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Together in a pressure cooker: Parenting children with disabilities during the COVID-19 lockdown

Yael Hochman, PhD a, *, Carmit-Noa Shpigelman, PhD b, Roni Holler, PhD c, Shirli Werner, PhD c

a School of Social Work, Sapir Academic College, D.N. Hof Ashkelon, 79165, Israel
b Department of Community Mental Health, University of Haifa, Israel
c Paul Baerwald School of Social Work and Social Welfare, Hebrew University of Jerusalem, Israel

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Abstract

Background: COVID-19 has had a disproportionate and unprecedented impact on children with disabilities, their parents and families. This impact has been particularly evident during periods of lockdowns and severe restrictions.

Objective: This study employed the social model of disability to illuminate negative and positive experiences of Israeli parents of children with disabilities during the first COVID-19 lockdown, as well as the way social environments, particularly educational and welfare services, shape that experience.

Methods: The study draws upon thematic analysis of written responses of 80 Israeli parents to open-ended questions.

Results: Three main themes were found: (1) lack of responsiveness of both informal and formal supports to family needs, mainly in the educational and welfare systems; (2) juggling multiple roles and tasks along with the parents’ routinely intensive caregiving role; and (3) the impact on the family’s wellbeing and relationships.

Conclusion: These results are discussed in light of the social model of disability, showing how social restrictions and barriers affect both negative and positive experiences of these families. Also discussed are practical implications for future crises.

The COVID-19 crisis and parents of children with disabilities

Research on the experience of parenting children with disabilities indicates the multiple challenges it poses for parents and families. These parents are at risk of distress, poor physical health, mental health, and general wellbeing. A growing body of work has stressed the role of contextual factors in shaping their experience. Driven largely by a social perspective of disability, these studies have pointed to the importance of formal and informal supports, parents’ interactions with service providers, and their ongoing battle over their children's rights and service provision.

While empirical research regarding the experience of parents to children with disabilities and the contextual factors affecting them is growing rapidly, knowledge on how these factors are at play during emergencies such as COVID-19 is still limited. The present study focuses on the experience of parents to children with disabilities during the first lockdown in Israel.

Families of children with disabilities during emergencies

Studies on emergency preparedness have emphasized the social vulnerability of people with disabilities during such turbulent times, and the way social barriers, such as difficulties in accessing resources and services, affect their coping during the disaster as well as in the long term. The pandemic and the restrictions imposed to counteract its spread, especially lockdowns, have caused major disruptions in the lives of families worldwide. Recent
studies of COVID-19 lockdowns have pointed to the potential adverse impact on the mental health and wellbeing of parents and other family members.8–11 Parents of young children have been especially vulnerable, as they were confined to their homes;12 received conflicting information from the media;13 lost financial resources; had to reconcile work and family life, suffered from disrupted social networks,15 and lost welfare service support.

Although COVID-19 lockdowns may be stressful for all, evidence suggests that children with disabilities are more strongly affected.8,12,14–16 They face greater difficulties than children without disabilities due to the disruption of their routines and loss of essential services and supports.8 With schools shutting down and moving to online teaching, and social distancing, they face greater isolation and adjustment difficulties.9,11 Further, they are usually unable to use their personal assistants or paraprofessional treatment without being physically present at school—impossible for most during lockdowns.11

Further, recent evidence suggests that the COVID-19 lockdowns may also have a disproportionate detrimental impact on parents of children with disabilities,8,14,18–21 who may experience greater levels of concern, stress and priority to reconcile their caregiving role with their paid employment compared to parents of children without disabilities.12,21 Further, they should not lose sight of some evidence suggesting COVID-19 lockdowns may also provide families some positive opportunities for growth,3 such as strengthening family cohesion.15 Very little research has explored the experience of parents of children with disabilities during the peak of the pandemic (i.e., the first lockdown).10 Particularly lacking is knowledge on the meanings they attribute to this unprecedented crisis, and the way they experience its unique challenges and potential benefits.

Theoretical framework

Scholarship on parents and families of children with disabilities has been traditionally dominated by the individual, medical, or deficit perspective, which equates disability with individual impairment and personal tragedy.22 Likewise, studies have frequently viewed the parenting and family experience as one of loss, grief, stress, burden, and chronic sorrow.23 This line of research has also tended to decontextualize parents’ experience from the broader social context.24 The current article is grounded in the social model of disability, which shifts the focus from the individual deficit to the social structures that marginalize people with disabilities.7,22,27 This shift is relevant for studying parents’ experience in at least two respects. First, it offers the opportunity to unpack the complex ways in which parents negotiate, work through, and give meaning to their parental experience.25 Second, it encourages us to focus on contextual factors, such as availability of services and support.26,27

The current study

In our study, the social model of disability was employed to illuminate both the negative and positive experiences of parenting children with disabilities during COVID-19 lockdown, as well as the way educational and welfare services shape that experience. Out of approximately 320,000 (10.9%) children with disabilities in Israel, about 265,000 (83%) receive special education services through the school system. Most of the latter (80%) study in mainstream schools, 62% in mainstream classes, and 18% in special classes. The remainder (20%) study in specialized schools.8,22 Children with disabilities are entitled by law to various paramedical services and specialized educational support. The Equal Rights for Persons with Disabilities Law, 5758–1998, requires educational services to be accessible, both physically and pedagogically, to the needs of children with disabilities. However, regulations have only recently been fully enacted, and there is still a large implementation gap.30 Children with disabilities and their parents can also be entitled to various welfare services, from personal assistance to leisure activities, which are often not anchored in law but in internal regulations, and their provision often involves high discretionary power.31

During the first wave (March–May 2020), Israeli authorities undertook various protective measures, including severe restrictions on gatherings with non-nuclear family members, and limiting movements to a very short distance away from one’s home. For much of the time, individuals were allowed to leave their homes solely to obtain essential services, and even venturing out to nature or open playgrounds and parks was prohibited. Schools, including special education schools, were temporarily closed, leading to the curtailment of therapeutic interventions usually provided by the Ministry of Education. Paramedical services were not delivered face-to-face and, in many cases, not even virtually.12 Finally, distance learning was not implemented during the beginning of the lockdown and when it was, it was insufficiently adapted to the unique needs of children with disabilities.21

Methods

This study is part of a larger mixed-methods research project on the impact of COVID-19 on Israeli families and parents of young children with and without disabilities. It relies on open-ended questions included in the final section of a mostly quantitative, closed questionnaire.

Data collection

Data were collected via an online Hebrew survey utilizing the Qualtrics software, distributed via WhatsApp and Facebook groups for parents of children with disabilities. We approached groups that were familiar to us, as well as additional groups using keywords such as “parents” and “disabilities.” The questionnaire forms included a brief presentation of the research and its main goals, of ourselves and our academic affiliations. Data were collected in April 2020, when Israel was under almost full lockdown as was described above.

The open-ended questions referred to the experience of parenting a child with disability during COVID-19: (1) How is your relationship with your child today similar to or different from the relationship before COVID-19? (2) What challenges do you encounter now in relation to COVID-19? (3) What helps you as a parent to cope with these challenges? (4) What would you expect the Ministry of Education, Ministry of Welfare or other service providers to do for you and your family during these times? Each question offered unlimited response space to encourage thick description. Indeed, most responses were detailed enough to allow us to thematically map the parents’ experience. Quotations were translated into English and checked to ensure the original meaning was retained.

Participants

Out of a convenience sample of 100 parents of children with disabilities in our larger study, 80 (70 mothers) responded to the qualitative open-ended section of the survey. As indicated in Table 1, the mean ages of the parents and their children were 39.44 (SD = 4.50) and 6.81 years (SD = 3.04), respectively. In 37 cases (46%), at least one parent had lost their job or had been furloughed during the pandemic, and in 17 cases (21%) both parents continued working on a smaller scale. Their children’s disabilities included...
reviewing the coded transcripts, de-
relevance against the collated data extracts. Finally, a discussion
initial categories, assessed the associations between them and
across the participants

approach aimed at identifying units of meaning arising from each
employed initial open hand coding using a bottom-up inductive
impressions in order to become familiar with the data. Second, each
reread the textual data separately and wrote down their initial
themes and subthemes.

used investigator triangulation.35 In terms of re-
pants' responses. To determine the themes' trustworthiness, we
promote credibility, we provided a rich description of the
phenomenon under study35 by quoting excerpts from the partici-
ents' responses. To determine the themes' trustworthiness, we
used investigator triangulation.35 In terms of reflexivity, all authors
reside in Israel and were subjected to the COVID-19 restrictions. As
the research team included participants with and without disabil-
ties who had children with and without disabilities, the discussion
increased the researchers' reflexivity regarding their own positions
and beliefs about the phenomenon and decreased the potential of
bias in data coding and analysis.

Ethics

The study was approved by the Ethics Committee of the Paul
Baerwald School of Social Work and Social Welfare at the Hebrew
University. Before completing the survey, participants provided
their informed consent. Furthermore, participants could choose to
skip any question.

Results

The lockdown period was experienced by most of the partici-
ants as negatively influencing the parent’s wellbeing and family
relationships. However, parents also described it as contributing to
discovering parental and familial strengths within the context of
caring for a child with a disability. Analyses yielded three main
themes: lack of support system responsiveness to families’ needs,
juggling multiple roles and tasks, and family relationships during
COVID-19.

“We were left alone”: lack of support system responsiveness to
families’ needs

The COVID-19 lockdown has left families of children with dis-
abilities facing lack of responsiveness by support systems: “Our
whole support system collapsed, no help from grandparents and
immediate family members. My son’s therapeutic settings closed
down and so did his classes. We were left alone.” First, informal
support, ordinarily provided by the extended family, neighbors and
friends, was denied. In light of this denial, many parents repeatedly
described the urgent need for instrumental assistance in managing
daily life, as well as their growing need for emotional support: “We
really need physical help with the special girl. I don’t know how to
ask for it since there are so many restrictions”.

Second, many parents were left without the adequate formal
supports ordinarily provided by the education and welfare systems
in face-to-face settings. According to their account, government
policy was not tailored to meet the needs of children with disabil-
dities and their parents, making it hard for both to cope.

Education system: The parents were particularly critical of the
education system. Many criticized online learning for being unre-
responsible to their child’s needs and for imposing a burden on par-
ents who were required to mediate their children’s learning: “The
distant learning is impossible without adult help.” Parents stressed
that online learning had to be tailored to the needs and learning
styles of children with disabilities, for example via small-group
sessions. Further, many stressed that actions should be taken to
enable the special education system to return to normal, such as
opening more classrooms and expanding school hours: “The Min-
istry of Education needs to bring special education children back to
school, including transportation […] as well as to remotely assist
special education children with weak immune systems who stay at
home.”

Parents also expressed disappointment with the communication
between educational staff, themselves, and their children. They
stressed their need for open, direct, and ongoing communication,
and their concerns regarding the impact of a lack of such commu-
nication for their child’s mental health: “They should focus on
helping the children with disability emotionally. Initiate personal

Table 1
Demographic characteristics (N = 80)

| Category                        | N (%)       |
|---------------------------------|------------|
| Gender                          |            |
| Male                            | 10 (12.5)  |
| Female                          | 70 (87.5)  |
| Age                             | M = 39.68 (SD = 4.92) |
| Marital status                  |            |
| Married or cohabitating         | 67 (83.75) |
| Single parent household         | 9 (11.25)  |
| Unknown                         | 4 (5)      |
| Disability                      |            |
| Employment following COVID      | 7 (8.75)   |
| Lost their job or furloughed    | 37 (46.25) |
| Both parents continued working on a smaller scale | 17 (21.25) |
| Continued working as usual      | 26 (32.5)  |
| Education years                 | M = 16.42 (SD = 3.34) |
| Socioeconomic status            |            |
| Above average                   | 26 (32.5)  |
| Average                         | 40 (50)    |
| Below average                   | 14 (17.5)  |
| Number of children              |            |
| 1                               | 6 (7.5)    |
| 2                               | 27 (33.75) |
| 3                               | 27 (33.75) |
| 4 or more                       | 17 (21.25) |
| Unknown                         | 3 (3.75)   |
| Children with disabilities      |            |
| Age                             | M = 6.81 (SD = 3.04) |
| Gender                          |            |
| Boy                             | 54 (67.5)  |
| Girl                            | 26 (32.5)  |
| Disability                      |            |
| Autism                          | 37 (46.25) |
| Intellectual disability         | 14 (17.5)  |
| ADHD                            | 9 (11.25)  |
| Motor impairment                | 3 (3.75)   |
| Medical and genetic problems    | 5 (6.25)   |
| Developmental impairments       | 6 (7.5)    |
| Hearing impairment              | 2 (2.5)    |
| Mental illness                  | 2 (2.5)    |
| Comorbidity                     | 2 (2.5)    |

autism (n = 37), intellectual disabilities (n = 14), ADHD (n = 9),
motor impairment (n = 3), developmental impairments (n = 6),
medical and genetic problems (n = 3), hearing impairment (n = 2),
mental illness (n = 2), and combined diagnoses (n = 2).

Data analysis

Thematic analysis was employed as this method systematically
identifies, organizes, and offers insight into patterns of meaning
(themes) across a dataset.35 In the first stage, all authors read and
reread the textual data separately and wrote down their initial
impressions in order to become familiar with the data. Second, each
employed initial open hand coding using a bottom-up inductive
approach aimed at identifying units of meaning arising from each
participant separately, followed by a search for repeated patterns
across the participants’ answers. Third, all authors discussed the
initial categories, assessed the associations between them and
and grouped them into main themes. These themes were checked for
relevance against the collated data extracts. Finally, a discussion
with the entire research team was held, which involved authors
reviewing the coded transcripts, defining, and naming the final
themes and subthemes.

To promote credibility, we provided a rich description of the
phenomenon under study35 by quoting excerpts from the partici-
pants' responses. To determine the themes' trustworthiness, we
used investigator triangulation.35 In terms of reflexivity, all authors
I would expect to receive increased help following COVID-19, that the system would provide more hours ... because the gap really needs to be filled, and I would expect them to send help to his kindergarten and not have to travel far for it.

Beyond educational services, many addressed the dire consequences of discontinuing various services, particularly paramedical and counseling services that were usually provided during the school day. According to them, this had a grave impact on both the children’s functioning (regression or lack of progress) and parental coping. Lacking such services, parents found themselves fulfilling professional roles, creating an additional workload. Some felt frustrated, as they perceived themselves as lacking the appropriate skills, especially without guidance:

Living together in the same pressure cooker […]. I had to deal with the learning issues and the emotional aspect that used to be in the hands of professionals, and was now my job. I was stressed and all day I found myself shouting and commanding everyone to do things my way.

Welfare services were also criticized by most parents for lack of responsiveness to their instrumental and emotional needs and for failing to fill up the vacuum created due the reduction in both informal support and educational services. Since most services for children with disabilities are routinely provided within the education system, parents were left with many unmet needs and an expectation that the welfare system would pick up the slack. Parents stressed that ongoing communication with welfare staff would help tailor solutions to their child’s and the family’s specific instrumental and emotional needs:

I would expect them to call and find out how the child is doing, what he needs at home to help him cope […] he doesn’t have a computer. I would expect welfare staff to provide a child with special needs with an electronic device […] no one cares for them ...

Octopus parenting: juggling multiple roles and tasks

We use the metaphor of “Octopus parenting” to describe parents’ need to reorganize their lives to be able to carry out multiple roles and tasks in light of the previously described limited support.

One major challenge was responding simultaneously to the needs of the child with disability and those of other household members, especially younger children. This challenge deepened among parents whose child’s impairment required intensive daily care. For example, “My child has a motor disability, with low physical functioning that requires a lot of constant physical activation... He is not independent in anything and cannot cope alone for more than five minutes.”

Parents felt that balancing the needs of various family members always had its toll, often in terms of inappropriate response to the needs of either the child with disability or siblings:

A baby with Down syndrome that I need to work with and be a physical therapist, speech and occupational therapist, which takes time and energy that sometimes comes at the expense of the older ones. When I do find time to work with them on the tasks they receive from school, the little one doesn’t necessarily get what she needs.

Many parents also described the challenge of work-home balance. The intensive caring for their child led to job distress, working in irregular hours, and sometimes impaired functioning in either or both domains. One mother, described the difficulty of “responding to a child’s needs in the middle of an urgent job […] all the burden is on the parents […] you have to first address the children’s needs and shift workload to late hours.”

This octopus parenting took its toll and parents were left with little time of their own needs, reporting negative emotions stemming from the burden and from their perception of their parental functioning, including anger, guilt, nervousness, anxiety, fatigue, and loneliness. For example, “I have guilt feelings about my functioning as a parent. I don’t do enough physical exercise with the children and I don’t make good enough use of this period”; “I am more prone to nervousness and fatigue than usual.”

Note, however, that parents did not describe solely negative experiences. Some described this period as an opportunity for much needed rest and relaxation from their usually busy routine. They appreciated the time they had to get closer as a family and the opportunity to devote themselves to caring for their children. For example, “We spend much more time together instead of running around caregivers, therapies and hospitals”; “Things are more relaxed and peaceful compared to loads and tensions around everyday tasks.”

Optimism about their capability to cope, often seen as a result of parenting a child with a disability, was an important coping resource. One mother referred to this as “built-in optimism”: “We have the right proportions about life, especially following the upbringing of a special child. We make efforts to celebrate the good in life, hold our head up high, and hope we get through these challenging times soon.”

“Friction and nerves”: family relationships

The limited support and the need to juggle multiple roles had a crucial impact on parent-child and sibling relationships. These were described as mostly tense and conflictual. At the same time, spending more time together sometimes strengthened family relationships and even led to growth.

Parents described how the COVID-19 lockdown brought significant challenges to the relationship with their children. The latter’s intensive needs were described as causing great stress and strained relationships: “My son is completely dependent on me, from morning to night and not just half the day. It’s more exhausting and creates friction and nerves.”
Some of the difficulties were ascribed to the child’s psychological condition. Many parents described school closure, confinement to the home and a disrupted daily routine as triggering a deterioration in the child’s condition, expressed in greater anxiety, irritability, social disengagement, and maladaptive behavior compared to the pre-COVID time. In some cases, this led to emotional disconnection between parents and children and to difficulties for parents to understand their children’s wishes:

We see regression and also new behaviors. The autistic symptoms are more prominent, and this affects how I perceive him in comparison to the pre-COVID period and compared to his siblings. It’s difficult for me to contain him and allow him to be who he is, and this creates an emotional distance between us that leads to negative feelings.

Some felt they lacked the skills and knowledge to cope with the impact of the lockdown on their children’s behavior and emotions. They were uncertain how to explain the situation to their children and felt helpless and guilty regarding the interactions with them: “It’s difficult to set boundaries and I feel guilty about my functioning as a parent”; “Many hurdles in my parental authority arose due to the inability to leave the house.”

Many parents also reported increased conflicts and communication difficulties between the child with the disability and their siblings. One mother noted that “the situation of having a child with special needs and another healthy one creates multiple conflicts between them; the little one has learned to give up on many things for him”. Another stated that her child with disability “has to communicate all the time with his two siblings and it causes him great frustration because they have very rigid patterns and he fails to communicate with them.”

Alongside these difficulties, the prolonged lockdown was perceived as an opportunity for parents to gain deeper understanding of their child’s abilities and needs, strengthening their sense of parental competence by developing parenting skills tailored to their child’s needs. They consequently felt that their actions contributed to their child’s progress and development, which increased their sense of satisfaction and personal meaning: “Our relationship became closer. He is at home with me all day, I see his development daily and feel a significant part of it”; “I seem to have become my son’s therapist […] and it advances him greatly, and makes me happy and satisfied.”

Some also described positive aspects in the relationships between siblings such as the ability to play together for extended periods and learning new ways to communicate. One mother noted: “My 10-year-old son is on the autistic spectrum. During this period, he plays more with his 7-year-old sister […]. They even created new joint games.”

**Discussion**

This study examined experiences of parents of children with disabilities during the first COVID-19 lockdown in Israel. Findings revealed the far-reaching educational, social, and emotional impacts the lockdown has had on children with disabilities and the entire family system. Families faced a new and complex reality dominated by absent or reduced supports, mainly in the education and welfare systems. Parents experienced burden as they struggled to maintain a daily routine that involved juggling multiple tasks and roles, affecting their own wellbeing and family relationships.

Our findings regarding the burden and reduced wellbeing of parents of children with disabilities are consistent with previous studies showing that children with disabilities and their families are highly vulnerable during emergencies, including recent studies on COVID-19. Most importantly, in line with the social model of disability, our findings indicated that these highly burdensome experiences were the result not only of their child’s impairment, but also contextual factors, such as the failure of the education and welfare systems to adequately address children’s and families’ needs. Lack of or inaccessibility of service provision led parents to serve as their child’s teacher and therapist while juggling the demands of (un)employment, household tasks and other everyday responsibilities. In this sense, the COVID-19 crisis built upon and reproduced existing social hierarchies, exposing the rigidity and lack of responsiveness of formal services to children with disability and their families. As a consequence, the heavy weight of adapting to the situation was placed on the parents who were forced to cope alone and adapt themselves and their children to the maladapted system.

A key insight of the social model is that equity requires any policy, including emergency preparedness policies, to address the unique needs of people with disabilities. Otherwise, these so-called “general policies,” supposedly neutral and universal, often end up marginalizing people with disabilities or at least failing to address their needs. Indeed, various studies conducted both before and during the COVID-19 crisis have identified that emergency preparedness policies only seldom refer to people with disabilities, nor do so superficially without deep understanding of how emergencies uniquely impact people with disabilities and their families, and of the kind of tailor-made solution that are necessary.

Thus, by overlooking disability, COVID-19 policies have had adverse consequences for these children with disabilities and their families. A prime example is the closure of schools and the move to online learning. Previous studies have shown that such protective measures have negative consequences for most children and families. Our study reinforces those that indicate that children with disabilities and their families are disproportionally affected due mainly to the inaccessibility of the new form of learning, the need for various kinds of professional support that are routinely provided within schools, and the limited opportunities for social interactions outside the school system.

Furthermore, our study focused on how parents themselves experienced the crisis. A useful concept that captures the participants’ experiences is “parents’ disability”, which emphasizes the need to understand these parents as a unique social category, as they experience many of the discriminatory practices and attitudes their children face. The current findings point to the complex and fragile social space in which parents in disability operate in times of global crisis. Specifically, COVID-19 exposed and intensified the instrumental perception of parents of children with disability, which refers to policy makers’ frequent perception of these parents as being solely an instrument of treatment and rehabilitation for their children: they are expected to negotiate, advocate, and mediate their children’s needs. The theme of “octopus parenting” highlighted this perception of parents as being naturally expected and obligated to adjust to new roles as part of their “professional parent” identity.

Along with these difficulties and challenges, and consistent with recent studies which highlight the positive aspects of parenting of children with disabilities, some parents appreciated the lockdown period for the opportunity of being together as a whole family, and reported greater cohesion, improved relationships, joy and discovery of new family strengths. Some parents even found this period to be a time of relaxation and rest from the intense lifestyle and struggles that characterize the routine of raising child with a disability. Finally, some described an improved relationship with...
their child, characterized by better understanding of their needs, the ability to see strengths and abilities not acknowledged before, and the opportunity to tailor their care as parents to their children.

Importantly, our findings add to these recent studies by pointing how the positive experiences described by some of the parents were often enabled specifically by the experience of parenting a child with a disability. For example, the opportunity for parents to develop their parental competence and skills increased their sense of satisfaction and personal meaning. Such an experience was also found in pre-COVID studies, which pointed to the caring role of such parents, and the way it sometimes provided them with opportunities for fulfilling experiences, increased meaning, enrichment, and personal growth.2,4,52

Despite its contribution, the present study had several limitations. First, it was conducted during the first lockdown and thus the long-term impact of the pandemic could not be appreciated. Additionally, it was based on a convenience sample recruited via social media applications available only in Hebrew. Underrepresented were people from the ultra-Orthodox Jewish and Palestinian-Arab communities, less affluent parents, parents without access to technology and those who might have faced a burden too significant to spare time and attention to completing the questionnaire. Further, the wording of some of the open questions was not neutral but rather designed to elicit the challenges parents faced. Nevertheless, positive aspects of their experiences were spontaneously elicited. Finally, due to lack of data on the child’s educational setting, we were unable to reach a conclusion on how this key factor shaped parents’ experiences.

Conclusions

The results demonstrated the complex situation faced by families of children with disabilities due to lack of services accommodated to their needs. This situation imposed an additional burden on those families, emphasizing the need to provide them with tailored formal support in emergencies. The findings point to the need to accommodate children with disabilities and their families when planning for and responding to national and global emergencies: solutions should address not only physical health, but also emotional and social wellbeing.

Specifically, the results indicate that COVID-19 restrictions, particularly the closing of schools, have significantly limited families’ access to paramedical services. Thus, there is an urgent need to rethink the availability of emergency welfare services for these families at times of crisis. One solution is to upgrade the telehealth platforms to provide remote sustainable care programs for children but also parental consultations and psychological support. Finally, a more family-oriented practice is invaluable. Along with support for children with disabilities, the emotional burden of parents during this period—and always—must be considered, including in the form of guidance and counseling. Such services would do well to focus on the entire family system, connect the care to the environment and the barriers it poses on these families, and acknowledge the positive aspects of the parents’ experience.

Conflicts of interest

We have no conflicts of interest to declare.

References

1. Espe A, Munson J, Dawson G, Koehler E, Zhou XH, Abbott R. Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. Autism, 2009;13(4):375–387. https://doi.org/10.1177/1362361309105658.
2. Montes G, Halterman JS. Psychological functioning and coping among mothers of children with autism: a population-based study. Pediatrics. 2007;119(5):e1040–e1046. https://doi.org/10.1542/peds.2006-2815.
3. Burke MM, Hodapp RM. Relating stress of mothers of children with developmental disabilities to family-school partnerships. Ment Retard. 2014;52(1):13–23. https://doi.org/10.1353/mer.2013.0536.
4. Ryan C, Quinlan E. Whoever shouts the loudest: listening to parents of children with disabilities. J Appl Res Intellect Disabil. 2018;31:203–214. https://doi.org/10.1111/jar.12354.
5. Peek L, Stough LM. Children with disabilities in the context of disaster: a social vulnerability perspective. Child Dev. 2010;81(4):1269–1270. https://doi.org/10.1111/j.1467-8624.2010.01466.x.
6. Stough LM, Sharp AN, Resch JA, Decker C, Wilken N. Barriers to the long-term recovery of individuals with disabilities following a disaster. Disasters. 2014;38:437–410. https://doi.org/10.1111/dis.12151.
7. Shpigelman CN, Gelkopf M. The experiences and needs of individuals with disabilities exposed to chronic political violence. Disabil Rehabil. 2016;39(1):23–35. https://doi.org/10.3109/09638288.2015.1032064.
8. Evans S, Mikócka-Walus A, Klas A, et al. From “It has stopped our lives” to “Spending more time together has strengthened bonds”: the varied experiences of Australian families during COVID-19. Front Psychol. 2020;11. https://doi.org/10.3389/fpsyg.2020.00967.
9. Holmes EA, O’Connor RC, Perry VH, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. Lancet Psychiatry. 2020;7(6):547–560. https://doi.org/10.1016/S2215-0366(20)30081-1.
10. Li Z, Ge J, Yang M, et al. Vicarious Traumatization in the General Public, Members, and Non-members of Medical Teams Aiding in COVID-19 Control. Brain, Behavior, and Immunity. 2020. https://doi.org/10.1016/j.bbi.2020.03.007.
11. Di Palma M, Morales A, Delvecchio E, Mazzeschi E, Espada J. Immediate psychological effects of the COVID-19 quarantine in youth from Italy and Spain. Front Psychol. 2020. https://doi.org/10.3389/fpsyg.2020.579308.
12. degi Espinosa F, Mietko A, Raimondi M, Impenna M, Scognamiglio E. A model of support for families of children with autism living in the COVID-19 lockdown: lessons from Italy. Behav Anal Pract. 2020;1:9. https://doi.org/10.1007/s40617-020-00438-7.
13. Mowbray H. In Beijing, coronavirus 2019-nCoV has created a siege mentality. BMJ. 2020;368:m516. https://doi.org/10.1136/bmj.m516.
14. Ashbury K, Fox L, Denz E, Code A,roseub U. How is COVID-19 affecting the mental health of children with special educational needs and disabilities and their families?. https://doi.org/10.13234/osf.io/veydy; 2020.
15. Fergus JM, Vitiello B, Pleser PL, Clemens V. Challenges and burden of the Coronavirus 2019 (COVID-19) pandemic for child and adolescent mental health: a narrative review to highlight clinical and research needs in the acute phase and the long return to normality. Child Adolesc Psychiatr Ment Health. 2020;14:1–11. https://doi.org/10.1186/s13034-020-00325-3.
16. Theis N, Campbell N, De Leeuw J, Owen M, Schenke KC. The effects of COVID-19 restrictions on physical activity and mental health of children and young adults with physical and/or intellectual disabilities. Disabil Health J. 2021;14(3):101664. https://doi.org/10.1016/j.dhjo.2021.101664.
17. Monnickendam-Givon Y. Children with Disabilities during COVID-19; 2021 [Hebrew] https://sl.knesset.gov.il/globals/SHM/MM/083615c1c3c3e3-eb11-8127-104e0fa052a2_083651c3c3e3e3e2-eb11-8127-104e0fa052a2_11_18070.pdf.
18. Eshraghi AA, Crystal I, Alesiandri M, et al. COVID-19: overcoming the challenges faced by individuals with autism and their families. Lancet Psychiatry. 2020;7(6):481–483. https://doi.org/10.1016/S2215-0366(20)30197-8.
19. Neece C, McIntyre LL, Penning R. Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities. J Intellect Disabil Res. 2020;64(10):739–749. https://doi.org/10.1111/jir.12769.
20. Wain P, Patalay P, Molrecht B, McElroy E, Cresswell C. Report 02: Covid-19 Worries, Parent/carer Stress and Support Needs, by Child Special Educational Needs and Parent/carer Work Status. 2020. https://emergingminds.org.uk/wp-content/uploads/2020/05/Co-SPACE-report-02_03-05-20.pdf.
21. Willner P, Rose J, Sterndt Kruse B, et al. Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. J Appl Res Intell Disabil. 2020;33(6):1523–1533. https://doi.org/10.1111/jar.12811.
22. French S, Swain J. Whose Tragedy? towards a Personal Non-tragedy View of Disability. Sage, 2004.
23. Samadi SA, Abdullahi-Boghrabadi G, McConkey R. Parental satisfaction with school partnerships. Child Dev Care. 2020;64(10):739–749. https://doi.org/10.1111/jir.12769.
24. McLaughlin J, Goodley D, Clavering E, Fisher P. Families Raising Disabled Children: Enabling Care and Social Justice. London: Palgrave Macmillan; 2008. https://doi.org/10.1007/978-0-230-58351-1.
25. Kanter AS. The Development of Disability Rights under International Law: From Charity to Human Rights. Routledge; 2014.
26. Ryan S, Runswick-Cole K. Repositioning mothers: mothers, disabled children and disability studies. Disabil Soc. 2008;23(3):199–210. https://doi.org/10.1080/09669635.2008.1935397.
27. Shakespeare T. The social model of disability. In: Davis LJ, ed. The Disability Studies Reader. second ed. Routledge; 2006:197–204.
The Ministry of Health.

Preparedness of the Health System for In

Ministry of Justice Commission for Equal Rights of Persons with Disabilities. Accessibility Status in the Education System at the Start of the 2019-20; 2019 schoolyear [Hebrew] https://www.gov.il/he/departments/news/school_accessibility_situation_2019.

Gal J. The perils of compensation in social welfare policy: disability policy in Israel. Soc Serv Rev. 2001;75(2):225–244.

Yarkatzi D. Following Parents’ Complaints: Exceptions for Special Education Children Were Approved; 2020, March 28. Walla! News [Hebrew] https://news.walla.co.il/item/3349149.

Weisblau E. Treating Special Education Students in the Shadow of the Corona Pandemic: Initial information and possible points for discussion [Hebrew] https://knesset.gov.il/globaldocs/MMM/69d9bb96-806e-ea11-8104-00155d0aee38/2_69d9bb96-806e-ea11-8104-00155d0aee38_11_13764.pdf.

Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101. https://doi.org/10.1191/1478088706qr03oa.

Oliver M. The social model of disability: thirty years on. Disabil Soc. 2013;28(7):1024–1026. https://doi.org/10.1080/09687909.2013.818773.

Yates S, Dickinson H. Navigating complexity in a global pandemic: the effects of COVID-19 on children and young people with disability and their families in Australia. Publ Adm Rev. 2021;81(6):1192–1196. https://doi.org/10.1111/puar.13352.

Dimka J, Mamelund SE. 1918 influenza outcomes among institutionalized Norwegian populations: implications for disability-inclusive pandemic preparedness. Scand J Disabil Res. 2020;22(1):175–186. https://doi.org/10.16993/sjdr.725.

The Ministry of Health. Preparedness of the Health System for Influenza Pandemic; 2007 [Hebrew] https://www.health.gov.il/Subjects/emergency/preparation/DocLibitora/BIO_TORA/PANDEMIC_FLU.pdf.

Aishworiya R, Kang YQ. Including children with developmental disabilities in the equation during this COVID-19 pandemic. J Autism Dev Disord. 2020;1–4. https://doi.org/10.1007/s10803-020-04670-6.

Ameis SH, Lai MC, Mulsant BH, Szatmari P. Coping, fostering resilience, and driving care innovation for autistic people and their families during the COVID-19 pandemic and beyond. Mol Autism. 2020;11(1):1–9.

Yish-Am M. "Not against All Odds": Parents in Disability – A New Legal Paradigm (Unpublished Doctoral Dissertation). Israel: Haifa University; 2017 [Hebrew].

Darling RB. Toward a model of changing disability identities: a proposed typology and research agenda. Disabil Soc. 2003;18(7):881–895. https://doi.org/10.1080/0968759032000127308.

Read J. Disability, the Family, and Society: Listening to Mothers. : Open University Press; 2006.

Ryan S. People don’t do odd, do they? Mothers making sense of the reactions of others towards their learning disabled children in public places. Child Geogr. 2005;3(3):291–305. https://doi.org/10.1080/14733280500352920.

Blum LM. Mother-blame in the Prozac nation: raising kids with invisible disabilities. Gend Soc. 2007;21(2):202–226. https://doi.org/10.1177/089124320698178.

Brett J. The experience of disability from the perspective of parents of children with profound impairment: is it time for an alternative model of disability? Disabil Soc. 2002;17(7):825–843. https://doi.org/10.1080/096879002000039195.

Hastings RP, Allen R, McDermott K, Still D. Factors related to positive perceptions in mothers of children with intellectual disabilities: a systematic review and narrative synthesis. J Appl Res Intell Disabil. 2019;32(5):1255–1279. https://doi.org/10.1111/jar.12617.

Brighton C, Wills J. How parents describe the positive aspects of parenting their child who has intellectual disabilities: a systematic review and narrative synthesis. J Appl Res Intell Disabil. 2002;15(3):269–275. https://doi.org/10.1046/j.1468-3148.2002.00104.x.

Myers BJ, Mackintosh VH, Goin-Kochel RP. “My greatest joy and my greatest heart ache:” Parents’ own words on how having a child in the autism spectrum has affected their lives and their families’ lives. Res Autism Spectr Disord. 2009;3(3):670–684. https://doi.org/10.1016/j.rasd.2009.01.004.

Hastings RP, Taunt HM. Positive perceptions in families of children with developmental disabilities. Am J Ment Retard. 2002;107(2):116–127. https://doi.org/10.1352/0895-8017(2002)107%3C0116:PIFOCES2.E2.CO;2.

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