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Staying connected during COVID-19: Family engagement with adults with developmental disabilities in supported accommodation

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ABSTRACT

Background: Enduring family engagement and informal support is crucial to the health and well-being of adults with developmental disabilities (DD) residing in supported accommodation. The COVID-19 pandemic and restrictive measures enforced in residential settings have resulted in changes in daily routine and modified the ways families can interact with and provide support to residents. Yet, the impact of these changes has not been empirically explored.

Aim: Explore how family caregivers have interacted with and supported their relatives with DD residing in supported accommodation during the pandemic.

Methods: Changes in frequencies of communication modes and types of informal support were measured through a cross-sectional and anonymous online survey which completed by 108 family caregivers of adults with DD.

Results: Most family caregivers adopted remote communication technologies; however, these were not perceived to be effective in filling the gap created by reduced face-to-face contact. While families were able to provide emotional support and advocacy using digital technologies, they were limited in their ability to provide significant social support.

Conclusions: Findings may help key stakeholders develop and implement novel strategies and policies to accommodate the changing circumstances and to ensure continuity of family engagement and informal support in the context of COVID-19.

What this paper adds

COVID-19 and risk reduction policies have changed the life condition, services, and supports for people with developmental disabilities (DD). Specifically, measures such as lockdown and social distancing have challenged the social network's ability to interact and provide informal support to people with DD. However, the impact of these challenges has not yet been empirically assessed.

The present study bridges this gap in knowledge by providing, for the very first time, empirical evidence on the various ways in which family caregivers interacted and supported their relatives with DD residing in supported accommodation during the pandemic.

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Furthermore, the finding goes beyond mapping the communication and paints a complex picture of how these changes were related to the nature and scope of informal support families could provide remotely to their relatives.

Overall, the findings demonstrate the proactive approach taken by families to ensure the continuity of support with their relatives. In the absence of face-to-face visits, families quickly adopted new remote communication methods (such as video calls) to interact and support their relatives. The finding also illuminates the family's perception that despite the continuity of communication, they were limited in providing multifaceted informal support and their need for service providers' support and transparent policy to enable a more successful approach.

The study provides evidence to guide policy design and service provision in supported accommodation to ensure continuity of family engagement and informal support in the "new normal" reality created by the COVID-19 pandemic.

1. Introduction

The COVID-19 pandemic and associated government response and policies have had significant ramifications for adults with developmental disabilities (DD) in supported accommodation, their families, and the services they receive. Preliminary evidence suggests that people with DD and those residing in supported accommodation are particularly vulnerable to adverse outcomes associated with COVID-19 (Landes, Stevens, & Turk, 2020). Moreover, the public health response to COVID-19 has created additional challenges: policies of lockdown and quarantine have resulted in changes in daily routine, staff roles and in the involvement of families and other informal support networks (Lau et al., 2020; Piguillem & Shi, 2020). The impact of these changes has yet to be empirically assessed. The present study aims to explore one aspect of this complexity: How family caregivers interact with and support their relatives with DD residing in supported accommodation during COVID-19.

1.1. Family informal support for adults with DD in supported accommodation

The importance of family involvement and informal support to the health and well-being of adults with DD residing in supported accommodation has been long recognised (Araten-Bergman, Bigby, & Ritchie, 2017; Baker & Blacher, 2002; Duvdevany & Arar, 2005; Giesbers et al., 2020; Schwartz, 2005; Schwartz & Tsumi, 2003; Seltzer, Krauss, Hong, & Orsmond, 2001). There are ample evidence that the quality and quantity of one's informal support are significant predictors of positive outcomes such as health, social participation and well-being (Bigby & Fyffe, 2012; DuBois, Renwick, Chowdhury, Eisen, & Cameron, 2019; Kozma, Mansell, & Beadle-Brown, 2009; Krauss, Seltzer, & Jacobson, 2005).

Horowitz (1985) identified four functions of family and informal support provided: emotional support, direct instrumental support, financial assistance, and mediation with formal service providers and monitoring the quality of services. While emotional support refers to empathy, caring, love, and trust, instrumental support involves practical help in specific instances of need, such as personal care, healthcare and social needs (House, 1981). Research suggests that these functions require a long-term commitment and a deep understanding of the person's needs, and are not easily replaced by formal services (Araten-Bergman et al., 2017; Bigby, 2008; Krauss et al., 2005).

1.2. 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 (e.g. people with disabilities and people residing in supported accommodation). The government adopted various control measures ranging from social distancing and self-quarantine to total lockdown, depending on the severity of the outbreak.

The first wave of the COVID-19 pandemic in Israel occurred on March-May 2020. For example, on March 25th the Israeli government restricted the distance people could travel from home and in April–May 2020 a full lockdown was imposed (Israeli Ministry of Education, 2020).

Moreover, the government 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 DD residing in government and private supported accommodation (Shalom, Ben-Simhon, & Goren, 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). 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.

Furthermore, while in early May 2020 most restrictions were eased for the general population, restrictions on residents of supported accommodation remained in place (Israeli Ministry of Health, 2020a, 2020b). 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 specialised policy towards people with disabilities in supported accommodation was discriminatory and an explicit breach of human and civil rights (Alon, 2020; Kan, 2020; Yarkatzi, 2020).

1.3. The present study

While the course of the pandemic is unclear and unpredictable, there is little doubt that some restrictions on social engagement and

movement are likely to remain for a significant period. At this point, it is critical to understand the implications of these restrictions on the ways family members interact with and support their relatives in supported accommodation services. Specifically, it is important to understand whether families adopt new ways of communication to engage with their relatives; and if so, what are these ways, and how effective are they in compensating for the limitation in face-to-face contact?

The present study reports on results from a cross-sectional survey of family caregivers of adults with DD living in supported accommodation. The study relied on family members self-reports on their experience supporting relatives with DD before (retrospective – referred to routine times) and during the COVID-19 pandemic.

The study had three aims. First, to understand the nature of support and contact between family caregivers and their relatives with DD in supported accommodation during the COVID-19 pandemic. Second, to explore whether the frequencies of communication modes and types of informal support have changed before (in routine times) and during the pandemic. Specifically, the study aimed to explore whether families have adopted new ways of communication to maintain contact with their relatives during the pandemic. Finally, to evaluate whether families were satisfied with their interaction with their relatives during the first wave of the outbreak.

2. Material and methods

2.1. Participants and procedure

A convenience sample of 108 family caregivers of adults with DD in supported accommodation was recruited using social media posts on WhatsApp, Facebook, online groups and forums. The researchers provided a short introduction about the aim and nature of the research, along with a link to the online survey. The survey link was also disseminated via a snowball technique where participants who choose to do so could distribute the link in parents and family online groups.

To ensure anonymous responses, no personal data were collected and recorded in the survey. The survey was compiled using Qualtrics software, and data were collected during the peak of the first wave of the outbreak (April-May, 2020) when disability accommodation services were under lockdown, and all family visits were banned.

2.2. Measures

The anonymous online survey included four sections, as described below.

2.2.1. Sociodemographic characteristics

The participants were asked to report on their own and their relatives' sociodemographic characteristics (e.g., age, gender, family status, living arrangement, and COVID-19 status).

2.2.2. Communication with residents

The participants were asked to retrospectively report on the nature and scope of their engagement with the person with DD before and during the pandemic (i.e., "In general (routine) times, how often do you engage with the person in supported accommodation?" or "During the time of the pandemic, how often do you engage with the person in supported accommodation?").

Items addressed various modes of communication, such as face-to-face visits, phone calls, video calls, text or voice messaging. For each mode, they were asked to rate the frequency of use on a 6-point Likert scale (from *never* to *at least once a day*). In addition, the participants were asked to report whether they adopted any new communication method during the pandemic (yes/no) and to rate, on a 4-point scale (from *not at all* to *extremely helpful*), the extent to which it has contributed to their relationship and engagement with the person with DD.

2.2.3. Satisfaction with communication

Participants were presented with a series of statements on their satisfaction with the frequencies of communication modes before (retrospective self-report) and during the pandemic. For each statement, they had to report whether it applied to them (yes/no; e.g. "I would like to meet more"; "I would like to have more phone calls"; "I would like to have more updates from staff"; "I would like to have less face-to-face contact"; "I would like to have fewer phone calls"; "I would like to have fewer updates from staff"; "I'm happy with our communication and wouldn't change a thing").

2.2.4. Informal support type and frequency

Participants were presented with five types of informal support: emotional support ("I provide emotional support (listen, provide advice) to the person"), social support ("I am socially engaged with the person"), financial assistance ("I provide financial support to the person"), assistance in decision-making ("I support the person in making decisions") and advocacy ("I assist the person getting the services they need"). For each type of support, participants were asked to rate whether they provided the support (yes/no) and whether the amount of the support has changed during the time of the pandemic. Response options included "no change", "I am providing more support during the time of the pandemic", and "I am providing less support during the time of the pandemic."

2.3. Data analysis

Data were analysed using IBM SPSS Version 26. Descriptive statistics were calculated to map the circumstances of the participants

and the people they support. Preliminary analysis of the chi-square test and one-way ANOVA found no significant differences between subgroups (impairment type, type of residential setting, gender, and family relations) in relation to communication modes. Therefore, all subsequent analysis was conducted on the entire sample (n = 108). Paired *t*-test analyses were conducted to examine changes in frequencies of communication modes and types of informal support before (retrospective self-report – referred to routine times) and during the time of the pandemic.

2.4. Ethics

The study protocol and method were approved by the Ethics Committee of the Faculty of Social Welfare and Health Sciences at the (blinded) University. Participants completed the survey voluntarily, after reviewing and signing an electronic informed consent form.

3. Results

3.1. Demographics

Most (75 %) of the participants were parents of adults with DD, 21 % were siblings and the remaining 4% were other family members, such as sisters-in-law or cousins. The majority (80.6 %) were women, and 80 % reported being the legal guardian of the person with DD. Sociodemographic characteristics of the residents with DD, as reported by their family caregivers, are presented in Table 1.

3.2. Changes in communication modes

Paired-samples *t*-test were conducted to compare the frequencies of communication modes before and during the pandemic (see Table 2). As indicated in the table, there was a significant difference in the frequencies of various communication modes before and during the pandemic. Not surprisingly, the data indicated a significant decrease in frequencies of face-to-face contact, from 90.8 % reporting contact of at least a couple of times a month before the lockdown, to only 31.6 % during COVID-19 ($t(107) = 11.40$, p < .01).

Moreover, while there were no significant changes in the frequencies of family contact via phone calls and text messaging, there was a substantial increase in the reliance on remote technology such as video calls (via WhatsApp, Skype or Zoom). Before the pandemic, 72.4% of participants reported that they had never used such technology to keep in touch with their relatives, whereas during the lockdown, only 35.8 % reported never using this technology ($t(107)$ = -8.81 p < .01). In fact, 64.2% of families reported that during COVID-19, video calls were their main way of communication and 59.1 % used them to engage with their relatives in the supported accommodation at least once a week. Moreover, among the participants who reported engaging with their relatives via video calls, only 7.1 % reported this type of communication as being "not helpful at all"; 14.3% rated it "not very helpful"; 39.3% rated it "somewhat helpful", and 39.3% rated it "very helpful".

3.3. Satisfaction with communication

The analysis of the participants' responses to various questions regarding their communication modes revealed a significant decrease in the level of satisfaction with their communication during the pandemic (see Fig. 1). While 54.5 % reported being satisfied to the point that they would not change a thing in the way they routinely communicate with their relatives, only 11.6 % reported this level of satisfaction during COVID-19. Most participants reported wanting to be more involved in their relatives' lives during the pandemic: 5.9.5 % wanted to have more face-to-face visits, and 28.1 % wanted more frequent phone and video calls. Finally, while most caregivers (55.5 %) expressed a desire to receive more information and support from frontline staff during the pandemic, only 9%

Table 1
Sociodemographic characteristics of adults with DD (n = 108).

Variable	%
Gender	
Male	55.1
Female	44.9
Age	
18–21	9.2
22-40	63.2
41-60	23.5
61 and over	4.1
Primary impairment	
Intellectual disability (ID)	59.5
Autism spectrum disorder (ASD)	30.6
Co-occurring ID with psychiatric disorder	9.9
Supported accommodation	
Group home	64.8
Supported community living	35.2

Table 2

Paired *t*-test comparisons of communication frequencies before and during COVID-19 (n = 108).

Modes of communication	Before**COVID-19 (%)	During COVID-19 (%)	Before COVID-19 M(SD)	During COVID-19 M(SD)	T (df)
Face-to-face visits					
Never	9.2	68.4			
Several times a month	15.4	7.1			
Once a week	48	10.3	2.97(1.00)	1.05(1.66)	11.40 (107)*
Several times a week	20.3	7.1			
Every day	7.1	7.1			
Phone calls					
Never	29.5	26.5			
Several times a month	8.2	3.1			
Once a week	4.1	15.3	3.06(1.94)	3.11(2.05)	.275 (107)
Several times a week	23.5	11.2			
Every day	34.7	43.9			
Text & voice messages					
Never	72.5	66.3			
Several times a month	2	2			
Once a week	3.1	4.1	1.16(1.94)	1.41(2.07)	1.81 (107)
Several times a week	7.1	9.2			
Every day	15.3	18.4			
Video calls					
Never	72.4	35.8			
Several times a month	6.1	5.1			
Once a week	8.2	16.3	.92(1.54)	2.57(1.92)	−8.86 (107)*
Several times a week	9.2	23.4			
Every day	4.1	19.4			

* $p < .01$.

** The term "Before COVID-19" was defined generally as the frequency of engagement in routine times; The term "During COVID-19" was defined as the frequency of engagement in the first wave of the pandemic and lockdown in Israel (March-May, 2020).
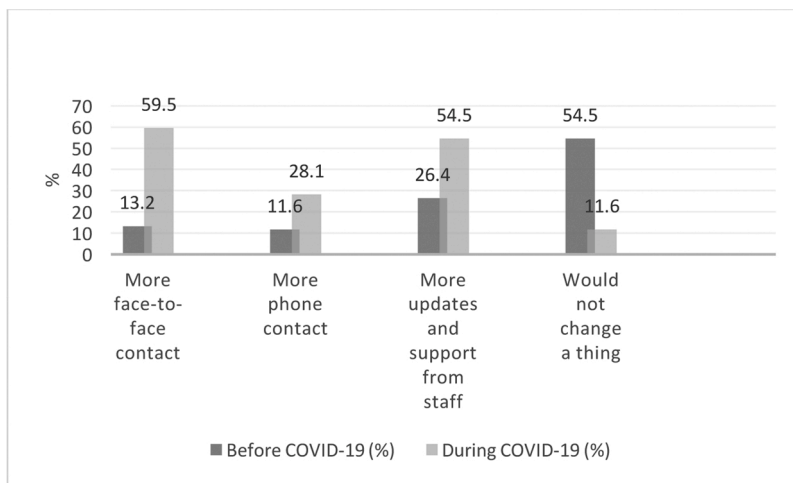

Fig. 1. Frequencies of satisfaction with communication before and during COVID-19* (n = 108).
*The term "Before COVID-19" was defined generally as the frequency of engagement in routine times; The term "During COVID-19" was defined as the frequency of engagement in the first wave of the pandemic and lockdown in Israel (March-May, 2020).

reported that such support was available to them.

3.4. Changes in informal support by caregivers

The participants reported changes in the type and amount of informal support they were able to provide before and during the pandemic. It comes as no surprise that the lockdown policy has resulted in a reduced capacity to provide social support: 67.6 % reported a decrease in the social support they provided during the pandemic compared to the pre-pandemic period (routine times). Nevertheless, the majority (61.1 %) of family caregivers responded that despite the social distancing measures, they managed to maintain or even increase the level of emotional support they provided during the pandemic relying on remote communication methods. There were no significant changes in caregivers' assistance in finance and decision-making: only 13 % of participants

reported being required to provide more financial support at the time of the pandemic and 17.6 % provided more assistance in decision-making. However, 38 % of participants reported a substantial increase in the advocacy they provided during the time of the pandemic.

4. Discussion

Past research has highlighted the significance of informal support for the health and well-being of people with DD living in supported accommodation (Duncan-Mayers & Huebner, 2000; Reinhard, Fox-Grage., & Feinberg, 2016; Schwartz & Rabinovitz, 2003). The first wave of the COVID-19 outbreak and the consequent risk mitigation measures enforced in disability services (such as social distancing and lockdown) have disrupted the residents' routine, including the provision of formal and informal supports (Rose et al., 2020). Given the current public health estimates that the pandemic is likely to have a prolonged impact, people with DD, their families and service providers need to adjust to this "new normal". Policymakers, as well as service providers, are now required to implement novel strategies and policies to ensure continuity of support and the quality of services.

Strategic planning for future policy and practice requires empirical evidence on the impact of changes related to COVID-19 on people with DD and their families. The present study provides such evidence by illustrating some of the adaptations in family-resident engagement, as well as identify caregivers' perspective on the impact of these changes on various types of informal support.

Overall, our findings indicate that family caregivers quickly found new ways to communicate with their relatives. Families acknowledge the importance of continuity of their support in uncertain times and are actively seeking ways to stay in touch. Hence, despite the social distancing, many reported that they increased the frequency of engagement with their relatives during the pandemic, substituting in-person visits with remote communication. In addition to the increased frequencies of previously available communication modes, such as phone calls and text messaging, most families also adopted new media such as video calls.

Our findings corroborate previous research indicating the significant contribution of new technologies to the relationship and support in times of crisis and uncertainty (Caton & Chapman, 2016; Shpigelman, 2018; Simon, Goldberg, & Adini, 2015). For example, it may be the case that adopting remote communication technologies such as video calls provides an opportunity for families to communicate with their non-verbal relatives as these visual measures could facilitate various ways of communication that are not available via phone. Specifically, video calls may allow utilising augmentative and alternative communication (AAC) aids (Hynan, Goldbart, & Murray, 2015) and/or reliance on simple gestures (Lancioni et al., 2020).

However, the findings also indicate that despite the families' proactive approach, these communication modes were not perceived as effective in filling the gap created by the reduced face-to-face contact. In general, caregivers reported a significant decrease in satisfaction with their engagement with their relatives during the lockdown. Many expressed the desire to continue interacting face-to-face despite the restrictions. However, in light of the risks, they also expressed the need for frontline staff to facilitate more opportunities for remote communication with their relatives. For example, frontline workers (e.g., physical and mental rehabilitation workers) in supported accommodation should promote technology use by people with DD for social activities and communication with others in routine (Lancioni et al., 2020). In addition, the frontline workers have to assess each person's needs and abilities and accordingly accommodate the technological platform (Hynan et al., 2015).

Furthermore, special consideration should be given in times of crisis when people with DD are especially vulnerable to the violation of their human rights and are often heavily reliant on others to uphold their rights and to monitor the quality of support they receive (Bigby, 2020). Possibly, due to the COVID-19 restrictions, the families tended to feel that they had limited opportunities to monitor the quality of service, and fewer informal channels to keep up to date with their relatives' activities in the supported accommodation. Many families expected frontline staff to be more proactive in keeping the family informed about the relatives' day-to-day activities and well-being.

Our findings illustrate the variability in the informal support the family provided at the time of COVID-19 and the strengths and weaknesses of relying on remote contact. While the families reported that they were able to provide emotional support and advocacy, they were limited in their ability to provide significant social support to their relatives in supported accommodation. Previous studies have demonstrated similar trends. For example, video calls were found effective in helping people with DD stay connected with their social networks and in reducing feelings of distress within the care environments (Barlott et al., 2019; Buchholz, Holmgren, & Ferm, 2020). However, in contrast to the general population, it seems that family caregivers, residents, and staff did not meet the potential of video calls to promote social engagement. For example, people did not engage in social activities, such as listening to concerts or playing an online game together (Barlott et al., 2019). It seems that for people with DD embracing the opportunities provided by digital technologies for remote social activities is far from straightforward and requires intensive support (such as pre-planning and training) (Callahan & Inckle, 2012; Son et al., 2020). Mäkinen (2006) emphasises the importance of considering an opportunity, access, and skills when exploring technology use and support. Not everyone has access to technology and many people with DD and caregivers (mainly elderly) may not have to digital literacy and confidence in using it (Chadwick, Wesson, & Fullwood, 2013; Werner & Shpigelman, 2019). Therefore, person-centered supports in time of social distance and lockdown should address the needs, communication skills, and technology literacy skills of the residents. Service providers should consider novel strategies to promote technology use by people with DD and their families and provide opportunities for remote social activities utilizing the digital environment (Hynan et al., 2015; Lancioni et al., 2020).

Hence, it is important to provide training on technology use for staff, people with DD, and their caregivers. The staff should also modify and facilitate technology use by people with DD, for example providing assistive technology that enables people with DD to initiate video calls without frontline staff's physical presence (Lancioni et al., 2019; Light, McNaughton, & Caron, 2019). However, it is clear that simply providing training and access to communication technologies is not sufficient. Research suggests that organisational

culture plays a substantial role in to what extent communication technologies are used with and by people with DD (Parsons, Daniels, Porter, & Robertson, 2008) and there is a crucial need for substantial change in the organisational culture in supported accommodation. Significant changes in organizational policy funding leadership, role descriptions and performance measures are required to build a more supportive environment for technology use and adaptation to different circumstances in routine and times of crisis.

4.1. Limitations and future directions

Despite the contribution of this study in providing evidence on the nature and frequency of engagement with and informal support for people with DD in residential settings during COVID-19, several limitations should be addressed in future research. First, the reliance on a convenience sample and online recruitment limit the representativeness of the sample and the generalisability of the findings. It is possible, for example, that caregivers who completed the survey were more engaged in their relatives' lives and more familiar with digital technologies. Similarly, it might be that caregivers of non-verbal residents felt that they did not capture their experience and were reluctant to participate. The sample was also heterogeneous in relation to the characteristics of caregivers and people with DD, limiting the generalisability of our findings.

Second, the cross-sectional survey relied on caregivers' report, leaving unanswered questions such as the impact on the residents' quality of life and well-being. Future quantitative and qualitative research should explore these issues in-depth, accounting for multiple perspectives, including those of the residents and disability service providers and policymakers.

Moreover, some additional qualitative exploration may add 'thickness' to the survey findings and offer an in-depth understanding of the lived experience of staff, people with DD and their caregivers during the COVID-19 pandemic.

Finally, the findings provide a snapshot at one point in time. Longitudinal data are required to understand trends in family interaction and informal support during different stages of the pandemic and to explore their long-term impacts.

4.2. Conclusions

The present study aimed to understand how families can interact and provide informal support to their relatives in supported accommodation in times of crisis such as COVID-19. The findings may provide significant insights into the reality faced by people with DD and their families. This input is vital to future policy design and service provision. Future studies should also unpack the experience of these realities from various prospective such as the perspectives of people with disabilities, service providers, organisations managers and policymakers.

The findings illustrate the difficulty of ensuring informal support engagement in the life of people with DD in times of social distancing and lockdowns. Acknowledging the pivotal role of family caregivers in times of uncertainty necessitates strategic planning and the development of explicit policies and mechanisms to facilitate the families' engagement in the residents' lives which will consider the needs, resources, and experiences of staff, family members and residents.

Service providers might consider accommodating staff roles and developing dedicated processes for staff to facilitate and support regular contact between family and residents. In some cases, frontline staff can also plan interventions and activities that can be delivered remotely, such as cooking dinner or watching a movie together to maintain the family-resident social routine.

Furthermore, remote communication depends on technological infrastructures and literacy. Hence, special consideration should be given to building the capacity of family caregivers and residents to communicate in various ways and to provide and facilitate access to digital devices (i.e. smartphones, tablets and laptops as well as accessible internet connection). In this context, staff should be proactive in supporting flexible communication modes.

Finally, in the absence of face-to-face contact and changes in routine, staff members must maintain an open line of communication with families, allowing for regular updates and assistance. One possible strategy is to nominate a staff member as the primary point of contact for families to facilitate communication. These and other strategies should be considered as part of a broader discourse on how to maintain communication and provide formal and informal support for people with DD in the uncertain time of COVID-19.

CRediT authorship contribution statement

Tal Araten-Bergman: Writing - original draft. **Carmit-Noa Shpigelman:** Writing - original draft.

Declaration of Competing Interest

The authors report no potential conflicts of interest.

Acknowledgments

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