





Homeward bound: Exploring the motives of mothers who brought their offspring with intellectual disabilities home from residential settings during the COVID-19 pandemic

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Abstract

Background: At the start of the COVID-19 pandemic, some parents in the Netherlands decided to bring their offspring with intellectual disabilities, who normally live in residential care, home. The present study explored why the mothers decided to bring their offspring home.

Method: Interviews were carried out with seven mothers of adults with intellectual disabilities. An interpretative phenomenological approach was used to establish in-depth accounts of the mothers' experiences.

Results: The analysis yielded three overarching themes: (a) Families are indispensable; (b) the complex role of being a mother of a child with intellectual disabilities; and (c) Who is looking out for our offspring during COVID-19?

Conclusions: The mothers experienced a strong sense of wanting to do what was best for their offspring with intellectual disabilities during COVID-19. The study provides insight into why mothers remain involved in the care for their offspring and the complexity of navigating lifelong care responsibilities.

KEYWORDS

adults, COVID-19, intellectual disabilities, mothers, residential care

1 | INTRODUCTION

Parents generally play a central role in the care and (social) support of their children with intellectual disabilities (Van Heumen & Schippers, 2016). Even after their offspring has moved out of the family home, parents often remain closely involved in the care of their offspring (Boelsma et al., 2017). As part of their continuing support for their offspring, parents will usually have to negotiate or coordinate this support with social and healthcare professionals. However, parents can find it difficult to develop collaborative relationships with

professionals (Ryan & Cole, 2009). The failure to develop collaborative relationships between parents and professionals can act as a barrier to effective service delivery for people with intellectual disabilities, as well as a barrier to provide sufficient support to families (Hastings, 2016; Jansen et al., 2017; Steel et al., 2011).

Through their lifelong bond, parents may play a unique role in the life of their offspring with intellectual disabilities, characterised by a profound understanding of the needs of their child (Ten Brug et al., 2018). However, as with all offspring, as they grow up and become more autonomous, their wishes and needs may change. For

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people with intellectual disabilities, who remain reliant on their families, this may become challenging for the parents and for the person with intellectual disabilities (Curryer et al., 2019; Giesbers et al., 2020). To ensure good quality of life for all family members, including the person with intellectual disabilities, it is important to support the family as a system (Hastings, 2016; Seligman & Darling, 2009), and to understand the needs of parents.

Although all families with children are affected by the COVID-19 pandemic (Luttik et al., 2020), the situation has been particularly challenging for parents of children with intellectual disabilities (Alexander et al., 2020), given their reliance on professional and informal support (Embregts et al., 2021; Summers et al., 2021; Toseeb et al., 2020). The lockdown in the Netherlands entailed several phases, during the initial lockdown period (March 15–June 1); schools, sport clubs, restaurants, hotels, cinemas and museums were closed. People could go out for a walk or visit others – with no more than two persons, keeping a 1.5-m distance at all times. With respect to care for people with intellectual disabilities, day care settings closed and people with intellectual disabilities living in residential facility were not allowed to have visitors or visit their families. In the first week of June regulations changed, and schools, restaurants, cafes, museums and cinemas re-opened. Day care settings re-opened for people with intellectual disabilities and from the 15th of June visitors were allowed to visit residential facilities. During the first period of the pandemic in the Netherlands, the closure of the residential facilities for people with intellectual disabilities did not only have a significant impact on the lives of people with intellectual disabilities (Embregts et al., 2020), but also on their families as they were neither allowed to visit their relative with intellectual disabilities nor were they able to invite their relative to the family home for a visit or short stay. As a consequence of this measure, some parents decided to bring their offspring back to the family home (Verkaik et al., 2020).

The aim of the current study was to obtain an in-depth understanding of why these mothers decided to bring their offspring with intellectual disabilities home during the initial lockdown in the Netherlands. The study aimed to answer the questions: what were the mothers' motives to bring their offspring home and were any of these motives rooted in past experiences? Reaching an understanding of why these mothers decided to bring their offspring home at that critical moment, involves exploring how they view their role as a parent, how they characterise the relationships with their offspring, and their experience of collaborating with support workers. Interpretative phenomenological analysis (IPA) as the qualitative method allowed for an in-depth exploration of this topic.

2 | METHOD

2.1 | Participants

Seven participants took part in the study, all mothers of adults with intellectual disabilities who normally lived in residential care facilities but were temporarily living with their families due to the COVID-19

outbreak. The characteristics of the participants and their offspring are shown in Table 1 and pseudonyms are used throughout the paper. The mean age of the mothers was 60.7 years. The mean age of the offspring was 29.7. All had intellectual disabilities, six of the seven had a diagnosis; Down syndrome ($n = 4$), autism ($n = 1$), chromosomal deficiency ($n = 1$), not specified ($n = 1$). All offspring received care under the Dutch Long-term Care Act [Dutch: Wet Langdurige Zorg (Wlz)]. Under this act, they were assigned to one out of six care profiles based on their level of functioning and support needs. The support needs of the offspring ranged from levels 3 to 5; 3 meaning living with more intensive help, 4 living with more intensive help and behavioural support and 5 living with intensive help and intensive behavioural support.

2.2 | Semi-structured interview

Semi-structured interviews were conducted. An interview schedule was developed covering the following key topic areas: (a) the family situation; (b) why the mothers decided to take their offspring home; (c) changes due to COVID-19 (e.g., Can you tell me why you made this decision? How has your living situation changed due to COVID-19?), (d) the mothers' views on the care provided by the residential facility (e.g., How do you feel about the care provided to your son/daughter by the residential facility? How are you involved in the care for your offspring, now that he/she is living in a residential facility?), (e) how the mothers had experienced their child leaving home (e.g., how did you experience your offspring moving out of the parental home?); (f) the parent–child relationship (e.g., how would you describe your role in the life of your son/daughter?). The interview schedule was discussed with the research team and after the first interview; and (g) future care, was added to the interview schedule. The interview guide can be requested from the authors.

The interview stuck closely to the experiences of the mothers and what they wanted to talk about. All topics (a–g) of the interview schedule were covered. Other salient or pressing topics raised by the mothers were also followed up by the interviewer. At the end of the interview, participants were given the opportunity to raise topics that had not been discussed yet.

2.3 | Procedure

Ethical approval was obtained from the Ethics Review Board of Tilburg University; RP-157).

Convenience sampling was used; the participants were recruited by the first researcher via informal parental networks the first researcher was familiar with. After the first participant was recruited, a snowballing technique was used to find other participants, who met the inclusion criteria. In total, four participants were recruited from these parental networks. The other three participants were recruited through intellectual disabilities services in the Netherlands, that are members of the Academic Collaborative Centre Living with an

TABLE 1 Participants and offspring with intellectual disabilities

Pseudonyms	Age	Marital status	Level of education	Number of children	Age child with ID	Gender child with ID	Number of years the child lived in residential care	Time spend in residential care ^a	Additional diagnosis of the child	Level of support of the child
Mary	64	Married	Honours Bachelor degree	3	32	Female	10	Fulltime	Down syndrome	4
Jill	68	Married	Honours Bachelor degree	3	39	Female	10	Fulltime	Down syndrome	4
Sandy	64	Married	Honours Bachelor degree	4	26	Female	4	Fulltime	Down syndrome	4
Susan	55	Re-married	Honours Bachelor degree	2	24	Female	5	Part-time	n/a	5
Ellen	67	Widow	Honours Bachelor degree	3	34	Female	10	Fulltime	Down syndrome	3
Lisa	55	Married	BTEC Level 3 Extended Diploma	2	28	Male	9	Part-time	n/a	4
Christina	52	Married	Honours Bachelor degree	3	25	Female	4	Part-time	Autism	3

^aFulltime: generally do not go back to the family home during the weekend. Part-time: stay at the family home 2–3 days a week.

intellectual disability at Tilburg University. The link person at the intellectual disabilities services contacted mothers, who met the inclusion criteria. With the mothers' permission, the contact person provided their names to the researchers. The first researcher then contacted the participants by phone or via email, and informed them about the study and provided them with information about the study and the research procedure, as well as the consent form. All participants provided written consent and emailed their consent forms to the first researcher. No incentives were offered. Participants included in this study were mothers of adults with intellectual disabilities, who were living full time or part time (going to the parental home 3–4 days a week) in residential care and who had temporarily moved back to their family home during the pandemic.

The interviews took place in different phases of the lockdown. Four of the seven interviews took place during the initial lockdown period (March 15–June 1). Three interviews took place after this initial lockdown period, in the second week of June. All interviews took place before the 15th of June, and none of the offspring of the participating mothers had returned to the residential care facilities at the time of the interviews.

Due to the COVID-19 pandemic, all interviews were conducted through audio calls using Skype for Business. Face-to-face interviews may have been preferred, but research suggests telephone interviews can provide similar quality data (Braun & Clarke, 2013).

The interviews were conducted by the first author. The duration of the interviews ranged from 58 min to 2 h and 18 min ($M = 1$ h and 18 min). The interviews were audiotaped with the participants' informed consent and transcribed verbatim.

2.4 | Data analysis

IPA was used to analyse the interviews (Smith & Osborn, 2008). This approach involved exploring why the participants decided to bring their offspring home at the start of the COVID-19 outbreak, and if any of their motives were rooted in past experiences.

The first author (F.V.) carried out the data analysis and followed the four phases that are outlined in the IPA method (Smith et al., 2009). A careful audit process was built into each stage of the analysis, involving different members of the research team. During the first phase, the first author transcribed the data and read and re-read the transcript. In the second phase, the first author carried out the initial coding. The notes from the first two phases of the analysis were then discussed with the second author (S.G.) and potential emergent themes were discussed in detail, the emergent themes were formulated. Finally, the emergent themes were clustered into the overarching themes. These overarching themes were then discussed with the research team (F.V., S.G., A.J., P.E.), to examine patterns of similarities and/or differences across cases.

At each phase of the analysis, the results were discussed with the second author (S.G.) to audit the process. The first author made reflective notes after completing each interview, this was done to reflect on how they may have influenced the course of the interview

and the nature of the data that was gathered, to help ensure the transparency and rigour of the analyses (Smith & Osborn, 2008). A log was also kept, to record all the key decisions that were made during the process of the analysis. The interview transcripts were analysed in Dutch, and the findings were then translated into English to discuss within the research team. With respect to the writing process, quotations were translated into English through a translation-back-translation procedure, carried out by one native English and one native Dutch speaker, both independent of this study. This process was repeated until a high level of congruence between the Dutch quotes and the translated quoted was achieved.

3 | RESULTS

The three overarching themes that emerged from the analysis were: (a) families are indispensable; (b) the complex role of being a mother of a child with intellectual disabilities; and (c) who is looking out for our offspring during COVID-19? The first two themes each have three inter-related subthemes. The third theme has two inter-related subthemes.

It is important to note that the interviews started by discussing the mothers' experiences with regards to COVID-19. When analysing the interviews, it seemed that the underlying issues raised by the mothers were strongly embedded in the general context of caring for their offspring with intellectual disabilities. That is, some of the motives to bring their offspring home seemed to be rooted in past experiences. The pandemic seemed to be a watershed moment that made the mothers reflect on the complex nature of their parental role and made a number of longstanding issues more salient or urgent.

The first two themes start with a description of issues experienced during COVID-19, followed by the issues and experiences from the past. The last theme specifically focuses on COVID-19.

3.1 | Families are indispensable

3.1.1 | I want and need to stay involved in the care for my offspring

All mothers talked about past challenges with their offspring's support services in the context of the pandemic and their concerns for their offspring's wellbeing. Past difficulties appeared to be linked to their uncertainty that their offspring would be safe in the residential facility. They had doubts about whether the support workers felt the same sense of responsibility as they did as parents, to keep their offspring safe. For some mothers, these concerns were the main reasons they gave for bringing their offspring home. However, they felt that the residential workers failed to understand that they were motivated by a wish to protecting and doing what was best for their offspring. As a result, it fed into a longstanding sense of unease about their relationship with support workers.

The mothers said they felt it was important for their offspring to move to residential care. It also seemed important for the mothers to plan this transition early, so they were able to help their offspring settle and advocate on their behalf, when they felt necessary. Jill, Sandy and Christina talked about the positive impact moving from the family home has had on their offspring, such as becoming more independent. Yet, the mothers were acutely aware of the critical role they continued to play in relation to the quality of care and wellbeing of their offspring when they moved to residential care.

Even though moving to residential care was seen as positive, the mothers could find discussions with support workers to be challenging. For example, Jill felt she was in a vulnerable position when addressing concerns about the wellbeing of her daughter.

And it is also very difficult that when you say something, it is very quickly seen as an accusation, or it actually is accusatory. But if you do criticise someone, the other person goes on the offensive. That is difficult if you feel vulnerable because you feel they have neglected your child or do not understand and do not want to listen. And then you do not feel respected. (Jill)

The mothers wanted to be able to discuss what they felt was best for their offspring with support workers. They talked about how they tried to maintain communication with support workers and tried to solve problems together. However, some mothers indicated that this was difficult at times. Susan explained that it felt tiring sometimes and feared that the effort of addressing new issues would never end.

Most of the time, or almost always, we have a solution in mind and almost always put it forward, and in the short term that offers some respite. But new problems keep arising and unfortunately that means that we need to jump into the breach again. (Susan)

3.1.2 | Family and professional support are not interchangeable

Heightened health concerns due to COVID-19 seemed to make some mothers think about what would happen if they were no longer able to care for their offspring. However, mothers who had encountered health concerns in the past said COVID-19 did not raise extra concerns about future care. Being confronted with their mortality in the past, already stimulated them to make (formal) arrangements for future care. The mothers who felt they had not found the right person to take over future care for their offspring, were worried. The COVID-19 outbreak prompted some mothers to make formal arrangements relating to the future care of their offspring.

In the context of discussing their offspring's care during the pandemic, all mothers expressed a wish for family or others close to their offspring to be involved in their future care. The mothers felt that,

alongside professional support, their offspring would always need family support. They felt that family provided distinctly different support from professionals, characterised by genuine attention, unconditional love and instinctive awareness. Mary believed that parents had unique insights into their offspring's feelings and instinctive awareness of their needs. Jill felt that her sensitivity and insight, developed over a lifetime and could not be replaced, in the short term, by support workers.

Some mothers had expected better care from support workers, but recognised that they had limited resources and time. Susan and Jill, in particular, thought that their offspring's needs had been overlooked. Susan felt her daughter's best interests were not protected, and that the residential facility did not make decisions based on what was best for the residents, but based on what was best for the facility. For example, choosing a cheaper diaper brand, even though they were uncomfortable for those who had to wear them. Jill thought that support workers failed to pick up signs that her daughter was feeling unwell. These types of experiences strengthened the mothers' view that family input is needed to ensure their offspring get the care and support they need. 'I am still here as a representative, but there will come a time when I won't be around. That is my greatest concern, I want her interests to be protected and I feel that's not happening at the moment' (Susan).

All the mothers had children with and without intellectual disabilities, and they talked about the importance of siblings being involved in the future care of their offspring with intellectual disabilities. However, the mothers wanted to be the primary supporter for as long as possible, to allow their other children a chance to live a life without caring responsibilities. Jill, Sandy and Christina mentioned the importance of having a network of support for their other children offspring, for when they had taken over caring responsibilities for their siblings.

3.1.3 | We want our offspring close

At the start of the COVID-19 pandemic, all mothers, like any parent, wanted their offspring to be safe. Most mothers described their initial impulse to take their child home as being based on an instinctive desire to have their children with them during a time of crisis. They feared being separated from their offspring due to COVID-19-related restrictions and expressed a strong desire to be able to see their offspring.

Before COVID-19, all mothers saw their offspring regularly and most came home at weekends. The mothers described their families as being close. Thus, after their offspring with intellectual disabilities moved out of the family home, the mothers wanted to be able to maintain family bonds and for these bonds to be valued by support workers. For example, Christina appreciated the relaxed way she could visit her daughter. 'Normally, everyone can just come and go. It is not an institution. It is simply a home. It's small-scale and everyone is welcome' (Christina).

3.2 | The complex role of being a mother of a child with intellectual disabilities

3.2.1 | Having to make decisions for my child is complex

Even though the decision to bring their offspring home at the start of the COVID-19 outbreak significantly affected their offspring's life, the mothers explained that the severity of the situation made it an easier decision for them.

When this started, it was very clear to us: we are your parents and we decide that this is what we want to do. But as time goes on and things are opening up, I start to think, you have your own life and your own wishes and as the situation progresses you get more of a say in what happens. (Sandy)

However, as Sandy's quote illustrates, the challenges of having to make decisions for their offspring came to the fore again as time went on. The mothers seemed to struggle with balancing consideration of their offspring's wishes and autonomy with their own wishes and ideas. This was mainly noticeable for mothers whose offspring had a mild to moderate intellectual disability. For example, Mary, Jill, Sandy and Ellen knew their daughters wanted to go back to their own home but worried that they were unable to think through the consequences of returning to the residential facility (e.g., 1.5 m distance, not being able to see other people). Mothers whose offspring had more severe intellectual disability experienced other challenges. For example, Lisa's son preferred to remain with his parents. She had to decide when it would be best for her son to return to his residence.

The temporary move back into the family home also led parents to reflect on the role they played in their offspring's lives. Sandy came to realise that her daughter had grown into an adult woman and she struggled with having to set boundaries for her daughter, such as restricting the contact she was allowed with her boyfriend. In addition, Sandy noticed she found it easier when others (i.e., support workers) helped set the boundaries in her daughter's life.

The challenges of making decisions on behalf of their offspring were also discussed outside the context of COVID-19. Sandy described the sense of burden she felt having to make decisions for her daughter. She sometimes felt she had to make decisions against her daughter's wishes, to protect her, but indicated that she found this difficult. Lisa said she worried that she might be overprotective when making decisions for her son. In these situations, it helped to discuss her thoughts with professionals.

3.2.2 | The wellbeing of my child is my priority

Despite a sense that the mothers had felt their offspring, and they themselves, benefited from taking a step back and encouraging more autonomy, COVID-19 required the mothers to step back in, as they

had to decide whether they wanted to bring their offspring home or not. Their wish to do what was best for their offspring and to protect them, made them bring them back to the family home.

(..) So yeah within thirty minutes I had to decide what I wanted to do, not knowing how long this was going to last, if I was going to be able to make the necessary arrangement with work. (..) I made that decision based on my gut feeling, I cannot explain it to her, I do not want her to be locked up. (Susan)

Throughout their offspring's life, the mothers strongly felt, it was their role to promote their offspring's wellbeing. The mothers whose offspring were least able to voice their own interests, felt a greater responsibility to protect their offspring's wellbeing. Susan explained that she was more instinctively protective towards her daughter with intellectual disabilities. When their offspring was younger, some mother literally described themselves as being their offspring's voice. However, as they got older, the mothers believed it was important to take a step back. For example, Christina felt that both she and her daughter benefited from her becoming more independent. Seeing how well her daughter was faring in the residential facility made it easier for her to let go of the role she used to have.

She has to learn how to express what she does and does not like. That is going really well, actually. I can let go more and she can do more herself. I think it is going well for her and because of that it is easier for me to let go. (Christina)

3.2.3 | Setting out a path for my child with intellectual disabilities

Some mothers said they set out their own path to offer their offspring different opportunities than were offered by professionals or society, but sticking to their own path may have caused worry whether this was indeed a suitable path for their offspring. Having their offspring living at home 24/7 during the COVID-19 outbreak, gave the families an opportunity to see how they had grown and developed over the years. Sandy felt that the approach she had taken with her daughter had set her on a good path. Thus, the time spend together during the COVID-19 pandemic led the mothers to reflect on past decisions and were reassured by their offspring's development.

All offspring had lived with their family until reaching adulthood, and all mothers described how they strived to include their offspring with intellectual disabilities in the life of their family and society, just like their other children. All mothers said that they acted on their instinct when making decisions for their offspring and had learned, over the years, to trust their instinct. Sometimes, they talked about doing the opposite of what professionals recommended or accepted practice. For example, Jill wanted her daughter with Down syndrome

to attend a mainstream school, even though this had not been done before. She described the struggle to create this opportunity for her daughter, in the face of opposition from some professionals.

During the forum discussion a man stood up and said to me: I would like to report you to Child Services because I think you are mentally abusing your child. He was referring to the way we decided to raise our child. (Jill)

3.3 | Who is looking out for our offspring during COVID-19?

3.3.1 | Our worries and concerns are not seen

The COVID-19 pandemic and regulations implemented by the residential facilities made some mothers concerned and they felt the effects the regulations had on them and their offspring were not recognised. For example, Mary and Jill found it difficult to see that support workers could go in and out of the residential facilities, while parents were not allowed to visit their own offspring. These regulations were regarded as inconsistent and some mothers thought the rules reflected how their role as parents was devalued by service providers and broader society.

Susan and Christina worried about the way the management of the residential facilities interpreted the regulations. Their past experience had led them to believe that the management would adopt a strict interpretation of the regulations, in order to avoid any risk of them being liable if residents got infected. This interpretation left no room to do what was best for the residents or their families. Knowing that other residential facilities had tried to find solutions made it particularly difficult for them. For example, other services were allowing parents to go for a walk outside with their offspring.

Christina worried that an approach that merely focused on keeping the infection risk to a minimum would have negative consequences for the residents' social inclusion.

(..) At her facility a lot of them are afraid of COVID-19 and therefore they like living in this protected environment. However, the more they get used to it [the protective environment], the harder it will be for them to return to society. (Christina)

Ellen felt disappointed by the lack of information provided by the residential facility and the service provider. She felt it was important to keep in contact with staff and other parents, and to discuss how their offspring could eventually return to the residential facility safely.

Most mothers felt their concerns were not understood by the residential facility and that the best interest of their offspring was not reflected in the regulations, some experienced greater worry due to lack of information.

3.3.2 | We are not represented in (national) policy

Some mothers said that they had experienced uncertainty due to the COVID-19 regulations set out by the government. They felt that they lacked clear guidelines about how the general regulations applied to their specific situation.

Furthermore, the mothers whose offspring were more vulnerable to COVID-19 worried about what would happen if their offspring got infected with COVID-19 and became seriously ill. The mothers whose offspring were less vulnerable, were not as worried about the risk of infection. Jill worried about whether or not her daughter would be admitted to an intensive care unit. At the time of the interviews, the intensive care units were over-run in the Netherlands. Jill feared that rapid and unethical decisions were being made whether to treat COVID-19 patients, without consultation with loved ones. Jill missed clear communication from care organisations about such issues, to help families deal with these concerns. Lisa felt frustrated because she believed that people with intellectual disabilities and their family members had been forgotten in the chaos of the situation.

We feel this group [people with intellectual disabilities] has been forgotten in the chaos of this situation. They did not receive any attention in the media and they were last in line when it came to handing out medical supplies. It is extremely frustrating. (Susan)

4 | DISCUSSION

This study explored why these mothers decided to bring their offspring with intellectual disabilities home from a residential facility at the start of the COVID-19 outbreak. The main reasons they gave for taking their offspring home were as follows: doing what was best for them, providing protection and not wanting to be separated from their offspring. The mothers' reasoning and their motivation appeared to be rooted in their history of caring for their offspring with intellectual disabilities. As such, in addition to the COVID-19-related experiences, this study provided an insight into the lifelong caring relationships of mothers of people with intellectual disabilities.

This study shows that a history of service concerns seemed to influence the mothers' decision to take their offspring home. The mothers felt their offspring would be better protected from a COVID-19 infection in the parental home. They also worried that support workers would not be as committed or cautious as families, in their efforts to prevent infection. Previous research exploring the move of offspring with intellectual disability out of the family home, have found similar worries for parents (Jacobs et al., 2018). They may, for example, worry that support workers will not provide the same care and might not feel the same responsibility to protect their offspring's quality of life (Werner et al., 2009). This study adds to existing research, as it explored the experiences of mothers whose offspring had lived out of the family home for several years. It suggests that the worries parents experienced before the move, came to the fore during

the time of the COVID-19 pandemic. This is in line with Brown (2013), who found that parents are more aware of the complexity of their role as parent of a person with intellectual disability, when going through a transition.

The mothers in the current study believed their family support was characterised by genuine attention, unconditional love and an instinctive awareness of their offspring's needs. The mothers felt these elements were unique to family support and that their offspring would always need this type of support, in addition to professional support. This is not a novel finding (Sanderson et al., 2017; Van Asselt-Goverts et al., 2013). However, the current study shows that continued difficulties to establish genuine partnership and dissatisfaction about the support for their offspring strengthened the mothers' resolve to remain involved in their offspring's care. Previous research has shown that trust in services reduces when parents do not feel valued or respected (Tracy, 2014) and that parents often feel their role is not recognised or valued (Ryan & Quinlan, 2017). The current study shows that these mothers continued to struggle with finding their place in the care for their offspring and trying to find the right balance between family and professional support.

Furthermore, the decision to bring their offspring home during COVID-19, laid bare the complexity of having to make decisions for their offspring. Some mothers noticed their offspring wanted to go back to the residential facility. These mothers struggled with navigating the tension between their wish to protect their offspring by having them in the family home (e.g., from not being able to visit their family or do their usual activities once they would return to the residential facility, from a COVID-19 infection) and their offspring's wishes to return to the residential facility and the relationships and activities they enjoyed. Others noticed their offspring wanted to stay at the family home, they had to take account their offspring's wishes whilst keeping in mind what was best for their future. The findings of the current study indicate that decisions making for their offspring were, at times, complex for these mothers. Those with mild intellectual disabilities tended to want to go back to the residential facility. They had to balance their own wishes with a need to respect the autonomy of their son or daughter. Mothers whose offspring had more severe intellectual disabilities tended to want to stay at the family home. These mothers had the contrasting challenge of trying to encourage their offspring's sense of autonomy. All mothers valued the increased autonomy of their offspring. They had encouraged and arranged the move of their son or daughter out of the parental home. This is consistent with previous research, which has shown that parents can play a key role in building the decision-making capacity and autonomy of their offspring with intellectual disabilities (Van Asselt-Goverts et al., 2013). However, in line with previous research, the current study also shows that parents may find it difficult to know what is best for their offspring, and to balance their need to protect their offspring with respect for their offspring's own wishes (Curryer et al., 2019; Giesbers et al., 2020).

Lastly, the decision to bring their offspring home might have been influenced by the fact the mothers felt that specific guidelines for people with intellectual disabilities and their families were missing.

They were worried that they would not be able to visit their offspring due to the restrictions.

Some mothers also felt people with intellectual disabilities and their families were a forgotten group as they felt the effects the restrictions had on them and their related concerns were barely acknowledged by the government or service providers. They had taken on a major responsibility by bringing their offspring home, but there seemed to be little recognition of the impact this had on these families. Similar concerns that people with intellectual disabilities and their families were at risk of being forgotten due to the chaos caused by COVID-19 have been raised in the United States and the United Kingdom (Hassiotis et al., 2020; Silverman, 2020).

There are a number of implications for practice and research. First, policy makers should take into account the living situation of people with intellectual disabilities and their families. These mothers were very involved in their offspring's life, separating them from their offspring with intellectual disabilities in times of crisis, may have significant impact on the quality of life of these families. Government should consider the impact restrictions could have on people with intellectual disabilities and their families, and may need to adjust policy to protect them from the impact restrictions may have on their lives. Failing to do so may force people to make big impact decisions in order to protect their own wellbeing as well as the wellbeing of their offspring, as shown in the current study.

Furthermore, residential facilities as well as intellectual disabilities services should offer support to persons with intellectual disabilities and their families in times of crisis. These mothers made a complex decision (e.g., taking their offspring home), without knowing how long it was going to last. It may have been helpful for parents in this situation to be able to discuss this decision with professionals or other support workers they trust, to ensure the best decision was made. Shared decision making could have supported the family members as well as the person with intellectual disabilities, to make a good decision for all parties concerned (Shogren et al., 2017). It might also have been helpful if someone at the residential facility or from the care organisation had maintained contact with the mothers, to discuss potential needs or questions that arose as time went on. As described in the current study and in line with findings of Rose et al. (2020), COVID-19 has had a big impact on the emotional wellbeing of people with intellectual disabilities and their families. The decision to bring their offspring home brought many complex feelings to the fore. It is recommended to reach out to parents who have made the decision to take their offspring home, to provide support, if needed, after what they have experienced and to help the person with intellectual disabilities and the parents settle back into their normal routine.

Future research should explore how parents and family members have been affected by past experiences, and how these experiences shape the role they play in the life of their relative with intellectual disability. This study shows that during stressful times, past experiences may come to the fore again and may influence the decisions parents make. Parents' continued role as decision-maker in the life of their offspring should also be explored further. This is a complex role, for which parents and family may require lifelong support. Future

research should explore the experiences of adults with intellectual disabilities who were brought home during COVID-19.

Only mothers were interviewed for this study, most were highly educated and the majority were married. Future research should focus on mothers from different backgrounds, and include fathers. Few studies have investigated the experiences of fathers (Taylor et al., 2016), whose experiences and needs may differ from mothers (Luijckx et al., 2019). The sample size (seven) is in line with the sample sizes of IPA studies, allowing for an in-depth exploration of the sample's experiences (Smith et al., 2009). However, it would be beneficial to try to recruit a larger number of participants in future studies. The researchers decided not to carry out a member-check. Member-checks are not always completed in IPA studies (Smith et al., 2009), however, it is acknowledged that this may be a limitation. Lastly, a statement about the position of the first researcher needs to be made, as they have a sibling with intellectual disabilities who returned to the family home during the pandemic. While this relationship provided the first researcher with unique insights into these families' motives, great care was taken to avoid making assumptions when completing the interviews and carrying out the analyses. To help achieve this, reflective notes were kept after each interview (Smith & Osborn, 2008) and routinely discussed with the second author and at the research team meetings.

To conclude, COVID-19 and the decision to take their offspring home seemed to bring the complex nature of being the mother of a person with intellectual disabilities, to the fore. Previous research shows that during transitions, parents are often more aware of the complexity of their role (Brown, 2013). During COVID-19, the mothers brought their offspring home to do what was best for them and to protect them. These decisions were made against a backdrop of disappointing past experiences with service providers and a society, they felt, failed to sufficiently protect and support people with intellectual disabilities. However, having their offspring living back in the family home the mothers more aware of complexities surrounding their offspring's autonomy and the different points of view. The complex and dynamic nature of parent-child relationships were highlighted in this study, and their continuing importance when dealing with real world challenges.

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CONFLICT OF INTEREST

The authors declare there is no conflict of interest.

DATA AVAILABILITY STATEMENT

Author elects to not share data Research data are not shared.

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