

A qualitative study on parents' concerns about adult children with intellectual disabilities amid the COVID-19 pandemic in South Korea

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Abstract

Background: This study aimed to understand parents' concerns about their adult child with intellectual disabilities due to the restriction of community-based services amid the COVID-19 pandemic in South Korea.

Methods: In-depth interviews were conducted face-to-face or by telephone with 19 parents of adult children with intellectual disabilities who had to stop using community-based services.

Results: Participants worried that their adult child was not aware of the seriousness of COVID-19, was more susceptible to the COVID-19 virus, could not recognize self-infection and could have fatal consequences of getting infected with COVID-19. They expected challenges in their adult child's life (losing a daily routine, being isolated, regression in skills, becoming bored, lacking physical activities and increased behavioural challenges) but also experienced adjustments and hopes.

Conclusion: The study demonstrated parents' worry about their adult child becoming infected with COVID-19, highlighting the urgent need for community-based services to address psychosocial challenges during the pandemic.

KEYWORDS

COVID-19, intellectual disability, parents, South Korea, worries

1 | INTRODUCTION

The coronavirus disease 2019 (COVID-19) pandemic has been a serious global issue. Since the first case was identified on 20 January 2020, in South Korea, COVID-19 has continued its spread, and the Korean government implemented a three-level social distancing scheme depending on the severity of the infection, classified into Levels 1 to 3. In response to the COVID-19 outbreak in February 2020, the government asked citizens to self-isolate under social distancing rules (Level 2: no private or public indoor gatherings of more than 50 people or outdoor gatherings of more than 100 people). As the pandemic evolved, South Korea loosened its social distancing rules to a more relaxed 'distancing in daily life' (Level 1: sustainable way of life and social interactions that prepare society for the possibility of long-term prevalence of COVID-19; Korea Central Disaster

& Safety Countermeasures Headquarters, 2020). This allowed the phased reopening of facilities that had been shut down amid the coronavirus outbreak between May and August 2020. However, the policy returned to Level 2 social distancing in August 2020 as the risk of COVID-19 resurged, again restricting social care services for people with disabilities.

Although data on COVID-19 trends among people with intellectual and developmental disabilities are lacking, these individuals are known to be more vulnerable to the COVID-19 pandemic (Courtenay & Perera, 2020; Cuypers et al., 2020; Landes, Turk, et al., 2020). They have a higher rate of mortality due to pneumonia (Landes, Stevens, & Turk, 2020) compared to people without disabilities, and they also experience a higher prevalence of comorbidities associated with poorer COVID-19 outcomes (i.e. disease severity and mortality; Turk & McDermott, 2020).

Under a government policy to protect people who are vulnerable to serious illness, most day programmes and other social services for people with disabilities, which had been provided by community welfare centres, were shut down. Community care and support services are very important for people with disabilities to lead a self-reliant life in the community, and those services were not being provided, which may bring additional challenges (Armitage & Nellums, 2020; Brondino et al., 2020). Due to the spread and prolonged crisis of COVID-19 and suspended community support, family caregivers of adult children with disabilities likely also face increasing challenges. It is important to understand the unique concerns of parents as the main caregiver and major source of support for adult children with intellectual disabilities. Recently, concerns related to COVID-19 have been studied among parents of children with chronic illness, such as paediatric liver transplant recipients (Menon et al., 2020) or paediatric cancer (Darlington et al., 2021). Only a handful of empirical studies has focussed on the impact of COVID-19 on families of people with intellectual and developmental disabilities (Linehan et al., 2020; Neece et al., 2020; Redquest et al., 2020; Willner et al., 2020). However, few empirical studies have explored parents' concerns about their adult children with intellectual disabilities, who are often dependent on community-based services that were reduced during the pandemic.

This study aimed to explore parents' concerns regarding the challenges of their adult child with intellectual disabilities during

the COVID-19 pandemic in South Korea. The research question is: What are parents' concerns about their adult child with intellectual disabilities during the COVID-19 pandemic? Given the absence of community services, this study considered the concerns of parents who were taking care of a child with intellectual disabilities and highlighted their needs. Understanding parent-caregivers' concerns could help healthcare professionals and stakeholders of community support services develop and provide targeted education and resources for this population to address concerns and improve their quality of life in the community during the COVID-19 pandemic.

2 | METHODS

2.1 | Participants

Participant selection criteria were as follows: main caregivers of an adult child who (a) was registered to have an intellectual disability under the Act on Welfare of Persons with Disabilities in South Korea and (b) had used day services in community welfare centres prior to their closing due to COVID-19. As shown in Table 1, 18 mothers and one father participated in in-depth interviews. Participants' demographic information, such as their age and whether they live with a spouse and take care of other children, and their adult child's demographic and disability information are

TABLE 1 Participant characteristics (N = 19)

Parent						Adult child with intellectual disability		
Pseudonym	Age	Gender	Education	Living with spouse	Adult children without disability	Age	Gender	Disability severity
Somi	56	Female	High school graduate	Yes	None	22	Male	Severe
Naeun	58	Female	High school graduate	Yes	None	31	Male	Mild
Yuri	64	Female	High school graduate	No	None	40	Male	Severe
Sumin	77	Female	University graduate	Yes	1	45	Male	Moderate
Haeun	65	Female	Elementary school graduate	Yes	1	27	Male	Severe
Yeri	55	Female	2-year college graduate	Yes	1	28	Male	Moderate
Hyena	52	Female	High school graduate	Yes	1	24	Female	Moderate
Daeun	55	Female	High school graduate	Yes	1	27	Male	Severe
Minji	52	Female	University graduate	Yes	1	21	Male	Severe
Sujin	54	Female	High school graduate	No	None	26	Male	Severe
Bora	59	Female	University graduate	Yes	None	31	Male	Moderate
Sohee	58	Female	2-year college graduate	Yes	1	28	Female	Severe
Eunji	50	Female	High school graduate	Yes	1	24	Male	Severe
Jiwon	59	Female	High school graduate	Yes	1	29	Male	Moderate
Somin	47	Female	High school graduate	Yes	1	21	Male	Severe
Yena	64	Female	Graduate degree	Yes	None	37	Female	Moderate
Eunmi	59	Female	2-year college graduate	Yes	1	33	Female	Mild
Junho	53	Male	University graduate	Yes	3	24	Male	Moderate
Yunji	53	Female	High school graduate	Yes	1	26	Male	Moderate

described in the table as factors that may influence their interaction with their adult child with intellectual disabilities. The parents' ages ranged from 47 to 77, with a mean age of 57.36 ($SD = 6.76$). Eleven participants were high school graduates or lower and eight participants had completed 2-year college or were university graduates. Seventeen of the participants were living with a spouse and two were not. All participants were living with their adult child at home. Thirteen participants had other adult children without intellectual disabilities. Given these characteristics of the participants, the study findings can be transferrable to middle-aged and older parents who are the main caregivers of adult children with intellectual disabilities living in the community.

Participants' adult children ranged in age from 21 to 45 years old ($M = 28.63$, $SD = 6.42$). Of the 19 adult children, 15 were male and four were female. Under the Act on Welfare of Persons with Disabilities in Korea (Korea National Law Information Center, 2017), all adult children of the participants had a 'severe' classification of intellectual disability, which refers to an IQ score below 70. Specifically, nine adult children had severe levels of disability (IQ score below 35) with high support needs because of remarkable difficulty in adapting to daily and social life. Eight had moderate levels of disability (IQ score between 35 and 50), meaning they can learn the simple behaviours of everyday life with some supervision and help. They could go by themselves to limited places they had learned to visit (e.g. community centre). Two had mild levels of disability (IQ score between 50 and 70), meaning they were capable of social and vocational rehabilitation through education. They had the ability to access the community more independently. Of these 19 individuals, three were nonverbal and the rest could use verbal communication either occasionally or frequently.

Prior to COVID-19, adult children with intellectual disabilities received various day services such as lifelong education, vocational rehabilitation, and other recreational programmes in community welfare centres. Amid the pandemic, although regular face-to-face services at the centre were suspended, seven participants reported that their adult child received 'emergency services' involving one-on-one caregiving; 12 reported that online services were occasionally offered.

2.2 | Procedures

Participants were recruited using purposive sampling in July 2020. To recruit the participants, study announcements outlining the study purpose, inclusion criteria, procedures and contact information of the researchers were sent out via email to community welfare centres that provide services for people with disabilities but had been shut down due to COVID-19 and are located in metropolitan areas (i.e. Seoul, Incheon and Gyeonggi) of South Korea. Then, the research team verbally explained the purpose and procedure of the study to the director or staff members of several agencies and asked them to deliver the study announcement to

eligible individuals. The study announcement was also posted on the research team's social networks (Facebook and Instagram) to recruit participants. Twenty-two participants voluntarily contacted the research team, but three did not meet the inclusion criteria of disability type and service use. Thus, 19 parents participated in the interviews.

The study was approved by the institutional review board of the Sungkyunkwan University with which the principal investigator (the first author) is affiliated. Prior to the interviews, all potential participants were informed about the study purpose and interview procedures via online chat or telephone. Written consent forms with detailed information about the study were obtained from all participants. Then, the researchers arranged the time and mode of interview (i.e. face-to-face or telephone) with each participant.

In-depth individual interviews were conducted by three researchers in July 2020. Two researchers (MAK and SMJ) have PhDs in social work and experience conducting qualitative studies with people with intellectual disabilities, and the other researcher (SH) was a master's student in social work who has clinical experience with people with intellectual and developmental disabilities. Because of restrictions related to the COVID-19 situation at the time of the study, 11 in-depth interviews were conducted via telephone. Eight participants were not comfortable sharing their experiences via telephone or preferred in-person interviews; thus, face-to-face interviews were arranged and conducted at a private space that allowed for sufficient social distancing precautions to ensure the safety of research participants.

Participants were asked to openly talk about their experiences with their adult child with intellectual disabilities during the COVID-19 pandemic. The interviews began with a question to help build rapport with the participants and then proceeded with semi-structured questions developed by the research team in advance based on literature reviews and short interviews with potential participants. The present study is part of a larger project, in which the interviewers asked questions about the life challenges of the participants and their adult children with intellectual disabilities during the COVID-19 pandemic. Responses about participants' worries regarding their adult children with intellectual disabilities and overall life challenges were included in this study. The main questions we used were: 'What challenges does your adult child with intellectual disabilities face during the COVID-19 pandemic?' and 'What are you worried about regarding your adult child with intellectual disabilities during the COVID-19 pandemic?' Interviews lasted between 40 and 60 min, and all participants received a 30,000 won (equivalent to about 25 dollars) gift certificate for their participation at the end of the interview. The interviewers' reflections and field notes written at the time of the interview were immediately shared with the research team members and new findings from the interview were discussed. The research team discussed whether to keep recruiting more participants. When the team reached consensus that the data had reached saturation, the recruitment and interview process ended.

2.3 | Data analysis

Recordings of the interviews were transcribed verbatim. Common themes and patterns among participants were identified according to the six-step method of thematic analysis suggested by Braun and Clarke (2006). Using ATLAS.ti software, three researchers (MAK, SH, and JS) read the transcripts until they felt familiar with the contents of all transcribed materials, then independently assigned open codes to each phrase and sentence from each transcript. Then, we reviewed each code and compared the codes. Similar codes were organized to capture the common meanings of the initial codes. Researchers both independently and collectively searched for subthemes and themes by reviewing the grouped codes and associated quotes. Refined subthemes were collated under two major themes after inconsistent choices were resolved among the research team members. After repeated reviews and discussions among researchers, definitions and titles of the themes that represented the essential meanings of the parents' perceptions of their adult child's life changes after COVID-19 were identified. We made sure the titles of the themes were consistent with the content and the description was supported by verbatim extracts from the transcripts. Finally, we selected quotes that were the best example of the context of each subtheme.

3 | RESULTS

As Table 2 shows, findings from the thematic analyses yielded two themes and 11 subthemes related to the parents' worries about their adult child with intellectual disabilities.

3.1 | Concerns related to keeping adult child safe from COVID-19 infection

3.1.1 | Not being aware of the seriousness of COVID-19

All participants worried that their child would be exposed to the COVID-19 virus due to low awareness of the seriousness of COVID-19. Although some participants said that they did not know how their adult child perceived COVID-19 because of poor communication, most participants mentioned that their adult child seemed not to recognize the seriousness of the COVID-19 pandemic and how detrimental COVID-19 could be to their health.

Thus, it was difficult for their adult child to follow public health guidelines such as not going to high-risk places or wearing a mask. Many participants were worried that their adult child might not wear a mask properly when using public transportation alone (even though wearing a mask is mandatory when using public transportation in South Korea due to the pandemic). Participants continuously told their adult child that they should wear a mask and should not touch things in public places, but their adult child seemed to not understand well and failed to keep themselves safe from the COVID-19

virus. Participants were worried because their adult child often was not patient and had difficulty controlling their behaviours and thus, it took a long time to form the habit of wearing a mask and following public health guidelines. Worrying that their adult child might not follow public health guidelines made the participants prohibit their child from going out alone and using public transportation, despite their adult child's wishes.

3.1.2 | Being more susceptible to the COVID-19 virus

Most participants said they felt extremely anxious about the risk of infection because they thought their adult child with intellectual disabilities was more vulnerable to COVID-19 than people without intellectual disabilities. They thought that their adult child was more likely to get infected when exposed to the COVID-19 virus because of a weak immune system, although many did not provide specific reasons why their immune system would be weaker. However, five participants mentioned that their adult child experienced medical conditions, such as hypothyroidism, epilepsy with seizures, and heart problems, and currently or previously took medications. Parent worried that these pre-existing conditions would make the adult child more susceptible and vulnerable to the infection. Thus, they thought that COVID-19 might be fatal for their adult child with intellectual disabilities.

3.1.3 | Lacking information about COVID-19 and not recognizing the infection

Some participants were worried that their adult child may get exposed to the virus due to the lack of information about COVID-19. In South Korea, once an individual tests positive for COVID-19, known affiliated public community centres announce the patient's contact routes from the day they started having symptoms to the day they were hospitalized on a website so that other citizens can be aware of possible exposure to the virus. The public frequently checks such information to avoid places where patients visited, but participants said their adult children were more vulnerable because they lacked such information and strategies to avoid the risk of infection.

Their adult child might not easily recognize their physical symptoms and bodily changes if positive for COVID-19. Furthermore, their adult child might not be able to communicate their infection to others due to the lack of communication skills and in some cases, nonverbal status. Therefore, the participants mentioned that extra careful monitoring is needed for their adult child.

3.1.4 | Possible consequences of getting infected with COVID-19

Participants showed fear and anxiety when they described possible consequences of their adult child becoming infected with

TABLE 2 Themes, subthemes, and quotations

Theme 1 Concerns related to keeping adult child safe from infection of COVID-19	
Not being aware of the seriousness of COVID-19	<p>I'm worried about my child not wearing a mask properly while using public transportation. If he wears it, he puts it under the chin because it is difficult to breathe with the mask on. He's claustrophobic, so he doesn't want to wear a mask. Even if I told him to wear a mask, he takes it off right away if I am not with him. (Yeri, mother of son with intellectual disability aged 28)</p> <p>I can't let my child take the subway. It's scary. He touches things everywhere. I can't let that happen. Oh no. I'll keep him inside at home for a while. (Haeun, mother of son with intellectual disability aged 27)</p>
Being more susceptible to the COVID-19 virus	<p>Most people with intellectual disability have a weak immune system. If my child gets infected by the virus, it would be serious. ... I watched interviews of patients infected with COVID-19. It was so painful for even healthy people, so people who have chronic illness would not have been able to overcome it. If my child gets infected, would he be able to overcome? (Yunji, mother of son with intellectual disability aged 26)</p>
Lacking information about COVID-19 and not recognizing the infection	<p>If we get COVID-19, we can get through it, but our child can't. My child is not even aware of and can't say whether or not she has symptoms. Let's say that I have the virus in my body, so I have a headache—then I can sense the symptoms quickly and go to the hospital for screening. But my child seems to be insensitive to sensory stimuli. When she is sick, I don't think she can feel that she is sick as fast as other people without disability. So, I think we should keep an eye on it. (Eunmi, mother of daughter with intellectual disability aged 33)</p>
Possible consequences of getting infected with COVID-19	<p>If you know where you've been, there's a record, and you can track the spread of the COVID-19. But, how are you going to deal with the child's infection of COVID-19 if you don't know where he was exposed and where he has been visiting? How are you going to track it? (Bora, mother of son with intellectual disability aged 31)</p> <p>If my child gets COVID-19, it is the end. He wouldn't know he has it and he cannot communicate about it. I am so scared. I don't meet anyone because I don't want to harm anyone. I'm under lots of pressure. If we get infected, I think the situation would become out of control and there won't be anything that we can do. (Yuri, mother of son with intellectual disability aged 40)</p> <p>If my child gets infected with COVID-19, I doubt he would go to the hospital and lie down on the bed. I don't think he can. He would not even be able to get testing. He would be so scared to see doctors with white gowns. How scared would he be if all the people wearing white gowns were looking at him? (Daeun, mother of son with intellectual disability aged 27)</p>
Theme 2 Challenges in adult child's life due to the pandemic	
Losing a daily routine	<p>We've spent the last three years to make my child have a stable routine now. What's the point of this if it goes down the drain? I'm worried that he will go back to the past when he doesn't have a routine life. (Naeun, mother of son with intellectual disability aged 31)</p> <p>When we stay at home, I don't usually tell my child what to do and just leave him as he wants. It has been 6 months living like this, and we got used to it. So, I wondered if he would not like to go to the center. I wonder how long it would take to get back to the way things were before COVID-19. (Daeun, mother of son with intellectual disability aged 27)</p>
Being isolated	<p>My child can't go outside and there's no one to talk to. He can't speak well, and he can't communicate with others well. He must be frustrated, too. ... He often talks to himself while holding a phone. (Haeun, mother of son with intellectual disability aged 27)</p>
Regression in skills	<p>If COVID-19 gets prolonged, my child's social life would be ruined. I feel like she will get awkward with friends. Even yesterday, she met her teacher for the first time in several months and she seemed to be very awkward. She has been spending time alone. I want her to hang out with people and socialize, but being alone can make her change her personality. (Eunmi, mother of daughter with intellectual disability aged 33)</p> <p>When my child stops doing things he routinely does, he tends to regress. If he does not socialize, then he would get stuck there. Because he does not have social skills, he doesn't seem to get bored when left alone. So, he gets isolated more and more and doesn't want to go out. There's nothing we can do about that. He will get more and more stuck inside at home. Since children with [intellectual disabilities] have few social skills, they need repeated training to sustain independent life in the community. Even with dozens and hundreds of repeated trainings, it is hard to go out to society. It would get harder and harder just to go out into society, and it would be even impossible for them to have a social life if COVID-19 is prolonged. (Sujin, mother of son with ID aged 26)</p>
Becoming bored and losing vitality	<p>Before COVID-19, my child got up and took a shower and moved around and had breakfast. But nowadays, he doesn't move nor get up. So, everyday life is the same all the time. (Daeun, mother of son with intellectual disability aged 27)</p> <p>He used to take pills when he can't sleep. He usually took half a pill then. But nowadays, he cannot sleep even with one whole pill. The dose of medicine has increased. He got depressed and keeps crying day and night. He said he is so sad and lonely. He is at home and takes a lot of pills, so his mouth got swollen. He can't sleep. He keeps crying. Because the ups and downs of his emotions got severe, he keeps saying that he has tears in his eyes. He has a lot of stress. (Naeun, mother of son with intellectual disability aged 31)</p>

(Continues)

TABLE 2 (Continued)

Lacking physical activities and experiencing deteriorated health	<p>My child has gained more weight nowadays because she doesn't try to move. After gaining some weight, I was wondering if she had a problem with her thyroid, so she got some checkups. The results were a little bad, so I'm always worried about her health. (Hyena, mother of daughter with intellectual disability aged 24)</p> <p>My child keeps using the computer, so he has headaches and then gets frustrated. He often twists his body. And only craves food. (Yunji, mother of son with intellectual disability aged 26)</p>
Increased behavioural challenges	<p>My child was peeling a sweet potato and cut his hand. Before, he used to reach his hand to me and have his hand treated. But this time, he wouldn't let me touch him and pulled out his hair because he was frustrated. His pores on the front of his head are all pulled out. He still wears a hat to cover that. He found out later by watching himself in the mirror that he was angry. He couldn't relieve [his stress], so he expressed it in a very extreme way. (Somi, mother of son with intellectual disability aged 22)</p> <p>When my child gets stressed out, he shivers. I know it just by looking at him. He bites his mouth and wrist until it leaves marks. Imagine how painful is it. Most people cannot bear the pain. He would have pain, but that's how he relieves stress. (Yuri, mother of son with intellectual disability aged 40)</p>
Adjustments and hopes	<p>He seems to get it little by little. He's been wearing a mask since the spread of COVID [starting last year]. When the teacher made him wear it on the way back home, his mask was always in his pocket. He took it off right away. He took it off when the teacher couldn't see him and came home without the mask. But nowadays, he gets his mask whenever he's going outside. He does it by himself. He always wears it properly from the time he gets out to 2 to 3 hours and more. ... 'If you don't wear a mask, you cannot go to the center nor you cannot take the subway. The teacher wouldn't let you come in'. I told him that you have to wear a mask to go to the welfare center. He kept wearing it since then. He's good with wearing a mask nowadays. When I ask him to go out, his first thing is to get his mask even if it's nighttime. (Haeun, mother of son with intellectual disability aged 27)</p> <p>It was definitely hard at first, but as the lifestyle repeated, we got used to it. At first, she asked me when she can go back to the center. As COVID-19 spread and become a huge deal, she understood the situation and she found her own way to play with herself with her hobbies. Even when she is at home all the time, she has her own life routine such as drawing, coloring Mandara, and listening to music on YouTube just like us. In the afternoon, she turns on the Bluetooth speaker and listens to music while singing along. After the meal, she does hula hooping. It was not easy at first, but since the pattern got repeated, she found her own rhythm. (Sohee, mother of daughter with intellectual disability aged 28)</p>

COVID-19. They expressed negative views of COVID-19 as inevitably having fatal consequences because they believed that their adult child would not be able to cope with the new situation of COVID-19 due to their lack of verbal communication. Particularly, participants feared that their adult child would not know or be able to communicate how they were exposed to the virus, which is the most important information to prevent further spread. The participants were worried that tracking the route of their adult child after becoming infected would be difficult, and it would be a serious problem that could lead to further infection of others. They were concerned that their child would become infected and cause harm to others.

Also, participants were distressed that their adult child depended on their caregiving and that their lives would be significantly affected if their adult child came into contact with or contracted COVID-19, specifically regarding quarantine. Their paramount fear involved their adult child struggling to do daily activities alone, such as toileting, dressing and eating. Due to this dependence, participants said they would not be able to keep their adult child separate from them after being infected. Thus, it meant that they also would get infected from their adult child and they 'would die together'.

Participants also expressed concerns about whether their adult child would be able to follow medical procedures and stay isolated for a long time under the control of medical professionals if infected with COVID-19. They thought that their adult child would not be cognitively aware of a situation in which they could be separated

from their family and have to quarantine at a hospital for treatment. Such worries made the parents literally 'lockdown' themselves and even threaten their child, saying 'COVID-19 will kill you if you go out'.

3.2 | Challenges in adult child's life due to the pandemic

3.2.1 | Losing a daily routine

All participants mentioned that their adult child with intellectual disabilities needed a lot of time and repetitive practice to acquire most basic skills for daily living and creating a routine. The participants' biggest concern was that sudden changes such as the closure of community welfare centres already disrupted their adult child's daily routine. It took years of effort to establish the daily routine of getting up early in the morning to get ready to go to the welfare centre, taking the shuttle from the welfare centre, having lunch at the centre, participating in diverse activities during the day and returning home. They were concerned that if COVID-19 persists, this daily routine would be lost. Many participants worried that not being able to use the centre for more than 6 months due to the pandemic had voided these accomplishments. Participants mentioned that once their adult child gets used to something, they are reluctant to change and it is very difficult for them.

3.2.2 | Being isolated

The participants were worried about their children not interacting with others and being isolated from society. Even before the COVID-19 pandemic, their adult children had limited opportunities to meet others, thus limiting their interpersonal relationships. Regularly attending classes and trainings at the centre was the only way for their adult children, who are not able to verbally communicate well, to meet and socialize with teachers or friends of their age with disabilities. Participants commonly said that for their adult children, people they met at the centre were their only friends and colleagues. However, COVID-19 and the closing of community centres reduced their social interactions and communication to almost nothing except interactions with family members at home. The participants said that the adult child's world just 'stopped', because they did not go to the centre and spent all day alone at home. Haeun, the mother of a son with intellectual disabilities aged 27, said her adult child often pretended to talk to others on the phone because he did not have anyone with whom to talk.

The participants mentioned that their child's social life had disappeared and the only social interactions they had were cut off due to the closure of the centre. They feared it would worsen their child's disconnection from society compared to others without intellectual disabilities. Although social distancing was recommended by the government due to COVID-19, people without intellectual disabilities have found alternative ways to connect with others through non-face-to-face methods or by socializing in a safe environment such as outdoors. However, there were no alternative ways for their adult child with intellectual disabilities to connect with society other than going to the centre. Stigma about people with intellectual disabilities in their neighbourhood made it difficult for the adult children to get around comfortably outside the house. Some parents mentioned that their adult child with intellectual disabilities can feel that people treat them as a child or look down on them; therefore, they avoided interactions with people and perpetuated their isolation.

3.2.3 | Regression in skills

Participants were concerned that the adult child's skills that they had acquired through years of various classes and trainings at the centre would diminish during the period when the centre was closed due to COVID-19. Most participants said that their adult child was afraid of social relationships or often anxious due to their intellectual disabilities, they liked to be alone and they had a hard time interacting with people. Thus, attending the centre represented an opportunity to improve their children's social skills. However, they were worried their adult child's social skills might 'go backwards' and they would perceive new daily life patterns such as staying at home alone during COVID-19 as 'their daily routine'. In Korea, it is not easy for people with intellectual disabilities to engage in daily activities and live independently in the community. The participants' adult children with intellectual disabilities also had spent long years being stuck at home, and the participants

tried hard to help them engage in the community, such as going to the welfare centre. Participants were worried that if this life pattern continued, their adult child might struggle to go back to the community and become socially active again after the pandemic ends. Particularly, participants said their adult child did not like doing something new, and they worried that their child may keep negative habits and lifestyles formed during the COVID-19 pandemic and would continue to regress, even after it ended. Thus, all participants said they were afraid that it would take a considerable amount of time to help their child acquire life skills and readjust to their previous life if the shutdown continues. Furthermore, participants whose child was receiving vocational training to get a job and lead an independent life worried about them losing their job skills, which eventually would make it more difficult for the child to become independent after COVID-19. Naeun, the mother of a 31-year-old son with intellectual disabilities, said she felt worried that her child's social skills would regress, and she wondered if she should take a risk and meet with the parents of other children with intellectual disabilities who used the centre to provide opportunities for their children to spend time together and practice social skills.

3.2.4 | Becoming bored and losing vitality

All participants mentioned that they made sure their adult child avoided crowded places, such as a library, café, museum, movie theatre or church. Their adult child often liked to visit these places, and thus, they were not able to enjoy a cultural life. Because their adult child did not go to work or school, enjoying such hobbies was often their only form of pleasure. Participants said their children's daily lives became boring and repetitive, marked by feeling that there was nothing they can do in the community. Even though family members had much more time together at home in the pandemic, they had not figured out how to meaningfully connect with one another. Some participants mentioned that each family member would spend most of time in their room without any interaction because of the lack of verbal communication skills or having nothing to say. Other participants mentioned that they do not want to bother their adult child because it can be stressful or nagging. Consequently, their adult child became quiet and sullen.

Participants said their adult child seemed to feel frustrated and stressed out because they had to spend all day doing nothing. Almost all participants said that their child's emotional ups and downs became worse because it was difficult for them to spend time doing nothing.

3.2.5 | Lacking physical activities and experiencing deteriorated health

Most participants also worried that the physical activity of their adult child had decreased, because their major activity in daily life was going to the centre. It was not easy for their adult child to deliberately engage in physical activities and manage their health without access to the community centre. Moreover, their adult child had more snacks and unplanned meals while staying at home all the time,

which inevitably made them gain weight. The participants worried about their adult child having health problems as a result of weight gain and lack of physical activities.

Because of such worries, participants made efforts to 'manage their children's health', such as controlling their meal portions, taking a walk together, engaging in physical activities when they go out or exercising whenever they had time. They were forced to limit snacks and control meals because they were worried about their children not controlling their appetite. Thus, they repeatedly reminded their children that they had gained weight, resulting in the children's consciousness of their weight and poor health.

3.2.6 | Increased behavioural challenges

Participants mentioned that their adult child felt frustrated and increasingly distressed about staying at home all day and being unable to do what they wanted. Before COVID-19, their child often visited the community centre to relieve stress by enjoying hobbies, such as having a coffee, watching a movie, drumming or exercising. Because they could not engage in those activities, their adult child often engaged in problem behaviours, such as yelling, biting their hands, picking at their nails or skin on their fingers or hitting their heads, sometimes even making themselves bleed. The frequency of these challenging behaviours increased, and new behavioural problems emerged. For example, one participant mentioned that whenever there was a fight scene on TV, her child could not control their emotions and would shout, leading to family anxiety when watching TV. Other participants were concerned that their adult child, who struggled to express when they are in pain, would injure themselves through these problem behaviours.

3.2.7 | Adjustments and hopes

A few participants reported that their adult child with intellectual disabilities had adjusted to life during COVID-19 and created a new lifestyle. Some participants mentioned that their adult child realized the importance of wearing a mask after a long learning curve. At first frustrated and reluctant to wear masks, these adult children now understood the reason for wearing masks when going out and now always wore them. The participants had their adult child watch TV news to see people who were sick and dying because of COVID-19. Additionally, adult children were constantly instructed by their parents with the phrase, 'You have to put on a mask and wash your hands. If not, you will get sick'. Somi, the mother of a son with intellectual disability aged 22, took her son to public places such as a coffee shops and demonstrated how to comply with COVID-19 guidelines.

In the beginning, adult children demonstrated challenges finding new activities to replace their time in the community centre, but they began to develop regular activities, such as getting up in the morning, having breakfast, spending some time engaged in their

hobbies, having lunch and then taking a nap. Some participants witnessed the possibility of their children adapting to a new life and hoped that their children would be able to adapt when other new situations arose. For example, Jiwon, the mother of a son with intellectual disability aged 29, had been training her son to be independent from a young age and thought that he would be dependent on his parents or a personal assistant and would come to rely on them if she kept helping him too much. Thus, she was training him to eat meals independently when she leaves him alone; fortunately, he seemed to be learning how to live on his own during the COVID-19 pandemic.

4 | DISCUSSION

Our study confirmed parents' anxiety about keeping their adult child with intellectual disabilities safe from COVID-19 and concerns related to the adult child's life challenges during the pandemic. Although COVID-19 has brought challenges to all parents caring for a child due to the suspension of educational services and possible risk of infection, the participants' adult children with intellectual disabilities were more vulnerable because they did not have any alternative activities and social connections during the day without using community welfare services in Korea. The challenges they had before the COVID-19 pandemic had worsened during the pandemic, so their challenges should be highlighted. Our study revealed that parents' concern about their adult child getting infected with COVID-19 was the major source of their anxiety. They were worried about their adult child not being able to adhere to public health guidelines for preventing COVID-19 infection. Consistent with the opinion that minimizing the risk of infection and improving access to information about the disease is needed (Courtenay, 2020), the findings show that it is important to educate people with intellectual disabilities about COVID-19 and the importance of adhering to public health guidelines that are easier for them to understand.

Parents also were concerned that their adult child was at high risk of getting infected with COVID-19 due to limited physical and cognitive functions. Parents' concerns about greater risk of infection among people with intellectual disabilities were consistent with previous study findings (Turk & McDermott, 2020). Our study also highlighted parents' concerns about their child's poor communication skills and inability to be quarantined alone if they were infected with COVID-19. Professionals who provide care to COVID-19-infected patients whose intellectual abilities are limited need to understand their unique needs and strategies, such as effective ways to communicate with patients to evaluate their illness progression and understand their healthcare needs and isolation of patients to prevent the spread of illness (McGonigal, 2020). Further investigation is needed to develop strategies for communicating with adults with intellectual disabilities, such as using nonverbal communication.

Our results also showed that parents are highly concerned about their child's life challenges during the pandemic, such as the loss of routine and regression in skills for daily living, which would

make them further isolated from society (Boyle et al., 2020). Our study findings are consistent with previous findings that COVID-19-related curtailment of services in the community might increase the risk of psychosocial problems among people with developmental disabilities who have greater healthcare needs and are dependent on community services (Aishworiya & Kang, 2020). Sudden changes in life patterns and loss of their routine may increase their level of loneliness, anxiety and distress, potentially leading to compromised psychological well-being and increased behavioural problems. It is likely that their vulnerability to loneliness resulted from negative social attitudes and low expectations, skill deficits and limited opportunities to experience social and emotional connectedness with others (Gilmore & Cuskelly, 2014). Lacking physical activity that otherwise may reduce aggressiveness or self-injurious behaviours (Srinivasan et al., 2014) may increase psychological stress and related challenging behaviours among adults with intellectual disabilities, as previously noted in the literature (Courtenay, 2020).

In this study, some community centres were providing the participants' adult children with intellectual disabilities with remote support, yet it seemed that remote services did not address the participants' worries. In Kim et al.'s (2020) study, the same sample of participants reported that their adult children had access to telephone-based or live-streamed classes. However, they perceived that remote services were not helpful for their adult children because they lacked the ability to handle the remote devices, could not concentrate during remote interactions or needed individual support. They expressed the need for regular contact or accessible information regarding available services during COVID-19 (Kim et al., 2020).

As the study findings elucidate, the parents' concerns about their adult child getting infected with the virus and being affected by psychosocial changes are severe in the COVID-19 pandemic, marked by uncertainty and unprecedented social change. We should interpret this finding with keen reflection on the cultural context of Korean society. It is possible that Korean social and cultural contexts may contribute to a greater sense of responsibility among parents of adult children with intellectual disabilities. These parents often feel obligated to take care of their adult child, and having a child with a disability may add more anxiety in Korea, where interdependence is emphasized rather than independence (Stone, 2004). In addition, adults with intellectual disabilities are likely to stay at home and do not have alternative day activities other than visiting community welfare centres. Such limited day services for adults with intellectual disabilities may add more responsibility and burden to their parents as caregivers in Korea.

Particularly, in the face of the COVID-19 pandemic, Korean people have shown their sensitive and arguably hypersensitive alertness regarding the pandemic. Thanks to such vigilance, Korea has contained the infection effectively, which has been internationally well recognized. We want to emphasize that whether adult children with intellectual disabilities face a high risk of infection or would be permanently affected, especially regarding their social skills, to the degree their parents fear is not the point of debate. Rather, this level

of fear and gloomy outlook among parents is concerning and warrants understanding and attention from both clinical and research perspectives.

4.1 | Limitations

The study findings should be interpreted with caution. First, our study participants were the parents of adults with intellectual disabilities living in the community and receiving support from family members and thus, their life patterns may be different from those living in supported-living placements or congregate care homes. Future studies could identify caregivers' or staff members' concerns regarding adults with intellectual disabilities living in other forms of accommodations, such as institutional settings. Second, parents' concerns about their child may differ based on the child's severity of disability, functioning level and available support resources. Future studies could consider how the parents' concerns are affected by these characteristics and resources. Third, our study findings relied on parents' perceptions and thus, the challenges experienced by adults with intellectual disabilities may be different than their parents' concerns. Future studies could explore first-hand experiences regarding psychosocial challenges from the perspectives of those with intellectual disabilities. Fourth, our study focussed on worries rather than other experiences and thus, future studies could explore parents' coping strategies to address such worries or how adult children with intellectual disabilities can learn new skills and behaviours to adjust to the COVID-19 pandemic. Finally, our study did not address the impact of the parents' concerns on the parents or child. Future studies could address how the parents' concerns about their child affected their strategies of keeping their child safe from the virus or influenced the parents' mental health.

4.2 | Implications

This study can inform community welfare agencies and healthcare professionals who provide support for adults with intellectual disabilities and their family caregivers to reduce the risk of infection and develop a community care system during the pandemic now and in the near future. As the pandemic has persisted, voices have demanded the need to adjust to the 'new normal' and establish a system for other crises when the previous community system does not work. Our findings provide implications for specific interventions that could address the challenges of adults with intellectual disabilities living in the community and alleviate anxiety and concerns of family caregivers during the COVID-19 pandemic.

The focus of preventive efforts regarding COVID-19 is limiting face-to-face contact with others, which is partly regulated by the government. Thus, utilizing virtual technologies is an alternative way of addressing the psychosocial challenges of adults with intellectual disabilities and their parents' concerns. Although remote support has been adopted and tested in different settings since the advent of

the pandemic (Taber-Doughty et al., 2010), more innovative support services using telehealth and online technology are being provided for children with developmental disabilities and other people living independently with intellectual disabilities during the COVID-19 pandemic (Eapen et al., 2021; Zaagsma et al., 2020). However, people with developmental disabilities often have low access to information technology (Lee & Lee, 2020), and their experiences with remote services were not perceived as helpful in Korea (Kim et al., 2020). Although it is difficult for adults with intellectual disabilities to concentrate on online activities, more accessible remote services that can meet their needs and interests should be provided. For example, virtual social interactions and continuous skill trainings appropriate for their intellectual and cognitive functioning should be provided to help them maintain a daily routine and interpersonal relationships. Using mobile phone video or group calls, which are familiar to people with intellectual disabilities, can be a good way to provide opportunities to communicate with others. Such support services using technology can increase independence and a sense of security among those with disabilities who receive in-home care (Tassé et al., 2020).

Also, practical and logistical resources in case people with intellectual disabilities get infected also should be provided; for example, providing a standardized manual for people with intellectual disabilities and their caregivers in case they are infected with COVID-19, such as whether they should be accompanied by caregivers, how to create isolation spaces and how to support daily life when isolated. Recently, a manual for responding to infectious disease among people with disabilities was developed (Korean Ministry of Health & Welfare, 2020); it provides detailed guidelines for service providers working with people with disabilities at community welfare centres and institutions. More accessible information about the management of COVID-19 risks among people with intellectual disabilities is needed.

In addition, it is a good strategy to educate people with intellectual disabilities about the importance of adhering to infection control strategies, which would reduce the risk of infection and address their parents' worries. Communities should develop and disseminate COVID-19-related information, such as how to properly wear a mask, keep a safe social distance, understand symptoms and self-diagnosis of COVID-19, understand how to trace the routes of confirmed patients and understand emergency text messages, in a way that people with intellectual disabilities can understand well. This education could encourage self-control behaviours that prevent them from contracting the virus, taking into account the level of communication.

Furthermore, healthcare professionals should provide individualized psychosocial services either online or in person for parents who are experiencing extreme anxiety about their adult children getting infected and the consequences of the infection. The providers should understand that such anxiety is not unreasonable and results from the parents' sincere concerns about the unknown trajectories of the novel virus. Particularly, Korean culture, in which individuals feel and act responsibly for the collective health of the

country, should be understood. Because parents reported fears that go beyond optimal carefulness, accurate and updated information on COVID-19 and appropriate precautions during the pandemic should be provided. In addition, providing virtual support groups to share their feelings and exchange emotional support among parents would be helpful.

5 | CONCLUSION

This study provided empirical evidence of the challenges of people with intellectual disabilities who previously depended on community-based services during the COVID-19 pandemic from their parents' point of view. Their concerns can help professionals identify current challenges and areas for further improvement for families of adult children with intellectual disabilities. This study suggests directions for community care and public health services for people with intellectual disabilities who are vulnerable to COVID-19, so that they can lead a self-reliant life in the community in the event of a disaster.

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CONFLICT OF INTEREST

All authors have no conflict of interest to declare.

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