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Original Article

Changes in life experiences of adults with intellectual disabilities in the COVID-19 pandemics in South Korea

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ABSTRACT

Background: The COVID-19 pandemic has had a significant impact on adults with intellectual disabilities who are dependent on community services.
Objective: This study explored the experiences of adults with intellectual disabilities from their perspective during the COVID-19 pandemic in South Korea, where most community-based services were suspended.
Methods: We conducted in-depth interviews with 15 adults with intellectual disabilities who lost access to services during COVID-19 pandemic. Inductive thematic analysis was conducted.
Results: Five overarching themes emerged: changes in (a) daily life, (b) health behaviors, (c) family relationships, (d) social relationships, and (e) social participation. Most participants experienced the loss of daily routines and healthy behaviors, family conflicts, and social isolation, but they also developed new ways of adapting and finding a new normal.
Conclusions: The findings offer valuable evidence of ways to develop and stabilize community-based services during a pandemic, with insights into the experiences of people with intellectual disabilities.

The coronavirus disease 2019 (COVID-19) pandemic has continued its spread, with a significant impact on vulnerable populations around the world. As a socially disadvantaged population, people with intellectual disabilities (ID) have been shown to be more vulnerable during the pandemic because they may have comorbidities that place them at higher risk of poor COVID-19 outcomes.[1–4] People with ID are more vulnerable to mental distress associated with COVID-19 due to multimorbidity, difficulty understanding and communicating about health and hygiene guidelines, and a strong need for daily routines.[5] They might be also more vulnerable because they have high rates of mental health comorbidities compared with the general population[6,7] that could be exacerbated during the pandemic.

During the COVID-19 pandemic and lockdown, many individuals with ID lost significant support in their lives.[8] Although individuals with ID received various types of support, they often lacked necessary support during the lockdown.[9] In a previous study[10] study, most caregivers reported that individuals with ID lost at least one of their educational or health care services and needed remote social services by telephone or video during COVID-19 restrictions.

A lack of support and services brought significant changes in the lives of individuals with ID. Family caregivers, parents, and siblings worried about disruption of their daily routine.[11,12] Individuals with ID reported decreased physical activity and increased sedentary behavior and screen time, such as television, computer, or smartphone use.[13] One study[14] found a significant increase in behavioral incidents, especially aggression among adults with ID living in residential facilities, during the COVID-19 lockdown in the Netherlands. Another study[9] found that the most noted consequence of the lockdown for people with ID in Spain was decreased contact with social relationships, followed by limited recreational or leisure activities or professional services. A recent study[15] qualitatively interviewed six adults with mild ID living in the

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community and found that they lost social contact and in-person interactions with others, experienced a change of lifestyle being stuck at home, and had difficulty understanding preventive measures during the lockdown in the Netherlands.

In Korea, the government established a social distancing policy in response to COVID-19 and requested the suspension of multiuse facilities, including community welfare centers providing day programs and other social services for people with disabilities, in February 2020 during the first wave of the pandemic. About 73.5% of social welfare facilities nationwide were closed for more than 4 months.[16] Since then, with various waves of the pandemic, social welfare centers went through openings and closings. Although the proportion of people with ID living in facilities is higher compared to other types of disabilities,[17] the majority of people with ID live in the community. An estimated 223,228 people with intellectual disabilities live in Korea, and about 88% of them reside in the community.[18] Of these individuals, 160,112 are adults aged 18 or older and account for about 81.2% of these community-dwelling residents.[18] Community care and support services are very important for those people with ID to lead a self-reliant life in the community.[19] However, those services are currently suspended or reduced due to COVID-19. Thus, individuals with ID living in the community, often dependent on community care services, may face unique challenges. Although a new service system for people who previously used community care services is needed, a systematic plan has not yet been established in South Korea.[20]

Recent literature provided evidence that individuals with ID face challenges in daily and social life due to COVID-19, but mostly focused on children with ID from their families' perspective.[21,22] Only a handful of studies explored life challenges among adults with ID living in the community from their perspective.[9,15] These studies were either limited to people with mild disabilities who live independently with a paid job or used structured questions, making it difficult to generalize findings or gain a deeper understanding of experiences. Thus, this study aimed to qualitatively understand how adults with diverse levels of ID experienced challenges and adapted to their new lifestyles in the community during the shutdown of services during COVID-19 from their perspective.

Method

Participants

Eligible participants were adults with ID who had used day programs and services provided by community welfare centers and agencies that were suspended during the COVID-19 pandemic. A purposive sample of 15 adults with diverse levels of ID living in the community participated in the study. Participants reported their demographic and disability information, as shown in Table 1. In Korea, individuals with an IQ score of 70 or below are registered in a national disability registration system as having ID. Due to concerns that labeling the severity of ID worsens stigma attached to the population, the categorization of ID severity levels was discontinued by the Korean Welfare of Disabled Persons Act in 2019. For the present study, the following categories were used to describe the participants: (mild: IQ score between 50 and 70; moderate: IQ score between 35 and 50; and severe: IQ score below 35).

Data collection

The sampling and the interview procedures were concurrently conducted between July 6 and 21, 2020, in Korea after approval from the institutional review board of the university affiliated with the principal investigator. The study used purposive sampling. We recruited individuals who had to stop their regular use of welfare center services due to the COVID-19 pandemic. Through community welfare centers and agencies for people with ID, we distributed study recruitment information to recruit participants who satisfied the inclusion criteria. Potential participants contacted the researchers either personally or through the center staff to schedule an interview.

Two authors, each with a PhD in social work and extensive experience conducting qualitative research regarding people with ID, and another author, a masters' student in social work with clinical experience working with people with ID, conducted in-depth interviews. In the process of data collection, the three authors who conducted interviews regularly discussed key findings together after each interview and stopped recruitment of new participant when new information was not being produced to address our research questions and data reached saturation.[23] For 11 participants who were not comfortable interviewing on the phone, the interviews were conducted in person, following guidelines to minimize the risk of COVID-19 infection. The other four interviews were conducted via phone. The face-to-face interviews were conducted in a private room or uncrowded cafe near the participants' residence that were accessible without public transportation. Both the researchers and participants wore masks during the interviews.

Before the interview, the researcher explained the purpose and procedures of the interview and obtained informed consent from each participant. The participants were told they could stop the interview if they felt uncomfortable or tired. During the interview, researchers observed the participants and allowed break time if

Table 1
Participant Characteristics (N = 15).

Pseudonym	Age	Gender	Education	Coresiding Family Members	Disability Severity
Yoonho	31	Male	Drop out of college	Father, mother	Mild
Yejin	27	Female	High school graduate	Mother	Mild
Jina	19	Female	High school graduate	Father, mother	Moderate
Minjae	28	Male	High school graduate	Father, mother, brother	Moderate
Taejun	31	Male	Drop out of college	Father, mother, sister	Mild
Sora	24	Female	High school graduate	Father, mother, brother	Moderate
Yoonsu	25	Male	High school graduate	Father, mother	Severe
Sunwoo	29	Male	High school graduate	Father, mother, brother	Mild
Danbi	38	Female	Drop out of elementary school	Older sister, nephew	Moderate
Jihoon	26	Male	High school graduate	Mother, brother	Moderate
Sarang	28	Female	High school graduate	Father, mother, brother	Severe
Hyojin	22	Female	High school graduate	Alone	Severe
Woobin	28	Male	High school graduate	Father, mother, sister	Moderate
Jiyeong	32	Female	High school graduate	Mother, uncle, brother, nephew	Moderate
Sohyun	33	Female	High school graduate	Father, mother, sister	Mild

they seemed tired and wanted a break. The main guiding interview question was: “How has your life changed since you couldn't use day services and programs during the COVID-19 pandemic?” This question was supported by prompts, such as “How was your daily and social life before COVID-19?“; “What are the most challenging changes you have experienced due to the COVID-19 pandemic?“; “How did you feel when you experienced that?“; and “Why do you think you felt that way?” The interviews ranged from 20 to 50 min.

Despite the research team's anxiety about potential challenges of qualitative interviews with people with ID, most of the interviews were smooth and insightful. All three participants with severe disability understood the questions well and were able to verbally communicate with the interviewer. We had shorter interviews, about 30 min, with three participants with mild or moderate disability, who sometimes struggled with pronouncing certain words or verbalizing their feelings and opinions. Some participants seemed to be lost when asked to compare their life before and after the pandemic. So, the researchers indicated the exact timing, such as January 2020, to help participants imagine their prior lives. When participants seemed puzzled or did not seem to understand the question, researchers tried to simplify the questions. For instance, some participants seemed puzzled when asked to explain their “participation in the community.” Researchers explained this term with examples: going out, using public transportation, going to the welfare center, and other activities outside the house. Each participant received a gift certificate for $30 after the interview.

Data analysis

All interviews were audio recorded and transcribed verbatim. Inductive thematic analysis was conducted to identify salient themes reported by the participants.[24] Using ATLAS.ti software, the first two authors reviewed the transcripts independently until they became familiar with data. Open codes were assigned to each phrase and sentence based on participants' life challenges and adaptation to the pandemic. The authors grouped codes and identified subthemes through discussion until a consensus was reached. The authors discussed any potential for overlap between themes and subthemes and determined the themes based on what participants described, not the researchers' interpretation. Analysis continued until new themes did not appear and richness of themes was achieved. We did not quantitatively predetermine the number of participants to reach data saturation, but rather determined thematic saturation when codes from a majority of participants were enough to construct common themes, as suggested by Braun and Clarke.[25] We also tried to find important patterns in the data, although some subthemes were not noted by all participants. For example, eight codes, such as “listening to music to soothe feelings,” “practicing computer skills that have been taught at the center,” and “going for a walk after meals” formed the subtheme of “developing alternative activities.” Through discussions among the researchers, seven initial subthemes were merged into three subthemes, which formed the first theme of “changes in daily life.” Finally, all authors defined themes that allowed conceptual distinctions across themes and subthemes and selected quotes that illustrated the themes. When reporting participants’ narratives, pseudonyms are used to protect their confidentiality.

Results

As shown in Table 2, 12 subthemes emerged amid five overarching themes: changes in (a) daily life, (b) health behaviors, (c) family relationships, (d) social relationships, and (e) social participation.

Changes in daily life

Participants' daily life had been filled mainly with scheduled activities while attending services at a welfare center. Not being able to go to the center due to COVID-19 had completely changed participants’ everyday life. Their daily lifestyle, such as sleep patterns, had shifted to irregular due to the lack of daily activities. Their increased free time was mostly spent alone without meaningful activities at home while family members were busy with their life in the daytime. Participants gradually developed alternative activities on their own to spend meaningful time and replace the activities they previously engaged in at the center.

Loss of healthy routine. Although some participants tried to maintain a pattern similar to life before COVID-19, most said they lost their daily routine. Before the pandemic, routines included getting up early, preparing to go to the welfare center, and spending all day at the center. However, with the welfare center closed, participants had an irregular lifestyle pattern. To illustrate, Sarang, who previously woke up at 6:40 a.m. every morning to prepare to go to the center, said her sleeping habits changed since its closure. She fell asleep at 3 a.m. and woke up at noon because she had no reason to get up early. Other participants had irregular sleep patterns, such as taking naps during the day or going to sleep late at night. After their families left for work or other tasks in the morning, participants had nothing to do during the day.

Killing time alone. Most participants said they felt bored spending the day alone. Not only did their daily routine disappear, but they also could not find any activities to replace center activities besides watching TV, playing online sports and games, and watching cartoons or movies on their computer or cell phone all day. Since the COVID-19 outbreak and facility closures, they had nothing to do and were distressed about spending time alone at home. For them, going to the welfare center was their only outing; nothing could replace that.

Developing alternative activities. Some participants said they got used to spending time alone and found new hobbies. They gradually found ways to spend time usefully and soothe the boredom of not going to the welfare center. Activities included dancing, practicing computer typing skills they learned at the center, uploading photos on social media, listening to music, or going for a walk alone. Sora described feeding stray cats and learning piano and art through private academies. Some participants spent time doing activities sent to them by the welfare center, such as planting seeds or cooking rice or fried eggs with guidance from online videos.

Changes in health behaviors

As participants’ daily and social lifestyles changed, their health-related behaviors that shape their health and well-being also were affected by restricted access to community welfare centers. Notably, unhealthy eating habits such as mindless eating, junk-food binges, or skipping meals became common practice. Given their decreased physical activity and preexisting health conditions, they made efforts to compensate for their previous level of physical activity and maintain a healthy lifestyle.

Changes in eating habits. Most participants said their eating habits changed since community services closed due to COVID-19. They previously had a regular pattern of eating breakfast before going to the welfare center and dinner after coming home. However, during COVID-19, participants woke up late and ate alone. Some participants could eat meals their parents prepared before going to work, whereas other participants cooked their own meals. But in most cases, participants showed irregular eating habits such as only eating one meal a day, eating whenever they felt hungry, or

Table 2
Themes, Subthemes, and Quotations.

Theme	Subtheme and quote
Changes in daily life	a) Loss of healthy routine
	I'm tired these days, so I wake up too late. There's nothing special to do when I get up. So, I take a nap in the daytime. (Yoonho)
	I have been playing with my smartphone all day. I mostly play games. (Yejin)
	I spend 8 h a day at home on my computer. My mom doesn't scold me for spending that much time on my computer. After I get up, I take my medicine, shower, and then get on the computer. I usually watch baseball and basketball games or cartoons on the computer. I take breaks to eat breakfast, lunch, and dinner but spend the rest of the time on the computer. That's my daily routine. (Yoonsu)
	b) Killing time alone
	There's nothing to do when staying home. It's tiring. There's nothing to do except watch TV. It's my only pleasure these days. (Hyojin)
	I do nothing at home. There's nothing special to do. I don't go on a computer. I just watch TV. I get bored. (Jihoon)
	Before COVID-19, I had many plans during the day, but now there is none. The only schedule for the day is gone. It doesn't matter day by day. It is always same. My daily schedule has become nothing without the center. (Yoonsu)
	c) Developing alternative activities
	I'm bored. So, I found something I can enjoy. It's fun. I get up in the morning and work out and relax at home. After feeding stray cats, I go to academies. Then time flies. Going to piano and art academies, working out, and feeding cats has become my schedule and daily routine. Feeding and caring for stray cats has become my hobby. I do that Mondays whenever I am free. I met them on the street and asked if I could feed the cat, and they said it was fine, then we got close. The cats are so cute I cannot bear it. When I go there, they run to me and come near me. They purr and cling to me for food and keep meowing. If I just stayed at home, I would be so bored and sad. It's nice to have somewhere to go. It's better than just staying at home. I'm happy. (Sora)
	I like James Last's songs, so I wrote the lyrics in English. I downloaded an application for listening to music. I listen to the music by myself and found the English lyrics in the dictionary. (Sunwoo)
Changes in health behaviors	a) Changes in eating habits
	I don't have an appetite at all. I don't know why. Maybe it's because I am alone and lonely. (Jina)
	My mom can't make my lunch, so she gives me money to eat out. I would eat out from many different fast food places and take turns between fried rice, Chinese cold noodles, etc. (Yoonho)
	b) Efforts for healthy lifestyles
	I work out on treadmill at home. I have epilepsy and am not allowed to go to the gym. My mom bought me a treadmill to work out at home. (Yoonho)
	I always wear a mask and sanitize my hands whenever I go out. I wasn't a people person back then either, but I tell people to meet when COVID-19 is over. (Hyojin)
Changes in family relationship	a) Contributing to the household
	When my mom asked me to help her with hanging and bringing the laundry, I did it. When my mom cooked rice, I also helped her with setting the table for meals. I brought the dishes and spoons. I wasn't good at it, but it seemed tiring for her to do it alone, so I tried to help. (Jiyeong)
	I helped my family with chores like washing dishes, folding laundry, and sometimes even doing the laundry. My mom wrote instructions to do the laundry, and I followed them. My mom wanted me to help her. She seemed satisfied when I helped her, so sometimes I volunteered even before being asked and would say, "I'll do the dishes when I finish eating." (Yejin)
	b) Spending more time with family members
	I fought a lot with my brother because he nagged me to take medicine. He consistently told me to take my medicine, and that frustrated me. I'm older than him, but he didn't treat me with respect. He nagged me all the time, and I got tired of it. That medicine was for my depression, but I hated it. I felt bad when I took it, but my family wanted me to, so we argued about that. (Minjae)
	My mom told me what to do, like "Don't go on your phone too much and clean your room," but I didn't want to. She acted annoyed, so I snapped at her, too. We didn't fight, but I told her to just leave it and I will clean it afterward. But she wanted things to be cleaned up right away. I just wanted to lay down a bit. I got frustrated more often than before. But I thought this should be changed as I got headaches often and I felt dizzy. First, I went to see doctor but was told to see a psychiatrist. They said my stress level is high and I seemed depressed. Nowadays, I have regular appointments for depression. (Jiyeong)
Changes in social relationships	a) Feeling lonely and isolated
	Before COVID-19, I hung out with friends at the center, but I do not have any friends now. I get so anxious, and get tons of stress not being able to go to the center. I'm an only child, so I have no one to hang out with at home and it's boring to be alone at home. I have nothing to do by myself. (Yoonho)
	I feel discouraged to talk to people and I don't feel confident with myself. When I was in elementary school, I got bullied. Since then, I try not to go outside [cries]. (Yejin)
	It's awkward meeting new friends outside of the center. I do not know them well and I'm new to them. There's not much to talk about. (Minjae)
	My mom asked me why I am so frustrated staying at home playing on my phone and everything, and I cannot tell her I'm having a hard time and I need her help. I cannot tell her that because she seems tired. I cannot tell my brother, either. He yelled at me saying, "What is so hard for you? What's wrong with you?" I cried a lot and I wanted to kill myself. I didn't want to live anymore and wanted to be with my dad. So, I saw my psychiatrist and got medicine. I just want this COVID-19 to be over and go back to work again. I was fine when I was going to work, but it's really hard for me since staying at home. (Jiyeong)
	b) Not knowing how to connect
	I miss my friends at the center. I wonder if they are doing fine. I wonder more how they are doing than missing them. I felt suffocated that I cannot meet them and keep in touch with them. I know that my friends or teachers from the center are busy, so I cannot call them often. It's been a while since I called my friends because I don't know what to say. (Sora)
	I hope my teacher cares about me. I miss her. After COVID-19 is over, I want to hug her. I think of her and miss her a lot. When I'm bored, I think of her and want to give her a big hug. (Sarang)
	The very first thing I want to do after the suspension ends is meet with my teacher because I couldn't meet with her for several days. I want to catch up with the teacher once I can go to the center. (Jihoon)
	It's too bad not being able to meet my friends at the center. I cannot reach out to them because they may be annoyed if I keep in touch with them. I should be able to meet them after COVID-19 is over. (Minjae)
	d) New ways of making social relationships
	I call my friends and tell them to keep in touch. They are at home relaxing and enjoying time by themselves. A friend told me that he did some artwork and I told him he did a good job over the phone. (Sunwoo)
	I call my grandmother and aunts every week. I enjoy chatting with them. Also, I talk to the person who sells drinks on the street. She is nice to me because she knows me well. I often go to the pharmacy and I talk with the pharmacists. I take a look at the medicines and buy some medicine. They are really friendly and nice to me. (Yoonho)
Changes in social participation	a) Feeling imprisoned

Table 2 (*continued*)

Theme	Subtheme and quote
	I'm so bored and frustrated. I am sick of it. I can't stand not being able to go outside. We cannot go to the center, so I can't meet my friends or my teachers and we can't do programs there. I like wandering outside by myself. I want to meet my friends, hang out with them, and eat something good. (Jihoon) I want to go out, but I can't. Many people got infected with the virus so I can't go out. Before COVID-19, I often went to the movies and to the mall, but since the pandemic I couldn't go there. I want to go anywhere, but I can't because there are a lot of people out there. (Sora) b) Not being allowed to go outside I can't go outside. My mom doesn't want me to go out. Staying at home all the time is boring, so I want to go out. It's frustrating. I get pissed off. (Jihoon) I couldn't go outside since the COVID-19 pandemic because my mom didn't allow me to. I have a curfew. (Minjae) I stay at home all the time [nearly cries]. On the TV, they say it is not OK to go out and it might not be safe to eat out at a restaurant because there may be people with the virus. So, I don't feel like going out, and my mom tells me not to go out because we can get infected anywhere. (Yejin) c) Decreased opportunity for job training I can't remember anything I learned. I'm afraid I will have forgotten everything I trained on when I go back. Now I can't do anything. That makes me worry so much. The first thing to do when the center opens again is to get back to work. I wanted to get a job after getting vocational training, so I planned to get a job starting next year. But I just want to get employed right away. The teacher at the center will help me. I get frustrated because I cannot get a job in this situation. (Jihoon) My mom wants me to get a job, and I feel the same as her. My mom seems to be anxious watching me doing nothing. So, she wants me to do something as soon as possible. (Yejin) Because of COVID-19, I haven't worked since February. It's frustrating because I have to make my living, but I can't do that right now. I have to make payments like paying rent. I heard that my working contract can be extended, but I'm not sure. If not, I have to find a new job and go to job interviews again. I tried to find jobs but because of COVID-19, none were available. (Hyojin) d) Feeling relaxed I wasn't frustrated by that. I didn't feel that way. Just thinking like if I have to go, I'm going or if I can't, I'm not going. (Hyojin) It's fine now that I have just a few schedules. I was tired of too many things to do in one day, but I can just relax now. It was hard for me back then. My legs hurt, too. I'm enjoying time to relax more. Also, I hate to hear that man talking about cars. I hate him. It's much better that there's no chance to run into him. (Yoonsu)

eating junk food when their parents were at work. Boredom and loneliness contributed to changes in eating and helped explain their loss of appetite and poor eating habits.

Efforts for healthy lifestyles. Participants mentioned that their family members were concerned about their health and recommended exercise. However, most participants said they were not worried about their health. Some participants walked frequently (outside or on a treadmill) to compensate for the suspension of physical education programs at the welfare center or tried to follow a healthy lifestyle during the pandemic. Several participants had preexisting health problems such as epilepsy, atopic dermatitis, Bechet's disease, or tinnitus. Those participants said they sometimes felt worse due to these health problems and believed that their immune systems were weak. Thus, they were more cautious and worried about getting infected with COVID-19.

Changes in family relationship

COVID-19 brought significant changes to participants' relationships with family members. Participants realized the increased caregiving burden on family members during the pandemic and felt a responsibility to contribute to their household. On the other hand, increased time with family members at home inevitably led to more family conflicts and consequently, more stress and psychological symptoms.

Contributing to the household. Some participants contributed to the household to reduce the increased burden during the pandemic by helping with chores such as washing dishes, doing laundry, and preparing meals. They helped their family because they thought it would be hard for other family members to take care of them throughout the pandemic and this was their way of showing appreciation. Participants shared that being able to contribute to the household gave them great joy.

Spending more time with family members. Some participants said they enjoyed spending more time with their family at home during COVID-19. However, most participants said they often had conflicts with their family. While at home with their family, they did not have any plans or structured activities. Rather, they mostly did things by themselves in their own rooms. Those who mainly watched TV at home and avoided tasks such as taking medicine or doing homework said they were considered “lazy” by their family members. Family members nagged them to fulfill their responsibilities. Such conflicts led to feelings of stress and even significant psychological symptoms for participants. Jiyeong had intense conflicts with her family due to being at home and was diagnosed with depression. She needed to take medicine and even thought about committing suicide.

Changes in social relationships

Participants' social relationships were significantly affected by the closure of community welfare centers. Because the only place participants felt they could have social interactions with others had been closed, they became socially isolated during the pandemic. They missed their friends and teachers from the center; however, they could not socially connect to people due to a lack of confidence and feeling uncomfortable. Thus, they felt lonely and did not receive understanding and support from family members. A strong desire for social interactions made some participants develop new ways of continuing social relationships without face-to-face interactions.

Feeling lonely and isolated. Participants said they had no chance to talk to people because they did not have access to the welfare center, and their only friends were peers at the center. They had been close to their friends from the center, but now they had drifted apart. Participants said they had felt comfortable talking to friends at the center because they related to them and felt understood. It was a safe place where they could interact. However, when they left the center, they lost those social relationships. They said they feared developing relationships and communicating with new people outside the center due to unfamiliarity. Parents and other family members were the only people available for a conversation.

Participants said the prolonged time of not interacting with people caused stress, worry, and depression. Sarang talked about being suddenly sick for no apparent reason while alone at home and said that “bad and gloomy thoughts” increased her pessimism about her situation. Participants said managing stress was challenging, and taking walks to relieve stress was only a temporary coping strategy. Despite having difficulties at home, they could not talk with their family about their difficulties, and there was no one to comfort them. Some participants said that other family members did not seem to understand what they were going through and could not offer comfort.

Not knowing how to connect. Participants used to meet and have time together with their friends and teachers at the center at least once a week before COVID-19. Since the pandemic hit, they were removed from their only friends. Participants missed their teachers and friends at the center and thought of them often, wondering how they were doing. Although they wanted to connect with their friends, they could not reach out. Most participants could not even make a phone call to their friends or teacher. The reasons varied: “I don't have a cell phone,” “I am shy and uncomfortable communicating on the phone,” or “I don't want to disturb them.” These barriers related to logistics, hesitance to communicate, worries, and fears stood in the way of maintaining social connections.

New ways of making social relationships. After COVID-19 closures, some participants had a strong desire for social interactions and continued their relationships by calling or messaging friends and relatives to talk about their daily lives. Conversations with those people made them feel better. Some participants walked around their neighborhood and talked to strangers who were kind to them. Jina said it was nice and comforting to communicate with peers on social networking sites.

Changes in social participation

Due to concerns about getting infected with the COVID-19 virus, participants had limited opportunities for social participation. They mainly stayed inside, feeling imprisoned at home and not allowed to go outside by their parents. Particularly, participants who previously participated in vocational programs lost their opportunities for job training that potentially affected their employment. On the other hand, some felt relaxed and comfortable as they became distanced from their previously busy schedule and got used to staying at home.

Feeling imprisoned. Participants said their biggest challenge was feeling frustrated about not being able to participate in outside activities. Before COVID-19, they had regular leisure activities at the center, including barista training, baking, dancing, or outdoor activities, such as physical exercise or going out via public transportation on weekends. But after COVID-19, they rarely went out due to fear of COVID-19. They were limited to visiting hospitals or grocery stores and were often accompanied by their parents. Some participants could go out alone once or twice a week to stores or to take a walk alone, but they feared being infected with COVID-19. Participants said that visits and activities at the welfare center were a great source of vitality in their lives and not being able to attend the center due to COVID-19 impaired their ability to get out in the community.

Not being allowed to go outside. Most participants wanted to go outside to work out or visit grocery stores but were prohibited by their parents. They recognized that their parents kept them from going out because they feared they would die of COVID-19, and Minjae described this as a “stay-at-home order.” Yejin said she was not allowed to step outside, reminding herself of news reports indicating that everyone should stay home.

Decreased opportunity for job training. For participants, the welfare center was a place where they learned new skills through training. After COVID-19, they said they were anxious because they could not learn new things and experience achievements. Six participants who participated in vocational or job training at the center worried about the regression of their job skills due to the closure. Sora said she wanted to become an independent adult who could live by herself, imagining what it would be like when her parents die. She wanted to be trained at the center in preparation. In particular, participants who received vocational training worried that their employment plans had to change and required finding new skills and jobs due to the suspension of vocational training and job arrangements. Hyojin and Jiyeong, who participated in a job training program, said they had financial problems because they went from working five days a week to having their jobs suspended.

Feeling relaxed. Some participants said that being unable to participate in programs at the welfare center was not too bad. Rather, they said that it had been tiring to participate in many programs at the center and that they felt comfortable and liked to relax at home. They didn't feel bored staying at home. Yoonsu appreciated not having to interact with a colleague whom he had a conflict with at the center. Woobin expressed comfort about getting used to staying at home and being on the computer.

Discussion

This study provided empirical evidence of life changes experienced by adults with ID after the outbreak of COVID-19 pandemic from their perspective. Adults with ID experienced various life challenges and adaptations since the shutdown of community services due to the pandemic. Our findings can inform the development of alternative ways of helping adults with ID establish a new daily routine and adjust to interpersonal relationships, family dynamics, and social participation during COVID-19.

Our study participants used to attend community services regularly, but they lost their daily routines due to suspended or reduced services at the center. Because they had nothing to do all day and received less support, their sleep and daily patterns became irregular, and they mainly spent time meaninglessly by themselves. This is consistent with previous findings that showed many family caregivers were concerned about the disruption of their children's healthy routine and activities.[11,12] This study's findings also show the possibility of developing a new lifestyle among adults with ID, such as creating their own hobbies and new routines. It is promising that they had strategies to cope with restrictions related to the COVID-19 pandemic. Appropriate support and training are needed for adults with ID to develop new routines, find meaningful activities, and adjust to a new normal in the pandemic.

Although participants said their eating patterns became irregular, many tried to protect their health, contrasting the results of a prior study that reported that more than half of individuals with ID had reduced physical activity and negative physical changes from the perspective of caregivers.[26] A previous study found a significant decrease in physical activity and increased screen time in a sample of people with developmental disabilities.[13] Physical health is prerequisite for mental health and thus, maintaining health in the pandemic is important. Whether and how health or health behaviors changed were reported only from participants’ perspectives in the current study. It would be beneficial to investigate changes with an objective measure of health status. Furthermore, working out at home or engaging in outdoor activities alone may increase physical activity, but people with ID may find it difficult to remain motivated about health-promoting behaviors without support.[27] Therefore, it is important to provide the social support necessary to promote healthy behaviors.

Due to spending more time at home, participants in our study had increased interactions, either positive or negative, with family members. Some reported that they acknowledged their family's struggles and tried to contribute to the household. Others spent more time on their own rather than communicating with family members. Staying together in the same space for a long time triggered nagging, fights, and conflicts. Parents reported feeling concern and stress when their adult child with ID lost their healthy routines, and subsequent conflicts were a major source of caregiving burden.[28,29] These results show that relationships with families can be improved by maintaining the healthy daily lives of adults with ID. It is necessary to provide education and family-based interventions to enhance positive interactions and create shared interests and activities among family members.

Adults with ID in our study reported notable challenges in their lives, such as losing opportunities for social contact and relationships, which is consistent with previous findings.[9,15] They felt isolated, frustrated, and depressed due to social isolation. People with ID are more vulnerable to disconnection from interpersonal relationships because they often have anxiety and fear about building social relationships. Some participants developed alternative ways to maintain social relationships with people using remote technology. A previous study[15] similarly found that experiences of maintaining social contact using technology during the COVID-19 pandemic differed (feeling fun and comfortable vs. experiencing difficulty making contact remotely) among participants with ID. However, most adults with ID only maintained familiar relationships with people that they usually met at the center, such as teachers or peers with ID who understood their disabilities. It is possible that verbal communication difficulties, which are prevalent among adults with ID, made communicating with unfamiliar people more difficult.[30] It would be beneficial for people with ID to learn how to communicate with people using technology when they feel lonely. Community centers should take the lead in providing opportunities for individuals with ID to engage in new relationships with people. For example, peer mentoring programs can help build their motivation and confidence to engage in relationships with people without ID.[31]

All participants in the current study said they felt imprisoned because they could not participate in various social involvements, such as leisure activities or work experiences through community services, which prevented them from releasing physical energy and made them feel mentally frustrated. Adults with ID often engage in vocational or leisure activities as a way to socially integrate.[32] Participation in leisure, arts, recreation, and employment activities is an important aspect of life contributing to the health and well-being of people with ID.[33,34] However, most people with ID in our study felt like they lived in a prison, not because they were determined to protect themselves from the risk of COVID-19, but because their parents did not allow them to go outside. The ideal outcome would be that parents seek to prevent the risk of COVID-19 infection in a way that does not violate the self-determination and freedom of adults with ID. As Deci and Ryan[35] emphasized that personal competence, autonomy, and relatedness can promote psychological health and well-being. However, it is not easy for adults with ID who are assigned a guardian to balance their need for support and protection and their right to self-determination and autonomy.[36,37] Most importantly, parents should create alternatives to guardianship instead of making decisions for them.[38] Parents should consult with practitioners, who could suggest best practices for parents and adult children with ID to reduce the risk of COVID-19. Experts could also educate adults with ID to promote competence to cope with challenges related to COVID-19 by using various training options (e.g., video interaction, phone, and interactive chat) so that adults with ID could implement supported decision-making. Based on the need for community welfare services or community participation during the pandemic among adults with ID, welfare center leaders should not only discuss issues with the parents as guardians but also hear the voice of adults with ID, thus not relying on parents' opinions and strengthening the stigma of incompetence attached to those with ID. Whereas others found that individuals with ID needed virtual social services by telephone or video,[10] our study participants did not report needing alternative services that would offer opportunities for social participation. It is possible that they have experienced low satisfaction with remote services in Korea.[29] Because adults with ID can develop competence and autonomy online by connecting with people and exchanging support,[39] it is important for them to engage in diverse virtual activities using a range of technologies during the pandemic.

The findings of this study inform the implementation of care for adults with ID and their families in the community during and beyond the pandemic. Individuals with ID have been isolated and further excluded from society based on a deficit-based model,[40] which intends to protect them from harm but often becomes oppressive. In a social crisis, such as COVID-19, individuals with ID need individualized care that allows them to maintain their daily lives and continue their social participation. From a strengths-based perspective as depicted by the supports model,[41] individuals with ID can build meaningful interpersonal relationships and participate in society in a way that bridges mismatches between personal competence and environmental demands. Although professionals should identify and empower physical, cognitive, social, and emotional competence among adults with ID, they should also provide support that can help them address the challenges and expectations associated with the environments in which they want to be integrated. This support model based on a strengths-based perspective can be applied to adults with ID who are socially isolated and not integrated into the community, even after the end of the pandemic.

Limitations

One limitation of the current study is that although our sample included people with diverse levels of ID, the experiences of those with profound ID but without verbal communication skills may not be reflected. It is important for future research to understand their experiences using proxy reports or observation techniques. In addition, most participants lived with and received support from family members; only one participant lived independently. Future studies should examine how family support affected their life during the pandemic. A key strength of our study is that we interviewed individuals with ID and explored their perspectives about the pandemic instead of relying on the perspectives of proxies such as their caregivers. However, it is possible that their perceived challenges and support might not be consistent with parent caregiver reports. It would be informative to seek comprehensive understanding from diverse perspectives on their life through interviews with people with ID and their matched parent caregivers and other family members. Moreover, our study participants reported diverse characteristics. Demographic information (e.g., age and gender) and severity of disability (i.e., severe or mild) may influence their adjustments to a new lifestyle amid COVID-19. In addition, our study sample previously participated in diverse community-based daytime activity programs that were suspended or reduced in the pandemic. Depending on the purpose of the programs and services they used to attend, their challenges and adjustments during the lockdown could differ. For example, those who used the services to acquire job skills may have different challenges than those who attended leisure activities. Finally, this study was conducted during the first wave of the COVID-19 pandemic, when community services had been suspended for 4 months after the first reports of COVID-19 in Korea. It is likely that as the spread of COVID-19 has fluctuated and government responses evolved, adults with ID may have coped with challenges and found a new normal. Future studies could qualitatively explore their adaptation processes over a long period and their need for support.

Conclusion

The effects of the COVID-19 outbreak and restriction of community services on adults with ID, who often need support to lead a self-reliant life in the community, have been very detrimental. They experienced significant life challenges in the COVID-19 pandemic, but they also had potential to adapt to a new life by maintaining activities and social relationships. This study can inform clinicians seeking to develop alternative forms of community care for adults with ID amid COVID-19 or other major public health crises. Health routines, positive family interactions, interpersonal relationships, and community participation are important components of life that can facilitate positive outcomes regarding social inclusion. This study highlights the need to provide individualized remote services and support to strengthen their daily routine and health, family integration, and interpersonal relationships and social participation during the pandemic.

Ethical approvals

This study was approved by the ethics committee of Sungkyunkwan University (SKKU 2020-06-008). The research was undertaken with the understanding and written consent of each participant.

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Conflicts of interest

All authors have no conflict of interest to declare.

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