Living with Disability
RESEARCH CENTRE
Supporting inclusion of people with cognitive disability

Adults in supported accommodation during COVID-19 lockdown: families' perspective

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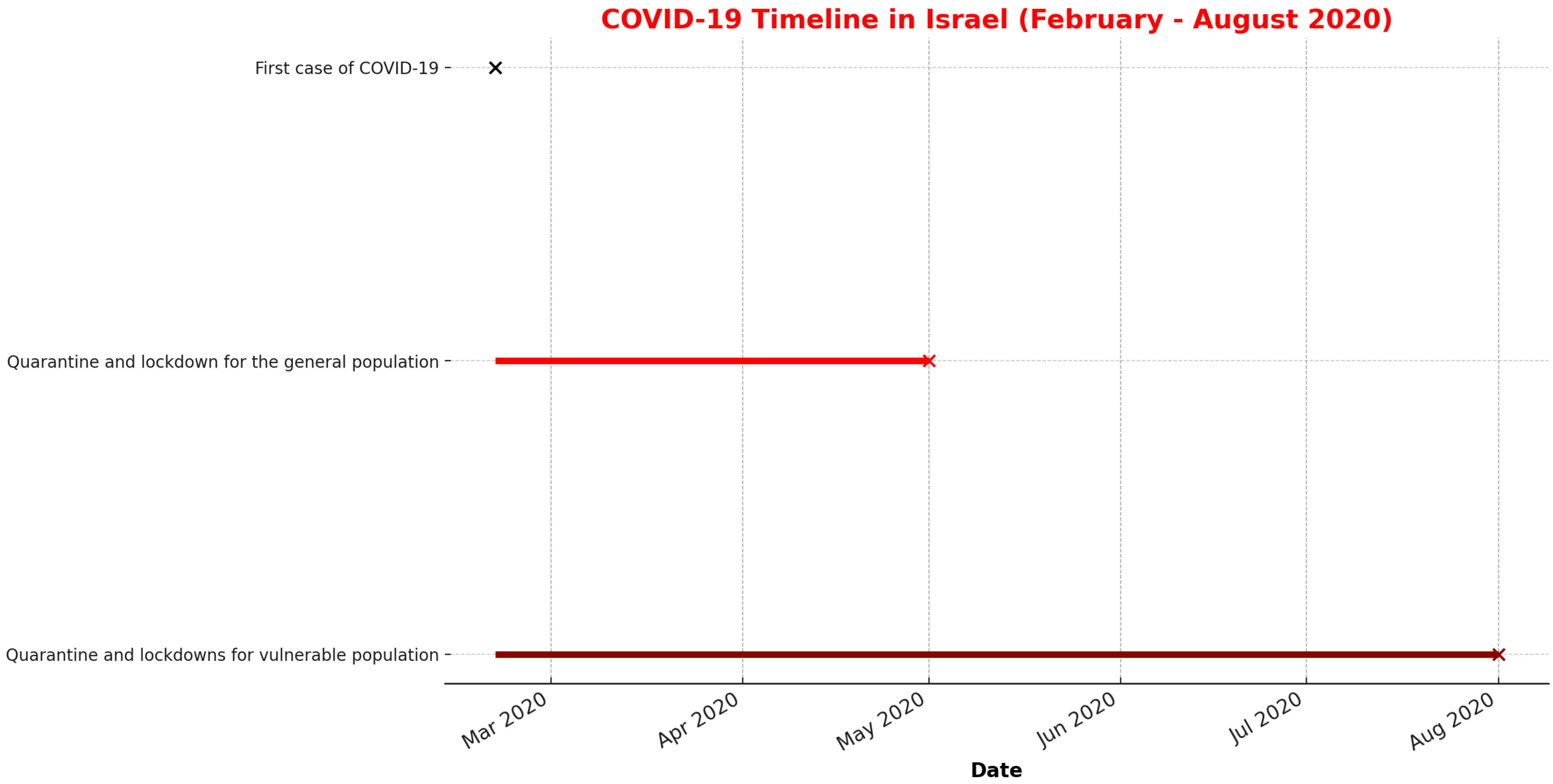
COVID-19: People with intellectual disabilities

- The COVID-19 pandemic and its associated social restrictions have had significant ramifications for adults with intellectual disabilities and their families.
- People with intellectual disabilities and those living in supported accommodation are especially vulnerable to the adverse effects of the pandemic (World Health Organization, 2020).
- The public health response to COVID-19 has created additional challenges: policies of lockdown, social distancing and quarantine have resulted in changes in:
  - Daily routine
  - Staff`s roles
  - informal support provided by family members

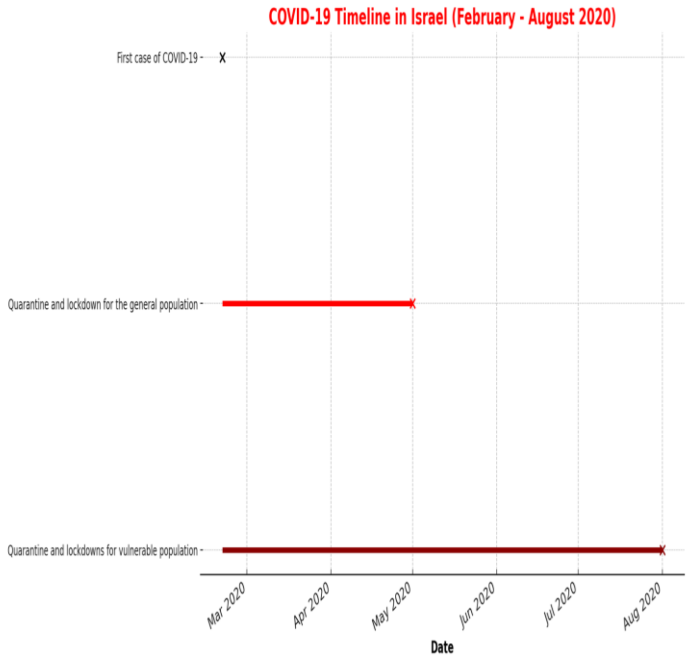

COVID-19 Timeline in Israel (February - August 2020)
First case of COVID-19
Quarantine and lockdown for the general population
Quarantine and lockdowns for vulnerable population
Mar 2020
Apr 2020
May 2020
Jun 2020
Jul 2020
Aug 2020
Date

Government response for people with intellectual disabilities

- Further restrictions beyond those imposed on the general population.
- Services relied on multiple sources of guidance to interpret public health information within the context of their settings:
  - General guidelines developed by the Ministry of Health
  - Specific regulations developed by the Ministry of Labour, Social Affairs and Social Services
  - Ad hoc Guidelines developed by Local public health units
  - Internal policies

Government response for people with intellectual disabilities

- Lockdown and social distancing
    - Residents were restricted from leaving their rooms/facilities
    - Restrictions were imposed on all face-to-face and direct contact with people outside the service, including the banning of all family visits and external service providers.
    - Only the permanent staff could meet the residents wearing PEP.
    - Community services, including day programs, and vocational and recreational services were closed.
    - Mainstream healthcare and social services were delivered via telehealth.
- While most restrictions were eased for the general population in early May, restrictions in supported accommodation remained in place (Israeli Ministry of Health, 2020).
- This decision triggered policy debates and advocacy efforts: family carers protested in the Israeli media and took legal action, arguing that this specialized policy is discriminatory, unwarranted, and a clear breach of residents' human and civil rights." (Alon, 2020; Kan, 2020)



The present study

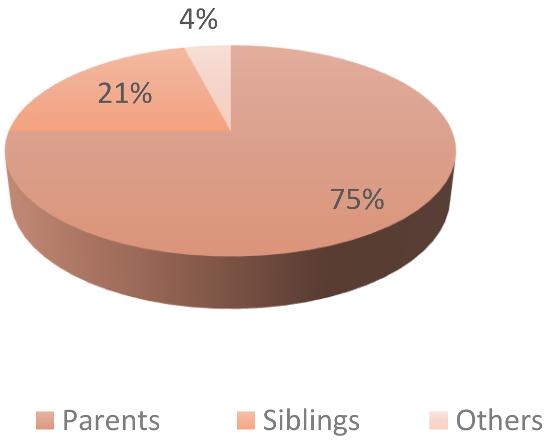
- Mix method design: Cross-sectional survey and qualitative interviews.
- Cross-sectional survey with 108 family carers of adults living in supported accommodation services during lockdown.
- Aims:
  - To understand the scope and nature of informal support and contact between family carers and their relatives in supported accommodation during the COVID-19 lockdown.
  - To explore changes in scope, engagement modes and types of informal support provided before and during the lockdown.
  - To evaluate the extent to which carers were satisfied with their engagement and support during the lockdown.

Family engagement with adults with developmental disabilities in supported accommodation: Online survey

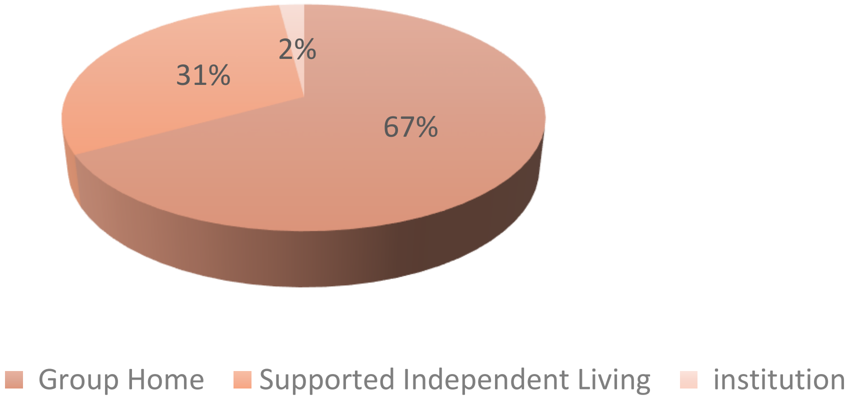
- A convenience sample of **108 family carers** of adults with intellectual disabilities residing in supported accommodation.
- Online survey:
  - Sociodemographic characteristics.
  - Modes and frequency of engagement (face-to-face visits, phone calls, video calls, text or voice messaging) before and during the pandemic.
  - Satisfaction with the frequencies and mode of engagement before and during the pandemic.
  - Informal support scope, type and frequency.
  - Facilitators and barriers for engagement.

Online survey - participants

- A convenience sample of 108 family carers of adults with intellectual disabilities residing in supported accommodations.

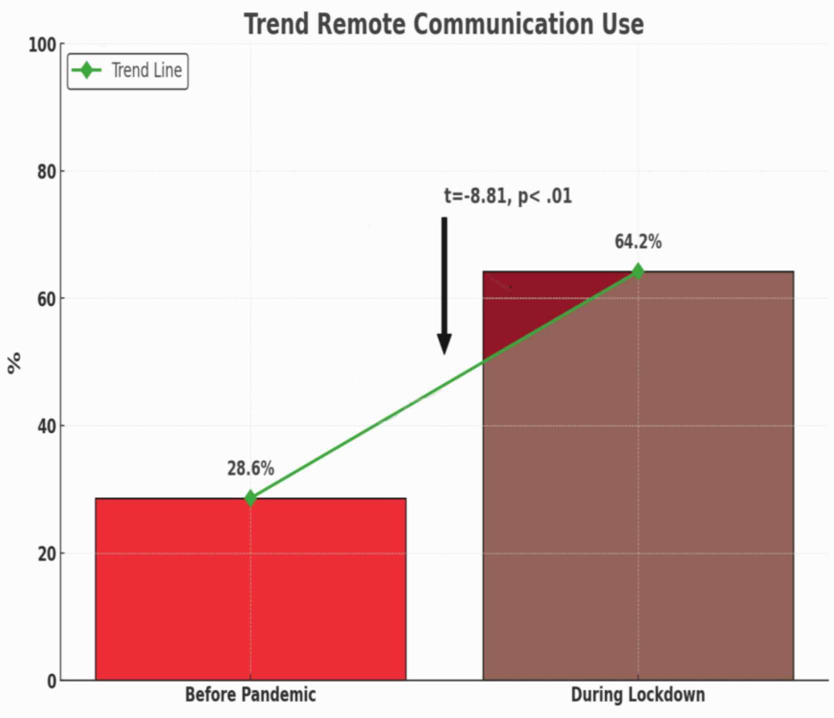


- Supported accommodation service type :



Findings: Changes in communication modes

- Carers found new ways to communicate with their relatives 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.
- A significant decrease in the frequency of face-to-face contact, from 90.8% reporting contact at least a couple of times a month before the lockdown, to only 31.6% during the lockdown ($t(107) = 11.40$, $p < .01$).
- Increase in use of remote communication methods, 28.6% before lockdown to 64.2% during the lockdown ($t(107)= -8.81$ $p < .01$)
  - Among the participants who reported using remote communication methods, the majority (78.6%) found it helpful or very helpful.



Findings: Most carers wanted to be more involved in their relatives’ lives during lockdown

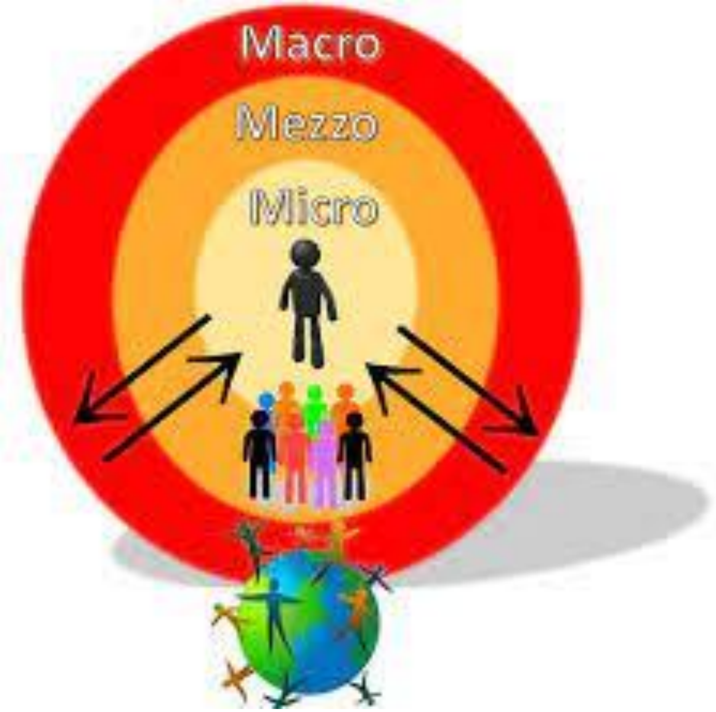
- 59.5% wanted to have more face-to-face visits.
- 28.1% wanted more frequent phone and video calls.
- 55.5% wanted to receive more information and support from frontline staff.

But

- Only 9% reported that such support was available to them.

Exploring families experience during lockdown

- Aim: to explore family carers’ experience supporting people with intellectual disabilities residing in supported accommodation during the COVID-19 lockdown.
- Recognising that different factors shape the experience across the person and family system in the community context. The analysis focuses on exploring the impact of the lockdown on two systems of human ecology (Bronfenbrenner, 1979)
  - The microsystem: The impact on the person, their family and their relationships.
  - The mezzo system: Experience engaging with the organisation, service providers and service communities.



The microsystem: Impact on people with intellectual disabilities

- Carers raised concerns about the person’s physical health and physiological well-being. They described how changes to the person’s routine, changes in staff roles and the availability of support had negatively impacted the emotional state of the person.

  “We can understand that these guys faced a harder time when their families suddenly disappeared, they could not go to work, all activities just stopped and they had to stay locked in their room all day….My son started experiencing nervous outbursts in this 'pressure cooker…’.” (Rachel, mother)

- Some carers indicated that the destructions of daily routine increase the incidence of behaviours of concern especially when people have limited understanding of the situation:

  “…I can see the regression … he is agitated, anxious… he can certainly curse when he is anxious …” (Sarah, mother)

The microsystem: Impact on people with intellectual disabilities

- Carers raised concerns about the disruption of the residents’ healthy lifestyles and habits:

  “I don’t know what they’re eating now she has gained a lot of weight, obviously just eating junk… Before there were salads, fruits, you know healthy food, but now, I think she lost it, she 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,… it’s not good for her.” (Ronnie, mother)

- Carers 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.

  “I am very stressed because for nine years he has not had seizures of epilepsy but from February to June he had four!… they had to change his medication” (Talia, sister)

The microsystem: Impact on people with intellectual disabilities

- On the other hand, some carers described that the situation created by the lockdown had a positive effect on the person's well-being:
  - **"... I get the impression that she experiences this period as a summer camp; she wakes up whenever she wants; she spends all day at home with her friends, her boyfriend, everything is relaxed" (Hannah, sister)**

The microsystem: Impact on the family carers, “it is exhausting.”

- Some carers were struggling to adapt to the changing circumstances themselves. They describe being worried about their own health, feeling overwhelmed by competing demands, and struggling to manage daily routines while meeting the changing support needs of the person.
  - **“This situation it is so exhausting…. I know that the recent period [lockdown] cost me my health…. There is a health price to all of this(Sharon, mother)**
- The disruption of services led to a sudden and unexpected change in their responsibilities; in some cases, parents described feeling helpless, losing control over the situation and the impact this had on their physical and mental health.
  - **“We got a message from the group home that from this minute the 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 the head. It was very very very hard…. I began to take tranquillizers because of it, I just could not function” (Ruth, mother)**

The microsystem: Impact on the family carers, “it is exhausting.”

- Some carers struggled with mixed emotions, uncertainty and confusion about their roles and responsibilities in the changing circumstances brought about by the pandemic and lockdown.
  - **“If I want to be 100% honest with you I am conflicted about the whole thing. On one hand, I wanted to run and be with him but on the other hand, I felt relief that others are taking care of him. …I am emotionally drained… f I was thinking about my parents who asked me to take care of him; I am now responsible and I felt like I didn't fulfil my responsibilities… I worry a lot but they [staff] won’t let me in, so I cannot help him, and actually they are responsible ..” (Leah, sister)**

Microsystem : The impact on the carer-resident relationship, “Communication is most important.”

- Carers acknowledged the importance of continuity of their support in uncertain times. Thus, they went “above and beyond” to stay in touch during the lockdown.
- For many residents especially non-verbal people or those with severe profound intellectual disabilities , remote communication was not always effective, often resulting in residents feeling confused and abandoned.
  - **“He saw us [via video call] but didn’t understand why we couldn’t come … I kept telling him that we did not leave him and we are waiting for the government to let us visit” (Jill, mother)**

Microsystem: The impact on the carer- resident relationship, “Communication is most important.”

- Informal support and communication is dependent on the person’s digital literacy, availability of devices and staff members’ capacity and willingness to provide technical support.
  - **“There is a computer downstairs but one of the residents took over it and does not let any [other] resident touch it. So, I brought him a tablet but he was afraid to use it, and there was no one there to help him with it. (Anna, sister)**
  - **“…the support worker gave him her cell to make a video call with our family. She made the call but didn’t realise that he doesn’t know how to even hold a phone. I was trying to explain to him how …but he did not understand …. Most of the time I saw only his bald head(Rita, mother)**

Microsystem: The impact on the carer- resident relationship, “Communication is most important.”

- On the other hand, some carers felt that the lockdown had brought them closer together. The use of remote communication has created new opportunities to spend more time engaging in new activities together.
  - **“I am working from home, so I have more time now . We talk on Skype every day while in the past [before the pandemic] we rarely talked." (Dave, father).**
  - **“Now she has her own Smartphone keeping in touch is easier… we can share photos she can show us her things… when I visit my mother I put her on speaker and she is there with us … She can see her nephews my brother’s girlfriend… (Michelle, sister)**

2.Mezzo system: “No one wanted to know how he was feeling”

- Carers felt that the restrictions enforced by the services were necessary, yet they felt that services adopted strict interpretations of restrictions, prioritizing risk management and liability over the residents’ individualized support needs and well-being.
  - **“I think that the decision to lock down the 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 contact with the families, especially in this time where everything is falling apart”.(Sally, sister)**

  - **“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” (Rachel ,mother).**

Mezzo system: carer perspective of service response

- Carers were frustrated that services did not provide residents with suitable alternatives to recreational and occupational activities. Specifically, they raised concerns that staff were often unattuned to the resident's and their family's emotional state and the effect the pandemic and regulations had on them.
  - **"They do nothing with them; even normal people would go crazy doing nothing all day"(Debbie, mother)**
- Carers felt that they had to "fight the system" to maintain basic communication and to be informed about the resident's situation.
  - **"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; Last week, I asked them to find a time for me to talk with him [her brother]; this is only a five-minute talk because can't 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 much for the team … Now there is a new support worker thank goodness she is very open and willing to receive calls on her private phone. …So one week they refused and the following week, this new staff member felt sorry for me and made a surprise call" (Rebecca, sister)**

Mezzo system: carer engagement with other residents’ families

- In the face of the crisis and the limited information, carers reported relying on the support of other residents’ families.
- During the pandemic and specifically in time of the lockdown, carers maintained frequent contact with other families, sharing information and supporting each other via telephone calls text messaging and WhatsApp groups.
  - **“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… so I disseminate the instructions directly to the families; I also help other parents in special cases, such as children who have not met their parents for long time” (Miriam, mother)**

Mezzo system: carer engagement with other residents’ families

- Even carers who reported being less involved with other families before the pandemic reached out and joined family groups:
  - **“Over time he looked more and more depressed and it stressed me out, so I joined the parents’ WhatsApp group . Families there were very active and fought for the residents' rights to see us ... This group and the understanding that others are not accepting the situation as is ,made me feel better. ….when I was very stressed with my brother’s well-being this group was very supportive” (Emily, sister)**

Mezzo system: carer engagement with other residents’ families

- It seems that families' groups were a pivotal mechanism in advocating for the residents' rights :
  - **“The advocacy organisations that were supposed to represent our kids did not do it, and actually we [the parents] did and succeeded” (Leah, mother)**
- However, the atmosphere in the families' groups was not always positive. Some carers described conflict about advocacy efforts:
  - **“I had big arguments with some parents who thought I was going to kill their child because I was fighting for my right to see mine. They were hysterical and told me that I didn’t know what I was doing, and that I was putting everyone at risk. I told them, if you are concerned then stay away … I am fighting for my family” (Ruth, mother)**

Conclusions

- The findings provide valuable insights into the multifaceted challenges faced by carers.
- Highlight the adverse consequences of family disengagement on the health and well-being of both carers and residents.
- Illuminate the complexities of maintaining informal support and family involvement in the lives of people with intellectual disabilities living in supported accommodation during periods of social distancing and lockdowns.

Conclusions

Cares input is vital for shaping future policy developments, enhancing emergency preparedness planning in services, and providing quality support during times crisis.

- New strategies should be developed to actively involve family carers in the lives of the residents fostering a partnership between staff, families, and residents.
- Develop emergency preparedness policies
- Clear guidance in an accessible format for staff, adults with intellectual disabilities and carers.
- Better communication about changes in services - staff members must maintain an open line of communication with families, allowing for regular updates and assistance.
- Training for staff, people with IDD, and their family carers.
- Building the capacity of families and residents to communicate in various ways.
- Access to remote communication devices.

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Thank you

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