




Remote Support for Adults with Intellectual Disability During COVID-19: From a Caregiver's Perspective

Klaudia Wos* , Celina Kamecka-Antczak† , and Mateusz Szafranski† 

*Interdisciplinary Doctoral School of Social Sciences, Nicolaus Copernicus University in Toruń, Torun, Poland; and †Faculty of Philosophy and Social Sciences, Nicolaus Copernicus University in Toruń, Torun, Poland

Abstract

The reality of people with ID changed during the pandemic COVID-19. Most institutions supporting people with ID switched to remote work. This required some major adaptation to these individuals' new realities, their immediate families, and facility staff. Supporting and monitoring the quality of life of individuals with disabilities and their family members during a crisis is an essential topic of current research. This research project aimed to explore the experiences of parents of adults with ID in relation to remote support provided by public support agencies. In a qualitative study, the authors used semistructured individual interviews with caregivers of people with ID. Data analysis distinguished the following categories: parents as therapists, organization difficulties, material problems, lack of social contacts, positive solutions, and difficult behavior. The results show the difficulties of parents in balancing professional, domestic, and supporting tasks. The study was the first in Poland to report on the qualitative assessment of remote support for people with ID during COVID-19. Further, more extensive research is needed to search for solutions that respect the rights of people with disabilities to professional support.

Keywords: adulthood, ID, parents, practice, remote support

Background

The COVID-19 (coronavirus) pandemic is considered the greatest public health challenge of the 21st century to date (Gulati, Fistein, Dunne, Kelly, & Murphy, 2020). Nowadays, intensive research is being conducted on the quality of life of people with ID (Linehan et al., 2020; Mills et al., 2020). The research also concerns groups such as people with autism spectrum disorders (Houting, 2020), mental health service users (Kelly, 2020), or people with other types of disabilities (Jalali, Shahabi, Lankarani, Kamali, & Mojgani, 2020). This is because it is apparent that there is a lack of quickly implementable solutions to meet the needs and rights of people with disabilities in a time of crisis (European Association of Service Providers for Persons with Disabilities (EASPD), 2020). Very soon, questions began to be asked about how to support people with disabilities these days (Boyle, Fox, Havercamp, & Zubler, 2020; Turk & McDermott, 2020). It is also important because the ongoing process of holistic support and inclusion of people with ID has been disrupted and requires immediate attention (Luckasson & Schalock, 2020).

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Correspondence: Klaudia Wos, Doctoral School of Social Sciences, Nicolaus Copernicus University in Torun, Collegium Humanisticum, W. Bojarskiego 1 street, 87-100 Torun, Poland. Tel: 516 373 486; E-mail: k.wos@doktorant.umk.pl

People with ID are particularly exposed to the physical, psychological, and social effects of the COVID-19 pandemic (Courtenay, 2020). In terms of incidence, they are more vulnerable to infections and a severe course of disease due to frequent comorbidities (cardiac, metabolic, or respiratory) (Cuypers et al., 2020; Landes, Turk, Formica, McDonald, & Stevens, 2020; United Nations, 2020). According to the most recent report analyzing TriNetX data in terms of case-mortality trends from COVID-19, people with developmental and intellectual disabilities are exposed to a more significant case-mortality trend due to more frequent comorbidities (Turk, Landes, Formica, & Goss, 2020). The difference in COVID-19 mortality between people with and without intellectual and developmental disability (IDD) is measurable (Turk et al., 2020). The emphasis on maintaining social distance is mandatory. However, it causes many other difficulties in organizing technology-based support (Hughes & Anderson, 2020).

In addition, focusing on people with ID-limited cognitive abilities can lead to difficulties in understanding the nature of what is happening, the reasons for home isolation, and hygiene standards (Courtenay & Perera, 2020). Research shows that quarantine is associated with negative emotions such as anxiety, frustration, boredom, or restlessness resulting from a lack of information (Brooks et al., 2020). For people with ID, the change in the rhythm of life, the appearance of many new prohibitions and restrictions, and the occurrence of negative emotional states can trigger stress, cause or exacerbate mental

disorders, or lead to the escalation of negative behaviors (Courtenay & Perera, 2020; Navas, Amor, Crespo, Wolowiec, & Verdugo, 2020). Also, research on the situation of people with ID should include their immediate family, as they do not live fully independently (Rose et al., 2020).

Key barriers to overcome include limited access to professional care and effective implementation of remote support forms (Zaagsma, Volkers, Swart, Schippers, & Van Hove, 2020). Barriers can stem from cognitive difficulties in understanding information technology and lack of access to phones or computers due to poverty (Inclusion Europe, 2020). On July 8, in response to the Inclusion Europe petition, the European Parliament (2020) passed the Resolution on the Rights of People with Intellectual Disabilities and Their Families in the COVID-19 crisis. In addition to the critical issue of limited access to health services, the petition authors also point to access to professional care. Currently, researchers and professionals are asking: *How can remote care be organized?* or *Who takes responsibility for ensuring high-quality services?* (Alexander et al., 2020).

We conducted the research in Poland, which implies specific sociocultural and political backgrounds. In order to show how adults with ID function in Poland, it is important to present the available forms of support. After completing compulsory education (in most cases in special schools¹), they are usually clients of day centers providing occupational therapy and rehabilitation. Regardless of the degree of disability, most adults with ID in Poland (except those with profound disabilities) attend these institutions (Occupational Therapy Workshops (OTW), there are less than 800 centers for about 30,000 people throughout the country). They are public and free of charge and based on state regulations. The priority of these institutions is to develop social and vocational skills. Despite legal regulations, in most cases, the support provided does not lead to employment in the open or subsidized labor market. Polish reports show that less than 1% of these institutions' clients find a job each year (PFRON, 2014). The forms of support offered by these institutions are diverse and depend on the needs of the clients (e.g., psychological therapy, sports activities, social skills training, rehabilitation exercises, speech therapy, and assistance in developing key skills for functioning in everyday life, such as maintaining hygiene, cooking, or cleaning). Activities take place Monday through Friday for 8 h at a time. Efforts to encourage the independence of people with ID, such as support for employment on the open market or supported housing, are still insufficiently implemented in Poland and are organized outside the system, mainly by NGOs. Therefore, the most common form of support for adults with ID in Poland is institutional support. We focused our research on adults with ID who are clients of such institutions and still live with their parents (carers).

The reality of people with ID described above changed overnight. The COVID-19 epidemic requires everyone to function under changed conditions (Buheji, 2020; Hughes & Anderson, 2020). In Poland, all educational institutions, universities, and institutions supporting people with disabilities

(including OTW) were closed in mid-March by the state authorities' decision. The sudden and prolonged closure led to a transition to a remote mode of support. Most of these previously mentioned facilities were closed completely or temporarily during the nationwide lockdown due to the coronavirus cases. Currently, as we enter 2021, the situation has not changed significantly.

The responsibility for day-to-day care and supervision fell more heavily on the caregivers. Their previously stable lives (when their adult offspring were in a care facility) were disrupted for the lockdown duration. Immediate family members became teachers, therapists, and conversation partners (replacing peers). However, they had to remain employees and parents and fulfill their domestic responsibilities. The situation for parents of adults with ID has become highly challenging, resulting in decreased mental health (Willner et al., 2020). Researchers suggest that carers received far less support than they needed, not only from professionals but also from immediate family and friends (Harris, 2020; Willner et al., 2020). Access to information and possible support forms was also a significant problem, particularly in the pandemic's early period (Willner et al., 2020).

Methods

Design

This article presents a research project conducted from May to July 2020, when almost all daycare centers in Poland were closed and operating remotely. We conducted the study using semistructured qualitative interviews with parents of adults with ID. The research project aimed to explore their experiences related to remote support provided by public institutions. The project asked the following research questions:

1. How do parents of adults with ID describe the process and quality of remote support during the lockdown caused by the COVID-19 pandemic?
2. From the parents' point of view, what were the biggest problems in introducing and implementing remote support forms?
3. What solutions/changes to remote forms of support for adults with ID do parents suggest?

Selection and Recruitment

The selection of participants for the project was purposive (Creswell, 2013). An invitation was sent to 36 geographically closest public day care facilities (OTWs) to conduct the research. After meeting and presenting the objectives of the research project, 10 facilities decided to participate. Thanks to their cooperation, we conducted the interviews with parents in individual online meetings (using widely available instant messengers). All institutions attended by adults with ID were located in urban areas. Invitations to participate in the study were sent to all caregivers (parents of their adult clients) by e-mails in the 10 selected facilities. Then, they were given a set

¹More information about the Polish education system for people with disabilities can be found here: Gil M. (2007). From segregation to equalization: The Polish perspective. *Journal of Contemporary Issues in Education* 2(1), 40–52.

time limit to respond. Finally, two individuals in each facility volunteered to participate.

Participants were 22 parents (16 mothers and 6 fathers) of adults with ID (aged 23–50). All had a certificate of moderate or severe ID and lived with their parents. Caregivers were selected according to the following criteria: they were the primary caregiver of an adult with ID, had a son or daughter attending a daycare facility, and were willing to participate in the research project. Each of the 22 interviews focused on a different person with ID. The caregivers did not know each other as they lived in different locations.

Procedure

Before the interviews began, we explained the study's purpose to participants and assured them that the study would be completely anonymous and confidential (Babbie, 2006). Parents were assured that they could withdraw from participation in the project at any time or refuse to answer any questions they found uncomfortable. Informed consent to participate in the study was given verbally due to the form of the research. The Institutional Review Board approved the research project at Nicolaus Copernicus University in Toruń. Interviews lasted between 45 and 60 min and were conducted at a time and place convenient to the participants. The names of the interviewees were coded—we assigned pseudonyms according to the following pattern: C1 = Caregiver 1, C2 = Caregiver 2.

Analysis

Each interview was recorded (with the consent of the interviewees) and transcribed verbatim. Before we began the analysis, all project participants approved the Polish version of the interview transcript. A professional translator translated the Polish transcription into English. The authors, who are fluent in Polish and English, approved the translation. Next, we analyzed the collected materials in English and compared the two language versions to avoid interpretative mistakes. The data were analyzed in the coding and categorization procedure according to guidelines suggested by Flick (2018) and Creswell (2013). In the first step, the data followed an open coding procedure. Then, the categories were formed by the first author and reviewed by the research team. Finally, we clarified any discrepancies together as a research group and identified the following categories:

- A. Parent as therapist.
- B. Organization difficulties.
- C. Material problems.
- D. Lack of social contacts.
- E. Positive solutions.
- F. Difficult behavior.

Results

Remote support offered to individuals with ID took a variety of forms. The most common forms were video calls and video

TABLE 1
Themes and subthemes generated by the analysis

| Theme | Subthemes |
|---------------------------|---|
| Parent as therapist | Required of constant support Lack of time Fear of losing skills Difficulty in taking up a job Lack of independence No variation of tasks Lack of professional rehabilitation equipment Low frequency of meetings |
| Organization difficulties | Need for assistance Respite care Lack of support in daily duties Need for hybrid solutions (combination of face-to-face and online meetings) Lack of digital skills |
| Material problems | Need for financial support Lack of money to purchase electronic devices (printer, scanner, notebook) Appearance of unexpected expenses |
| Lack of social contacts | Missing friends Loss of opportunities to develop social skills Loneliness Low frequency of meetings |
| Positive solutions | Adapting tasks to the needs and possibilities Constant contact Possibility of video meetings |
| Difficult behavior | Unwillingness to do tasks at home Aggressive behavior Emotional agitation Refusal to cooperate |

or audio recordings suggesting tasks for the day. Facility staff also emailed written assignments with instructions. Less frequently used forms included telephone calls. Table 1 shows the themes and subthemes constructed from the analysis process.

Parent as Therapist

Home isolation forced me to constantly be with my daughter and help her do tasks. (C3)

During the interviews, parents often mentioned difficulties in organizing their time—combining their professional, domestic, and therapeutic duties (C21: “Every morning I worked together with X. Then a quick lunch and back to work. It was very hard for me to find time for everything”). A significant difficulty was also the lack of access to special equipment for the necessary rehabilitation exercises (C1: “My son needs special exercises for his spine, and I couldn't do it at home because we don't have such equipment”). Often, caregivers also pointed out the low diversity of the institution's staff's support—most of

their suggestions were computer-assisted tasks, mainly concerning basic skills such as reading, counting, or writing. The tasks were not adapted to the needs of adults and the development of their competencies. The caregivers most often took on the professional's role—organizing the day for their adult children and planning their activities' scope.

Material Problems

The possibilities at home are much smaller. At the institution, there is more equipment and more therapeutic aids. We can't afford to buy them. (C2)

The range of opportunities for activities undertaken at home was significantly reduced. This is related to the material problems that the caregivers pointed out. Some of them also had limited access to a computer or printer and could not afford to buy a new one (C18: "When my other son was doing online activities we couldn't use his laptop and we also need it for work but we didn't have the money to buy another"). For adults with severe disabilities, access to rehabilitation devices was much more difficult. However, simply having access to electronic devices that allowed constant contact with an institutional staff was also limited—once all household members went into a remote mode, the number of devices was insufficient.

Lack of Social Contacts

The absence of peers was the worst. My son has become withdrawn. (C20)

One of the most frequently mentioned problems was the lack of contact with friends experienced by the person with ID. Caregivers expressed concern about their adult offspring's social development, as the facility was the only place for them to meet others outside of the family environment (C15: "Meetings at the institution are very beneficial for my son. He talks to his friends on the phone, but it's not the same"). They also indicated that contact with other institutional clients was an essential part of their adult children's lives and helped them develop a sense of well-being. The proposed forms of contact between the professional staff and the person with ID did not include solutions to enable them to be in contact with their friends (C1: "X no longer has the kind of contact with his friends that he used to have, and he misses them very much").

Difficult Behavior

Sometimes I believed I wasn't coping with my own child. He worked and worked, and then suddenly he threw himself on the floor. He wouldn't do anything anymore. (C12)

Organizational difficulties, changes in daily routines, lack of contact with friends and institutional staff, and the emergence of new rules and regulations (e.g., home isolation) could cause

another problem often reported by caregivers. An increase in difficult behaviors and unwillingness to cooperate with the parent caused frustration and exacerbated an already complicated family situation. Working systematically to motivate adults to pay attention proved to be a significant challenge (C22: "X was tired of it all. She often refused to comply with instructions, shouted, and got irritated"). Parents also had to deal with this problem independently—without the support of professionals who had limited ability to respond quickly.

Organization Difficulties

Every morning I worked together with X. Then a quick lunch and back to work. It was very hard for me to find time for everything. (C21)

Family caregivers usually mention the need for assistance with daily activities, such as shopping or cleaning. The problem of respite care is still not sufficiently solved in Poland, and the pandemic made it more urgent to introduce new solutions in this regard (C3: "I would like someone to do the shopping for me or take care of my daughter so that I can go out and get things done in the meantime"). The current situation also revealed the low digital skills of the carers. Previously, they did not feel the need to use the internet or advanced software, which meant that their digital skills were low, making it difficult for them to help their adult offspring, for example, to attend online meetings (C22: "Someone would have to teach us how to use a computer. I have a problem with that"). One way that parents suggested was to meet in a hybrid format, such as organizing meetings in the garden (C21: "Let the activities be online, but the staff should also come and conduct meeting in the garden. It is safer there, and I will have some free time"). An essential issue here is the permanent care of an adult with a disability—parents were very often concerned about leaving their adult child alone at home without controlling what was happening.

Positive Solutions

My son missed his caretakers from institution very much. Fortunately, they could see and hear each other regularly. (C16)

Some facilities' positive solutions included adapting tasks to the individual's developmental level and professionally prepared guidance (C4: "All tasks were suited for my son. I am happy they were because this made it easier to explain"). In some cases, there was also an opportunity to consult problems with professional staff (C21: "I could phone my son's therapist and ask whenever I didn't know something"). However, these standards are not met by all facilities attended by people with ID, leading to widely differing opinions about the quality of distance care. In some cases, meetings with staff via video conversations took place regularly and almost daily. In contrast, some parents mentioned very infrequent contact from professional carers (C15: "Meetings should take place more often. One session a week on the webcam is not enough"). However, the vast

majority of respondents pointed to insufficient support. A significant problem is the lack of official state guidelines that would serve as a reference for the implemented practices.

Discussion

The Family's Role

Family plays a crucial role in supporting adults with ID during a pandemic (Alexander et al., 2020). This is also evident from the survey where almost 73% of the respondents ($N = 582$) identified the family as a support source. In comparison, professionals ranked second (37%) (Navas et al., 2020). However, this situation can lead to family overload (Courtenay, 2020). Having professional care in an institution gives parents a sense of security that the adult child's development is stable. Even though caregivers are optimistic about the frequency and quality of remote support, they fear that the home environment's lack of professionalism could lead to a regression in their adult offspring's skills. This fear (along with parents' high level of engagement in providing support in home conditions) may also have resulted in supportive tasks being brought to the forefront of family relationships (Rose et al., 2020).

The parents interviewed felt enormous pressure on the quality of support they could offer their adult children. To contribute to the good psychological well-being of people with ID and their caregivers, remote support services provided by professionals should not burden parents with therapeutic tasks but relieve them (Zaagsma et al., 2020). Even though their offspring were adults, parents did not allow them the opportunity to participate in video meetings or complete assignments independently. Because they still treated them as "little children," anxiety about them, disbelief in the possibility of acquiring new skills, and efforts to prevent regression became more important than their development and striving for independence (Lee, Park, & Recchia, 2015; Mansell & Wilson, 2010; Yoong & Koritsas, 2012). It was also essential for parents to have constant contact with professionals. The caregivers who experienced such contact rated the quality of remote support higher in their responses. This is one of the standards that need to be implemented. Regular contact with the professionals makes it possible to continuously monitor the person's functioning, follow the progress in their work, and make changes in the applied interventions if necessary.

Social Contacts

Experiencing isolation, fear, and loneliness is expected in the current pandemic situation (Brooks et al., 2020). Even before the epidemic, people with ID and their immediate environment experienced these feelings much more frequently than the general population (Gilmore & Cuskelly, 2014). It has been pointed out that people with ID are more vulnerable to loneliness (i.e., they experience it more often and, more importantly, they experience its negative consequences for mental and physical health more strongly). Suppose they are initially in poorer

health and physical condition due to diseases and disorders that accompany their condition. In this case, the current experience of loneliness associated with the COVID-19 pandemic is a particular threat that further exacerbates the preexisting condition by intensifying physical and mental problems (Turk & McDermott, 2020). One of the factors may be reduced social contact. Most of the social contacts of people with ID are limited to those created by their facility presence. A practical solution here would be to harness social media's power and prepare those who do not yet use it to maintain social relationships. Recent preliminary studies show that appropriate use of remote forms of support can benefit individuals with ID by increasing their sense of safety and connecting with others even more frequently than before the pandemic (Tassé, Wagner, & Kim, 2020).

Support Planning

Luckasson and Schalock (2020) emphasize the need for a holistic and integrated approach to planning support for people with ID during a pandemic. While concern for health and life safety is essential (which is provided by home isolation), we should not forget other aspects that make up the holistic well-being of people with ID, including access to support, professionals, peers, and community inclusion. These are aspects that have been developed over the years in both public policy and individual approaches. The authors emphasize the need to plan support so holistically that none of these aspects are neglected. The prepandemic calls for social justice or inclusion of people with ID are still relevant and remain so after the crisis (Luckasson & Schalock, 2020).

Limitations of the Study

Extensive research on the impact of COVID-19 on people with ID /IDD and their caregivers is ongoing (Linehan et al., 2020). Our study was the first in Poland to present the evaluation of remote support for people with ID during COVID-19. It is necessary to conduct further, more extensive research to generalize the results and find appropriate support options. We were able to conduct the interviews thanks to the cooperation of local support institutions. However, some institutions declined to participate in this research. This possibly resulted from the fear of parents' negative opinion about the forms of distance support they organized.

Besides, some parents did not agree to participate in the study. Numerous reasons for these decisions can be suspected. For example, parents' constant requests to participate in various surveys and interviews, their irritation with the situational chaos caused by distance therapy, or their disbelief in the possibility of change (e.g., systemic changes in institutions' functioning support people with ID). Our study's findings cannot be generalized to the entire population of people with ID and their caregivers, but we highlight some challenges that are worth considering. They may be valuable to practitioners and policymakers planning the functionality of emergency support systems.

Conflict of Interest

No conflicts of interest have been declared.

Ethical Conduct Statement

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants involved in the study. The research project was approved by the Institutional Review Board at the Nicolaus Copernicus University in Toruń.

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