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Distance Learning Experience of Korean American Parents of Children with Developmental Disabilities During the COVID-19 Pandemic

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# UNIVERSITY OF CALIFORNIA

Los Angeles

Distance Learning Experience of Korean American Parents of

Children with Developmental Disabilities

During the COVID-19 Pandemic

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Philosophy

in Education

by

Hyon Soo Lee

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### ABSTRACT OF THE DISSERTATION

Distance Learning Experience of Korean American Parents of Children with Developmental Disabilities During the COVID-19 Pandemic

by

Hyon Soo Lee

Doctor of Philosophy in Education University of California, Los Angeles, 2021 Professor Connie L. Kasari, Chair

Due to the COVID-19 pandemic, many schools halted in-person education in 2020 and switched their instructional delivery method to distance learning. Sudden changes in the learning format may present challenges for students with developmental disabilities, who need specialized instructions with carefully planned programming. Distance learning from home naturally requires more involvement from parents; however, culturally and linguistically diverse parents need proper accommodations to be effective collaborators to teachers. A high percentage of Korean American families are first-generation immigrants with limited English proficiency. They have faced systematic barriers and discrimination before and during COVID-19, including in schools and research. Using a social-justice oriented transformative framework, the current study explored barriers and facilitators related to distance learning among Korean American

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parents of students with developmental disabilities through parent interviews. The study was offered in English and Korean to accommodate families' language preferences, and community engagement methods were used throughout the research process. Participants were all firstgeneration immigrant mothers with school age children with developmental disabilities. Qualitative analysis of interview transcripts revealed that participants were concerned about their children's class participation, behavioral and mental health issues, lack of social opportunities, and inappropriate class levels. Although extremely stressed from burdens at home, Korean immigrant mothers reported that distance learning demystified American classrooms and led them to be more involved in their children's education. All participants used the KakaoTalk app to communicate with their friends and family; however, none of the schools used this app to reach out to Korean families. Participants appreciated educators that listened to parental concerns and included students during class. However, schools rarely provided cultural accommodations, and some parents experienced discrimination from service providers. Parents in areas with no Korean families around them reported feeling isolated. Participants faced barriers on multiple levels due to their unique situations: 1) raising children during a pandemic, 2) having children with developmental disabilities, and 3) being first-generation immigrants from Korea. Recommendations include collaborating with mediators who are fluent in both English and families' languages, understand cultural differences and have expertise in developmental disabilities to improve school-family communications and research participation of culturally diverse families.

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The dissertation of Hyon Soo Lee is approved.

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- "UCLA-커뮤니티가 함께하는 연례 자폐증 컨퍼런스 (The Annual Autism Conference by UCLA and Community Partners)". Lanterman Regional Center, Los Angeles, CA / March, 2021.
- "Applying Community-Partnered Participatory Research to Diverse Issues and Populations, Nationally." Panelist at the Community Leadership Institute for Equity (C-LIFE)
- Conference, Healthy African American Families, Los Angeles, CA / November, 2020. "Parenting Class for Korean American Families: Pivotal Response Training (PRT; 중심축 반응
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- "Partnerships and Collaboration with Community-Based Organizations." Plenary panelist at the annual Autism CARES (Collaboration, Accountability, Research, Education, and Supports Act) Meeting, Association of University Centers on Disabilities, Washington, D.C. / July, 2019.
- "Cultural Considerations in ASD." Guest lecture at California State University, Northridge, Los Angeles, CA / November, 2018.
- "한인을 위한 자폐증 연구: 2-Year Update (Autism Research for Korean Americans: 2-Year Update)." Asian Pacific Counseling and Treatment Centers, Los Angeles, CA / August, 2018.
- "Autism Intervention Research Network for Behavioral Health (AIR-B): Mind the Gap." Board of Directors Meeting, South Central Los Angeles Regional Center, Bell, CA / July, 2018.
- "한인을 위한 자폐증 연구 (Autism Research for Korean Americans)." Asian Pacific Counseling and Treatment Centers, Los Angeles, CA / July, 2016.

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- Lee, H.S. (2019, May). Building on the Strengths of Community: Addressing the Mental Health Needs of Korean Americans. Paper in symposium: Using community-partnered approach to connect with culturally diverse families: Examples from ASD research with Korean Americans presented at the 172<sup>nd</sup> Annual Meeting for the American Psychiatric Association, San Francisco, CA.
- Lee, H.S., Jones, F., Castellon, F.A., Smith, J., Lucas-Wright, A., Kataoka, S., Channa, I., & Kasari, C. (2019, May). *Community-partnered participatory research in autism: Engaging underresourced African American, Korean and Latino communities.* Poster presented at the International Society for Autism Research (INSAR) Annual Meeting, Montreal, Canada.

#### Introduction

From the spring of 2020 to the subsequent school year, the COVID-19 pandemic caused significant disruptions to students, families and schools, forcing them to switch from in-person education to distance learning under a stay-at-home order. This sudden shift differs from traditional models of distance education which are typically carefully planned and implemented based on decades of research (Dietrisch et al., 2020). Some scholars emphasize this distinction and refer to the pandemic-induced distance learning as *emergency remote teaching*, a temporary instructional method during a crisis (Peterson, Scharber, Thuesen, & Baskin, 2020). Such method may not easily lend itself to special education, which require highly individualized programming for students with special needs. For instance, Stenhoff and colleagues (2020) note that some students with developmental disabilities, without the usual supports in place, may have more difficulties than their typical peers in transitioning to and actively participating in distance learning. Since students receive education from home, some responsibilities for instructional delivery may inevitably transfer to parents, whose role as collaborators to teachers is essential during the pandemic; the lack of time, knowledge and experience in instructional delivery of some parents can act as barriers to accessing quality education (Stenhoff et al., 2020).

#### **Culturally Diverse Parents' Involvement in Special Education**

In the American special education system which expects parents to be equal partners with schools, culturally diverse families who may not have this shared understanding or do not speak English fluently are at a disadvantage (Kalyanpur, Harry, & Skrtic, 2000). Some educators do not understand families' cultures or are unwilling to investigate the meaning behind certain behaviors; non-English speaking parents of students with disabilities find it difficult to assist their children with homework (Hess, Molina, & Kozleski, 2006). Studies conducted during

COVID-19 show a similar pattern in which cultural differences become an obstacle to collaboration between schools and parents. In a recent qualitative study, special education teachers who shared their experience of transitioning to distance learning mentioned that their need for parental input increased during the pandemic; however, they felt disconnected from some families and had to rely on cultural or community liaisons to bridge the communication gap (Glessner & Johnson, 2020). An online survey with Korean immigrant parents living in the U.S. found that parents' limited English proficiency and difficulties meeting children's educational needs were significant stressors to parents during the pandemic (Hong, Choi, & Cheatham, 2021).

#### **COVID-19 Research with Racial/Ethnic Minorities**

Recent research with racial/ethnic minorities has highlighted how systematic barriers may contribute to negative health outcomes related to COVID-19; African Americans, Alaska Natives, and American Indians experience higher rates of hospitalization (Centers for Disease Control and Prevention, 2020) and African Americans and Hispanics/Latinos have higher death rates (Chicago Department of Public Health, 2020). The pandemic also triggered a recent surge in racially motivated hate crimes against Asian Americans, who have been victims of racialized verbal and physical attacks since their arrival in the late 1700s (Grover, Harper, & Langton, 2020). Studies have shown that Asians in the U.S. experienced increases in discrimination and associated mental health issues, such as anxiety and depression during the COVID-19 pandemic (Lee & Waters, 2020; Wu, Qian, & Wilkes, 2021). The accurate picture of COVID-19 related health outcomes among Asian Americans is far from complete, as many Asian American deaths from COVID-19 are undercounted or misclassified (Flagg, Sharma, Fenn, & Stobbe, 2020). In addition, different ethnic groups within the Asian American population are often lumped into an

umbrella category (e.g., "Asian", "Other"), ignoring each group's unique challenges, culture, language, immigration history in the U.S. and acculturation levels. In their review of COVID-19 health disparities literature, Yan and colleagues (2021) pointed out the issue of aggregating different groups and the systematic omission of Asian Americans in scientific studies, including those published in the highest impact journals. Researchers also need to be aware that linguistic minorities are excluded from most surveys. A lack of data about certain groups should not give a false impression that they do not face challenges; it is more likely that these problems are left unaddressed and need special attention.

#### Invisible Minorities in Telehealth Research in Autism Spectrum Disorder (ASD)

Telehealth refers to the use of computer and Internet-based technology to deliver health information and services (Dudding, 2009), and distance education is an integral component of telehealth (White, Krousel-Wood, & Mather, 2001). Prior to the pandemic, research on distance education with parents of individuals with developmental disabilities, such as ASD, was gaining momentum. However, the issues in data reporting practices and exclusion of cultural minorities that we see in COVID-19 research were also prevalent in past ASD telehealth research. The majority of these studies involved middle-class Caucasian parents of children with ASD or did not report race/ethnicity or income data at all.

For instance, Vismara, McCormick, Young, Nadhan and Monlux (2013) used videoconferencing and a self-guided website in a pilot study to teach Early Start Denver Model (ESDM; Rogers & Dawson, 2010), a naturalistic developmental behavioral intervention that targets social communication in young children with ASD, to eight middle-class, primarily Caucasian parents. In a subsequent study, Vismara et al. (2018) conducted a randomized controlled trial comparing parents' fidelity of implementation, website engagement and program

satisfaction between the group receiving telehealth ESDM parent training vs. a comparison group receiving less intensive, non-ESDM telehealth intervention. The study sample included 24 families: parents were required to speak English fluently in order to participate and were highly educated with 20 parents having either a college or graduate degree, and twenty children were non-Hispanic, but no further details about the race and ethnicity of children and their parents were provided.

Another telehealth parent training intervention for ASD is ImPACT Online, an Internetbased version of Project ImPACT (Ingersoll & Berger, 2015). In the pilot study by Ingersoll & Berger (2015), program engagement was examined in self-directed and therapist-assisted groups. Both groups received access to the ImPACT Online website containing self-directed lessons with narrated slideshows and learning activities, supplemental resources and a moderated forum, and weekly emails with tips related to intervention techniques with a link to the website (Ingersoll & Berger, 2015). The therapist-assisted group also received remote coaching via Skype videoconferencing software, selected due to its simplicity and familiarity based on feedback from parents and providers during focus groups (Ingersoll & Berger, 2015). The study's sample included 27 participants: they were all required to be proficient in English in order to participate, 70% lived in a rural or medically underserved areas, 81% were married, 66% had a college degree or higher, 78% of children were white, and only "few very low socioeconomic status families" were included, which the authors acknowledged as a limitation. (Ingersoll & Berger, 2015).

Following Ingersoll & Berger (2015), a series of additional articles was published using the same study sample (e.g., Ingersoll, Wainer, Berger, Pickard, & Bonter, 2016; Pickard, Wainer, Bailey, & Ingersoll, 2016), and therefore limitations regarding the sample hold true for

these studies as well. Additionally, Pickard et al. (2016) reported that although the study was conducted in rural and/or underserved areas, families were still required to travel to the research site three to four times to complete assessments, creating a barrier to participation for socioeconomically and ethnically diverse families.

Some research groups in the field of applied behavior analysis have also used telehealth parent training to target challenging behavior in children with ASD. To include families in rural and underserved communities, Wacker and colleagues (2013a, 2013b) coordinated with regional pediatric clinics located an average of 15 miles from participants' homes. These clinics were equipped with Sony PCS-1600 videoconferencing stations, at which families received live coaching from behavioral consultants located an average of over 200 miles from the clinics (Wacker et al., 2013a, 2013b). The sample in Wacker et al. (2013a) included 20 parents, most of whom had a degree beyond high school; 17 parents in Wacker et al. (2013b) had similar characteristics, as these studies had overlapping samples. No data on participants' race and ethnicity, income, and language spoken at home were presented in either study. Although small sample sizes, single subject design and very limited information on socioeconomic factors compromise these studies' generalizability, it is worth noting that these studies allowed rural families to connect with distantly located providers by partnering with local clinics that provided telehealth equipment and on-site support.

The Research Unit on Behavioral Interventions (RUBI) Autism Network took a similar clinic-to-clinic approach in which a parent training program targeting children's behavioral issues (RUBI-PT) was piloted at rural community sites with telehealth equipment and support staff, including a hospital, a primary care center and two schools (Bearss et al., 2017). Although the sample size was small (N = 14), the study reported detailed sociodemographic information

about the families, including children's race (71% white), maternal education (36% with a college or graduate degree), living arrangements (36% intact two-parent family), and household income (78.6% earning \$60,000 or less).

In another study with rural families of children with ASD exhibiting behavior challenges, a behavioral consultant delivered telehealth training to parents residing an average of 68 miles from the research institution using iChat videoconferencing (Machalicek et al., 2016). Three Caucasian parent-child dyads participated: two parents were married, one had a college degree, and no income data were reported. The study did not mention the sample size or characteristics as limitations.

Other domains that have utilized telehealth with parents of individuals with ASD are currently at pilot stages. Smith et al. (2017) compared in-person ASD assessment to the Naturalistic Observation Diagnostic Assessment (NODA) mobile app that guided parents (N = 51; 43% Hispanic, 41% Caucasian, 8% Black, 8% other; all spoke English fluently; no income data) to collect and share videos of their children with clinicians; Chen et al. (2017) piloted EpxAutism, an automated texting platform that prompted parents (N = 6; no sociodemographic data) to text their children's quality of life, the number and duration of meltdowns daily and alerted providers when "high risk" response was reported; Hepburn, Blakeley-Smith, Wolff, & Reaven (2016) tested the CBT-based Facing Your Fears multi-family intervention for youth with ASD and anxiety symptoms using the OoVoo program for video calls (N = 33; 88% of youth were Caucasian, 21% Hispanic, 9% African American, 3% Native American, 0% Asian; rural, middle class; 42% of parents had a college degree or higher; excluded if unable to speak and understand English fluently); Gibbs & Toth-Cohen (2011) collaborated with parents via WebEx

videoconferencing software to develop a website that assisted with occupational therapy sessions (N = 4; one single parent household; no data on race/ethnicity, income, or education level).

#### A Longstanding Problem in ASD Research: Inequitable Access

Inconsistent reporting of racial/ethnicity data across studies and inaccessibility of research in languages other than English contribute to the lack of cultural diversity in ASD telehealth research. No ASD telehealth interventions, to the author's knowledge, have included any non-English speaking participant. Usually, such studies do not mention whether the intervention was available in a language other than English; sometimes they explicitly state that they excluded participants who did not speak English fluently. With such standards, among families who speak a language other than English at home, 42% of them who speak English less than "very well" – that is, over 25 million people in the U.S. (U.S. Census Bureau, 2013) – would automatically be excluded from participating in research.

Research labs should re-evaluate current practices that rely on conventions that may not reflect and accommodate the changing demographics in the U.S. Not hiring multilingual research staff in locations with multilingual families or depending on traditional recruitment methods can inadvertently widen the already existing inequities in access to knowledge, research and services. Such practices were also observed in studies reviewed in this paper. Smith et al. (2017) only had English-speaking assessors; Gibbs & Toth-Cohen (2011) selected all participants from the author's private practice clinic; Vismara et al. (2013) enrolled participants who read the study description from the research center's website or called the center to inquire about ongoing studies on a first come, first served basis. As a result, in the field we often see a pattern in which studies continually enroll predominantly English-speaking, savvy and proactive parents. Even if the goal of a study is to pilot test a new intervention, not including a diverse sample in the pilot

stage deprives certain populations of the opportunity to provide feedback to researchers. These concerns should be noticed and acknowledged in the field – even if it was for practical reasons, not conducting inclusive research is doing injustice to families who are perpetually excluded from participating in novel and exciting scientific discoveries and allows current inequities in research continue.

For decades, ASD was associated with high economic status due to early research that relied on affluent, high-educated families with easier access to services – a myth that was dispelled when researchers started including more representative samples (Blacher & Christensen, 2011). While researchers have made some efforts to diversify samples, the lack of linguistic diversity and immigrants is still significant. By creating opportunities for marginalized communities to participate in research and pursuing more representative samples that reflect the population, studies can increase research rigor and social validity of findings. To make up for the loss that culturally and linguistically diverse families have experienced due to the unavailability of research that qualifies them as participants, researchers could make additional effort to specifically target these populations and catch them up to speed.

### Koreans in the U.S. and Special Education

As an ethnic group within Asian Americans, Koreans have been heavily affected by COVID-19 discrimination and historically underrepresented in developmental disabilities research in the U.S. There are approximately 1.8 million Koreans in the U.S., making up about 0.6% of the American population (U.S. Census Bureau, 2016). Among the six largest Asian groups that make up 88% of Asian Americans – Japanese, Filipino, Chinese, Vietnamese, Indian, and Korean – Koreans have the lowest percentage of American-born citizens (U.S. Census Bureau, 2004). Only 41% of Korean Americans were born in the U.S., and about 38% of Korean American adults do not speak English very well (Pew Research Center, 2021). Korean families mainly move to the U.S. to provide the best educational opportunities for their children or to complete their own advanced education (Lee, 2003). In Korea, education is seen as the most reliable and certain way of advancing one's socioeconomic status and gaining admiration from others; the Korean "education fever" is so high that some parents are even willing to go through family separation and send their children to English-speaking countries (Lee, 2011). The Korean culture that highly values education may partly explain the high education levels seen in demographic data on Korean Americans (U.S. Census Bureau, 2004).

Korean immigrant parents who have experienced both the Korean and the U.S. special education systems strongly emphasize that the U.S. is a better place to raise exceptional children due to available services and public attitudes that are more accepting of individuals with disabilities than those in Korea (Cho, Singer, & Brenner, 2000). Although the benefits of receiving special education in the U.S. are widely recognized by Korean parents, language barriers often thwart immigrant families' efforts to access services for their children (Stahmer et al., 2019). Formal translators provided by school districts do not seem sufficient, as Korean immigrant parents report that these translators lack knowledge in special education and therefore are not qualified to provide services during Individualized Education Program (IEP) meetings (Cho, Singer, & Brenner, 2000). Despite the cost, some Korean parents hire informal translators with training in developmental disabilities in order to effectively communicate with their children's schools (Cho & Gannotti, 2005).

Numerous studies in the past have recommended that researchers and schools take the time to understand families' cultures and preferred methods of communication and provide appropriate cultural accommodations. However, we have seen systematic barriers and lack of

accommodations hindering culturally diverse families of children with special needs from participating in research as well as communications with schools. With the COVID-19 pandemic forcing families to venture into new territory of distance learning – or more accurately, emergency remote teaching – more attention is needed on Korean immigrant families of children with developmental disabilities, who are at risk due to COVID-19 discrimination, their linguistic minority status, and the challenge of receiving special education remotely. In particular, the specific barriers and facilitators to distance learning for Korean immigrant parents and students with special needs and how schools accommodated their needs during the pandemic are unanswered questions.

#### **Transformative Framework to Address Inequities**

The transformative framework is a social justice-oriented paradigm that aims to address inequities through research (Mertens, 2007). It emphasizes respecting communities' cultural histories and norm, challenging the status quo in the society and providing a basis for social change (Mertens, 2012). There are four basic beliefs of the transformative paradigm: 1) The researcher needs to be aware of societal values and privileges; 2) To know realities, it is necessary to have an interactive link between the researcher and participants and to have respect for culture; 3) Methods should be adjusted to accommodate cultural complexities; 4) Follow the principles of respect, beneficence and justice (Mertens, 2007).

Distance learning for students with developmental disabilities is an emerging field and it is necessary to recognize and include the voice of marginalized communities who are often left behind. We can apply the transformative framework to distance learning research with cultural minorities. Examples include having open conversations and learning about their unique needs,

using culturally appropriate methods and tools to facilitate participation, and setting research goals that are aimed at solving problems in the community.

When gathering information about cultural and linguistic minorities not well-represented in research, data published outside of academia can offer some insight. For example, a report by SimilarWeb (2019) shows that the most popular messaging app used in the U.S. is Facebook Messenger; WhatsApp has the highest distribution of all messaging apps worldwide; South Korea is the only place in the world where KakaoTalk is the most popular platform in the country. The Pew Research Center (2018) reports that 49% of Hispanics in the U.S. use WhatsApp, compared with 14% of whites and 21% of blacks. These data suggest that there are cultural differences in app usage and that preferred communication platforms may vary depending on which country individual are from and when they immigrated. This could be useful information for researchers and schools when they work with culturally diverse families.

#### **Community-Partnered Participatory Research**

In addition to examining existing data, it is important to consult community members to understand cultural differences. Culturally and linguistically diverse families have been invisible in developmental disabilities research and much is unknown about them. To increase participation of culturally and linguistically diverse families, partnering with diverse communities is necessary.

Many well-intentioned studies that employ the traditional top-down model of research are met with poor translation and sustainability outcomes because they have not included the end users in the process (Laushey & Hefline, 2000). An approach that can help address the issues with the traditional method is community-based participatory research (CBPR), a collaborative

approach that encourages active participation from both researchers and the community (Blumental, 2011).

However, many collaborative research projects conducted at community sites still lack partnership in design and implementation and therefore, a variant of CBPR called communitypartnered participatory research (CPPR) was developed by Healthy African American Families, Charles R. Drew Medical University with support from the Centers for Disease Control and Prevention (Jones & Wells, 2007). CPPR is a manualized approach that emphasizes authentic community-research partnerships in all stages of research, including study design, recruitment, implementation, data analysis, and dissemination of findings (Jones & Wells, 2007) and aligns particularly well with the social justice perspective of the transformative framework. A study with parents of children with ASD has shown that by utilizing CPPR, researchers and community partners can engage racial/ethnic minorities, who are often disconnected from ASD research due to cultural and linguistic barriers (Stahmer et al., 2019).

#### **Current Study**

This study explored distance learning experiences of Korean American parents of children with developmental disabilities, focusing on barriers and facilitators to student learning and parent-school communications during the COVID-19 pandemic. The study utilized CPPR methods to include community members throughout the research process. Another critical element of this study was to help Korean American families voice their needs to stakeholders inside and outside the Korean American community. The study aimed to offer an opportunity for Korean American parents, who typically have very limited access to research due to cultural and language barriers, to participate in research in their native language and in a culturally sensitive manner.

### Methods

# **Participants**

To be eligible for the study, participants had to self-identify as ethnically Korean and have a school age (kindergarten to 12th grade) child with a developmental disability. They could be either English or Korean speaking. A total of 16 parents from 13 different school districts (13 in California, 2 in New York, and 1 in Alabama) reached out to the study investigator during the recruitment period, and all met eligibility criteria and were included in the study. All participants were female and first-generation immigrants born in South Korea. Participants' average age at immigration to the U.S. was 26.4 years (range: 11-39 years), and their current ages ranged from 27-57 years (M = 45.3 years). Except one parent, everyone had multiple children, with two being the most common number of children. One parent had two children with ASD, one school-age and one adult; all other parents had only one child with a developmental disability. With four holding graduate degrees and seven 4-year college degrees, the sample was generally highly educated, which is consistent with the typical characteristic of Koreans in the U.S. (U.S. Census Bureau, 2004). Household sizes ranged from three to seven people; half of the participants earned over \$100,000 annually and the other half earned less than \$90,000, with some families earning \$9,999 or less. Thirteen participants spoke Korean at home, two reported using English, and one used English and Korean equally. Participant demographic information is summarized in Table 1.

Participants were asked to report the demographic information of their school age child with developmental disabilities. All children were ethnically Korean except one Chinese child who was adopted. Nine children were male and seven female. The average child age was 10.9 years (range: 5-18), with one student in kindergarten, three in the second grade, two in the third

grade, four in the fourth grade, two in the seventh grade, one in the ninth grade, and three in the  $12^{\text{th}}$  grade, all enrolled in public schools. The most common type of developmental disability was ASD (n = 12), followed by intellectual disability (n = 3), speech delay (n = 2), ADHD (n = 1) and seizure (n = 1). Two children had more than one type of disability. The average age at diagnosis was 4.0 years (range: 2-10 years). Four students were placed in general education classrooms all the time, five spent some time in general education and some in special education classrooms, six in mixed disability classrooms and one in autism-only classroom. Child characteristics are presented in Table 2.

# Procedures

**Study development.** In the beginning stages of this research, the study idea was presented at the monthly meeting of the Autism Intervention Research Network on Behavioral Health (AIR-B Network), an academic-community partnership in its 13<sup>th</sup> year. AIR-B members include researchers, community-based organizations, schools, parents of individuals with ASD, self-advocates and developers of CPPR, Healthy African American Families. Community partners agreed that the current study's goals aligned with the group's mission to increase access to ASD information, services and research for under-resourced families. The study's design was revised based on both academic and community experts' feedback.

A protocol for a semi-structured, one-on-one interview containing 10 questions with follow-up probes was developed (see Appendix B). The questions aimed to elicit parent responses about how students and parents are coping with distance learning, challenges and facilitators, and parent involvement in education. The study investigator translated interview questions into Korean, texted both English and Korean questions via KakaoTalk to two AIR-B

Korean immigrant parents of students with ASD and confirmed that interview questions covered relevant topics and translations accurate.

**Recruitment.** Study flyers in English and Korean were posted on websites and Facebook groups popular among Koreans residing in the U.S. Flyers were also texted via KakaoTalk to allow Korean parent leaders to easily share information with other parents. Parents interested in the study contacted the study investigator by calling, emailing, or text messaging via Google Voice or KakaoTalk and scheduled an interview date. All communication regarding the study was conducted in the language participants initially used to contact the investigator or specifically requested; Korean was used with 15 participants and English with one. Participants were given a choice of a phone or a Zoom interview; all participants selected Zoom. Prior to the interview date, participants were sent an online survey containing the consent form and a demographic questionnaire, developed using the Qualtrics software (see Appendix C for the demographic survey).

**Participant interview.** Each Zoom interview began with reviewing the consent form with the participant and answering questions. Interview sessions were audio recorded and notes were taken during the interview. The average length of interviews was 54 minutes (range: 33 minutes – 1 hour and 51 minutes). Data collection continued for 47 days (October – December, 2020), until it was determined that saturation was reached. All 16 participants received a \$15 Amazon e-gift card for their participation.

#### **Data Analysis**

After the interview, recordings were transcribed by the investigator and trained research assistants. All completed transcripts were reviewed and corrected for accuracy by the investigator. An open coding of transcripts was conducted to generate a preliminary list of

categories that captured the essence of the excerpts. Through further examination and coding of transcripts, categories were revised, and a final set of codes was established. The definitions for the 13 codes are presented in Appendix D. Line-by-line coding was used to assign codes to phrases, sentences or paragraphs. Multiple codes were applied to an excerpt when applicable.

**Interrater reliability.** A Korean immigrant mother of a child with ASD, enrolled in a doctoral program in special education, was recruited as a second coder for the study. The second coder was trained to reach above moderate agreement on all 13 codes for two consecutive transcripts. Interrater reliability was calculated using Cohen's kappa, which classifies .41-.60 kappa value as moderate, .61-.80 as substantial, and .81-.99 as almost perfect agreement (Viera & Garrett, 2005). Once reliability was established, the second coder independently coded 30 percent of the transcripts (i.e., five transcripts), selected randomly. Codes were compared with the investigator's original coding. The reliability for each code is as follows: Learning Environment = 1; Camera Policy = 1; Family/Friends Communication Method = 1; Learning Pod = 1; Distance Learning vs. In Person = 1; Distance Learning Apps = 0.96; School / Service Providers = 0.93; Parent-School Communication Method = 0.91; Parent Role = 0.87; Student Skill / Behavior / Interaction = 0.80; Distance Learning Positives = 0.71; Parent Knowledge = 0.70; Collaboration/Advocacy = 0.62.

#### **Community Engagement**

In an effort to stay true to CPPR principles, additional steps were taken to maintain community engagement in research. During the study, updates were given at AIR-B partnership meetings to keep community members informed of the research progress. All study participants were invited to the AIR-B's annual community conference on ASD, this year held virtually in English, Korean and Spanish (*Self-Determination and COVID Successes in ASD;*  $\exists \exists \sqcup \downarrow \exists$ 

딛고 그려가는 자기주도적인 미래; Un Mapa Hacia su Futuro: Autodeterminación y Éxitos de

*COVID-19 en TEA*). Participating as panelists or attendees, families had an opportunity to share their stories that they had shared with the study investigator to a broader audience. In addition, infographics summarizing the study findings have been developed and emailed to study participants and posted on websites used for participant recruitment (see Appendix E for the infographic).

# Results

# **Student Skill, Behavior and Social Interaction**

Student attention and participation. Parents identified several aspects of distance learning that were challenging for their children. One of the most common difficulties was students not paying attention to the teacher and getting distracted during class. One parent gave examples of activities that her son with ASD engages in during class: reading comics, lying down, watching YouTube videos, and sleeping. Among all the schools mentioned in this study, this student's school was the only one that required students to turn off their cameras during class, and the mother was frustrated with this policy: "사실상 선생님은 학생들이 뭘 하는지

아실 수가 없어요... 보는 엄마는 속이 뒤집어 지죠 (There is no way teachers can know what

the students are doing... Watching that drives me nuts.)."

However, turning on the camera did not necessarily mean that the teachers could know or intervene when students were distracted. A mother of a girl with ASD commented: "[아이가] 컴퓨터 앞에 앉아 있지만 internally distract 되기 때문에 다른 생각을 하고 있단 말이에요. 뭐 선생님이 보기에는 화면상으로 집중하고 있는 것처럼 보이겠지만, 아이는 안 그런거에요 ([My child] is sitting in front of the computer but she gets internally distracted and

is thinking about something else. It may look to the teacher as if she is paying attention, but she's really not.)." Some students played with other programs on the computer, an inherent issue with distance learning which utilizes devices that can also be tempting toys for students. Other common issues with distance learning included students refusing to sit down, running away, and not responding to the instruction.

Social interaction. Students hardly had any time to socialize with their peers in an online format. The student who had to keep his camera off due to his school's policy did not get to know his classmates' faces. For most students, the only opportunities they had that were remotely close to peer interactions included asking questions to their teachers, briefly presenting to the whole class, or working on assignments together in breakout groups where organic conversations rarely took place. Parents of students with ASD expressed increased worries about their children's social opportunities, as seen in the following: "어후, [친구 사귀는 게] 많이 힘들죠. 원래 학교 다닐때도 힘들었는데, 더 힘들죠... 전혀 기회가 없어요. 실제로 또래를 만나서 놀 기회가 거의 없어요 (Gosh, it is very difficult [for my child] to make friends. It was already hard when she was going to school, but now it's harder... There is no opportunity at all. There are hardly any opportunities for her to meet her peers.)." Another parent explained that missed social opportunities meant her child with ASD could not learn important social skills by imitating peers, such as following rules and playing with others during recess.

**Different student abilities.** Students with limited speech or social skills were often overlooked by teachers and left out from conversations taking place in class. A mother of a third-

grade boy in an autism-only classroom for third, fourth and fifth graders spoke about class participation of her son, who has much difficulty communicating with others: "모든 수업 진행이 5 학년 위주로 가는거에요. 그리고 또 얘는 말을 못하니까 얘는 아예 시키지도 않아. 그러니까 얘는 그냥 앉아있는거야 (Everything in the class revolves around fifth graders. Since my child can't speak, he never gets called on. So he just sits there.)." A mother of a kindergartener with speech delays who was placed in general education said that her daughter is usually outgoing but has lost confidence since starting distance learning. Because instructions were all speech-based and the child could no longer use physical communication, she had trouble participating in conversations or presenting along with her classmates.

Every parent whose child was placed in a mixed disability classroom thought the current class level was inappropriate for her child. One parent mentioned that her child was only beginning to learn sight words whereas some students in the class could read a book fluently; she wished that small-group instruction time could be longer than the current 10-15 minutes so her child could receive more individualized attention. A third-grade boy with ASD placed in a classroom with second to fourth graders with different disabilities fell behind his classmates in some areas but also ahead in some ways; this made the mother wonder if her child was "wasting time at home". The following quote from the mother of a 12<sup>th</sup> grader with ASD struggling in his sixth-grade level class represents how parents in the study felt about mixed disability classrooms:

이 mixed class 라는 거, 이것이 별로 좋은 것 같진 않아요. 모든 장애가 너무 너무 다른데... 애들이 너무 너무 수준이 달라요. 어떤 애들은 정말, 완전히 말도 굉장히 잘 하고, 6 학년 레벨 수업이 너무 쉬워요, 걔들한테. 그리고 우리 애한테는 너무 어렵고. 이거를 분리를 해야하지 않을까 생각이 들어요... 학년의 문제가 아니라 각자 상황의 문제인것 같아요, 발달장애는. 자기 레벨에 맞게 가르쳤으면

좋겠[어요] (I don't think this 'mixed class' is working. All disabilities are very

different... All these students' levels are very different. Some students are extremely verbal, and this sixth-grade level class is too easy for them, whereas for my child, it's too difficult. I think the [class] should be divided... It's not a matter of grade level but individual situation when it comes to developmental disabilities. I wish students could receive education appropriate for their levels.).

Similarly, needs were unmet for students who had more skills than their classmates. A fourthgrader with ASD able to speak in full sentences was given tasks too easy for her and often had to wait for her classmates in a mixed disability class for third to fifth graders. Her mother felt that student levels listed in the IEP were too simplistic and that more individualized curriculum should be given based on accurate assessments.

Behavior and mental health concerns. Some parents recently noticed skill regression, disengagement from activities, increased problem behaviors and other concerning symptoms in their children. A mother of a high school senior with ASD addressed mental health concerns throughout the interview. Her son no longer engaged in sports and isolated himself in his room for days; she had to constantly remind him to eat and drink water. "This whole mental health is really taking a toll on our families, especially with special needs on a different level," said the mother, who knew other families suffering from similar issues, including addiction, online gaming, and isolation. She felt that schools needed to have a hard look at families, be more flexible and offer counseling for parents and students. The need for counseling was echoed by

another parent of a child with ASD. This mother, moved to the U.S. at the age of 34, wished that mental health services and information used in other communities could be available for Korean immigrant families who struggled to find helpful information for their children.

Students' skill regression evoked fear in some families, including this mother of a ninth grader with ASD and other parents she spoke with: "어려운건 다 다른데 공통적으로 이야기 하는게 한가지가 있어요. '아이가 서비스 받는 걸 멈췄더니, 그대로 있는게 아니라 후퇴하더라.' 더 퇴보가 되면서, 할 줄 알던 것들도 못 하게 되는 거, 그게 굉장히 큰 문제에요. 저희 아들같은 경우는 더 아기가 되었어요 (All families have their own challenges but they say one thing in common: 'When services stopped, our children did not stay at their current level but actually regressed.' Regressing and not being able to do things they used to do, that is a big problem. In my son's case, he became a baby.)." One parent mentioned that during the pandemic, her son with ASD started talking to himself noticeably more than before; a mother of a girl with intellectual disability reported significant increases in protesting and self-hitting behaviors in her child. Increased screen time due to students' use of electronic devices for leisure as well as school was another common concern.

Parents warned that returning to school for in-person instruction may be challenging for some students. The mother of a 12<sup>th</sup> grader with ASD who is "paranoid about getting the [COVID-19] infection" expected that her son is likely to struggle with the learning environment changing yet again. Two parents of elementary school students with ASD did not think their children would keep their masks on at school. "하루종일 얘가 [마스크를] 쓰고 학교에

7시간씩 있는다는 거는 거의 불가능할 것 같아서 (It will be almost impossible for him to

wear his mask all day, for seven hours at school,)," said the mother of a boy with ASD in the second grade. Another parent was worried about her daughter with intellectual disability, who often ate food with her hands, following safety rules at school.

Student successes and adaptations. Despite the struggles, students still improved in some skill areas and learned to adapt to their new learning situation. The mother of a second grader with intellectual disability reported that she used to relay all the information given by the teacher to her child during class, as the child did not understand the concept of distance learning at first. After several months, the child gained awareness that she was expected to respond to the teacher in the screen and became more responsive to the instruction. Another student with intellectual disability, who used to "zone out, as if watching TV (그냥 TV 보는 거에요. 멍하니

보고)", now participated more actively during physical education. After repeated practice, the student listened to teacher directions and imitated the movements; the mother no longer had to carry around the laptop to force the child to watch her teacher. Two parents of fourth graders with ASD shared that although it was still a challenge, their children learned not to turn off the class app or the computer during class. One of these students had severe anxiety when looking at the camera but now she could look at her teacher's and one-on-one aide's faces.

Six parents reported that their children's technology skills improved during the pandemic. A kindergartener with speech delays became skilled at muting or unmuting herself when she had to present or ask questions to her teacher. A second grader with ASD learned to type simple words and close the computer window when the class was over. Another student with ASD, in the fourth grade, could now locate correct class links, mute and unmute himself, turn his camera on and off and share his screen with the class. A high school senior with ASD was taught by his

mother how to check emails from school and separate different windows on the computer. As students gained more skills, they became more independent and required less attention from their parents. One mother shared that her high schooler with ASD even reassured her, saying: "엄마,

저는 집중 잘 하고 있어요. 엄마 옆에 없어도 괜찮아요 (Mom, I'm paying attention and doing well. Don't worry; you don't have to sit by me.)."

A few students made progress that was impressive to their teachers or parents. A second grade student, whose mother provided immediate feedback and assistance during distance learning, surprised her teacher with her rapid reading skill development. The mother of a 12<sup>th</sup> grader with ASD with advanced skills was very proud of her son's "ability to self-correct"; when he noticed playing games on his phone was hurting his grades, he deleted his favorite game. He also employed other coping strategies, including playing with his cats and counting down until Christmas with a visual, which were helpful for his mental health.

#### **Parent Role**

**Burden and stress from distance learning.** Regardless of students' skill levels, participants were unanimous that distance learning created a constant high-stress situation for parents. Even for the mother of the 12<sup>th</sup> grader with ASD with advanced skills, the pandemic "has been the toughest time since the initial diagnosis of autism". Another mother of a student with ASD echoed the sentiment:

[Distance learning]을 하면서 옆에서 학교 생활을 같이 해야 되니까 너무 어렵고, 너무 난감하고, 어떻게 해야될지도 모르겠고. 게다가 옆에서 도와주던 aide 도 없고 이러니까 이 역할을 내가 해야되고. '여기가 지옥이구나' 싶었는데, 와... (Since

starting [distance learning] I have been basically going to school with my son, and it's very difficult. I feel helpless and don't know what to do. Also, the aide that used to help

him was not there, so I had to take on that role. I thought, 'Wow, this is a living hell.') Almost all parents said that they had to watch their children all the time or attend classes with them; many parents described themselves as their children's "one-on-one aide" or "teacher". Parents covered a wide range of tasks during their children's class. Constant reminders for students to pay attention or participate in class activities were very common. When students exhibited behavioral issues, parents had to calm them down and redirect them. Parents provided verbal and physical prompts to their children throughout the class, including repeating and clarifying teacher instructions, assisting with challenging academic tasks, giving cues when children were asked to respond by the teacher, stopping children from unmuting and interrupting the class, reminding to wait turns, and taking out necessary class materials in between transitions. Students with limited cognitive or verbal skills mainly communicated through their parents, who had to explain to students what was happening in the class, help with formulating and asking questions to teachers. The mother of a fourth grader with ASD, who had to physically assist her child during occupational and physical therapy sessions, said half-jokingly: "저]?

거의 1:1 aide 처럼 하고 있으니까 진짜... 왜 저한테 pay 를 안주실까...[웃음] (I'm

practically her one-on-one aide... Why am I not getting paid? [laughs])."

Parents' responsibilities extended beyond the class times. In the morning before classes started, parents ensured that their children could start their day right by waking and dressing the child, setting up devices for distance learning, printing and organizing class materials, serving breakfast, keeping the child in a good mood, taking care of the child's siblings and situating them apart so they can focus on their classes, and logging into the class app on time. Many parents attended class with the students. During breaks and lunch, parents prepared snacks and meals ("I'm basically the room service"). After class, many parents helped their children with completing and submitting homework, prepared class materials for the next day, and recharged devices. Other day-to-day tasks included preparing the house for therapy sessions, meeting with service providers, taking children out for a walk, serving dinner and cleaning the house. Parents with younger children also had to shower children and put them to bed. One mother with three children, all aged 10 or younger, said that her time without children started around midnight – the only time she could check emails, complete paperwork for various services, and pay bills. Most parents did not have the capacity to take care of their own mental and physical wellbeing. Parents gave up social life, hobbies, sleep, and exercise; self-care was replaced by extra cups of coffee. One parent quit her job in the beginning of the pandemic. All parents interviewed in this study would relate to the participant that said: "As a caregiver and as a mother, my job is to hold it together and it's a 24/7 job."

Three parents admitted that because they were so exhausted, they skipped school at times, which meant that their children also missed classes. One of these parents was the mother of a high school senior taking adaptive physical education (APE): "내가 몸이 너무 힘든거에요. 나도 50 이 넘어가지고... [웃음] 그래서 APE 는 사실 내가 솔직히 들어갔다 안들어갔다 해요... 들어갔다가도 나중에 끝에는 나오고 (I'm over 50 years old. My body doesn't listen... [laughs] So to be honest, I sometimes skip APE... When I do go in, I leave early)." Another parent guilty of truancy confessed: "엄마가 먼저 선행을 하고 엄마가 선생님이 돼서 같이 하거나 가르치거나 해야 하는데 제가 여태껏 한번도 제대로 했던 적이 없어요. 그래서 그거를 지금 9, 10, 11. 3 개월 동안 다 놓쳤거든요, 예체능 (음악, 체육) 과목은 (I know the mom has to learn, become a teacher and teach her child, but I have never really done it. So we missed September, October and November. We've missed three months of music and physical education classes.)." One parent was given the option by the child's school to either receive occupational therapy via Zoom or be provided with materials so that the parent can implement sessions with the child. The parent chose the latter and reported on how the sessions were going: "그러니까 뭐 writing 쓰고 뭐 가위질이랑 색깔 칠하고 이런 것들이더라고요. 안하고 있어요 [웃음] (It involves activities like writing, cutting with scissors and coloring. Right, I'm

not doing those [laughs].)."

Newly gained knowledge about students. All parents reported that they learned something new about their children during the pandemic. When one parent of a 12<sup>th</sup> grader was asked what her son's strengths and challenges were, she replied, "저는 사실은 이 질문을 지난 학기에 받았으면은 모른다고 했을거에요. 왜냐하면 내가 애 학교 생활을 전혀 모르니까요

(If you had asked me this question last semester, I would have said, 'I don't know' because I knew absolutely nothing about his school life)." This mother recently learned that her son was in a sixth-grade level class and struggling to keep up. "지금 내가 이번에 원격 수업을 이렇게

해서 알게 된 것이, '아, 얘가 학교에서 하는 게 많지는 않구나' (This is what I learned from distance learning: 'Oh, my son isn't doing much at school')," said the mother. Another parent
found out that her child with ASD wanted to interact with peers more than she had expected, that he sang songs when he was not focusing on tasks, and that he liked books very much.

Several parents noticed the mismatch between what they witnessed at home and what teachers used to say about their children. The mother of the student in an autism-only classroom said that what she saw was unexpected:

그 전에는 [아이가 어려움이 있는지] 잘 몰랐어요, 솔직히 말하면... 근데 이게, 줌으로 하다 보니까 저도 같이 하잖아요... 보니까 이게, [gasp] 얘가 왜 이렇게 됐는지를 알겠는거에요... 저희는 여기 있으면서 학교에서 전화 한번도 받은 적이 없거든요. 무조건 가면 "오, [아이] 너무 잘 했어~" 매일 이래요. 저는 정말 잘 하는 줄 알았거든요 [웃음]. 근데 하나도 한 게 없는거야, 학교 내에서... 저는 다 [저희 아이]랑 비슷한 아이들이 [반에] 있는 줄 알았어요. 근데 너무 갭이 큰 거에요... 그러니까 [저희 아이]는 더 완전히 수업이나 이런 데에서는 밖으로 다

밀려나는거죠... 저는 너무 깜짝 놀란거에요 (To be honest, I didn't know that my

child was having difficulties... but seeing everything on Zoom [gasps], now I understand why he turned out like this... I had never received a call from his school. Whenever I went in, they said, "Oh, [your child] did great!" so I really thought he was doing well [laughs]. In reality, he was doing nothing at school... I thought my child and his classmates would be similar in level, but I see a big gap between them... So my child gets pushed aside during class... I was completely shocked to see that.).

Another parent, whose child was placed partly in general education, had a strikingly similar experience – teachers had said the child was doing great and the mother believed it. However, after observing distance learning sessions, she started to question whether the child's placement was appropriate ("일반반에서는 시간낭비만 하고 있었겠구나 (he must have just wasted his time in the general education class)"). She was seriously considering homeschooling now.

New strategies and skills. To help their children cope during the pandemic, parents had to learn to identify priorities, implement new strategies and apply new skills. The one participant who chose to be interviewed in English prioritized her son's mental health and made special efforts to reduce his stress: "We gotta pick and choose our battles. Things we must do no matter what, and there are things we could do without." She considered the SAT for college applications as something she could forgo and encouraged her 12<sup>th</sup> grade son to skip the test. She no longer limited her son's internet use because it was the only social outlet he could have during the pandemic. Her other efforts included taking late night walks with her son, reminding him to exercise and drink water, making him coffee every morning, texting encouragements and at times commiserating with him. She also coached her son with ASD to take care of himself first and then help other classmates when working on group assignments as he often struggled to efficiently allocate his time and energy. Utilizing her resources and advocacy skills, this mother helped her son pursue his interest in advanced math by connecting him with a researcher and reached out to his teachers to share parental concerns and made sure accommodations were in place. Another parent who emphasized the importance of mental and physical wellbeing shared her priorities for her children: eating healthy breakfast, going outside at least once a day to get sunlight, and talking about accomplishments for the day with family members in the evening. One mother with three children shared that she squeezed in 30 minutes in her daily schedule to

take a walk with her oldest daughter with ASD and give her undivided attention during this "Big Girls' Time."

Parents adopted new behavioral strategies at home to assist their children with distance learning. Some learned the skills from their children's behavioral therapists and teachers; some came up with their own. Several learned to arrange the environment by setting up a separate study space in the room, clearing distractions, allowing the child to choose materials to use and putting away others before classes started. Other parental strategies to motivate children included the use of reinforcers and token boards, making enticing toys available only during school time and allowing the child to play with them during breaks following active class participation.

Most parents reported that prior to the pandemic, they were unfamiliar with the apps used for distance learning, such as Zoom. Although some still had challenges with technology, others discovered positives aspects of utilizing apps, including attending school meetings remotely and accessing online library resources for free. One parent mentioned that more service options were possible now as many places offered telehealth services. However, some apps used by schools were prone to connection issues and not suitable for children with special needs. The mother of a child with fine motor difficulties said that the apps were "developed for typically developing students ([일반 아이]들을 기준으로 만들어서)" and "seemed inappropriate for children with disabilities (장애라던지... 불편한 아이들한테는 합당치 않다는 느낌)." Related issues involved schools assigning reading passages, educational clips, comprehension questions and math problems through various apps without appropriate modifications for students with special needs.

Schools demystified for immigrant parents. Distance learning was an eye-opening experience for parents with limited knowledge of K-12 education in the U.S. Thirteen of the 16 participants had immigrated to the U.S. as adults and to them, how students were taught was a mystery. The pandemic was the first time they were able to experience American classrooms firsthand. One mother described her impressions after observing classes of her 12<sup>th</sup> grade son with ASD:

아이를 한국에서도 학교를 보내다가 왔고, 저도 한국에서만 교육을 받았던 사람이니까... [현재] 선생님들이 굉장히 아이들을 이렇게 사기를 올려주고, cheer up 해주고, 칭찬도 많이 하고, 존중해주고, 말들에 귀 기울여주고 이렇게 하는게 참 좋았고...미국 교육을 받으면서 인격체로서 잘 성장해 나가고 있구나 하는 거를 제가 이 온라인 수업을 하지 않았으면은 알지 못 할 것들인데... 그런 것들을 볼 수 있[어서] 그게 참 좋아요. 제가 이제까지 IEP 를 하고 뭐 하면서도 사실 겉도는 사람이었는데... 이제까지의 학창 생활을 어떻게 해왔는지를 clear 하게 알 수 있어서 저는 지금 이 시기가 '아, 우리한테는 꼭 필요한 상황들이었다.' 이렇게 생각해요 (My son used to go to school in Korea and I was educated there as well... I really like how his [current] teachers cheer up, praise, respect and listen to students... Without distance learning, I wouldn't have known that the American education system is helping my child develop as a whole person, so I'm very glad that I got to see that. I

always felt left out from the IEP process... but I clearly understand now how my child

was being educated. So, I see this time as an experience that was much needed for us.). Not all parents had such a pleasant realization – some were dissatisfied with teachers and placements of students. One mother commented that she still felt very anxious that her Korean background and unfamiliarity with the U.S. system would lead her to miss out on important information about her child's education. Regardless of their satisfaction with schools, parents felt that it was important to gain a clear picture of what goes on at school. The parent who described this time as "much needed" said that she grew to like distance learning and would not mind continuing this format. Everyone else, despite the new knowledge and skills they gained, still highly preferred in-person instructions.

### **School and Services**

Communication methods used. Fourteen of 16 participants reported using emails to communicate with their children's schools. The second most common methods were phone calls/voicemails and text messages, mentioned by five parents for each method. On average, participants used 2.44 different types of communication methods with schools; the numbers ranged from one to nine. The parent who named nine different methods used by her son's school was extremely overwhelmed with the amount of information: "너무 많이 와요... 어떤게 정말

아이한테 필요한 건지를 알 수가 없어요... 비효율적인게 되게 많아요 (It is too much... I

can't tell which information is relevant for my child... I find it very inefficient.)." She also mentioned that the school uploaded partial information on the school website and the rest on social media, such as Facebook and Instagram, which caused frustration for both her and her son with ASD. See Table 3 for a comprehensive list of communication methods used by schools.

Some commented that the speed of communication with schools improved during the pandemic; however, there was still limited language support for Korean-speaking families. Two parents mentioned that their children's schools provided Korean translations for some information, but translations were provided inconsistently and lacking for the most part. A number of parents preferred written communication over spoken communication due to language barriers. One parent who immigrated at the age of 39 said, "저는 이게 [영어로] 말하는 거는 힘든데 쓰는거는 되거든요, 독해. 그래서 뭐 되든 안 되든, 또 Google Translate 도움도 좀 받고 해서 좀 적절하게 조합을 해가지고 이메일로 해요 (It's difficult for me to speak [in English] but I can write and translate. With the help of Google Translate, I combine words and phrases and write emails.)." Another parent moved to the U.S. when she was 23 and still struggled with communications over the phone: "나는 아무래도 전화로 하면은, 내가 못 알아듣는 말도 있을 수 있고 하는데, 이렇게 글로 쓰면 내가 모르면 사전 찾아볼 수도 있고 그렇기 때문에 그런 좋은 점은 있어요 (If I talk on the phone, I might not understand some parts but at least with written words, I can look them up in the dictionary.)." One mother, who moved to the U.S. at the age of 32, preferred voice calls but resorted to emails due to communication barriers:

저는 솔직히 전화를 하면 좋은데, 제가 이메일을 쓰는게 저는 [영어] 스피킹은 좀 힘들거든요 [웃음]... 전화는 제가 제대로 알아듣는 건지도 잘 모르고 얘기 하면서... 선생님이 제 발음 때문에 좀 못 알아들으실 때도 있고, 차라리 문자로 하는게 더

편하고 (I actually prefer to talk on the phone but I use emails because speaking [in

English] is hard for me [laughs]... Over the phone, I don't even know if I'm understanding correctly... Sometimes the teacher doesn't understand me due to my pronunciation, so I'd rather text.).

One mother, immigrated at the age of 34, had her husband take care of emailing the child's school. When the school emailed her COVID-19 related guidelines, she did not read them and instead asked other Korean mothers through KakaoTalk.

There were noticeable differences between communication methods that schools used with participants and those used by participants with their families and friends. Participants used 2.75 different types of communication methods with families and friends on average (range: 1-6), and everyone reported using KakaoTalk ("카카오톡 같은 경우는 이제 제 주변 한국분이라면 다 쓰고 계시고 (As for KakaoTalk, every Korean person that I know uses it)"; "저희는 제일 많이 쓰는게 카카오톡이고요. 거의 99% 카카오톡 쓰는 것 같아요 (We use KakaoTalk the most – I think about 99% of the time)"; ("그냥 다, 거의 카톡이에요. 전화도 거의 안하고, 거의 카톡이에요 (Everything is done on Kakao Talk. I don't even call people. I just use KakaoTalk.)."). At least three parents laughed when the investigator asked them such a "common sense" question to a fellow Korean immigrant ("카톡은 예. 당연히 카톡은 쓰고요, 예 [웃음] (KakaoTalk, yes. Of course I use KakaoTalk, yes [laughs])"; "[웃음] 무조건 카톡이 제일 우선이고요, 저희 아시는 것처럼 ([laughs] Definitely KakaoTalk, you know us)"; "카톡

쓰죠. 모두가 다 쓰고 있고 일단은 [웃음] (I use KakaoTalk. Everyone is using it [laughs]).").

Other common methods included text messages, used by eight parents, and phone calls, used by seven (see Table 3). The English-speaking participant, who reported using the highest number of methods with family and friends (i.e., six methods), explained how she varies the method used depending on who she is interacting with: "KakaoTalk for Koreans, WhatsApp for non-Koreans. I do Facebook with some people."

**Facilitators and unmet needs.** In general, parents were satisfied and appreciative when schools made the effort to incorporate parental feedback even when issues were unresolved. One of common problems families experienced was that school aides could not be of much help to students in an online setting. One mother of a fourth grader with ASD had discussions with teachers and aides, and although they tried several methods, they could not find a solution. However, the mother was grateful that the school staff was willing to listen to her concerns:

저희는 충분히 그것들의 논의는 있었어요... 얘기가 오갔던게 의미가 있었던 것 같고요. 그럼에도 불구하고 저희가 바뀐거는 없어요 [웃음]... 소통이 저희는 잘 이루어지고 있다고 생각이 되고 그 부분은 감사해요... 잘 받아들여주신

선생님들이 계셔서... (I feel that we had enough discussions... the fact that we talked about the issue together was meaningful. Nothing changed [laughs], but I appreciate the teachers who were communicative and open to suggestions.).

A school district in New York revamped its distance learning system after collecting parent input, and the effort was well-received by parents. A parent in the said district recalled:

3 월부터 6 월까지 갑자기 온라인으로 시작했었잖아요, 코로나 때문에. 그때는 굉장히 중구난방이어서 학부모들이 되게 불편해 했는데, 한번 survey 를 한 이후에 저도 그렇게 썼지만 아마 다른 학부모들도 그렇게 썼을 것 같은데, '여기 들어갔다 저기 들어갔다 이거 입력했다 저거 입력했다 하는게 너무 힘들다' 이런 얘기가 있었을 것 같아요... 새학기 시작하면서 모든 걸 한 사이트에서 클릭 하나로 해결할 수 있게 해줬기 때문에... 그거를 다 소화는 못해요. 하지만 연결을 해줬다는 그거 자체만으로도 너무 만족스러운거죠 (From March to June, we suddenly switched to distance learning due to COVID-19. Back then, things were all over the place and caused a lot of frustration to parents. The district conducted a survey, and I believe other parents and I mentioned something like, 'It's very difficult to visit many different sites and input login credentials.' Once new semester started, the district gave us a new site with everything on it, and all we need to do now is clicking the link... We can't digest all the information there, but I'm very satisfied that they managed to link everything into one.). Parents satisfied with their children's teachers and therapists often mentioned these service providers' "passion", "proactiveness", and "efforts to include students". A mother who was happy with her child's teacher gave examples of teacher efforts: the teacher checked in with

parents once a week for 15 minutes, incorporated parents' feedback immediately during class, uploaded students' artwork on the class website so classmates could share their work, and when taking attendance, she gave each student a turn to speak and had students interact with each other every morning. Some parents mentioned that teachers' and service providers' classroom

management and technology skills, established rapport with students, and ability to communicate in Korean were important.

Families were coping with various challenges associated with distance learning, including disruptions to services, suspended assessments, and the lack of adequate accommodations for children and parents' needs. The most emotional parts of the interviews, however, were related to the existing system, not the pandemic. A few parents cried and expressed helplessness while looking back at pivotal incidents that led their families to move or consider moving. One participant, who lives in a predominantly white neighborhood in Alabama, shared that her child in the second grade had to deal with racism at school. His classmates teased him for having an "ugly nose"; he regularly asked his mother to move to another state where he would not be the only Asian boy in the school. Recently, the family moved close to an autism center in Alabama where the mother enrolled her child for behavioral therapy services. However, she lost contact with the center after moving. While waiting to hear back, the mother ran into the center coordinator at her child's school by pure accident and asked what happened:

·너 나 알지 않냐'고, '어떻게 된거냐'고 했더니, 갑자기 캔슬 됐대요. 그럼 말을 해줘야지. 그것 때문에 이사를 왔는데... 그래서 얘가 내가 한국 사람이고 영어를 잘 못해서 얘가 이딴식으로... 그래도 이메일을 다 영어로 보내봤는데 이딴식으로 그랬나? 그런 생각도.. ('Don't you know me?' I asked, 'What happened?' And she said that his enrollment was cancelled. She should have told me. Our family moved because of that... This made me wonder if she dismissed me because I am Korean and don't

speak English well. I sent all the emails in English, but still, did she dismiss me for that reason?)

One family had gone through so many disappointing and hurtful events over the years that the pandemic became a breaking point. The mother of a third grade boy with ASD who had very limited verbal skills said that she gave up on receiving adequate education in the U.S. and that her family would be moving back to Korea soon. All the teachers she had met had low expectations of her child and neglected him during class; she had experiences of school staff losing her child at school. She also suspected abuse at one school because the child came home with injuries multiple times. She had been involved with lawsuits with the school, had her home searched by the Child Protective Services which she believed was a retaliatory action from a teacher, who faced no consequences from these incidents. The parent ended up switching schools, but things did not change much: "근데 똑같아요. 특수한 걸 아니까 그걸

이용하더라고요 (It's still the same. They know he has special needs. They abuse that)."

Although the U.S. education did not work out for her family, she hoped that in the future teachers and service providers would be held to a higher standard, provided adequate training and better screened so that other children with special needs can receive high quality services.

**Social isolation.** Among three parents who lived outside of California, two brought up their experience of social isolation as the only Korean families of children with special needs in their areas and voiced their needs for social support. These parents mainly relied on technology to be connected to other Korean families in a similar situation. The mother in Alabama interestedly asked the study investigator questions about California and shared that she was considering moving there someday to join a larger Korean community. She mentioned that her

main source of emotional support came from the open chatroom for Korean immigrant mothers of children with special needs in KakaoTalk because she "literally has no one around (저는 정말 주변에 아무도 없거든요)" and has "absolutely no opportunity to meet other Korean moms of children with autism (autism [아이를] 가진 한국 엄마 만날 기회는 진짜 없고)." Another mother, who lived in a suburban area in New York, regularly used the developmental disability forum on MissyUSA, a website specifically for married Korean women residing in the U.S. Although she wanted to meet another Korean parent who she can speak with freely in Korean and arrange playdates for children, it was difficult for her to find someone with a child at a similar level as her child with ASD. She explained: "저희 동네에 저희 아이같은 한국 애가 아무도 없거든요. [웃음] 저는 캘리포니아에 있는 사람들하고 되게 많이 상황이 달라요... 그런 부분에서는 굉장히 저는 좀... 뭐라 그러지? 되게 절실한 것 같아요, 그런 부분에서 (In my area, there is no Korean kid that's like my child. [laughs] My situation is very different from people in California... In that respect, I am... How should I put it? I am really desperate, in that regard.)."

#### Discussion

#### **Distance Learning: A Multidimensional Challenge**

The current study illustrated how Korean immigrant parents of students with developmental disabilities handled multiple layers of challenges presented to them during the COVID-19 pandemic. The first layer can be considered as the universal parent experience during distance learning, such as helping students adjust to the new learning format, increased daily responsibilities for parents, caring for children's physical and mental wellbeing, safety concerns regarding returning to school, and taking care of multiple children. Participants in this study reported high levels of stress resulting from these responsibilities – stressors that most parents raising children during the pandemic may relate to, including parents of typically developing children and those from non-immigrant backgrounds. The second layer of stressors experienced by the study participants is related to their children's developmental disabilities; parents expressed concerns about their children's special education goals, placements, services, needs unmet in mixed disability classrooms, skill regression, behavioral and social issues related to their children's disabilities, and parents having to provide hands-on assistance most of the time and therapy sessions at home. The third layer relates to challenges experienced as firstgeneration immigrants, and some of these experiences are unique to Korean immigrants. As linguistic minorities, parents in this study mentioned their difficulty in communicating with schools, especially when spoken language was used. All participants used KakaoTalk, a popular messaging app developed in Korea, to communicate with their friends and family; however, the app was never used by their children's teachers and service providers. Some families shared their experiences of discrimination prior to and during the pandemic, and those living in areas with a low Korean population reported feelings of isolation. Many parents in the study immigrated to the U.S. as adults and were oblivious to their children's school life before the pandemic; distance learning was an illuminating or shocking experience, depending on whether children's skill levels previously described by teachers matched what parents actually witnessed at home. With these different layers of burdens piling on top of each other, participants in this study were juggling a complex set of challenges encompassing many dimensions.

Despite the difficulties, dedicated educators and parents helped students cope with the new learning environment and achieve big and small victories. Distance learning gave parents the opportunity to become more involved in their children's education and collaboration with schools. Even when issues remained unresolved, parents were grateful for educators who made genuine efforts to listen to parents and incorporate their feedback. Parents also expressed that they wanted teachers' honest opinions about students' skill levels so that parents can know when to try new strategies with their children.

#### **Recommendations for Research and Practice**

Drawing from the literature and observations from the current study, several recommendations can be made to improve collaboration between schools and culturally diverse parents of children with special needs. A school district in Minnesota demonstrated a remarkable example of coordinated efforts to provide equitable access to education for students with special needs and English learners during the pandemic. In the first few weeks of distance learning, district leaders trained teachers in using accessibility tools on technology devices; technology coaches quickly onboarded parents unfamiliar with distance learning apps; special education staff continually assessed students' skills in individual or small group video calls; school/family liaisons fluent in families' languages and English learner (EL) teachers made phone calls and conducted home visits to ensure linguistic minority families had necessary tools and connected with them on a weekly basis (Peterson et al., 2020). Unfortunately, this was not the case for Korean parents in the current study; most families experienced significant disruptions to their children's special education services, including halted assessments and the lack of appropriate accommodations for students to participate in learning. It seemed that their schools were already struggling to provide adequate special education, and therefore they had no capacity to provide

cultural accommodations for Korean-speaking families. Only two parents reported receiving occasional language accommodations from schools, and even those were not consistently provided. School districts' actions during this time of crisis made their priorities more apparent; the Minnesota school district intentionally prioritized equity for special education students and linguistic minorities, whereas many Korean families in the current study experienced quite the opposite – cultural accommodations for minority families were the first things their schools chose to forgo.

Park and Turnbull (2001) found that Korean immigrant parents of children with special needs relied heavily on mediators when accessing various services and communicating with schools and service agencies. These mediators are similar to "informal translators" discussed in the interview study with Korean parents by Cho and colleagues (2000). In both studies, parents described mediators or informal translators as someone who is fluent in both English and Korean, knowledgeable about special education, and preferable to translators provided by school districts (Cho et al., 2000; Park & Turnbull, 2001). Park and Turnbull (2001) recommended that school systems locate, train and pay these mediators to reduce parental burden. The distance learning experiences of Korean immigrant parents in the current study could have been much different if such mediators were in place in the school systems. Mediators could also serve as advocates for linguistic minority families when parents face discrimination or unprofessional attitudes from service providers. It is hoped that in the near future school systems will prioritize equity for families with significant barriers to education and hire skilled mediators who can facilitate collaboration between schools and culturally diverse families.

Similar recommendations can apply to research in order to improve current practices that systematically exclude cultural minorities. Researchers can prioritize addressing inequities and

hire culturally diverse staff with skillsets to facilitate research participation in minority families. It is notable that a few parents who were more tech-savvy and acculturated varied their method of communication depending on whether they were interacting with Koreans or non-Koreans. Several parents also mentioned that they preferred written communication as it allowed them to search words in the dictionary and spoken communication was prone to misunderstanding. If researchers and educators were equipped with such knowledge, they would have another tool to use when approaching families that are often described as "hard to reach". It may be worthwhile to further explore families' preferred methods of communication and use of social media and other platforms to enhance collaboration with culturally diverse populations. As we move toward more inclusive research, it would be important to document specific strategies and tools used to engage minority communities so that other researchers can build on the new knowledge.

### **Limitations and Strengths**

A limitation of the current study is that participants were parents who had the time, skills and resources to meet via Zoom or phone. Their experiences are likely to be different from those who did not participate in the study. Recruitment methods relied on online postings, KakaoTalk messaging and word-of-mouth; due to the pandemic, it was not possible to recruit participants in person. A study on the perspectives of schools and service providers who work with Korean immigrant families of children with special needs would complement this research. It must be noted that this study presented only the parents' views; there could have been misunderstandings on the parents' part, especially as some parents had communication difficulties due to language and cultural differences.

This study aimed to give a voice to Korean immigrant families who are often excluded from research and illustrations of these families' lives during the COVID-19 pandemic. CPPR

methods was used in all stages of research, including design, recruitment, data analysis, and dissemination. Korean immigrant parents of students with developmental disabilities played critical roles in this study and were eager to help with various tasks; their contributions to this research deserve much credit.

# Appendix A

Table 1

## Demographic Information of Participants (N=16)

Language used for the study ( <i>n</i> )	Language spoken at home ( <i>n</i> )	Age ( <i>M</i> , range)	Age moved to the U.S. ( <i>M</i> , range)	Education level ( <i>n</i> )	Household size ( <i>n</i> )	Number of children ( <i>n</i> )	Annual household income ( <i>n</i> )
Korean: 15 English: 1	Korean: 13 English: 2 English & Korean equally: 1	45.3 (37-57) years	26.4 (11-39) years	Doctoral/ Professional degree: 1 Master's degree: 3 4-Year college degree: 7 2-Year college degree: 4 High school graduate/ GED: 1	3 people: 3 4 people: 9 5 people: 2 6 people: 1 7 people: 1	1 child: 1 2 children: 11 3 children: 2 4 children: 2	\$100,000 or more: 8 \$80,000-\$89,999: 2 \$70,000-\$79,999: 1 \$60,000-\$69,999: 1 \$50,000-\$59,999:1 \$40,000-\$49,999:1 \$9,999 or less: 2

*Note.* All participants were female and were born in South Korea.

## Table 2

## *Demographic Information of Students (N=16)*

Age ( <i>M</i> , range)	Gender ( <i>n</i> )	Grade level ( <i>n</i> )	Type of developmental disability ( <i>n</i> )	Age at diagnosis ( <i>M</i> , range)	School / Classroom placement ( <i>n</i> )
10.9 (5-18) years	Male: 9 Female: 7	Kindergarten: 1 $2^{nd}$ grade: 3 $3^{rd}$ grade: 2 $4^{th}$ grade: 4 $7^{th}$ grade: 2 $9^{th}$ grade: 1 $12^{th}$ grade: 3	ASD: 12 Speech delay: 2 ADHD: 1 Intellectual disability: 3 Seizure: 1 *Two children had more than one disability	4.0 (2-10) years	General education classroom all the time: 4 Some time in general education and some in special education: 5 Mixed disability classroom: 6 Autism-only classroom: 1

*Note.* All students were enrolled in public schools (13 in California, 2 in New York, and 1 in Alabama). All but one (Chinese, adopted) were identified as ethnically Korean by their parents.

## Table 3

Communication Methods Used by Schools vs Korean Immigrant Families (N=16)

	Used by school ( <i>n</i> )	Used with family and friends ( <i>n</i> )
Email	14	2
Phone call / Voicemail	5	7
Text message	5	8
Zoom	3	6
Schoology	2	0
ClassDojo	2	0
Facebook	1	1
Instagram	1	1
KakaoTalk	0	16
Other	2	3

 Other
 2
 3

 Note.
 Two parents that used "Other" methods with school mentioned: Google Voice, Remind, Seesaw, Welligent and school websites.

 Three parents that used "Other" methods with family and friends mentioned: WhatsApp, FaceTime and Skype.

## **Appendix B**

## COVID-19 Distance Learning Interview Questions

- 1. (Confirm child's diagnosis, age at diagnosis, school program, grade level as indicated on the demographics form) What are your child's strengths and challenges? Is he/she on grade level?
- 2. In both school and community, COVID-19 has changed the way students receive services. Please describe how your child's education and services have changed.
- 3. Does your child have an IEP? If so, how did COVID-19 change the process? Did you experience any difficulties with scheduling of meetings, receiving documents, or communicating with your child's team because of COVID-19?
- 4. Let's talk about the specific apps or programs that schools use to facilitate distance learning. What apps or programs does your child use to receive school education? What do you use to communicate with school staff?
  - a. Are these apps new to you, or were they ones you were already using?
  - b. Are there any ones you particularly like or dislike? Why?
- 5. How effective has distance learning been for your child? Why?
- 6. What kind of preparation do you do to ensure that distance learning sessions go smoothly for your child? Do these strategies work? Why or why not?
- 7. What is your involvement in the distance learning session? Do you attend with your child or is your child able to be independent?
  - a. Is your child part of a "learning pod" / small group with an in-person teacher, or are you looking for one?
- 8. What apps or programs do you regularly use when you communicate with your family and friends?
  - a. What do you like/dislike about these platforms?
  - b. Do you use these platforms to communicate with your child's teachers, school staff or therapists? Why or why not?
- 9. Where are you getting the information about schools' plans, changing guidelines, and resources these days?
- 10. What are the features of the app/program that are particularly helpful for your child, or do you think would be helpful? Do any current apps / programs have these features?

COVID-19 Distance Learning Interview Questions – Korean 코로나바이러스로 인한 원격 교육 – 부모님 인터뷰 질문

- (인구 통계 설문지에 기재된 아이의 진단명, 진단 나이, 학교 프로그램, 학년 확인할 것) 아이가 잘하는 것들과 어려워하는 부분들은 무엇이 있나요? 학년에 맞는 성적을 잘 따라가고 있나요?
- 학교 그리고 지역사회 내에서 코로나바이러스로 인해 학생들이 서비스를 받는 방법도 많이 달라졌습니다. 부모님의 아이의 교육과 서비스가 어떻게 달라졌는지 이야기 해주세요.
- 아이가 IEP 가 있나요? 그렇다면, 코로나바이러스로 인해 이 과정이 어떻게 바뀌었나요? 미팅을 잡거나, 문서를 받는다거나, 아이의 IEP 팀과 연락하는 데에 지장이 있으셨나요?
- 원격 수업을 위해 학교에서 쓰고있는 앱이나 프로그램에 대해 이야기 해보겠습니다. 현재 아이의 학교에서는 수업을 위해 어떤 앱이나 프로그램을 사용하고 있나요? 부모님께서는 학교 선생님과 스탭과 연락하기 위해 어떤 방법을 쓰시나요?
  - a. 이 앱/프로그램들은 이번에 새로 쓰시게 된 것들인가요? 아니면 원래
     사용하고 계시던 것들인가요?
  - b. 이 중에서 특히 선호하시거나 선호하지 않는 프로그램들이 있나요? 왜 그렇게 느끼시나요?
- 5. 원격 수업이 부모님의 아이에게 얼마나 효과적이라고 느끼시나요? 왜 그렇게 생각하시나요?
- 6. 원격 수업이 잘 진행되기 위해 부모님께선 어떤 준비들을 하시나요? 이 방법들이
   아이를 돕는데 효과적인가요? 어떻게 효과적인가요 / 왜 효과적이지 않은가요?

- 7. 아이의 원격 수업 도중, 부모님의 역할은 무엇인가요? 아이와 함께 참여하시나요?아니면 아이가 독립적으로 참여할 수 있나요?
  - a. 아이가 현재 "learning pod", 또는 다른 아이들과 선생님을 구하여 작은 그룹과외에 속해있나요? 또는 현재 구하고 계신가요?
- \* 부모님이 주변 친구나 가족들과 연락할때 어떤 앱이나 프로그램들을 주로 쓰시나요?
  - a. 이 프로그램들에 대한 좋은 점, 또는 안좋은 점들이 무엇이 있을까요?
  - b. 아이의 선생님들, 학교 스탭, 또는 치료사들과 연락할때도 이 프로그램들을
     쓰시나요? 이유를 설명해주세요.
- 학교의 계획들과 계속 변화하는 지침들, 그리고 제공하는 자료에 대한 정보를 어디에서 받고 계신가요?
- 10. 앱/프로그램들의 특징 중, 어떤 부분들이 부모님의 아이에게 특히 도움이 되었다고
   / 또는 될것이라고 생각하시나요? 이 도움되는 부분들을 포함하고 있는 현존하는
   앱/프로그램들이 있을까요?

## Appendix C

## Demographic Survey COVID-19 Distance Learning

### **Information about the Parent**

- 1. What is your gender? (Male / Female / Other)
- 2. What is your age? \_\_\_\_\_ years
- 3. Were you born in the US? (Yes / No)
  - a. (If "No", display 3a and 3b) Country of birth: \_\_\_\_\_
  - b. At what age did you move to the US? \_\_\_\_\_ years
- 4. What language do you speak most at home?
  - a. Korean
  - b. English
  - c. Other:
- 5. What is the highest level of education you have completed?
  - a. Elementary / Middle School
  - b. Some High School
  - c. High School Graduate / GED
  - d. Some College
  - e. 2-Year College Degree
  - f. 4-Year College Degree
  - g. Master's Degree
  - h. Doctoral / Professional Degree
  - i. Vocational / Technical Training
  - j. Other: \_\_\_\_
- 6. Are you currently:
  - a. Married
  - b. Separated
  - c. Divorced
  - d. Widowed
  - e. Living with partner
  - f. Single
  - g. Other: \_\_\_\_\_
- 7. How many people live in your house, including yourself?
- 8. What is your household income per year?
  - a. \$9,999 or less
  - b. \$10,000-\$19,999
  - c. \$20,000-\$29,999
  - d. \$30,000-\$39,999
  - e. \$40,000-\$49,999
  - f. \$50.000-\$59.999
  - g. \$60,000-\$69,999
  - h. \$70,000-\$79,999

- i. \$80,000-\$89,999
- j. \$90,000-\$99,999
- k. \$100,000 or more
- 9. What state/city do you live in?
- 10. How would you describe the community you live in? (Urban / Suburban / Rural)

## **Information about Your Child**

- 1. How many children do you have? \_\_\_\_\_
  - a. (*display 1a if the value above is more than 1*) How many of your children have developmental disabilities? \_\_\_\_\_
- 2. Please provide the following information about your child with developmental disabilities:

(Display according to the number of children with developmental disabilities)

## <u>Child 1</u>

- 1. What type of developmental disability does your child have?
- 2. At what age did your child receive the diagnosis? \_\_\_\_\_ years
  - a. If multiple diagnoses, please specify the type and age at diagnosis:
- 3. Gender: (Male / Female / Other)
- 4. Race/Ethnicity (check all that apply):
  - a. Korean
  - b. Other Asian / Pacific Islander
  - c. African American/Black
  - d. Caucasian/White
  - e. Latino/Hispanic
  - f. Native American
  - g. Other: \_\_\_\_\_
- 5. Current age: \_\_\_\_\_
- 6. Grade Level: \_\_\_\_\_
- 7. School District: \_\_\_\_\_
- 8. Type of school program:
  - a. Public
  - b. Private
  - c. Home schooled
  - d. Other: \_\_\_\_
- 9. Type of school placement:
  - a. General education classroom all the time
  - b. Some time in a general education classroom and some time in a special education classroom
  - c. Autism-only classroom
  - d. Mixed disability classroom
  - e. Other: \_\_\_\_\_

인구 통계 설문조사 (Demographic Survey – Korean) COVID-19 Distance Learning

## 이 연구에 참여하시는 부모님에 대한 정보

- 1. 부모님의 성별: (남/ 녀 / 기타)
- 2. 나이: \_\_\_\_세
- 3. 미국에서 태어나셨습니까? (예 / 아니오)
  - a. (If "No", display 3a and 3b) 출생국: \_\_\_\_\_
  - b. 본인이 몇살일 때 미국에 오셨습니까? \_\_\_\_\_ 세
- 4. 집에서 어느 언어를 가장 많이 쓰십니까?
  - a. 한국어
  - b. 영어
  - c. 기타:\_\_\_\_\_
- 5. 본인의 최종 학력에 체크해 주십시오:
  - a. 초등/중학교
  - b. 고등학교 중퇴
  - c. 고등학교 졸업 / 검정고시
  - d. 대학교 중퇴
  - e. 2 년제 대학 졸업
  - f. 4 년제 대학 졸업
  - g. 석사 학위
  - h. 박사 / 전문 대학원 학위
  - i. 직업 학교
  - j. 기타:\_\_\_\_\_
- 6. 본인에게 해당하는 사항을 선택해 주십시오:
  - a. 기혼
  - b. 별거
  - c. 이혼
  - d. 배우자 별세

- e. 파트너와 동거
- f. 미혼
- g. 기타:\_\_\_\_\_
- 7. 가정에 몇 명이 함께 살고 있습니까 (본인 포함)?\_\_\_\_\_
- 8. 연간 가족 소득이 어떻게 되십니까?
  - a. \$9,999 또는 이하
  - b. \$10,000-\$19,999
  - c. \$20,000-\$29,999
  - d. \$30,000-\$39,999
  - e. \$40,000-\$49,999
  - f. \$50,000-\$59,999 g. \$60,000-\$69,999
  - h. \$70,000-\$79,999
  - i. \$80,000-\$89,999
  - j. \$90,000-\$99,999
  - k. \$100,000 또는 이상
- 9. 어느 주 / 도시에 살고 계십니까? \_\_\_\_\_
- 10. 본인이 살고 있는 지역은 어느 것에 해당합니까? (도심 (urban) / 중소도시

(suburban) / 시골 (rural))

### 아이(들)에 대한 정보

- 1. 자녀가 총 몇 명 있으십니까? \_\_\_\_
  - a. (display 1a if the value above is more than 1) 발달장애가 있는 아이는 몇 명 입니까? \_\_\_\_
- 2. 발달장애가 있는 아이(들)에 대해 다음 질문들에 답변해 주십시오:

(Display according to the number of children with developmental disabilities)

### 발달장애가 있는 자녀 1

- 1. 이 자녀는 어떤 발달장애가 있나요? \_\_\_\_\_
- 2. 아이가 몇살때 진단을 받았나요? \_\_\_\_\_ 세
  - a. 만약 발달장애 진단을 여러개 받았다면, 종류와 진단받은 나이를 명시해주세요:\_\_\_\_\_

- 3. 아이 성별: (남/ 녀/ 기타)
- 4. 아이의 인종 (해당되는 것에 모두 체크해 주십시오):
  - a. 한국계 (Korean)
  - b. 한국계 이외의 다른 동양인 (Other Asian / Pacific Islander)
  - c. 흑인 (African American/Black)
  - d. 백인 (Caucasian/White)
  - e. 라틴계 / 히스패닉 (Latino/Hispanic)
  - f. 미국 원주민 (Native American)
  - g. 기타:\_\_\_\_\_
- 5. 나이:\_\_\_\_세
- 6. 학년:\_\_\_\_
- 7. 교육구 (School District): \_\_\_\_\_
- 8. 학교 종류:
  - a. 공립 (Public)
  - b. 사립 (Private)
  - c. 홈스쿨링
  - d. 기타: \_\_\_\_\_
- 9. 학교/학급 배정 (placement):
  - a. 전과목 일반 학급 (General education classroom all the time)
  - b. 일반 학급과 특수 학급에 부분적으로 배정 (Some time in a general education classroom and some time in a special education classroom)
  - c. 자폐 학생을 대상으로 한 특수 학급 (Autism-only classroom)
  - d. 다양한 장애가 있는 학생들을 대상으로 한 특수 학급 (Mixed disability classroom)
  - e. 기타: \_\_\_\_\_

## Appendix D

Distance Learning (DL) Interview - Coding Definitions

Learning Environment: home environment and resources that affect students' DL

- Internet and technology issues (both equipment and human errors)
- Lack of study space / financial resource
- Siblings distracting the student or needing the parent's attention during DL

**Student Skill / Behavior / Interaction**: student's skills, behavioral / mental health issues, social interaction, participation and attendance in class

- Regression or improvement in skills; newly acquired skills; student adapting to the new learning situation; students' skill level differences and comments about the class level being too easy or difficulty for the student
- Behavioral concerns during DL; struggles due to disrupted routine/schedule or the lack of structure; withdrawal from activities; family mental health; increased screen time; safety concerns regarding going back to school
- Not paying attention in class; disengagement; difficulty with participation and assignments; left out from class activities; students' class attendance
- Interaction with peers

**Parent Role:** how parents help (or are unable to help) their child focus, cope with stress or improve skills

- Behavior management strategies, prioritization of tasks
- Burden from helping their child at home (e.g., cooking, dressing the child, preparing for DL, having to sit by the child all the time during DL and acting as an "one-on-one aide", not having time for self, giving up jobs)
- Parent's cultural or educational background affecting the child's education

**Parent Knowledge** (pre-COVID and/or newly gained): parents discuss new knowledge, skills, perspectives they have gained since the pandemic and/or their lack of knowledge before COVID-19

- Knowledge about their child, teachers, service providers, school and the education system
- New skills gained (e.g., learning new behavior management strategies, utilizing new DL apps)
- What parents used to do vs. what they do differently now

**School / Service Providers:** roles and characteristics of school districts, educators and service providers who were helpful (or unhelpful); how family's needs are met (or unmet) by school / service providers

- Strategies used and efforts made by school / service providers to facilitate DL
- Class management (e.g., school start / end times, class length, how teacher manage pace and allocate class time, number of students in the class)

- Disruption to services (e.g., changes in service hours, issues with diagnosis, assessment and placement, communication with the IEP team)
- Lack of accommodations (e.g., no modifications to difficult assignments, providing tasks above students' level without supports, lack of linguistic / cultural / social support for diverse families)
- Service provider qualifications, service quality, and special education / service system

**Collaboration / Advocacy**: parent initiates interactions with school / service provider, speaks up or takes action to resolve issues relating to their child's education (or mentions a plan to do so); school / service provider incorporates parent feedback and ideas to solve problems; the outcome does not need to be positive (i.e., the issue can still remain or be in the process of being resolved)

- Parent notifies school / service providers about what is happening at home
- Parent demonstrates their knowledge of advocacy strategies
- Parent requests (or plans to request) specific accommodations for their child
- School / Service provider listens to parents about concerns and suggestions, and incorporates feedback to resolve issues

**DL Positives:** positive things that came out of DL; something explicitly described as good, convenient or relieving

**Camera Policy:** whether schools / teachers require students to leave cameras on or off during class; also applies to service providers

DL Apps: distance learning apps used by school and students; descriptions of app features

**Parent-School Communication Method:** methods used by schools, teachers and parents to communicate and whether these methods are effective

**Family / Friends Communication Method:** methods used by parents to communicate with their family and friends and reasons for choosing such methods

**Learning Pod:** whether the parent knows what a learning pod is (small groups of students taught in person by a hired teacher); also code parents' comment on whether a learning pod would be helpful for their child

**DL vs In Person:** (coder to choose DL or In Person, based on the parent's comment) parent's preferred format of education for their child; opinion on which is more effective

### Appendix E

### Infographic of Findings

## 연구 리포트: 발달 장애가 있는 자녀를 둔 한인 부모님들의 원격 수업 경험

UCLA 박사과정 연구원 이현수 (Soo Lee)

판데믹으로 갑작스럽게 원격 수업으로 교육을 받게 된 가족들, 특히 발달 장애가 있는 학생들에게는 우여곡절이 많던 한 해 였습니다. 원격 수업으로 인해 힘들었던 점, 도움이 되었던 사람들, 학교와의 소통에 대해 부모님들을 대상으로 인터뷰를 진행 했습니다. 미국에서 목소리를 내기 어려운 한인 가족들의 이야기를 미국 연구원과 교육자들에게도 알리고 있습니다.



#### 연구 절차와 참여자





이 연구는 커뮤니티 파트너 참여 연구 기법을 사용하여 가족들이 연구 절차의 시작부터 끝까지 포함될 수 있도록 노력을 기울였습니다.

#### 자녀에 대한 걱정



많은 부모님들께서 자녀의 원격 수업 참여도, 사회성을 기를 기회, 수업의 난이도, 정신 건강, 퇴행, 스크린 타임 등에 대한 우려를 갖고 있었습니다.

부모님의 역할 원격 수업이 가능케 한 일등 공신인 부모님들은 자녀의 수업 도중은 물론 수업 전과 후까지 쉴 새가 없었습니다. 본인을 위한 일이라곤 아침에 커피 한잔이 전부라는 부모님들도 계셨습니다. 아이를 돕기위해 선생님들께 꾸준한 연락은 물론, 직접 행동치료까지 배운 분도 있는가 하면, 학교에서 한국어 서포트를 제공해주지 않아 학교와의 연락에 어려움을 겪는 부모님들도 있었습니다. 힘든 시간이지만, 성인이 되어 이민을 오신 부모님들은 미국 학교 생활을 이번에 처음 보게되어 배운 점도 참 많았다고 입을 모았습니다.

#### 학교와 서비스



14명의 부모님께서 자녀의 학교가 이메일로 연락을 준다고 하셨습니다. 학교에서 두번째로 많이 쓰는 연락 방법은 전화나 보이스 메일 이었습니다. 부모님들이 일상에서 가장 많이 쓰는 카카오톡과는 확연한 차이가 있었습니다. 영어가 불편한 부모님들은 학교에서 말 대신 글로 연락을 해주길 바라셨습니다. 학교에서 한국어 서포트를 제공한다는 부모님은 단 두명이었고, 그마저도 부분적으로 제공되었습니다. 한인이 적은 지역에 사시는 부모님들은 외로움과 인종차별을 견디고 계셨습니다. 부모님들이 꼽은 원격 수업에 도움이 되었던 사람은 열정적이며 학생들을 포용해주는 선생님들 이었습니다.

참여해주신 부모님들은 1) 판데믹 상황에서 아이를 키우고 2) 자녀가 발달 장애가 있고 3) 1세대 한인 이민자라는 특수성이 있어 여러 겹의 어려움을 헤쳐가고 있었습니다. 학교와 연구는 다양한 니즈가 있는 가족들을 위해 이들을 이해하는 전문가를 적극 활용해야 할 것 입니다.

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