

‘I cannot be missed yet’: A qualitative study of carers of family members with an intellectual disability about long-term care planning during the COVID-19 pandemic

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Abstract

Background: Family carers of people with an intellectual disability sometimes need to transfer their caregiving tasks for example because of illness or ageing. We examined carers' experiences with long-term care planning and the impact of the COVID-19 pandemic on their intentions to engage in long-term planning in the Netherlands.

Method: Twenty-five semi-structured interviews with family carers of people with an intellectual disability were conducted and 169 answers to an open question were thematically analysed. Data collection took place at three timepoints during 2020 and 2021.

Results: Family carers were recurrently concerned with long-term care planning, especially with finding people to whom they can entrust their tasks. However, they perceived barriers in care planning. The COVID-19 pandemic reinforced awareness of long-term care planning and moved some to action.

Conclusions: The perceived urge to plan by family carers has grown due to the COVID-19 pandemic. The current study provides valuable insights for stakeholders to support them in this.

KEYWORDS

COVID-19, family carers, future care planning, intellectual disabilities, long-term care planning, quality of care

1 | INTRODUCTION

Relatives of a family member with an intellectual disability who requires time-consuming care and support often have to find someone to take over this care for a substantial period of time for instance because of illness, health problems due to old age, overload or the combination with other (care) tasks. Their family members with an intellectual disability, for example a child, a sibling or partner, may live at home, but also in a residential facility or other form of housing. A lack of a plan for the future is a major source of stress and worry for

parents and siblings (Greenwood et al., 2019; Taggart et al., 2012). Most research suggests that there are often no concrete plans and that agreements are not recorded (Brennan et al., 2018; Lindahl et al., 2019). Relatives sometimes have aspirational plans that represent what they would like to see happen, but have not explicitly discussed (Taggart et al., 2012).

Several positive effects of being a relative have been described in the literature, such as an increased sense of purpose in life, having more patience, and being more appreciative of the small things in life (Beighton & Wills, 2019; Yoong & Koritsas, 2012). Despite these

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positive effects, providing care for an individual with intellectual disabilities can place a heavy burden on the carer. Considerable research has shown that relatives of people with intellectual disabilities can experience physical and psychological strain and high levels of stress and anxiety (e.g., Panicker & Ramesh, 2019; Staunton et al., 2020; Yoong & Koritsas, 2012) and that growing up with a sibling with an intellectual disability has impact on family life and siblings' further life (Kruithof et al., 2021; Roling et al., 2020).

Long-term care planning is increasingly urgent for parents of children with an intellectual disability because the life expectancy of people with an intellectual disability has increased, and they outlive their parents more often (Kamstra et al., 2017). Parents continue to worry about this situation, especially when they themselves have health problems and are getting older. In addition, many have no external support and are often heavily burdened with care tasks (Ryan et al., 2014; Springvloet et al., 2020; Ten Brug et al., 2018). Siblings can also experience pressure: as they grow up, they anticipate taking a greater role in providing care (Heller & Arnold, 2010). In some cases, siblings experience a double burden if they need to provide care to their sibling with a disability, their parents and their own family (Brennan et al., 2018).

The reason that many carers of a family member with an intellectual disability do not plan care ahead of time, is that they experience several barriers in making plans for the future (Bibby, 2012), such as their lack of confidence in current and future care facilities, and emotional difficulty of letting go of care responsibilities for a relative and the ensuing confrontation with their own mortality. Other barriers are that they are unsure where to start (Lindahl et al., 2019; Ryan et al., 2014), they do not want to burden others, and they do not know anyone who could take over their care tasks. Moreover, people around them, including care professionals, often do not raise this topic themselves (Taggart et al., 2012). The family member with a disability may sometimes create barriers; for example, they may not want to leave home.

The COVID-19 pandemic could influence awareness of future planning and the overall long-term planning process. In the Netherlands, most families were confronted with the COVID-19 pandemic when a lockdown was announced in March 2020. Residential care facilities initially closed their doors for visitors for around 3 months and then gradually opened again. Daycare centres and school facilities also closed completely for a few months and then often reopened. Domiciliary care was sometimes continued, but was hindered by quarantines, illness, lack of personal protection equipment and fear for contagion. Overall, family members received less professional care and support (Boeije et al., 2021; Embregts et al., 2021). Since the beginning of the pandemic, restrictive measures, like social distancing, closing of shops and restaurants, wearing facemasks and working at home, have been withdrawn and reinstated several times.

COVID-19 and the preventative measures can be regarded as additional stressors for carers of people with intellectual disability (Willner et al., 2020). During the pandemic they were confronted with a dangerous and threatening situation for their health and presence,

which often underlies engagement in future planning. Additionally, the family carers were left more on their own (Budnick et al., 2021; Embregts et al., 2021) and the pandemic has potentially lead to a higher intensity of involvement which might affect awareness of the vulnerability of their position and division of tasks in the caring network. Next to this the visiting restrictions raised all kinds of questions about well-being of both the family carers and their family members with intellectual disability, the communication and the contribution of family caregiving in relation to professional staff (Araten-Bergman & Shpigelman, 2021; Boeije et al., 2022).

The aim of this study was to give insight into long-term care planning and the potential impact of the COVID-19 pandemic and to determine how we can improve the support with long-term care planning for carers of family members with an intellectual disability. In this study we addressed the following research questions:

1. What are triggers for carers of family members with an intellectual disability raising awareness of the need for long-term care planning?
2. What barriers do carers of family members with an intellectual disability experience in thinking about and making arrangements for when they are no longer able or willing to provide the care and support themselves?
3. What are the experiences of carers of family members with an intellectual disability with talking about long-term care planning with others and with making arrangements?
4. How has the COVID-19-pandemic impacted long-term care planning?

2 | METHODOLOGY

2.1 | Design

As a methodology, we chose a generic approach to descriptive-interpretive qualitative research that focuses on understanding the meanings, purposes and intentions people give to their own actions and interactions with others (Elliott & Timulak, 2021). We designed a study with two rounds of qualitative interviews and one round with an open question on a questionnaire. The first round consisted of qualitative interviews with carers of family members with an intellectual disability about long-term planning (August–September 2020) and the second round of qualitative interviews with carers of family members with an intellectual disability addressed the impact of COVID-19 on their lives, including the impact on long-term planning (May 2021). The third round of qualitative data collection consisted of an open question as part of a survey distributed on a large scale (October 2021). Two carers of family members with intellectual disability cooperated with and advised the project team about the design, wording of questions, the questions posed in the interviews and on the questionnaire, and the interpretation and dissemination of results. These two experts-by-experience were reimbursed for their work.

TABLE 1 Participants in the three rounds of qualitative data collection

Characteristics of carers of family members with an intellectual disability	Round 1 August 2020 (N = 11)	Round 2 May 2021 (N = 14)	Round 3 October 2021 (N = 169) ^a
Sex			
Female	6 (55%)	10 (71%)	120 (71%)
Male	5 (45%)	4 (29%)	48 (28%)
Age (years)			
25–50	2 (18%)	3 (21%)	9 (5%)
51–60	2 (18%)	5 (36%)	39 (23%)
61–70	6 (55%)	5 (36%)	65 (38%)
> 70	1 (9%)	1 (7%)	55 (33%)
Relationship with family member			
Parent	8 (73%)	9 (64%)	110 (65%)
Sibling	3 (27%)	4 (29%)	46 (27%)
Partner	0 (0%)	1 (7%)	3 (2%)
Other (e.g., children, friends)	0 (0%)	0 (0%)	9 (5%)
Living situation of a family member			
Residential institution	6 (55%)	0 (0%)	87 (51%)
At home with relative	1 (9%)	6 (43%)	43 (25%)
Housing initiative by parents	3 (27%)	0 (0%)	24 (14%)
Independent with ambulatory supervision	1 (9%)	8 (57%)	14 (8%)
Intellectual disability of the family member			
Mild	1 (9%)	10 (71%)	61 (36%)
Moderate	5 (45%)	3 (21%)	47 (28%)
Severe/profound	5 (45%)	1 (7%)	47 (28%)

^aDue to rounding numbers or missing data, some totals do not add up to 100%.

2.2 | Recruitment of carers of family members with an intellectual disability

2.2.1 | Recruitment in Round 1

For the first round of interviews, 11 carers of family members with an intellectual disability were recruited in July 2020 via the newsletter of the Program Full Life of the Dutch Ministry of Health, Welfare and Sport (see Table 1). Their family members with an intellectual disability all had additional problems or limitations, such as motoric problems, sensory limitations or health problems, and they had various living arrangements.

2.2.2 | Recruitment in Round 2

In the second round of interviews, 14 carers of family members with an intellectual disability participated. The participants had either family members who were living with them at home or were living independently with ambulatory supervision (see Table 1). They were approached if they had indicated on a COVID-19 survey (13 April–7 May 2021) that they were willing to be interviewed.

2.2.3 | Recruitment in Round 3

For the third round of data collection, a survey (15 October–5 November 2021) about COVID-19 was distributed to 541 family carers in total. First, it was distributed among all members of the Dutch Panel Living Together (Panel Samen Leven), 350 relatives of people with mild or moderate intellectual disability. The survey was also distributed to participants who reacted to the newsletter in the first round and to participants who had been recruited for a study on quality of life of family carers in 2019 and who had expressed interest to participate in related research. In total 169 family carers answered an open question about their concerns for the future. The characteristics of this group are described in Table 1. All participants in our study who were parents of children who were not legally competent had appointed legal representatives, such as a mentor, administrator or trustee.

2.3 | Data collection

2.3.1 | Round 1 data collection

After consenting to participate, in the first round interviews were held with carers of family members with an intellectual disability based on

a topic list about long-term planning. Topics were derived from the literature on care planning and dealt with aspects such as awareness, barriers, talking about the transfer of tasks, needs and reasons for long-term planning. Interviews took 60 min on average.

2.3.2 | Round 2 data collection

In the second round, interviews addressed the impact of COVID-19 on the lives of the carers and of their family members with an intellectual disability. When asked about the future in the light of COVID-19, they talked extensively about long-term planning without prompting. On average these interviews took 45 min. In both the first and second round, interviews were held by telephone or video link. They were recorded with consent and transcribed verbatim. All participants received a gift voucher for their participation.

2.3.3 | Round 3 data collection

The anonymous survey was conducted from 15 October 2021 to 5 November 2021. Reminders for the survey were sent after 10 days. The survey was administered online and on paper when they stated this as their preference. Answers were typed by respondents in the online surveys; answers from the paper questionnaires were manually imported in data manager. In this round an open question invited respondents to elaborate on their answer to the question 'Has the COVID-19 pandemic triggered concerns about a situation in which you can no longer care or support your family member?'

2.4 | Analysis

All data were analysed following the steps of thematic analysis: becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and producing a report (Braun & Clark, 2006). The transcripts of the first round of interviews were analysed by the second researcher (C.L.) and independently analysed by one of the other researchers (H.B. or F.S.). The second round of interviews were analysed by the principal researcher (H.B.) or the second author (C.L.). The initial codes were based on the literature, predominantly Bibby (2012), Brennan et al. (2018) and Taggart et al. (2012), and derived from the independent analyses, and were discussed until consensus was reached. Qualitative data analysis software (MaxQDA) was employed to assign codes or keywords to data segments. After searching for and reviewing themes, the answers to the open questions were added and analysed as well. Relevant themes were then clustered to create and define main themes that are discussed in the results section. The steps taken and the outcomes of the analyses were discussed with the two experts-by-experience. Quotes from all three rounds of data collection were used. Here they have been edited for readability.

2.5 | Ethical approval

Data from the Dutch Nivel Panel Living Together are analysed anonymously, and processed according to the panel's privacy policy, which complies with the General Data Protection Regulation (GDPR). According to Dutch legislation, neither obtaining informed consent, nor approval by a Medical Ethics Committee, is obligatory for carrying out research using the panel.

3 | RESULTS

3.1 | Triggers raising awareness of the need for long-term planning

For most relatives who provide care to family members with an intellectual disability, the question of what will happen if they can no longer provide this care has been in the background for some time, and at certain times they became more aware of the issue.

3.1.1 | Specific moments

This was often linked to ageing, diminishing health or awareness of their mortality. They noticed, for example, that caring had become more difficult for them lately. Some had recently lost parents or people around them. One interviewee stated:

I started thinking about it because I realized that I'm getting older. And I thought that if our son is going to outlive me, then I must do something. That happens at some point. You see people of your own age dying around you, then it strikes you. (Father, 74 years, Round 1, Int2)

In the Netherlands, when children turn 18 their parents are no longer automatically their legal guardians. Some interviewees reported that at that moment they began thinking about long-term care planning. All parents had appointed legal representatives and often took one or more of these roles themselves, such as a mentor, administrator or trustee.

3.1.2 | Other reasons

Other reasons for a growing awareness of the future were also reported, for instance when couples who provided joint care decided to separate or when one of them became ill. Then they suddenly felt they were more on their own with regard to supporting their family member and they started thinking of their vulnerability.

Siblings often foresaw that some or all of their parents' care tasks would ultimately fall to them. They were often troubled for a long time by this aspect and had questions about it. In some families, the

care tasks that were needed for the family member with an intellectual disability gradually expanded or became more complex. As a result, these carers understood that they would probably be unable to sustain their commitment because it could not be combined with other obligations and needs. As one interviewee stated:

If I could organize it properly, I'd have my hands free to do some other things, too. You must not forget that I now have outsiders at home – the professionals – who I have to take into account every day. I will soon be a grandmother and I am really looking forward to that. With everything else that I have to do now, I wouldn't have time for my grandchild. My other daughter deserves time too. But in the current situation it won't work. (Mother, 61 years, Round 1, Int4)

3.2 | Barriers for long-term planning

Most interviewees reported that they put off long-term planning, even if there were times when they reflected on their role in the life of their family member with an intellectual disability. They experienced barriers to long-term care planning.

3.2.1 | Emotional topic

First, for all interviewees it was an emotional topic, and the sadness and feelings of guilt of abandoning a family member could get in the way.

My sister is the youngest in our family and given the trust she has in me, I find it difficult to gradually let this go. (Round 3, open answers)

One of the mothers reported that it was difficult for her that her adult child spent a few days a week in an institution to ease her own task. She thought she should take care of her child, who functioned at a level of a 3-year-old. Some interviewees reported that they had spent their entire lives trying to make their family members with an intellectual disability comfortable and trying to protect them from grief:

Our son has been living in that care facility for over 20 years now. And he has people around him who never get visitors and have a very dull and monotonous life. We are afraid that this will also happen to him. (Father, 64 years, Round 1, Int11)

3.2.2 | Everyday costs energy

A second barrier was that the care situation in the home often demanded all the interviewees' time and energy and they could not

pay attention to anything else. Far-reaching responsibilities burdened their relationships, family, friendships, work and their own well-being. If others sometimes pointed out an impending overload, this could be a time to think about sharing and partly transferring care and support.

My daughter is not a difficult child and you can easily have her around. It's just that you always have to arrange something. That's actually the main point. I have to take her everywhere: all the sports she does and all the clubs. I also want her to be able to participate in society. But yes, she has to go back and forth. And also with holiday trips she could actually go along very well or fit in well with that. She could participate in children's entertainment programs when she was 12 with children of 8, but if you are 21 and you participate with children of 8, that is no longer possible. She thinks it's childish. (Mother, 57 years, Round 2, Int6)

3.2.3 | Looking for a good alternative

Another reported barrier was that the interviewees did not see a good alternative for their own efforts. For many of them it had taken a long time to find suitable housing and care arrangements, and some were still searching. These interviewees reported feeling very despondent about this situation.

I wanted to let my son stay overnight in a caring facility. And I had quite annoying conversations about this with the client advisors who, based on his papers, didn't even talk to me because he wouldn't fit because he needed too much individual guidance. I understand that and there is no room for that. You have to choose between staying overnight or receiving care. I notice that they pay a lot of attention to the right target group because if they have the wrong client in it, this will cost them money and that makes placement much more difficult (Mother, 47 years, Round 2, Int1)

A number of parents had joined together to set up a small-scale residential facility with care and support for their children. If suitable housing and care were arranged, this gave them peace of mind because it prevented a crisis if they suddenly became unable to provide care.

3.2.4 | No one else can provide this care

Besides housing and care, another reported concern was about the overall quality of life of the family member with an intellectual disability. This often concerned aspects that only the interviewees appeared to understand due to their intimate knowledge of exactly what their family member needed. Most interviewees were afraid that no one

else could provide care as they do. Moreover, due to the misunderstanding they encountered in people around them, they sometimes broke off contact and ended up with few people they could rely on. They also did not want to burden others, as the mother below explained:

My other daughter is very busy and has two growing children who have her full attention. She has a busy job and she has little time. So I don't dare ask her which care tasks she could take over when I cannot provide care. We always make appointments to talk seriously about how things should be in the future, but that appointment is always cancelled. (Mother, 67 years, Round 1, Int10)

3.3 | Talking about long-term planning and making arrangements

3.3.1 | Avoiding and keeping silent

Interviewees reported that they often dread a conversation about long-term planning because they do not know how others will react. Sometimes people close to them, such as siblings of the person with a disability, wanted to talk about it as well, but no one knew how to get started. This unspoken wish to talk about it, the resulting feeling of pressure in the family and doubts about the future course of events were mentioned in the following interview:

Every now and then I talk about it with my daughter. And then she says: 'Yeah, fine, then I'll take care of it and don't worry about it.' But at other times I doubt that she will do this. When she finally has to act, will she pay enough attention to it or will she want to get rid of the problem quickly?" (Father, 71 years, Round 1, Int7)

3.3.2 | Support and understanding

Other interviewees reported that when they finally talked about it, others were happy to help. This made the interviewees grateful about keeping the family together.

I was talking to my son about his brother's future. Then he said: 'Have you forgotten that I'm still here?' I never expected that. I've always said I don't want to burden my kids with providing care for their brother. So I never asked them about it. But now they've both said they want to stay involved. (Mother, 49 years, Round 1, Int12)

A few interviewees reported on families in which the family member with an intellectual disability was involved in the decisions and the steps taken. The following interviewee explained how this led to mutual realisation about the vulnerability of their living situation and the security of looking at arrangements for the future:

Last year we went to look at residential facilities to get an impression of what they are like, how they operate and how the residents live. And that of course also gave him some peace of mind that there is somewhere where he can live in the future. His grandmother suddenly became incapacitated due to a stroke, so he knows that can happen. That fear is always with him. And maybe he is thinking 'Now I'm just alone with my mother'. I hope that the idea of a residential facility will appeal to him a bit and that he can end up on a waiting list somewhere. (Mother, 58 years, Round 2, Int10)

3.3.3 | First step in long-term care planning

Interviewees reported that talking about the future and possibly asking for help created openness about the situation and sometimes created space to consider long-term planning together. A number of them stated that they had arranged a gradual takeover of care tasks, which often turned out well and gave them more confidence in sharing the care with others, with professionals and with their social network. Many also reported sharing mentorship and trusteeship with their partner or with their children, which can provide peace of mind:

If you arrange this, you get some peace of mind. If you don't, you will feel restless, because you don't know how it will go. And of course you're always more concerned about a child with an intellectual disability than about your children who have left home and now have their own lives. It gives peace of mind because I don't have to worry if I suddenly can't do it myself anymore. (Father, 74 years, Round 1, Int2)

3.4 | Impact of COVID-19 pandemic

On the questionnaire, 169 respondents answered a closed question about future concerns as a consequence of the pandemic. Of this group, 54% affirmed that the pandemic had triggered concerns about a situation in which they can no longer care for their family members, while 46% reported that they were not more concerned about the future. In the subsequent open question they stated that they already had made arrangements and that it was all settled. Others wrote that the pandemic did not increase their usual worrying or that they were quite optimistic by nature, and some stated that they would probably think about this in the future.

3.4.1 | Threat of illness and death

Respondents who did have more concerns reported that they were afraid to catch COVID-19 and get seriously ill or even die:

Because I am in the risk group for the pandemic, I have been more concerned about how my son will fare if I become seriously ill and I can no longer provide care for him. That worried me sometimes! (Round 3, open answers)

Since the pandemic began, carers with a family member with an intellectual disability at home reported being considerably more concerned with long-term planning than those with other living arrangements. But those with family members living at residential facilities also reported concerns about the future.

I have indeed been busy with this question, even more than before. Because I couldn't support my loved one during the lockdown, since his residence was closed for visitors, but that also applies to the future. There will also come a time for me as a parent when I can no longer take care of him. (Round 3, open answers)

3.4.2 | Realising vulnerability of the network

In addition to the carer's own vulnerability, the interviews revealed other vulnerabilities in caring for family members with an intellectual disability. In some cases the family member with an intellectual disability temporarily moved from living independently or from a residence to live with the relatives in their homes, for instance to prevent quarantine or to take better care of them. This sometimes led to a realisation about the small size of their network:

Our increased support and her reliance on it during the time she lived with us made us even more aware that her own network needs to grow. The network of someone with an intellectual disability is small, which made it difficult to arrange something. During the lockdown it became especially clear what our support means. (Mother, 66 years, Round 2, Int8)

As a result of the pandemic some carers took very practical measures in case something should happen to them, such as changing the furnishing of the family member's house, arranging legal representation or ensuring information transfer in case somebody else suddenly had to take over.

I'm even more aware that I should buy everything she needs, such as enough clothes and a good mattress, I don't want to postpone that. I'm making arrangements for her funeral and inheritance where possible, and I have a folder with all the important papers. This to honor her wishes as much as I can. When I am gone I do not want to leave my children in a maze, as the only ones who will want to take it on. She and my siblings currently have no idea how everything is arranged. (Round 3, open answers)

3.4.3 | Exhaustion and need to recover

Respondents indicated they were exhausted and have been unable to recover due to the pandemic. They reported a need for extra support because they could no longer keep up with the demands of caring for their family member with an intellectual disability. The pandemic has amplified one barrier to thinking about long-term care planning in particular: respondents stated that it is pointless to think about alternative care because residential facilities have no capacity for weekend or overnight care. They expected that more carers will become exhausted, which will lead to more demand for residential care facilities and longer waiting lists.

The pandemic has caused stagnation in professional care. Arranging overnight and weekend care is difficult because the facilities are full. Parents who care 24/7 for a disabled child of course want to have a weekend off once in a while. If they manage to find weekend care, they don't do that once every six weeks, but every two weeks. And they will do that for the next fifteen years, so there is no turnover at all. (Father, 54 years, Round 2, Int7)

4 | DISCUSSION

4.1 | Main findings

Many respondents stated that they thought about what they would do if they become unable or unwilling to care for family members with an intellectual disability. This question often arose as they got older or when someone in their circle of friends or family became ill or died. Nearly all of them put the question aside when they experienced various obstacles to taking further steps. An important barrier to picking up the question was the intense emotion associated with the topic. The respondents were deeply concerned with ensuring a good quality of life for family members with an intellectual disability and preventing their pain and suffering. That is essentially what preoccupied them and what they would like to be sure about, but which they did not know exactly how to accomplish. The present study shows that carers experienced the COVID-19 pandemic as a time when they feared becoming seriously ill or even dying and when the vulnerability of the care system and their own involvement was revealed. Some of them became more engaged in long-term care planning during the pandemic.

4.2 | Discussion

Bibby (2012) warns that the risk of putting aside the question is that choices will have to be made in a crisis situation and may not match the wishes and needs of both the family and the person with a disability. During the COVID-19 pandemic carers worried that something

would happen to them and some started doing practical things, making legal arrangements and doing long-term care planning. In this way, the threat of the pandemic raised awareness and even led carers to overcome barriers and take concrete steps.

Although some of the respondents became more engaged in long-term care planning during the pandemic, this was not always done in mutual consultation. They apparently made up their minds and started to make arrangements without consulting others or engaging others. Bibby (2012) presents evidence that family members with an intellectual disability who are not involved, can be overwhelmed by the plans later on. Previous research shows that carers rarely involve their family members with an intellectual disability in planning because they do not want to induce stress (Bibby, 2012).

In our study, some respondents involved their family members with an intellectual disability in decisions about the future. It is possible that during the pandemic, circumstances facilitated the involvement of the family member with an intellectual disability since closer contact was possible because they were temporarily living together while social distancing measures made it difficult to talk to others eye-to-eye. Future research could focus on facilitators for involving family members with an intellectual disability and provide possible instruments for talking with them about long-term care planning.

We also found that carers often avoid speaking to others about what should be done if they become unable to provide care. Indeed, they all appeared to have difficulty with bringing up this topic. Some carers reported that their networks had become small and that taking over care tasks was not self-evident, because their family member with an intellectual disability was difficult to understand or destructive. This is in line with Willner et al. (2020) who showed that relatives of people with behavioural problems often receive less social support than other relatives. Bibby (2012) suggests that it can help if someone else puts the topic on the table and that when the network is fragile, an independent person or moderator could also explore the possibilities of a network.

We interviewed a number of respondents who had spoken to others in their family, resulting in what Taggart et al. (2012) called definitive plans. They were relieved about this as it often turned out better than they had expected and it helped to reduce stress and enhance confidence in future care. In addition, respondents rejoiced in their ability to keep the family together. Those who had made arrangements more often answered that the COVID-19 pandemic did not increase their worries because everything was settled. In a recent review, Brennan et al. (2020) concluded that there are many more positive outcomes for families once they engage in long-term planning.

In our study, we found a barrier that was also reported in previous research (Bibby, 2012; Taggart et al., 2012): the lack of confidence in current and future care facilities. This demoralises the search for facilities and prevents carers from thinking about alternatives. This barrier will probably grow in importance for two reasons: (1) the carers' increased awareness of unpredictable dangers for which they will need more professional help to prevent a lack of care and support, and (2) the carers are tired and have no time to recover because they live at home with their family member with an intellectual disability.

They will need more options for weekend care and day-care with a view to long-term facilities. In the Netherlands, as in some other countries (Brennan et al., 2020), healthcare policy emphasises reliance on families to provide care, for instance with personal care budget funding. The ageing population of people with an intellectual disability, the diminishing care capacity within family networks, and the shortage of professional staff all indicate a need to support carers and their family members with an intellectual disability so they can plan for their futures. This can be part of a reform of health care for people with intellectual disability that is provoked by the pandemic (Kavanagh et al., 2021).

There is a scarcity of systematic approaches to long-term care planning for adults with an intellectual disability and their family carers (Brennan et al., 2020). Although the topic is very prominent, the carers have little help with long-term care planning. Most seem to need a push to start taking steps and boost their confidence. We believe that professionals have a responsibility to look for questions that carers may have about the future and explore long-term planning, while respecting their feelings about responsibility and love. Carers seem to be open to suggestions from professional care providers and counsellors when it comes to contact with other carers and long-term planning.

4.3 | Strengths and limitations

A noteworthy strength of the current study is its longitudinal character. Awareness, barriers and concrete steps were measured during three different moments in the COVID-19 pandemic. As experts-by-experience were involved, we ensured the study addressed topics relevant in practice. Furthermore, this study investigated a diverse sample of carers of individuals with several degrees of intellectual disabilities.

There are a few limitations as well. The purpose of the three rounds of data collection varied. The first round focused on understanding long-term care planning, while the second and third rounds focused on the impact of the pandemic on family carers. At the same time, this revealed that the pandemic was prompting relatives to consider the transfer of their tasks and roles. In a somewhat later phase of the pandemic it also showed that relatives were actually working on measures to arrange future care.

Furthermore, the final round of data collection took place in October 2021 and this was far from the end of the pandemic. Future research could explore the further impact on long-term care planning.

4.4 | Conclusion and implications

The COVID-19 pandemic can be seen as a crisis that did not start with a blow but has developed slowly. This causes stress for, among others, relatives of people with intellectual disabilities. Some of them have felt threatened by COVID-19 in their health and thought the threat of death was real. In addition, the crisis confronted them with the loss of professional support and of informal sources of help. The crisis then

triggered them to overcome barriers and to take concrete actions to arrange possible transfer of care.

The current study therefore emphasises that the pandemic has triggered long-term care planning which in itself can be beneficial for people with intellectual disabilities, carers and their families. This necessitates to facilitate them in this step, for instance with systematic approaches to long-term care planning which include involvement of the family member and with pro-active support for carers who wish to take concrete steps. An important implication is to not deter carers who want to take steps now, for example by long waiting lists for facilities, but to support them with the aftermath of the pandemic. This is important for the well-being of the carers and for their caregiving role.

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CONFLICT OF INTEREST

There are no competing interests to declare.

DATA AVAILABILITY STATEMENT

The data sets generated and/or analyzed supporting the findings of this study are available from the corresponding author on request and subject to approval by the program committee of the Panel Living Together. This program committee supervises processing the data of the Panel Living Together and decides about the use of the data.

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