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

“I kept telling him that we did not abandon him”: Families of adults with intellectual disabilities residing in supported accommodation during the COVID-19 pandemic.

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COVID-19: People with intellectual disabilities

- The COVID-19 outbreak has had an enormous global impact. In response to the rapidly spreading pandemic, states have introduced public health measures to limit community transmission of COVID-19.
- 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 and quarantine have resulted in changes in daily routine and staff roles, and in the involvement of families and other informal support networks (Lau et al., 2020; Piguillem & Shi, 2020).

COVID-19: The Case of Israel

- The first case of COVID-19 in Israel was confirmed on February 21 2020.
- February to mid-March 2020: The Israeli Ministry of Health gradually introduced a series of public health instruments for the general population. These included restriction on gathering, travelling and social distancing, shutdown of the education system, entertainment and other public venues. People were advised to work from home and to wear face masks.
- April to May 2020: The Israeli government introduced periods of quarantine and nationwide lockdown.

Government response for people with intellectual disabilities

- The government response to the increased vulnerabilities of people with disabilities and the elderly included further restrictions beyond those imposed on the general population.
- Restrictions were nationally developed and monitored by the ministries of Labour, Social Affairs and Social Services.
- 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
    - Local public health units
    - Internal policies such as health and safety instructions

Government response for people with intellectual disabilities

- Lockdown: Service users were prohibited from leaving their apartments/service and restrictions were imposed on all face-to-face and direct contact with people outside the facilities, including banning of all family visits and external service providers. Only the permeant staff could meet the residents wearing PEP.
- Community services, including day programs, vocational and recreational services were closed.
- Mainstream healthcare and social services were delivered via telehealth.
- Early May 2020: most restrictions were eased for the general population, restrictions on residents of supported accommodation remained in place (Israeli Ministry of Health, 2020).
- 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).

The present study

- Mix method design: Cross-sectional survey and qualitative interviews.
- Cross-sectional survey 108 family carers of adults with DD living in supported accommodation.
- Study aims:
    - To understand the nature of support and contact between family carers and their relatives in supported accommodation during the COVID-19 lockdown.
    - To explore whether the frequencies of communication modes and types of informal support have changed during the lockdown.
    - To evaluate whether families were satisfied with their engagement with their relatives during the lockdown.

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

- A convenience sample of **108 family caregivers** 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

- 108 family caregivers of adults with IDD residing in supported accommodation:
    - 75% - Parents of adults with IDD
    - 21% - Siblings
    - 4% - Other family members (e.g. sisters-in-law or cousins)
    - 80% - reported being the legal guardian of the person
- Supported accommodation:
    - 67% group homes
    - 31% supported community living
    - 2% were living in institutional like facilities

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 frequency 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 ($t(107) = 11.40$, $p < .01$).
- No significant changes in the frequency of family contact via phone calls and text messaging.
- Increase in remote technology use such as video calls (via WhatsApp, FaceTime or Zoom). Before the pandemic, 28.6% of participants reported that they use such technologies to keep in touch with their relatives, whereas during the lockdown 64.2% ($t(107)= -8.81$ $p < .01$)
    - 64.2% of families reported that during COVID-19, video calls were their main way of communication
    - Among the participants who reported engaging with their relatives via video calls, the majority(78.6%) found this type of communication as being helpful or very helpful.

Findings: Changes in the type and amount of informal support

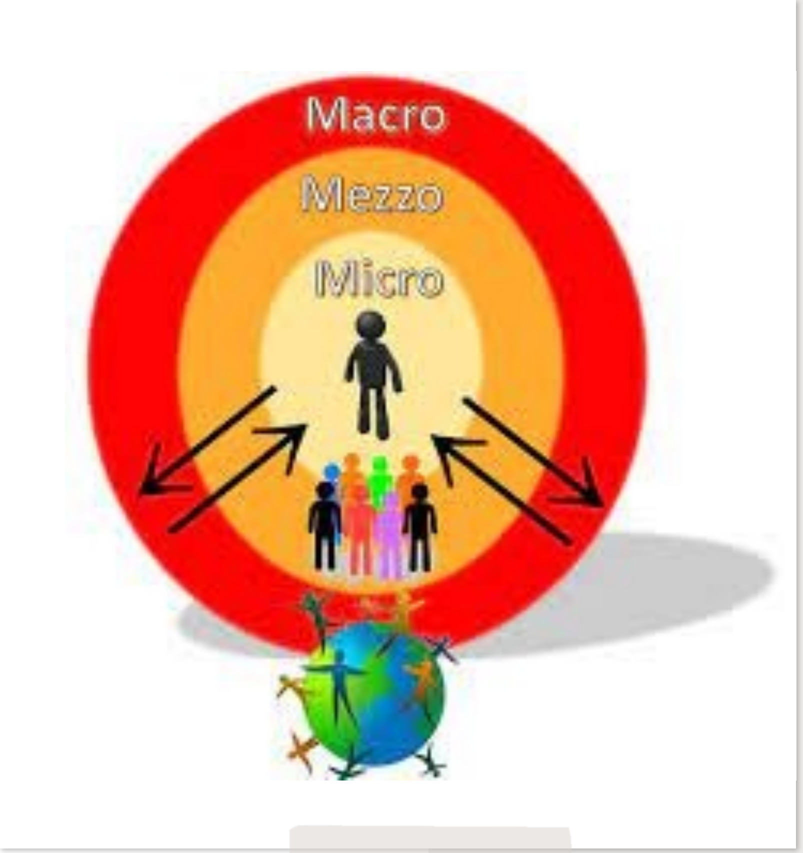
- The participants reported changes in the type and amount of informal support they were able to provide before and during the pandemic.
- 67.6% reported a **decrease in the social support** they provided during the pandemic compared to the pre-pandemic period (routine times).
- 61.1% of family carers 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.
- 13% of participants reported being required to provide more **financial** support at the time of the pandemic.
- 17.6% provided **more assistance** in decision-making.
- 38% of participants reported a substantial **increase** in the advocacy they provided during the time of the pandemic.

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% expressed a desire to receive more information and support from frontline staff during the pandemic.
- 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 pandemic.
- Recognising that different factors shape the experience across the person and family system, community context, and within society and culture, we discussed the carers experience across three systems:
    - 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 macro level: The general service system, policy and society.



Impact of lockdown on health and well-being of people with intellectual disabilities

- Carers raised concerns about the person’s physical health and physiological well-being. Carers reported that changes to the person’s routine, changes in staff roles and the availability of support and social engagement contributed to feeling of distress, loneliness and boredom.
- Some carers raised concerned about reduction in healthy lifestyles habits (sleep routine, exercise, healthy diet). They were concerned that these will result in deterioration of the person’s physical health.

“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 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.” (Ronnie, sister)

Impact of lockdown on health and well-being of people with intellectual disabilities

- Family carers reported that the person’s physical health has become worse during the pandemic and were concerned about how the situation were handled with limited access to health care:

“I was very stressed because for nine years he have not had seizures of epilepsy but from January to February he had four seizures, they had to change his medication” (Talia, sister)

Impact of lock-down on health and well-being of people with intellectual disabilities

- Carers described changes they noticed to the person’s mood and behaviour. They were concerned about increased prescription of psychotropic medication to manage these symptoms:

“We can understand that these guys faced a harder time when their families have suddenly gone, they could not go to work, other 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)

“I saw that Jonathan was depressed, sad, and apathetic; sometimes he also cried and asked to meet us [his parents]. I also know about his roommate that refused to get out of his bed all day” (Ruth, mother)

“At the beginning our conversations were happier; later I became worried because I have noticed that he was less happy and he looked depressed and less communicative. I worried that the social distancing and isolation for a such long period made a negative impact on him” (Anne, sister)

- Some carers indicated that the destructions of daily routine increase the incidence of challenging behaviour, especially when people had limited understanding of the situation:

“(due to the lockdown) I can see the regression … he is agitated, inpatient, anxious… he can certainly curse” (Sarah, mother)

Impact of lockdown on health and well-being of 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:

“It seemed that she [her sister] understood the situation, she keeps saying: ‘it is prohibited to go out or get in because there is Covid’ but it seems that she didn’t care about it. 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 impact of lockdown on carers

- Some carers were struggling to adapt to the changing circumstances themselves. they describe being worried about their own and family health, feeling overwhelmed by competing demands, struggling to manage their own daily routines and mental health while meeting the support needs of the person.
- 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 to 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 in the hostel. It felt like a five-kilo hammer fell on the head. It was very very very hard for me. I began to take tranquilizers because I could not function” (Ruth, mother)

“This situation is very much exhausting….The statistics also shows that mothers of children with special needs tend to get cancer and high blood pressure more than others. I myself have a lot of tumours. I know that the recent period [lockdown] cost me a mental health price” (Celeste, mother)

The impact of the lockdown on carers

- One sister described struggling with mixed emotions in response to her role and responsibilities in supporting her brother:

“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 but on the other hand, I felt relief that others takes care of him…..I was emotionally distressed since 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 of 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” (Leah, sister)

The impact of the lockdown on the care relationship

Families acknowledged the importance of continuity of their support in uncertain times and made great effort to stay in touch and to provide support during the lockdown. Many reported that they increased the frequency of engagement with their relatives during the pandemic, substituting in-person visits with remote communication.

Communication between the families and the residents was dependent on the person’s capacity, availability of devices and staff members' availability and willingness to provide support. Carers reported that video calls were not always helpful and residents felt confused and abandoned:

“He saw us [via video call] and I kept telling him that we did not abandoned him and that we were still waiting that the government would let us come and meet him” (Jill, mother)

"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.“ (Shane, brother)

The impact of the lockdown on the carer relationship

- A few caregivers felt that the lockdown have brought them closer together as it allowed them to spend time together and provided more opportunities to engage in different activities together.
- For example one mother described having her son back home with her:

“Usually he can't stand noises and that is the reason why celebrating Passover evening with all family is hard for him, but this year it was different. He was home for couple of weeks before, he loved to be with all of us and even read the Passover Haggadah and asked questions. I'll tell you the truth, it was the best Passover evening I have ever had with my son” (Ruth, mother)

- One brother described how the adoption of remote communication enabled them to communicate more frequently:

“I initiated more online meetings with him. We talked on Skype every day while in the past [before the pandemic] we rarely talked” (Isaac, brother)

The mezzo system: “No one wanted to know how he was feeling”

The majority of carers had negative perceptions of the way managers and the staff of the residential settings functioned and behaved during the pandemic, and in particular the lockdown.

Although the carers have realised the staff followed the instructions (top-down policy), they felt that each residential setting interpreted the national policy in a different way.

Carers felt that they had to “fight the system” to maintain basic communication and to be informed about the person’s situation. In the absence of clear policy guidelines carers relied on their personal relationship with staff members or alternatively felt they had to advocate strongly for the person rights:

“They [staff] didn't inform us that he 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. They [residents] are climbing the walls [bored and frustrated]” (Lea, mother)

The mezzo system: carer perspective of service response

“No one updates me or my father. Only when we ask for an update we get it. It is also depends on the personality of the staff member; now there is a new housekeeper that she is very open and wiling 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 [her 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 burden for the team." So one week they refused and the following week, the housekeeper felt sorry for me and made a surprise call” (Rebecca, sister)

“I warned the staff there is no way they move James to another apartment. It took exactly two weeks until I got a message that they are planning to close his apartment and move him to another one. My advantage over other parents is that I know the system from inside and know how it operates so I am always one-step ahead. I also have spies there 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 organise 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” (Sarah, mother)

The mezzo system: carers perspective of service response

“I think that the decision to lock down the residential setting was a good one in order 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 [COVID]” (Sophie, mother)

The mezzo system: carers perspective of service response

- The carers felt that the services weren’t accommodating and the residents were bored doing nothing. All recreational and occupational activities were stopped and in many cases there were no alternative and creative activities offered to the residents.
- It seemed that the policy was not flexible and not accommodating to the residents’ abilities and needs.

The mezzo system: carers engagement with other residents' families

- Carers of high functioning residents who live in smaller and less-structured community-based accommodation remained in frequent contact during the lockdown supporting each other, sharing information via phone calls/text messaging via WhatsApp group designated for the families. Furthermore, carers also assisted each others' families during the pandemic:

"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 children who have not met their parents for a long period of time" (Miriam, mother)

The mezzo system: carers engagement with other residents’ families

- Other carers, mainly relatives of low functioning residents who live in bigger and structured community-based accommodation, were less in touch with other families before the pandemic, however in time of crisis families initiate contact with other families:

“Over the time he [her brother] looked more and more depressed [in the video calls] and it stressed me out so I joined to the parents’ WhatsApp group that was very active and fought for the residents' rights. There was a lawyer that joined the group and represented the parents 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. Although it took time but when I was very stressed with my brother’s well-being this group was very supportive” (Emily, sister)

The mezzo system: carers engagement with other residents’ families

- It seems that the parents' groups was a key player in advocating for the residents' rights in the time of the lockdown:

“The organisations [NGOs] 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 parents' groups was not always positive. Some carers described conflict and disagreement among the families about the reality of the group home and 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 my child. 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. I told them that if you are concerned so stay away” (Ruth, mother)

The macro system: carers' perspective of national policy

- The majority of carers perceived the national policy and guidelineas discriminating and violating people with disabilities` human rights.
- Carers criticised the strict restrictions which were collectively conducted without taking into account the person's characteristics and support needs, and the lack of clear communication about instructions and transparency about how policy decisions concerning people with disabilities and services were made.

"When a person has a special needs [disability] card he is automatically categorised as part of at risk population and anyone in the system can decide for him and for his family and prevent his basic freedom to meet the people he loves and cares for. Like everything is allowed under the auspices of COVID. People with disabilities are not necessarily at risk population and policy makers have to keep in their minds the human rights of our children with special needs" (Sarah, mother)

Conclusions

Findings highlight the need for:

- Clear guidance in an accessible format for parents and adults with intellectual disabilities.
- Better communication about availability or changes to services is also needed and the effects of closure of day services on families require more consideration.
- Developing support services for families.
- Novel strategies and policies should be developed to ensure the continuity of family contact and informal support.
- Building the capacity of families and residents to communicate in various ways and to provide and facilitate access to digital devices.
- Staff members must maintain an open line of communication with families, allowing for regular updates and assistance.

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Thank you

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