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Adults with IDD in supported accommodation during COVID-19 lockdown:

The families' perspective --Manuscript Draft--

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Abstract

The present study aims to understand and describe family caregivers' perceptions and experiences regarding contact and relationships with their adult relatives with intellectual and developmental disabilities (IDD) living in supported accommodation during the COVID-19 lockdown. A qualitative phenomenological approach was applied in which 19 Israeli family caregivers (parents and siblings) were interviewed. Inductive thematic analysis revealed themes at the microsystem level (the resident, the caregiver, and their relationship), and at the mesosystem level (the caregivers' interactions with service providers and other residents' families). The findings highlight the pivotal role of family caregivers in times of uncertainty and the need to develop explicit policies and mechanisms to facilitate family engagement in the residents' lives.

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Introduction

The COVID-19 pandemic and its associated social restrictions have had significant ramifications for adults with intellectual and developmental disabilities (IDD) in supported accommodation and their families and impacted the services they received during this time. Research shows that due to both individual factors (e.g., health problems) and structural factors (e.g., one policy for all), adults with IDD living in supported accommodation are especially vulnerable to the adverse effects of the pandemic (Friedman, 2021; Landes et al., 2020; Landes et al., 2021; Safta-Zecheria, 2020). An epidemiological study indicates that adults with disabilities are at increased risk of infection, serious illness, and death associated with COVID-19 (Deal et al., 2023). Furthermore, state responses to the pandemic included the abrupt closure of health and social services and restrictions on movement and social interactions. The infection prevention and the restrictive measures also enforced within services resulted in changes in the daily routines of residents with IDD, including restricted access to health care and social support. For example, employment and daytime activities were cancelled and a strict visiting regime was introduced by services early in the pandemic: residents with IDD were not allowed to meet family and friends for months (Goldman et al., 2020; Landes et al., 2020; Rose et al., 2022).

The COVID-19 pandemic has resulted in an increased reliance on informal care provided by family members, particularly for individuals with IDD (Griffith & Hastings, 2014; Mansell & Wilson, 2010). A substantial body of evidence highlights the numerous challenges family caregivers routinely experience when supporting a person with IDD -- including high levels of stress, burden, and depression -- resulting in a need for respite and a supportive environment (Cramm & Nieboer, 2011; Hastings, 2002; Lee, 2013; Resch et al., 2012). Several studies have investigated the experiences of family and the impact of the

COVID-19 pandemic on relatives' mental health outcomes (Asbury et al., 2021; Burnett et al., 2021; Hochman et al., 2022; Linehan et al., 2022; Wanjagua et al., 2022; Werner et al., 2022). For example, a study conducted by Willner et al (2020) during lockdown showed that families of people with IDD reported significantly higher levels of anxiety and depression than relatives of people without disabilities. Similarly, another study examined the impact of COVID-19 on parents and children with IDD in the UK and found that both parents and children experienced disruptions in their daily routine and a sense of loss; the parents also reported feeling overwhelmed with new caregiving demands placed on them due to the withdrawal of support services and respite (Asbury et al., 2021). Studies have also shown a substantial decrease in quality of life among relatives of individuals with IDD during the pandemic (Cankurtaran et al., 2021; Pecor et al., 2021). However, these studies examined the impact of the pandemic on the mental health outcomes of family caregivers, primarily focusing on parents (mostly mothers) of young children with IDD or parents living with the person with a disability in the same household. There is limited research on the experiences of family members providing informal support to adults with IDD, and even less about those residing in supported accommodation. The present study aims to fill this research gap by exploring the subjective experiences of family members supporting adults with IDD in supported accommodation during COVID-19 lockdowns. By gaining insights into their experiences, the study seeks to provide a comprehensive understanding of the challenges and needs of family caregivers in this specific context, ultimately contributing to the development of appropriate support strategies and interventions.

The study context: Local government response to COVID-19

Similar to other countries, the Israeli government's response to the COVID- 19 outbreak was gradual and included various measures to enhance public health in general, as

well as specific guidelines for safeguarding vulnerable populations (such as people with disabilities and people residing in supported accommodation settings). The government adopted various risk reduction measures ranging from social distancing and self-quarantine to total lockdown. In April–May 2020, a full lockdown was imposed on the general population. The government's response to the increased vulnerabilities of people with disabilities and the elderly included further restrictions beyond those imposed on the general population. The Israeli Ministry of Labour, Social Affairs and Social Services imposed a total lockdown on approximately 17,000 people with IDD residing in government and private supported accommodation (Shalom et al., 2019). For approximately two months, the residents were prohibited from leaving their apartments and restrictions were imposed on all face-to-face and direct contact with people outside the facilities, including the banning of all family visits (Kashty, 2020). Furthermore, while in early May 2020 most restrictions were eased for the general population, restrictions on residents of supported accommodation remained in place. These restrictions were nationally developed and monitored by the ministries of health and welfare. Note that families and advocates were not involved in the decision-making process leading to these restrictions. This decision triggered policy debates and advocacy efforts, with family caregivers protesting in the Israeli media as well as taking legal actions, arguing that this policy specifically for people with disabilities in supported accommodation was discriminatory and an explicit breach of human and civil rights (Alon, 2020; Yerkatsi, 2020).

The present study

This study aims to describe and understand the family caregivers' experiences during the first lockdown in Israel, and the meaning the family caregivers attributed to these experiences. At the same time, it recognizes that different factors shape the experiences of

individuals and their family structure within the context of their wider community. Guided by Bronfenbrenner's Ecological Systems Theory (1979), the study focused on the participants' perspectives and experiences. The analysis focuses on exploring the impact of the lockdown on the different systems of human ecology: the microsystem and the mesosystem. By comprehensively examining these systems, the study has aimed to provide a holistic understanding of the challenges and implications faced by family caregivers during the COVID-19 lockdowns.

Method

The present study was part of a mixed-method research project conducted during the first wave of the outbreak in Israel (April-May 2020). In the first part of the research project, a web-based survey was conducted to collect quantitative data about the communication modes and types of support between the family caregivers and their relatives in supported accommodation (Authors, 2021 - removed for blind review). In the second part, reported here, a selection of the participants who completed the quantitative web-based survey volunteered to be interviewed and share their subjective experiences about their interactions with their relatives during the peak of the pandemic.

The present study was designed and carried out within a qualitative research paradigm to give voice to the family caregivers. A descriptive phenomenological approach was applied in order to gain a deeper understanding of the family caregivers' perceptions and lived experiences of the study phenomenon—the contact and relationship with adult relatives with IDD living in supported accommodation during the first lockdown of COVID-19 in Israel (Giorgi, 2009; Sokolowski, 2000; Starks & Brown Trinidad, 2007).

Recruitment and participants

A purposive sampling methodology was utilized to select participants who met two specific inclusion criteria. The first criterion sought Hebrew-speaking adults (aged over 18 years); as the in-depth interviews were conducted in Hebrew, targeting participants who are fluent in Hebrew was important to enable them to express their experiences freely and directly with the researcher. The second criterion was designed to address the study's aim to focus on family caregivers of individuals with Intellectual and Developmental Disabilities (IDD) residing in supported accommodation during the COVID-19 lockdown.

The participants were recruited using various recruitment strategies. First, during the lockdown, the researchers posted information about the broader qualitative component of the study (see Authors, 2021 - removed for blind review) on different social media platforms, including WhatsApp, Facebook, online groups, and forums. Of the convenience sample of 108 family caregivers who participated in the first part of the research project and completed the quantitative web-based survey, 16 caregivers expressed their interest and shared their contact details at the end of the survey. A member of the research team then contacted each participant via telephone, email, or social media platform (according to the contact details provided) to discuss the aims of the interviews, how data would be used and maintained, and reminded them that they were under no obligation to participate. The researcher also gave opportunities to discuss any questions or queries. After obtaining the participant's verbal consent, a time was scheduled for the interview.

Additionally, to ensure inclusivity and capture the experiences of family caregivers less proficient in social media, a snowball sampling technique was also employed (Parker et al., 2020). During interviews, the participants were also asked if they could share information

about the study and the researchers' contact details with others within their networks who fit the research criteria. Interested family caregivers could then reach out via telephone or email. The researchers followed up inquiries to provide a more detailed explanation of the study's purpose, assess eligibility, and schedule an interview. Three additional participants were recruited using this snowball technique.

The total sample of 19 participants (17 women and two men) included 15 parents of adults with IDD and four siblings. The age range of the participants was from 36 to 78 years old. The majority of the sample (11 of 19) were relatives of adults with IDD who live in supported community residential settings, and the others (8 of 19) were relatives of adults with IDD who live in group homes.

Group homes refer to accommodation shared by 4-8 unrelated people with disabilities who live under one roof or on one site and for whom 24/7 staff support is available. These accommodations typically host people with disabilities who have severe functional impairment or highly complex support needs (Bigby, 2020).

Supported community residential settings refer to a range of living arrangements where people with disabilities share an apartment and receive drop-in support and supervision managed by professional disability organizations. These services are designed for people who can manage many aspects of their daily lives that require some support to help them live independently in the community (Stancliffe et al., 2011). The demographic data of the participants and their relatives with disabilities are presented in Table 1.

Insert Table 1 about here.

Data collection

Interviews were conducted during lockdown, capturing the immediate experiences of the participants. An in-depth interview guide to capture the family caregivers' subjective experiences during the first COVID-19 lockdown was developed by the authors to cover the following topics: (a) personal and family characteristics and the nature of relationship with the person with IDD in routine time (for example "Tell me about yourself, your relative with IDD, your family"; "How is your relationship with your relative with IDD? How often do you communicate/meet?"), (b) support needs and family relationships with the person with IDD in the context of COVID-19, especially during the lockdown ("What, if anything, has changed in the relationship with your relative with IDD since the outbreak"; "How often do you communicate?"), (c) impact of lockdown on the physical health and well-being of the person with IDD and family caregivers ("How do you feel during this period in relation to the way you contact with your relative?"; "How does your relative react to this situation?"), (d) impact of lockdown on the provision of support and services, difficulties and opportunities experienced ("What do you think about the services provided to the residents and updates you get from the staff about your relative during the pandemic, and especially the lockdown?"; "Are you satisfied by these services?"), and (e) caregiver's perspective on the policy and practice in the supported accommodation service during the COVID-19 pandemic and in particular the lockdown ("What do you think about the policy enacted in the residential setting regarding the residents and the interaction with their families during the pandemic?"; "When was the last time you have been informed about your relative? What did you think about it, have you been satisfied by this information?"). The preliminary interview guide was reviewed by disability researchers and piloted with three participants to confirm the relevance of the content covered and to refine the phrasing of questions and prompts.

Interviews lasted between 30 and 90 minutes. Data were collected during the lockdown, thus all interviews were conducted remotely via phone or Zoom. Remote communication methods have been found to generate qualitative data of comparable quality to in-person interviewing (Archibald et al., 2019; Braun & Clarke, 2013). All interviews were audio-recorded and transcribed verbatim.

Data analysis

Inductive thematic analysis was undertaken to gain an in-depth understanding of the experiences of the family caregivers, and the meaning they attributed to these experiences in the context of the pandemic and the social restrictions (Braun & Clarke, 2006). In the first phase of the analysis, to increase its trustworthiness and credibility, each investigator separately coded the text of the transcripts to identify meaningful units of content. In the second phase, each investigator sorted the codes into potential themes. In the third phase, the investigators audited the analysis together and refined the identified themes. The codes associated with each theme were reread to verify that they formed a coherent pattern, revising the initial themes as needed. Next, the entire dataset was reread to refine the themes and to determine the relationships between the themes (Braun & Clarke, 2006). During the analytical process, the authors (the researchers) regularly discussed and refined the emergent themes. In addition, throughout the research process, they engaged in reflective processes, including “bracketing” and using self-reflective journaling to ensure the trustworthiness of data and limit bias (Ortlipp, 2008).

Ethical considerations

The study was approved by the authors' institutional ethics committees (removed for blind review). All participants gave informed consent to be interviewed, and all personal

identifiers of participants and services have been changed to preserve their privacy and confidentiality.

Results

The qualitative content analysis of the interview transcripts revealed three main themes regarding the family caregivers' experiences during the first lockdown of the pandemic. Following Bronfenbrenner's Ecological Systems Theory (1979), the themes are presented on two levels of systems: (a) the microsystem which focuses on the perspective of the impact of the pandemic on the person with IDD (i.e., the resident), the caregiver and their relationship, and (b) the mesosystem which describes the caregiver's perception of the services provided during the pandemic, including their interaction with service providers in the residential setting, and the interaction with other residents' families.

The impact of lockdown on the microsystem

This level of analysis refers to the impact of the pandemic on the person with IDD (the resident), the family caregiver (participant), and their relationship, as described below.

The impact of the lockdown on the residents: "The Covid-19 changed things around."

The family caregivers reported that due to the national policy of social restrictions and lockdown, they did not meet their relatives for approximately two months. During this time, the daily routine in the residential setting had changed significantly as employment and recreational activities often ceased without alternatives. The participants described how these changes in routine had negatively impacted the emotional state of the residents (the persons with IDD) which was manifested in heightened anxiety and behaviours of concern. Barbara

(mother) described it as: "Every change in routine is very dramatic for him [her son], especially stopping a job that he really likes."

Family caregivers also reported that changes to daily routines, changes in staff roles, and the availability of activities contributed to residents' feeling of distress, loneliness and boredom. As Caroline (mother) said: "They [residents] don't know what to do all day. They are stuck in their room with nothing to do, nowhere to go. They are climbing the walls [bored and frustrated]."

Some family caregivers felt that the new reality had a long-term impact on the resident's mental health and functional state, as Suzan (sister) described:

At the beginning, our conversations [via Zoom video call] were happier; later I became worried because I noticed that he was less happy and he looked depressed and less communicative. I am worried this social distance and isolation for such a long time has such a negative impact on him.

Ellen (mother) also described the negative impact of this situation on her son's mental health:

There is a common stupid concept that they [people with autism] don't feel, they don't care; anyway, they live in their bubble so we can do anything we want with them, who cares. I saw that my son was depressed, sad, and apathetic; sometimes he also cried and asked to meet us [parents]. I also know his roommate refuses to get out of his bed all day.

On the other hand, some participants described that the situation created by the lockdown had a positive effect on the person's well-being, as Emily (sister) described:

I get the impression that she [her sister] experiences this period as a summer holiday camp; she wakes up whenever she wants; she spends all her day at home with her friends, her boyfriend, no pressure, nobody is asking her to do anything, everything is relaxed.

Family caregivers also raised concerns by the disruption of the residents' healthy lifestyles and habits (for example sleep routine, exercise and healthy diet) due to the change in routine and limited engagement with support staff. They were worried this would result in deterioration of the resident's physical health. As Mia (mother) said:

I don't know what they're eating now; she has gained a lot of weight, obviously just eating junk. Before [the pandemic] there were salads, fruits, you know healthy food but when quarantine started, I think she lost it, eats only sweets, sandwiches, pretzels and she doesn't move or sleep because of all this sugar or maybe it's because nobody tells her to go to sleep. I just don't know, anyway she gained a lot of weight, it's not good for her.

Furthermore, family caregivers reported that the resident's physical health had deteriorated during the lockdown, and they were concerned about how this situation was handled in the context of limited access to healthcare. Sarah (mother) described the change in her son's physical health due to the lockdown: "I was very stressed because for nine years he has not had seizures (of epilepsy) but from January to February [2020] he had four; they had to change his medication."

The impact of the lockdown on the family caregivers: “The situation is very much exhausting.”

The family caregivers themselves were struggling to adapt to the changing circumstances. They describe being worried about their own health; many reported feelings of being overwhelmed by competing demands, struggling to manage their daily routines while meeting the support needs of their relatives. The disruption of services led to a sudden and unexpected change in their responsibilities. In some cases, the participants described feeling of helplessness, losing control over the situation, which in turn had a negative impact on their physical and mental health, as Ellen (mother) described:

We got a message from the group home that from this minute on all residents are in fact quarantined. I mean, all the recreational activities have been cancelled, they [residents] could not go home and even us, the parents, could not visit our children. It felt like a five-kilo hammer fell on our head. It was very very hard for me. I began to take tranquilizers because I could not function.

Caroline (mother) reported that she had to “fight the system” (the management of the residential setting and policymakers) to maintain basic communication with the residents during the lockdown. She described the situation as stressful with detrimental effect on her physical health: “This situation is very much exhausting. I myself have a lot of tumours. I know that the recent period [lockdown] cost me my health. There is a health price to all of this.”

Some family caregivers struggled with mixed emotions of uncertainty and confusion about their roles and responsibilities in the context of changing circumstances brought by the pandemic and lockdown. Naomi (sister) described it as:

If I want to be 100% honest with you I have mixed emotions about the whole thing. On one hand, I wanted to run and be with him [her brother] but on the other hand, I felt relief that others take care of him. I am emotionally drained, I didn't know what was going on with him but at the same time I felt guilty. I was thinking about my parents who asked me to take care of him; I am now responsible for him and I felt that I didn't fulfil my responsibility. I feel that I worry a lot but they [staff] don't let me get inside and see him so I cannot help him, and they are actually responsible for him.

The impact of the lockdown on the caregiver-resident relationship: “Communication is most important.”

The family caregivers acknowledged the importance of continuity of their support in uncertain times. Thus, they went “above and beyond” to stay in touch and support their relatives during the lockdown. Participants reported that they increased the frequency of engagement with their relatives during the pandemic and substituted in-person visits with remote communication. However, the communication between the families and the residents was dependent on the person’s digital literacy, availability of devices and staff members' availability and willingness to provide technical support. Emma (sister) described it as:

There is a computer downstairs but one of the residents took over the computer and does not let any [other] resident ... touch it. I brought him [her brother] a tablet but he is afraid to use it and there was no one [any staff member] to help him with it.

Naomi (sister) also described how staff’s limited understanding of the residents’ digital literacy needs resulted in disrupted communication with family:

Communication is most important. I have considered to buy him [her brother] a tablet but am not sure because he cannot use it by himself, he needs assistance! This requires time from a staff member to explain [to] him how to operate it [the tablet]. In Passover evening he was alone in his room so the support worker gave him her cell phone to make a video call with our family. She initiated the call but she didn't know that he even does not know how to hold a phone. I was trying to explain him how to hold the phone while we were speaking but he did not understand how to see my face and speak at the same time. Most of the time I saw only his bald head.

Family caregivers also reported that remote communication was not always helpful, and the residents felt confused and abandoned. Suzan, a sibling of a man with severe level of ID, described their Zoom meeting once a week:

He saw us [via video call] but didn't understand why we can't come and I kept telling him that we did not abandoned him and that we were still waiting for the government to let us [the families] come and meet him.

Ellen (mother) said that during their video calls, they tried to accommodate the situation for her son: "We told him that we love him and tried to support him in accordance to his abilities. We tried to make him understand that we did not abandoned him."

On the other hand, some family caregivers felt that the lockdown has brought them closer together as using remote communication technologies has allowed them to spend time together to engage in new activities. For example, Dave (father) described it as: "I initiated more online meetings with him [son]. We talked on Skype every day while in the past [before the pandemic] we rarely talked."

The impact of lockdown on the mesosystem

This level of analysis refers to both the caregiver's experiences and the impact of engaging with staff members in the residential setting and with other residents' families, as described below.

Family caregivers' perspective of the residential service and interaction with staff members: "No one wanted to know how he was feeling."

Most family caregivers felt that the restrictions enforced by the services were necessary to protect their relatives with IDD from COVID-19 infection and serious illness, yet they were concerned about the way management implemented national guidelines. They felt that the managers adopted strict interpretation of restrictions prioritizing risk management and liability over the residents' individualized support needs and well-being. The majority of participants felt that services were focused on providing the residents' basic needs, such as food and shelter, but neglected the person's and their family's psychosocial needs. Family caregivers were frustrated that services did not provide residents with suitable alternatives to recreational and occupational activities. Specifically, they raised concerns that often staff members were not tuned into the resident's and their family's emotional state and the effect the pandemic and regulations had on them.

Although Emily (sister) supported the residential service's policy to protect the residents' physical health, she was concerned by the lack of direct communication with the staff during the lockdown:

I think that the decision to lock down the residential setting was a good one, to protect the residents. However, I wish there would be more communication with the staff. I

wanted to get frequent updates. They had to maintain the contact with the families, especially in this period.

Caroline (mother) also said: “They [staff] do nothing with them [residents]; even normal people would go crazy doing nothing all day. I did see my son’s regression.” Later, she added: “They [staff] try to save money. COVID-19 is a good example [of] the fact that it is all about the money and not the residents' benefit.”

The family caregivers perceived the residential service’s policy as rigidly enforcing “one size fits all” restrictions without considering each person’s characteristics and support needs. Furthermore, all participants in our study felt there has been a lack of clear communication about the policy and transparency on how decisions about services were made. Caroline (mother) described it as: “They [staff] didn't inform us that he [son] stopped eating; we saw it [when they were allowed to meet]. No updates to the parents; we don’t know what they are doing with them all day.”

Participants felt that they had to “fight the system” to maintain basic communication and to be informed about their family member’s situation. In the absence of clear policy guidelines, they relied on their personal relationship with staff members or alternatively felt they had to advocate strongly for the person’s rights for social engagement. As Suzan (sister) described:

No one updates me or my father. Only when we ask for an update we get it. It also depends on the personality of the staff member; now there is a new support worker [who] is very open and willing to receive calls to her private phone. On last Thursday, I asked them [the staff] to find a time for me to talk with him [brother]; this is only five-minute talk because he is incapable to make long calls. They said "No, you have

already used your weekly Zoom." So I asked again "Maybe via WhatsApp?" and they said "No, this is too hard for the team." So one week they refused and the following week, this support worker felt sorry for me and made a surprise call.

Caroline, a mother who is also an activist and a consultant for the Israeli parliament on issues related to people with disabilities, described her communication with her son's organization staff and management:

I have spies there [residential setting] and they told me that there is a plan to close the apartment. I told them [staff]: "Listen, James is not moving to any other apartment. Not only he cannot come back home for two weeks, now you are going to move him to a new room, new environment that he doesn't know, for unlimited time?! Over my dead body!" I also told them that we are going to organize a protest against this decision. At the end, I got a message that James is staying in his apartment so, I understood that there is no other way than threatening if I want to get something for my son.

Family caregiver's engagement with other residents' families: "I joined [...] the parents' WhatsApp group that was very active and fought for the residents' rights."

In the face of the crisis and the limited information, the participants reported relying on the support of other residents' families. During the pandemic and specifically in time of the lockdown, they maintained and initiated frequent contact with other families, sharing information and supporting each other via telephone calls and text messaging on WhatsApp groups designated for the families. As described by Sheryl (mother):

I am very involved. In my role as head of disability group in a major political party, I get all the COVID instructions directly from the Ministry of Health or the Ministry of Social Welfare. So I disseminate the instructions to the families. I also help other parents in special cases, such as [adult] children who have not met their parents for a long period of time.

Even family caregivers who reported being less involved with other families before the pandemic reached out and initiated contact with other families in the context of the crisis. For example, Suzan (sister) described the first time she joined the families group. Although she was not very active there, she felt that the group content helped her cope:

Over time he [brother] looked more and more depressed [in the video calls] and it stressed me out so I joined the parents' WhatsApp group that was very active and fought for the residents' rights. There was a lawyer who joined the group and represented the families in front of the government ministries. This group and the understanding that others do something and not accepting the situation as is made me feel better. It took time but when I was very stressed with my brother's well-being, this group was very supportive.

However, the atmosphere in the parents' groups was not always positive. Some participants described conflict and disagreement among the families about the reality of the group home and advocacy efforts. One of the mothers, Ellen described this:

I had huge arguments with some parents who thought I was going to kill their kids because I was fighting for my right to visit my son. They were hysterical, anxious and told me that I don't know what I'm doing, that I'm putting my son and their children at risk.

Discussion

The past four years of the COVID-19 pandemic have highlighted the importance of understanding the impact of social restrictions, including lockdown measures, on marginalized groups such as people with IDD and their informal family caregivers. Our findings add to the growing body of evidence that highlights the detrimental impact of the pandemic, particularly the lockdown measures, on the mental and physical health of both people with IDD and their family caregivers (Budnick et al., 2021; Deal et al., 2023; Friedman, 2021; Gillespie-Smith et al., 2023; Landes et al., 2020; Landes et al., 2021; Rogers et al., 2021; Safta-Zecheria, 2020; Wos et al., 2021). However, what sets our study apart is the focus on a neglected group -- adults with IDD residing in supported accommodation. By exploring the experiences and perceptions of family caregivers, we provide unique insights into the reality of the specific challenges families and adults with IDD in supported accommodation environments faced during the lockdown. This understanding may enhance service and policy response and inform the development of effective strategies, ultimately improving the well-being and resilience of adults with IDD and their families in the present and future.

Our findings demonstrate the implications of the pandemic and lockdown at the microsystem level: the resident-family caregiver relationship. Consistent with previous research (Authors, 2021) (Hall, 2021; Llorente-Barroso et al., 2021), our findings demonstrated that the families resorted to remote communication to maintain frequent contact with their relatives with IDD during lockdown. Furthermore, while some family caregivers perceived this as a new opportunity for communication, for others the reliance on remote communication and digital technologies has proven to be challenging, due to the low digital literacy of residents and elderly family caregivers. The availability of devices and the

willingness of staff members to provide ongoing technical support emerged as significant environmental factors influencing the residents' engagement with their families during the pandemic. This finding highlights how the conditions within a person's physical and social environments play a crucial role in shaping opportunities for social engagement and overall quality of life (World Health Organisation, 2001). This underscores the importance of creating supportive environments for remote communication and the need for adequate resources and technical assistance to facilitate meaningful and effective communication between residents with IDD and their family caregivers. Creating a supportive environment encompasses removing barriers for use of and access to communication options. It is important to provide training in technology use for staff, people with IDD, and their family caregivers. The staff should also facilitate technology use by people with IDD, for example providing assistive technology that enables people with IDD to initiate video calls without frontline staff's physical presence (Lancioni et al., 2019; Light et al., 2019). However, simply providing training and access to communication technologies is not sufficient. Research suggests that organisational culture plays a substantial role in determining the extent communication technologies are used with and by people with IDD (Parsons et al., 2008). Therefore, substantial changes in organizational policies, funding, leadership, role descriptions, and performance measures are necessary to create a supportive environment for technology use and adaptation to different circumstances, both in routine times and in times of crisis.

The significance of relationships also emerges at the mesosystem level, where family caregivers experienced frustration with the limited direct and ongoing communication with staff members during the lockdown. In the context of the COVID-19 restrictions, families felt that they had limited opportunities to monitor the quality of service and had fewer informal

channels to stay updated on their relatives' activities in the supported accommodation. Many family caregivers expected frontline staff to be more proactive in keeping them informed about their relatives' routines and emotional state.

The United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) acknowledges the important role families play in promoting the human rights and well-being of people with disabilities and call for services providers to embrace family involvement in services. Furthermore, research on family involvement in supported accommodation conducted prior to the pandemic demonstrates that families wish to be informed about the support their relatives receive, want to participate in decision-making processes, and value good relationships with staff and managers (Bright et al., 2018; Jansen et al., 2018; Koelewijn et al., 2023; McKenzie et al., 2018). However, our findings suggest that families often feel disempowered by staff and managers in the disability services. This is particularly concerning during times of crisis such as the COVID-19 pandemic and lockdown. In such situations, people with IDD may be especially vulnerable to the violation of their human rights and at greater risk of abuse and neglect (Bigby, 2020). Hence, under these circumstances, the involvement of family caregivers and their ability to monitor the quality of service becomes even more critical.

Policymakers and service providers need to acknowledge and address the long-term consequences of disrupted care during the pandemic. New strategies should be developed to actively involve family caregivers in the lives of the resident fostering a partnership between staff, families, and residents. In this context, it is crucial to ensure that the views, experiences, and needs of family caregivers are taken into account in service delivery. By establishing effective communication channels and engaging families as valued partners, policymakers

and service providers can enhance the well-being and quality of care for individuals with IDD, both during routine and crisis situations.

Similarly concerning are the findings that family caregivers reported the services did not provide alternative recreational and occupational activities when external service providers were not allowed to enter to the residential setting, and the effect that had on the residents' functioning and well-being. These findings are consistent with the perspectives of people with IDD themselves, who reported that the interruption of social relationships with family and friends was the greatest consequence of lockdown, followed by missed recreational and leisure activities (Navas et al., 2021). It seems that despite the strong emphasis in disability discourse and policy over the last decades on disability human rights and person-centred approaches to service delivery (Ratti et al., 2016), the present study's findings indicated that in a time of national crisis such as the COVID-19 pandemic, the service management chose to return to the policy of "one-size-fits-all" and enforced national guidelines in all residential settings without taking into consideration personal characteristics, preferences and support needs of each resident. Our findings support the need for greater understanding and promotion of person-centred approaches to care with attention to supporting people with IDD, to the extent they are able, to discover and enjoy meaningful activities for their own well-being and mental health. This is especially important given that daily activities have been found to promote resilience during difficult times in people with IDD (Scheffers et al., 2022), by providing daily structure and a sense of predictability (Taggart et al., 2009).

Finally, the findings of the present study highlight the importance of family peer support. It seems that in the absence of connection with staff and limited information provided by services, the family caregivers created a peer support network (via a WhatsApp

group) of the residents' families for the purpose of information sharing, advocacy and mutual support. Participants in our study reported that these networks had become a major source of comfort for them as they provided a sense of security and support. Even family caregivers who reported being less in touch with other families before the pandemic joined this online group and initiated contact with other families in the context of the crisis. As found in other studies showing the potential of using online social networks for socio-emotional support during the pandemic (Delam & Eidi, 2020; Esteve-Del-Valle et al., 2022; Montesanti et al., 2023; Suresh et al., 2021), the families' social network seemed to help them cope with the uncertainty of this stressful situation and contributed to their well-being.

Limitations and Future Directions

Several limitations should be acknowledged and addressed in future research. Firstly, the convenience sampling approach used in this study may limit the generalizability of the findings. The sample consisted of family members who volunteered to share their experiences, which may introduce selection bias. The use of social media platforms to recruit participants and the reliance on snowball techniques may have skewed the sample towards younger, wealthier family caregivers. Despite our efforts and use of various recruitment techniques, the sample was relatively homogeneous, predominantly comprising female caregivers, particularly mothers.

This homogeneity overlooks the experiences of other family members, such as fathers and siblings, who may have distinct perspectives and experiences. Future studies should aim for more diverse and representative samples that include a broader range of family caregivers and relatives to provide a more comprehensive understanding of their experiences.

Secondly, the present study focused primarily on the perspectives of family caregivers. Future research should incorporate multiple viewpoints, including those of the residents themselves, staff members in residential settings, and policymakers. This would provide a more comprehensive picture of the family caregiver-resident relationship and the broader context in which it operates.

Finally, the present study captured the experiences of family caregivers during the first lockdown of the pandemic, offering a snapshot of a specific period. It is essential to gather longitudinal data that examine the changes in the family caregiver-resident relationship across different stages of the pandemic. Exploring the long-term impacts of the stressful situation on family dynamics and the well-being of both family caregivers and residents would provide more robust and nuanced understanding and insights into the sustained effects of the pandemic on this vulnerable population.

Conclusions

The present study aims to shed light on the perspectives and experiences of family caregivers regarding their contact and relationship with their relatives with IDD living in supported accommodation during the COVID-19 lockdown. The findings provide valuable insights into the multifaceted challenges faced by these families, encompassing their interactions with their loved ones, their views on the broader disability support system (including interactions with staff members), and the COVID-19 policies implemented in residential settings. This input is vital for shaping future policy developments, enhancing emergency preparedness planning in services, and providing quality support during times of crisis.

The findings highlight the adverse consequences of family disengagement on the health and well-being of both family caregivers and residents. They illuminate the complexities of maintaining informal support and family involvement in the lives of people with IDD living in supported accommodation during periods of social distancing and lockdowns.

Recognizing the pivotal role of family caregivers in times of uncertainty necessitates strategic planning and the formulation of explicit national and local policies and service responses to facilitate ongoing family engagement in the lives of residents. Such strategic planning must be comprehensive, considering the needs, resources, and experiences of staff, family members, and residents alike.

Furthermore, our findings underscore the need for a targeted national response, including funding for a dedicated information and support hotline for family caregivers. Additionally, raising awareness and addressing the unique communication and access needs of people with IDD and their families within health and welfare services are paramount.

While the recent global pandemic presented unprecedented challenges related to social distancing and lockdowns, lessons learned from other emergency situations (natural disasters, war, or terrorism) can be effectively applied within the context of COVID-19 (Rimmerman & Araten-Bergman, 2010; Shpigelman & Gelkopf, 2019). Our findings align with previous evidence emphasizing the importance of disability service providers strengthening connections with informal support networks and cultivating positive relationships with them (Araten-Bergman & Bigby, 2022; Bigby, 2008; Bigby et al., 2015). The findings demonstrate that an essential part of staff's professional engagement during the COVID-19 pandemic should involve building and maintaining strong alliances with residents and their family caregivers. Such alliances may facilitate the free flow of information, provide valuable

feedback, and assist in decision-making processes. The staff's role in fostering these alliances is pivotal to their person-centered approach to service delivery (Kruzich et al., 2003; Tournier et al., 2021). It is imperative for staff to recognize the unique knowledge of family caregivers, actively seek their input, and encourage their continuous involvement in the life of the resident. This approach is essential for providing quality services and supporting the health and overall quality of life of people with intellectual disabilities during both routine times and national crises.

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Table 1. The participants' demographics (n=19)

Participant (pseudonym, gender – F/M)	Family caregiver (participant)	Age of the person with a disability	Disability type*	Living arrangement
Ruth (F)	Parent	34	ID + Psychiatric disability	Supported community living
Sarah (F)	Parent	29	ASD	Supported community living
Ellen (F)	Parent	33	ASD	Group home
David (M)	Parent	28	PDD	Group home
Barbara (F)	Parent	29	ASD	Supported community living
Suzan (F)	Sibling	37	ID + ASD	Group home
Emily (F)	Sibling	35	ID + CP	Group home
Tamar (F)	Parent	26	ASD	Group home
Sheryl (F)	Parent	30	PDD	Supported community living
Olivia (F)	Parent	20	ASD	Group home
Emma (F)	Sibling	29	ASD + Psychiatric disability	Group home
Sophia (F)	Parent	30	ASD + Physical disability	Supported community living
Isabella (F)	Parent	23	Cognitive disability (cognitive decline) + Epilepsy	Supported community living
Dave (M)	Parent	20	ASD	Group home
Anna (F)	Parent	24	ASD	Supported community living
Alice (F)	Parent	35	ID + ASD	Group home

Mia (F)	Parent	52	ID + Physical disability	Supported community living
Naomi (F)	Sibling	71	ID + ASD	Group home
Caroline (F)	Parent	33	Cognitive disability (cognitive decline)	Supported community living

*ASD = Autistic Spectrum Disorder; CP = Cerebral Palsy; ID = Intellectual Disability; PDD = Pervasive Developmental Disorder