilities

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ABSTRACT

Objectives: Parental involvement is crucial for individuals with comorbid mild intellectual disabilities (MID) and autism spectrum disorders (ASD) who display challenging behaviour and reside in residential facilities. However, extant literature predominantly concentrates on the perspectives of parents of individuals with MID and ASD who display challenging behaviour and reside in their family home. In the current study, we aimed to understand the experiences and needs of mothers of residential living sons concerning their involvement.

Methods: Five mothers of adult sons with MID and ASD who display challenging behaviour and live in a residential facility were interviewed. Data were analysed using thematic analysis.

Results: Three overarching themes were identified in the data: Fighting for appropriate care and support; Searching for a level of involvement that suits me; What is important to me in terms of support for my son and myself.

Conclusions: Although mothers reported that they wanted to be less involved in caring for their sons, they struggled to scale back their involvement. Efforts should be made to reach both a suitable and sustainable level of involvement for individual mothers.

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Introduction

People with mild intellectual disabilities are characterised by significant limitations with respect to both their intellectual functioning (IQ 50-70) and adaptive behaviour, which originates prior to the age of 22 (Schalock, Luckasson, and Tassé 2021). The presence of mild intellectual disabilities is associated with various comorbid conditions, including autism spectrum disorders (Turygin, Matson, and Adams 2014). Autism spectrum disorders is the term used to designate a group of neurodevelopmental disorders characterised by limitations in social communication, restricted interests, and repetitive behaviours (American Psychiatric Association [APA] 2013). Estimates of the prevalence of autism spectrum disorders amongst people with mild intellectual disabilities range from 5.3 to 24.1% depending on the diagnostic criteria that is

used, and this comorbidity predominates in males (2.8 males for every 1 female) (Bryson et al. 2008).

Individuals with mild intellectual disabilities and autism spectrum disorders are more likely to display challenging behaviour than individuals with mild intellectual disabilities who do not have autism spectrum disorders (Bertelli 2019; Bowring, Painter, and Hastings 2019; Brosnan and Healy 2011; Lundqvist 2013; McCarthy et al. 2010). Challenging behaviour is defined as behaviour that (1) stands outside of prevailing social norms and is deemed to be culturally undesirable, either from the perspective of the individual displaying the behaviour or from family members or professionals, and (2) is of such intensity, frequency, or duration that it is disadvantageous, stressful or harmful for the individual themselves, their inclusion in community life, or for people in their immediate environment, including family members and professionals (Emerson and Einfeld 2011).

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Challenging behaviour comprises a range of behaviours, including, amongst other things, self-injurious, stereotypic, and aggressive/destructive behaviour (Rojahn et al. 2012). Such behaviour may gravely affect the lives of individuals with comorbid mild intellectual disabilities and autism spectrum disorders, namely in terms of physical injuries (Emerson and Einfeld 2011; Griffith, Hutchinson, and Hastings 2013) abuse or restrictive practices (Heyvaert et al. 2015), and social exclusion (Bigby 2012; Burke and Heller 2016; Ljungberg and Schön 2023). In addition, challenging behaviour may also affect the quality of life of the family members of individuals with comorbid mild intellectual disabilities and autism spectrum disorders. Indeed, research has shown that caring for offspring with intellectual disabilities and/or autism spectrum disorders who display challenging behaviour places a chronic strain on parents and is associated with increased parental stress and mental health difficulties (Baker, Seltzer, and Greenberg 2011; Barker et al. 2011; Burke and Heller 2016; Hastings 2002; Hastings et al. 2005; Ljungberg and Schön 2023; McStay, Trembath, and Dissanayake 2015; Most et al. 2006; O'Nions et al. 2018; Swaab, McCormack, and Campbell 2017; Tint and Weiss 2016). Moreover, these parents are more likely to experience physical harm (Griffith and Hastings 2014; Hodgetts, Nicholas, and Zwaigenbaum 2013; Ljungberg and Schön 2023; Swaab, McCormack, and Campbell 2017), the loss of a wider social and self-identity (Griffith and Hastings 2014; Ljungberg and Schön 2023), and social isolation (Griffith and Hastings 2014; Hastings 2002; Hastings et al. 2005; Hodgetts, Nicholas, and Zwaigenbaum 2013; Ljungberg and Schön 2023; McKenzie et al. 2018; McStay, Trembath, and Dissanayake 2015; Most et al. 2006; O'Nions et al. 2018; Swaab, McCormack, and Campbell 2017; Tint and Weiss 2016). Consequently, displaying challenging behaviour is often an important reason why individuals with intellectual disabilities and/or autism spectrum disorders move out of their family home into a residential facility (Knotter et al. 2013; Maes et al. 2003; Swaab, McCormack, and Campbell 2017). However, even when residing in a 24-h residential setting, parents often express a strong desire to remain actively engaged in their offspring's care, encompassing looking after them, assisting them with their daily needs, and ensuring their overall wellbeing. Additionally, they aim to provide ongoing support, enabling their offspring with intellectual disabilities and/or autism spectrum disorders, particularly those who display challenging behaviour, to live more independently.

This support furthermore involves equipping them with tools, opportunities, and skills necessary for a fulfilling life (Krauss, Seltzer, and Jacobson 2005; McKenzie et al. 2018; Schwartz 2005; Vereijken et al. 2022). For instance, parents highlight the continued need for family support even when their offspring reside in a residential facility, emphasizing the importance of genuine attention, unconditional love, and instinctive awareness (Vereijken et al. 2022). In fact, the involvement of parents in the care and support for individuals with intellectual disabilities that live in residential facilities is considered crucial, insofar as parents are a powerful source of social and emotional support, guidance, and advocacy (Baker, Seltzer, and Greenberg 2011; Bigby and Fyffe 2012; Blacher and Baker 1992; Sanderson et al. 2017; Zambrino and Hedderich 2021). Moreover, given that parents represent a constant in the lives of individuals with intellectual disabilities, their active involvement can help to ensure the proper functioning of staff and, in turn, improve the quality of care (Baker and Blacher 2002; Bigby and Fyffe 2012; Zambrino and Hedderich 2021). In addition, parental in person-centred approaches has been shown to positively affect individuals who display challenging behaviour (Tournier et al. 2021).

Reviews examining the experiences and needs of parental caregivers underscore that the needs of parents with offspring having intellectual disabilities and/or autism spectrum disorders encompass both professional and informal support, advocacy, and collaborative relationships with support staff (Griffith and Hastings 2014; Ljungberg and Schön 2023). However, it is evident from these reviews that a predominant focus of the available empirical studies has been on the perspectives of parents whose offspring reside in their family home (Griffith and Hastings 2014; Ljungberg and Schön 2023). In the Netherlands, a noteworthy 60% of individuals with intellectual disabilities live in residential facilities (Den Draak et al. 2016). Hence, understanding the experiences and needs of parents regarding their roles and involvement in the current living situation of their adult offspring, who have comorbid intellectual disabilities and autism spectrum disorders and display challenging behaviour is crucial. Parents may have chosen residential care due to unsustainable situations at home, hoping for a reduction in caregiving burden. This qualitative study aims to address this gap in existing literature by exploring the experiences and needs of mothers regarding their roles and involvement in the lives, care, and support for their adult

sons with mild intellectual disabilities and autism spectrum disorders who display challenging behaviour and reside in residential facilities. Given evidence suggesting that ASD and challenging behaviour may disproportionately impact mothers, leading to issues such as depression, anxiety, and stress, as well as affecting physical health (Hastings 2003; Tint and Weiss 2016), we have chosen to focus our research specifically on mothers.

Method

Participants

The mothers were recruited using a purposive sampling procedure. In total, five mothers participated in this study, all having sons with confirmed diagnoses of comorbid mild intellectual disabilities and autism spectrum disorders who display challenging behaviour. Additional inclusion criteria for the mothers were that their offspring (I) must have moved to a residential facility because living at home had become unsustainable due to the challenging behaviour, (II) be aged 18 – 40 years, and (III) have moved to a residential facility at least three years ago. The second criterion reflects that parents of older individuals are likely to be elderly and these parents' aging process may affect their active involvement in the care for their offspring (Baumbusch et al. 2017). The third inclusion criterion was determined to ensure that the experiences and needs of the mothers were not biased by the relatively recent transition of their son to a residential facility. Both demographic information and other information about the mothers and their sons are shown in Table 1, with pseudonyms being used to protect their confidentiality. The mothers were aged between 45 to 82 ($M = 59.4$) years and were all living with their respective partners. The sons were aged between 22 to 40 ($M = 30.0$) years and had moved to a residential facility between the age of 9 to 35 ($M = 18.6$) years. At the time of the interviews, between 4 to 18 ($M = 11.4$) years had passed since their sons had moved to a residential facility. All of the sons displayed aggressive/destructive behaviour. All sons resided in a 24-h residential support setting, implying living arrangements within the premises of a service provider with support staff present for a fixed number of hours per day, ensuring round-the-clock care and support entitlements. Additionally, they all received assistance under the Dutch Long-term Care Act (in Dutch: Wet langdurige zorg; Wlz). Based on their functional levels and specific support needs, each son was categorized under the highest care

Table 1. Demographic information of the participating mothers and their sons with mild intellectual disabilities who display challenging behaviour.

Pseudonym	Age	Number of children	Marital status	Occupational status	Pseudonym son	Age son	Age at times of move	Additional diagnosis	Challenging behaviour	Level of support
Mary	63	1	Married	Occupationally disabled; part-time voluntary work	Charlie	37	19	Gilles de la Tourette; Developmental Coordination Disorder	Aggressive/Destructive Behaviour; Stereotyped Behaviour	ZZp7
Angela	54	2	Married	Part-time occupation	Adam	27	12	Attention Deficit Hyperactivity Disorder	Aggressive/Destructive Behaviour	ZZp7
Hannah	53	2	Divorced, remarried	Full-time occupation	John	24	9	Multiple Complex Developmental Disorder	Aggressive/Destructive Behaviour	ZZp7
Liz	82	3	Married	Retired; part-time voluntary work	Tom	40	35	-	Aggressive/Destructive Behaviour	ZZp 7 + additional support indication
Sabrina	45	2	Married	Full-time occupation	Martin	22	18	Syndromale disorder	Aggressive/Destructive Behaviour; Self-Injurious Behaviour	ZZp 7 + additional support indication

profile for living and behaviour support, denoted as ZZP7 in Dutch, indicating that they lived with intensive help and intensive behavioural support. This level of care necessitates continuous, close-proximity care and supervision 24 h a day, primarily characterized by passive supervision. Permanent active observation is often unnecessary, with supervision required for both planned and unplanned care and support actions, wherein support staff must take the initiative to provide the necessary care and support (Jansen and Bakker 2019). Moreover, two sons with additional support needs were granted an extra support indication under the Wlz, known as ‘meezorg’ in Dutch. This designation aims to fund supplementary care for individuals with exceptionally intensive care requirements, defined as care needs exceeding 25% beyond what is provided by the assigned care profile (Jansen and Bakker 2019). Further details on care and support needs were not collected.

Interviews

The semi-structured interviews were conducted *via* the use of an interview guide, developed based on literature, that covered key topics that were developed for the purposes of this study. The interviewer began each interview by asking the mothers how they are currently involved in the life and support for their sons with comorbid mild intellectual disabilities and autism spectrum disorders who display challenging behaviour. The topics in the interview guide included (I) how the mothers experienced their involvement with their sons’ life and care and support, (II) how they envisioned their involvement in the (near) future, and (III) the needs that they had concerning their involvement. The entire interview guide can be requested from the corresponding author. By using multiple open-ended questions for each of the topics in the guide, a dialogue with the mothers was established in which the interviewer remained open to any other topics that were raised by the mothers. At the end of the interviews, the mothers were given the opportunity to raise any other topics that were significant to them but had not yet been discussed.

Procedure

Ethical approval for this study was obtained from the Ethics Review Board of Tilburg University (RP560). Contact persons of the Academic Collaborative Centre Living with an Intellectual Disability as well as contact persons of four care organisations that provide services

to people with intellectual disabilities that are affiliated with the Academic Collaborative Centre were informed of both the aim and nature of the study. These contact persons then subsequently identified, informed, and recruited potential participants to take part in the study. With their consent, the potential participants were then contacted by the researchers *via* Microsoft Teams to inform them further about the aim and procedures of the study as well as to check that they fitted the inclusion criteria. Contact persons initially identified eleven potential participants. However, six of them did not meet the inclusion criteria for this study. For example because they did not have a mild intellectual disability or they did not display challenging behaviour. The potential participants that did meet the inclusion criteria all expressed interest in participating. An appointment for an interview was planned at a time that was convenient for them, and, based on the participants’ preferences, an information letter and informed consent form were sent to them *via* email or post. All the mothers voluntarily agreed to participate in this study and provided written informed consent, either *via* email or post. The mothers received a gift voucher worth 40 euros as an incentive to participate.

The research team consisted of three researchers with an occupational background in the field of intellectual disabilities and two researchers with a background in respectively philosophy and ethics. The interviews were conducted in Dutch by the first author, an experienced researcher without occupational background in the field of intellectual disabilities, between June and October 2021. Due to (anticipated) governmental restrictions to prevent the spread of the COVID-19 virus, interviews were conducted *via* Microsoft Teams. Various studies conducted both prior to and during the COVID-19 pandemic suggest that videoconference interviews can be a useful supplement or replacement for traditional face-to-face interviews (e.g. Khan and MacEachen 2022; Krouwel, Jolly, and Greenfield 2019; Saarijärvi and Bratt 2021). With the consent of the participants, videoconference interviews were recorded using the record function in Microsoft Teams and transcribed verbatim. The interviews lasted on average 76.43 (range 61 – 95) minutes. To ensure confidentiality, all personally identifiable information in the transcripts was replaced with artificial identifiers. These modified transcripts, identified by participant codes, were then utilized in the analysis. Additionally, pseudonyms have been employed throughout the manuscript to further safeguard confidentiality.

Analysis

The inductive reflexive thematic analysis process followed six steps, as outlined by Braun and Clarke (2022). To enhance the depth of interpretation, all authors participated in the analysis, engaging in reflection on codes and the development of themes. Since the interviews were conducted in Dutch, the analysis was also carried out in Dutch. Upon thorough reading of the transcripts to acquaint themselves with the data, two researchers, neither of whom had an occupational background in intellectual disabilities, independently generated initial codes for using open coding. These initial codes were then meticulously discussed to reach a consensus. Following this, codes underwent auditing and refinement in collaboration with two researchers possessing an occupational background in intellectual disabilities. In the third phase of analysis, coded data fragments were systematically grouped based on shared similarities to begin constructing overarching themes. Subsequently, the coherence and consistency of these themes were evaluated internally (within each theme) and externally (between different themes) by all members of the research team. This iterative process facilitated the refinement of the thematic structure to ensure distinct, robust themes grounded in the dataset. Next, we defined and named the identified (sub)themes in Dutch, and provided Dutch core descriptions of each (sub)theme to maintain their meaning in the English translation. Finally, to accurately capture nuances in citations, the thematic analysis was written up in English with the assistance of a native English speaker, resulting in the production of a scientific report. It is essential to clarify that in the results section, when we mention 'mothers,' we are specifically discussing instances where mothers have shared solely their own experiences. If mothers discussed experiences involving both themselves and their partner or the other parent, we refer to them as 'they (and the other parent of their son).' Furthermore, the term 'parents' is used when mothers talked about parents in a broader context beyond just themselves.

Results

Three overarching themes were identified in the data: (1) Fighting for appropriate care and support, (2) Searching for a level of involvement that suits me, and (3) What is important to me in terms of support for my son and myself. The second theme has four subthemes, and the third theme consists of two subthemes.

Theme 1: fighting for appropriate care and support

Interviewed mothers reported that, when their sons continuing to live at home became unsustainable, they had to find a care organisation that could provide the required care and support to their sons, a process that mothers referred to as a fight. At the time of the interviews, the mothers were to varying degrees satisfied with the care and support being provided to their sons.

In their search for the best possible residential care and support for their sons, the mothers talked about how they encountered various obstacles, including years of waiting lists and care organisations refusing to support their sons on the grounds that their behaviour was considered to be too complex. Mothers expressed that, when their sons were finally placed in a care organisation, they (and the other parent of their son) often felt that the care and support that was provided was inappropriate, resulting in a renewed search for the best possible care and support for their sons. All the mothers therefore experienced this period as a difficult and intensive time. Angela, for example, described this period as a fight that made her feel powerless and desperate, while Sabrina described this period as a lonely one in which all care organisations refused to support her son:

Yeah you know, if you have to do it alone it can be quite lonely for a parent, there aren't a lot of places you can go ... if your child isn't living anywhere yet, as a parent you're sort of shouting into the void, which is really, we really experienced it that way, that you're not linked to anything, not part of anything, so everyone keeps their door closed to you. – Sabrina

However, after experiencing multiple negative experiences within other care organisations, Hannah and Sabrina were confident that their sons were finally receiving the appropriate care and support, with Sabrina describing both her and her son's current experiences as being something of a success story after years of fighting. These positive experiences could mostly be attributed to the fact that they (and the other parent of their son) and support staff shared the same vision over what appropriate care and support for their sons entailed.

In contrast to Hannah and Sabrina, Mary, Angela, and Liz, still saw room for improvement in the care and support provided to their sons. For example, Mary and Angela both expressed the wish for more (group) activities for their sons at their residence. Although these three mothers felt they were still fighting for the best possible care for their sons, they also acknowledged that improving the care and support is

quite challenging since their sons required extensive and complex care and support within a support system that is confronted with a high shortage of available staff (and related high staff turnover) and a lack of financial resources. In the words of Mary:

I am happy with how things go right now. Or, let me say it like this: I realize it will never ever be perfect. It is impossible to 100% satisfy all service users. So, I am content, but that's it. (...) I just wished they would actually do something, play a game with him, go for a bicycle ride, just something! But there's just no opportunity at all. - Mary.

Theme 2: searching for a level of involvement that suits me

Whilst all the mothers reported being heavily involved in their sons' lives and care and support, they also reflected on the suitability and sustainability of their current level of involvement. To address this, four subthemes were identified: (1) Our deep bond shapes my life, (2) Feeling to be primarily responsible, (3) Worrying about future care and support, and (4) Stepping back from the minutiae of daily living.

Subtheme 2.1 Our deep bond shapes my life

Several years after their sons moved to a residential facility, all the mothers reported that there was still a deep, reciprocal connection with their sons. As such, mothers were still heavily involved in their sons' lives and care and support. All of them reported having regular contact with their sons, with some reporting daily contact. In addition, all of the sons regularly visited their family home, mostly for the weekend. Although mothers enjoyed the regular contact and visits, they also experienced that this level of involvement determined their lives to a large extent. Liz, for example, reported how she felt that she almost did not have a life of her own, as she was constantly busy organising things for her son. Furthermore, Mary reported finding it hard to go on holidays and, therefore, she would only go on short holidays because she worried that her absence, and the subsequent change in routine for her son, would negatively affect him.

Subtheme 2.2 Feeling to be primarily responsible

Given that the mothers experienced that their level of involvement in their sons' life and support determined their own lives to a large extent, they also reflected on whether this level of involvement was sustainable. For example, Hannah reported that her son was the linchpin of her life, which, in turn, meant

that she constantly felt responsible for his wellbeing and that this responsibility affected almost every decision in her life. This situation had contributed towards the physical problems she was experiencing, and thus she wondered to what extent she wanted to remain involved in the life and support for her son:

But I think the physical complaints, the things I encounter in life, sure, they stem from that as well. I'm trying to find a way to cope with everything. How big is my role? How big do I want it to be? - Hannah.

Due to the difficulties stemming from their level of involvement which were experienced by all mothers, mothers reported that they wanted to scale back their involvement in the life and care and support for their sons. However, at the same time, the mothers reported that they struggled to do this in practice. Multiple factors contributed to these struggles, including the complex behaviour and associated complex support needs of their sons, the shortage of staff and financial resources, and the high staff turnover. Hannah, for example, reported how the shortage of staff and subsequent lack of weekend activities at the care organisation meant that she had to let her son visit the family home more frequently than she wanted, because she could not fully trust that he would be properly supported at the care organisation during the weekends, and was worried that he would not enjoy his weekend. Mary reported how her son lacked connection with his co-residents, which made her feel that she should let her son visit the family home very regularly so that he could have a good time at home. This led her to blame both herself and her husband for not being able to take a step back:

I think it's kind of our own fault, or, well, I don't know about fault, but we do take him home so often ourselves and to bring down the number of visits is of course much more difficult than bringing them up. - Mary

Conversely, Angela reported how she had struggled in the past when she tried to take a step back from the care and support for her son on multiple occasions, such as, for example, when going on holiday, as she was always contacted by support staff to de-escalate situations with her son. Since her son had received care and support from his current care organisation, she could finally go on holiday with peace of mind, as she trusted that her son would both receive good care and be understood by his support staff.

Subtheme 2.3 Worrying about future care and support

The urge to take a step back from the care and support for their sons also concerned mothers' realization of getting older. All of the mothers reported concerns over the care and support for their sons in the future.

For example, Mary expressed that she constantly felt tired because of taking care of her son. She expected that supporting her son would get even harder as she and her husband were getting older. In addition, Sabrina noted how she was terrified for the future, as the moment will come that she and her husband will not be able to look after their son anymore, either because they suffered from an illness such as dementia or because they had passed away. In addition, the mothers worried about who would look after their sons in the way they currently did. Liz, for example, felt that no one could take over her caregiving role, as this would imply that someone should dedicate their life to her son, which is too much to ask from anyone else but her:

Whichever way you spin it, there's no one who can take over from you. [...] So yeah, I do find that really hard. But you can't really ask anyone else to devote their whole life to it, because that's basically what it is. – Liz

Subtheme 2.4 Stepping back from the minutiae of daily living

In their attempt to find a balance between being involved in their sons' lives and care and support and their need to take a step back, Mary, Hannah and Sabrina reported wishing not to know everything about their sons. For example, Sabrina expressed that she did not want to be contacted by support staff for minor issues, such as what her son is allowed to buy at the grocery store. Furthermore, both Mary and Hannah reported that solving everyday problems should be mainly the responsibility of the support staff. Therefore, Mary explicitly chose not to read the daily reports about her son, as she felt that if she knew that her son caused some trouble, then she would not be able to stop herself from intervening. In her words:

Yeah, we can use an app to look at Charlie's daily reports, but I don't because I feel that would be a breach of privacy. Because it shows everything he does, what he's been doing, it's all there. I don't like that. So I don't look. [...] No, because then I'll read something and I'll think: son, how can you do a thing like that? And then he comes home and I'll say something and then... and I know it's not our problem, they have to solve it at [Care organisation]. But I won't be able to keep my mouth shut about it, so... I just don't want to know. – Mary

Theme 3: what is important to me in terms of support for my son and myself

The mothers reflected on their needs concerning the care and support for both their sons and them. Two subthemes were identified: (1) Seeking to share

responsibilities in a collaborative parent-staff relationship, and (2) Needing continuity and stability.

Subtheme 3.1. Seeking to share responsibilities in a collaborative parent-staff relationship

All the mothers expressed that they wished to share the care and support for their sons with support staff. Doing so requires a collaborative relationship between themselves and the support staff, which is dependent on various factors. Hannah, for example, reported how experiencing a sense of connection with the support staff allowed her to trust them to take care of her son. She experienced this connection with support staff in terms of being able to share her story with them, being taken seriously, having good conversations with them, and the support staff being open to their feedback. Sabrina felt that it was important that the support staff viewed parents as experts on their offspring's needs, and that they pay due attention to parents' values and standards when caring for their offspring. Angela felt it was important that both parents and support staff kept on searching to establish a connection over little things. For example, a birthday card she received from support staff showed her that they saw her as a significant other in the care and support for her son:

I guess it also touches upon what matters to you. Not if a birthday matters to you, but it's about the thought behind the card. Because that's what the support staff also said, as in, as in, I said we didn't know what to say, like how great and if you don't do it it's also fine, but yeah thanks ever so much. And they also said: no but we see how important you are to Adam, so also to us. – Angela

Subtheme 3.2. Needing continuity and stability

Despite their wish to share the care and support for their sons, all the mothers acknowledged the current shortage in staff and financial resources and the high staff turnover. They understood that this is a complex situation that cannot be easily solved and that their needs concerning the care and support for their sons could not all be fulfilled within this context. Despite this, the mothers still expressed the urgent need for continuity and stability in the care and support for their sons. Angela, for example, reported how parts of the support for her son discontinued upon the resignation of a support staff member. Moreover, Liz experienced it as being disastrous when a good support staff member resigns. She noted how her son did not understand why support staff resigned and wondered whether it was because they did not like him anymore:

Yeah, I do worry about that, because one moment you have a really nice one who's great with him and then just like that, they're gone again. [...] And that's something he doesn't get either: why did they leave? I like them, why did they leave me? Don't they like me anymore? That kind of thing. For the clients it's awful when good support staff leaves, because who knows who'll replace them. – Liz

The mothers not only expressed the urgent need for continuity and stability in the care and support for their sons for their sons' sake, they also saw this as important for themselves. Specifically, they felt that continuity and stability is necessary for building collaborative relationships with support staff, which, as described above, they considered to be a prerequisite for being able to share the care for their sons. Furthermore, Angela described how the high staff turnover rates resulted in her not always knowing who was caring for Adam, which made her feel like a number, rather than experiencing a relationship with the support staff:

The staff turnover is incredibly high, sometimes you have to call the group about something that didn't go well and Adam's been living there for nine years and it's like: Hi, this is Angela, Adam's mum, so you first have to introduce yourself and then you have to tell them something which is difficult enough as it is. [...] Which means that sometimes you're talking on the phone to people you don't know at all but you do have to share personal things with them. And that really makes you feel like just another number. – Angela

Moreover, the mothers reported that they needed continuity and stability to be able to take a step back from the care and support for their sons. For example, Hannah talked about how she felt she is the only stable factor in her son's life. She expressed that she needed continuity and stability within the support staff team and less in order for her to trust that her son was doing well and no longer needed her as much anymore.

Discussion

The findings of this study provide valuable insights into the experiences and needs of mothers of adult sons with mild intellectual disabilities and autism spectrum disorders who display challenging behaviour and live in residential facilities. Although their sons had been living in residential facilities for several years, all the mothers reported that still felt deeply connected to their son. However, they also experienced that they were heavily involved in their sons' lives. Whilst they expressed the wish to scale back on

their level of involvement in the care and support for their sons, they simultaneously struggled to do so in practice. These struggles primarily stemmed from the complex behaviour and associated complex support needs of their sons, the lack of continuity and stability in the care and support for their sons, and their feelings that they were and would continue to be primarily responsible for their sons' care and support.

When it became unsustainable for their sons to continue living at home, the mothers in this study indicated how they strove to find the best possible residential care and support for their sons. However, finding this care and support proved to be a 'fight' in which they encountered various obstacles, including years of waiting lists and care organisations refusing to support their sons on the grounds that their behaviour was deemed to be too complex. This is in line with parental experiences reported in other studies from a variety of countries (e.g. Wodehouse and McGill 2009; Werner, Edwards, and Baum 2009), but differed from experiences of parents of offspring without ASD and challenging behaviour in [country removed for blind peer review purposes], who reported that the wait for appropriate residential placement was even shorter than expected (Vereijken et al. 2023). Similar to Werner, Edwards, and Baum (2009) study, the mothers in this study's 'fight' for the best possible care and support continued after their sons' initial placement in a residential facility, as they continued to feel that they were and would remain primarily responsible for their sons' care and support and worried about their sons' care and support in the future. This underscores the fact that caregiving is a lifelong experience, irrespective of whether the family member resides in the family home. The mothers in this study also described the chronic strain associated with their caregiving role, which is in line with experiences reported before (Griffith and Hastings 2014; Ljungberg and Schön 2023; Marsack-Topolewski, Samuel, and Peterson 2023; Sonido et al. 2020). Even though their sons were no longer residing in the family home, this chronic strain upon the mothers in this study led them to feel exhausted, overburdened, and experience physical problems, which, in turn, led them to express the wish for a lower level of involvement. These findings differ from reports of parents of offspring without ASD and challenging behaviour who, after years of intensive support at home, noticed a positive impact of their offsprings' move to a residential facility (Vereijken et al. 2023). Future research could explore whether the current strain experienced by mothers of offspring with mild ID and ASD

displaying challenging behaviour who have moved to a residential facility is different compared to when their offspring still lived at home, could identify factors associated with current strain experienced by these mothers, and could explore possibilities to best support mothers of individuals living in a residential facility who experience chronic strain due to their involvement in their family members' care and support.

In parallel with this, the mothers struggled to take a step back from the care and support for their sons. One of the reasons for struggling to take a step back was the complex behaviour and associated complex support needs of their sons, which is in line with findings reported by Krauss, Seltzer, and Jacobson (2005). Supporting people who display challenging behaviour does indeed place great demands on professionals. For example, being confronted with service users who display challenging behaviour, especially aggressive behaviour, has been associated with decreased psychological well-being of direct support staff, higher burnout rates amongst direct support staff (Mills and Rose 2011), absenteeism from work, and, ultimately, higher staff turnover (Knotter et al. 2013). Staff turnover can be considered especially problematic in the care and support for individuals with mild intellectual disabilities and comorbid autism spectrum disorders, insofar as resistance to change and extreme distress in response to even small changes are distinctive features of autism spectrum disorders (APA 2013), and may even increase the display of challenging behaviour (Neil and Sturme 2014). As such, staff turnover may be an important maintaining process of challenging behaviour displayed by individuals with mild intellectual disabilities and autism spectrum disorders, which explains the importance that the mothers in this study placed on continuity and stability in the care and support for the well-being of their sons. Moreover, the mothers in this study not only emphasised the importance of continuity and stability for the well-being of their sons, they also highlighted its importance for themselves. Given the clear benefits of continuity and stability in care and support, future research should explore potential ways to reduce staff turnover, by, for example, fostering positive work factors (Hensel, Lunsky, and Dewa 2015). Moreover, in line with prior studies (Bonell et al. 2011; Cernikovskiy 2014; Hines, Balandin, and Togher 2014; Krauss, Seltzer, and Jacobson 2005; Zambrino and Hedderich 2021), the mothers in this study felt that continuity and stability are a prerequisite for building collaborative relationships with support staff. They reported needing this collaborative relationship to be able to share the care and support

for their sons, to trust in the quality of support provided by support staff, and consequently, to take a step back from the care and support for their sons. As such, a collaborative relationship with support staff, built on trust, honesty, and mutual respect (Keen 2007), would be beneficial for mothers, both when their offspring with an intellectual disability resides in the family home or in a residential facility. In previous studies, these relationships were found to be strong predictors of both the quality of life within families (Bhojti, Brown, and Lentini 2016; Werner, Edwards, and Baum 2009) and the empowerment of families (Lucyshyn et al. 2002). However, evidence on best practices with respect to effective collaborative relationships between mothers and support staff is lacking. The findings of our study contribute to the body of evidence regarding parental perspectives regarding such partnerships, but knowledge on support staff's perspectives is scarce (John 2020). Future research should therefore also explore the perspectives of support staff working at accommodations that provide residential care and support to adults with comorbid mild intellectual disabilities and autism spectrum disorders who display challenging behaviour.

Generally speaking, the care and support for people with intellectual disabilities and developmental disabilities with complex care needs (e.g. the target population of the present study) is characterised by a variety of challenges. On the one hand, increased life expectancy and improved healthcare technologies, amongst other things, increases the demand for care and support for people with intellectual and developmental disabilities in the coming years (Van der Biezen et al. 2022; van der Heide et al. 2018; Kuipers, Cramm, and Nieboer 2019; Ministry of Health, Welfare and Sport [Ministerie van Volksgezondheid, Welzijn en Sport] 2021). On the other hand, the available budget for healthcare is already stretched to the limit in many countries, while the World Health Organization predicts that there will be a global shortage of 18 million healthcare workers (World Health Organization 2021). Partly because of these challenges, family members are ever-more involved in the care and support for people with intellectual disabilities and developmental disabilities with complex care needs. For example, family members may complement residential care by providing meaningful activities for their relatives. The provision of such activities is important, insofar as a lack of meaningful activities is a psychosocial vulnerability-related factor for displaying challenging behaviour (Bowring, Painter, and Hastings 2019). In line with Krauss, Seltzer, and Jacobson (2005), the mothers in this

study also expressed concerns over a lack of meaningful activities, especially due to staff shortages during weekends, which made them feel responsible for offering these activities to their sons themselves. Consequently, the mothers experienced this as a burden, as it meant that they sometimes had to take their sons home every weekend. It is therefore of the utmost importance that support staff, family members and individuals with intellectual disabilities with mild intellectual disabilities and autism spectrum disorders who display challenging behaviour together have tailored conversations, where the needs and wishes of all involved concerning the involvement of mothers and other family members in care and support are considered, in order to reduce and prevent overburdening. Moreover, the mothers in this study reported that their desired level of involvement changed and decreased over time, which is consistent with the findings of other studies (Zambrino and Hedderich 2021). It is therefore important to continuously evaluate both the suitability and sustainability of the level of involvement of mothers in the care and support for individuals with mild intellectual disabilities and autism spectrum disorders who display challenging behaviour, such as, for example, during annual care evaluation meetings. In addition, the provision of professional and informal support to mothers and other family members, including parent-to-parent peer support (Dew et al. 2019; Ljungberg and Schön 2023), could be considered to alleviate maternal burden and proactively prevent future overburdening (Wodehouse and McGill 2009).

While the results of this study offer valuable insights into the experiences of a homogenous group of highly involved mothers caring for sons with comorbid mild intellectual disabilities and autism spectrum disorders displaying challenging behaviour, consideration should be given to some limitations. Firstly, while a sample size ranging from 10 to 15 participants was anticipated, unfortunately, participant recruitment posed more challenges than expected. This could potentially be attributable to the COVID-19 restrictive measures at the time of recruitment and the substantial caregiving burden experienced by mothers. Moreover, only mothers were interviewed. Future research should explore the experiences and needs of fathers in similar circumstances, considering the potential differential impact of challenging behaviour on parental stress between genders (Hastings 2003; McStay, Trembath, and Dissanayake 2015; Tint and Weiss 2016). Additionally, research could investigate the experiences and needs of parents of

daughters with comorbid (mild) intellectual disabilities with autism spectrum disorders, considering potential variations in the type and severity of challenging behaviour based on gender and intellectual disability levels (Crocker et al. 2006). Furthermore, the mothers in this study were actively involved in the lives and care of their sons, making them more accessible to care organizations affiliated with [removed for peer review]. Although this group of parents is challenging to recruit, exploring the experiences and needs of parents who are less involved could provide valuable insights. Lastly, all participating mothers had a high level of education. Future research could examine the experiences of parents with lower educational attainment, considering the impact of educational status on parental resilience in the context of raising a child with intellectual disabilities (Mohan and Kulkarni 2018). In addition to further research on parental perspectives, future studies could investigate the experiences and needs of other family members, such as siblings taking on parental roles. This is particularly important given the increased risk of psychological problems observed in siblings of children with intellectual disabilities and autism spectrum disorders (Petalas et al. 2009).

Conclusion

The present study provides valuable insights into the experiences and needs of mothers concerning their role and involvement in the lives and support for their sons with comorbid MID and ASD who display challenging behaviour and reside in residential facilities. Despite their sons residing in residential facilities for years, mothers in the study expressed enduring emotional connections. Nonetheless, they grappled with being overly involved in their sons' lives and desired to reduce their caregiving roles. However, they faced challenges in effectively scaling back their involvement. In a context in which the care and support for people with MID and challenging behaviour who display challenging behaviour is characterised by various challenges, efforts should be made to ensure that individual mothers find both a suitable and sustainable level of involvement in the care and support for their offspring. It is crucial to facilitate discussions among support staff, mothers, and individuals with mild intellectual disabilities to address the needs and preferences regarding the participation of mothers and other family members in care and support. This approach aims to mitigate and forestall overburdening. Given the evolving nature of these needs and

preferences, regular reflection, such as during annual care evaluations, is essential to assess the appropriateness and sustainability of maternal involvement. Additionally, offering both professional and informal support to mothers and other family members, including parent-to-parent peer support, can alleviate maternal burden and proactively prevent future overburdening.

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Ethical approval

The study was conducted in accordance with the Declaration of Helsinki and approved by the Ethics Review Board of Tilburg University.

Informed consent statement

All of the participants involved in the study provided written informed consent.

Disclosure statement

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Data availability statement

The research data cannot be shared.

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