








# Impact of COVID-19 on Adaptive Skills and Psychiatric Symptoms in South Korean Children With Autism Spectrum Disorder

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**Objective:** We examine the effect of COVID-19 on South Korean children with autism spectrum disorder (ASD), using a comprehensive online caregiver survey.


**Method:** Caregivers of 132 children were recruited among 292 children identified with ASD in a large general population epidemiologic cohort from a suburban South Korean city. Using the Korean translation of the CoRonavIRuS Health Impact Survey, adapted for autism and related neurodevelopmental conditions (CRISIS-AFAR), data were collected at 3 time points (3 months before the pandemic, from January to June of 2021, and 3–4 months after). Changes in adaptive living skills, lower- and higher-order restrictive and repetitive behaviors (RRBs), co-occurring problem behaviors (activity/attention, oppositional, and anxiety/affect) were assessed over time. Characteristics of more vulnerable subgroups were identified.

**Results:** Among 132 children with ASD (81.1% boys, mean  $12.6 \pm 1.88$  years of age), a significantly larger proportion maintained their initial level of adaptive living skills (43.9%), RRBs (39.4%–51.5%), and co-occurring problem behaviors (>75%) when compared with the proportion of children who worsened or fluctuated ( $p < .001$ ). Less than 25% of the participants showed worsening in any domain from the first to second time point and from the second to third time point. Participants who demonstrated stability in activity/attention problem behaviors and lower-order RRBs had significantly better baseline physical health ( $p = .032$ ) and higher intelligence, greater ability to attend general education, and milder language deficits (all  $p = .027$ ).

**Conclusion:** The majority of South Korean children with ASD demonstrated stability despite the lack of consistency or structure during the pandemic. A 2-year longitudinal follow-up study is underway.

**Plain language summary:** Caregivers of 132 South Korean children with autism rated their children's behaviors at 3 months before the pandemic began and at two timepoints during the height of the COVID-19 pandemic in 2021. A larger group of children maintained their initial levels of adaptive functioning, autism symptoms, and co-occurring behavioral problems. Fewer than 25% showed progressive worsening over time, highlighting the resilience of a majority of children with autism during this difficult period. The study also found that better physical health was protective against behavioral challenges, while children with more severe autism symptoms, or cognitive difficulties, needed additional support—especially in environments lacking consistency and structure.

**Key words:** autism spectrum disorder; COVID-19; epidemiology; adaptive behavior; behavioral symptoms

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It has been suggested that individuals with autism spectrum disorder (ASD) are at higher risk for adverse outcomes following the severe acute respiratory syndrome associated with the coronavirus 2 (SARS-CoV-2, COVID-19) pandemic. It has been reported that approximately 25% of children with ASD have immune deficiencies or dysfunction,<sup>1</sup> including a pro-inflammatory state,<sup>2</sup> which may increase their likelihood of contracting COVID-19 and experiencing attendant complications.<sup>3,4</sup> High levels of comorbid mental disorders<sup>5,6</sup> increase the risk for pandemic-related declines in the mental health,<sup>7</sup> making it possible that individuals with autism have difficulty adapting to effects of the pandemic, including social

isolation, inconsistent schedules, limited access to services, and so forth.<sup>1,2,8</sup> Many individuals with ASD have difficulty anticipating environmental disruptions and preparing flexible responses to associated abrupt changes.<sup>2</sup> Social distancing disrupted daily routines, and constantly changing quarantine guidelines limited predictability in the daily lives of these youth. Furthermore, access to essential therapies and services was limited (eg, applied behavior analysis [ABA] therapy).<sup>2</sup> Confinement, changes in daily routine, and suspension or reduction of usual services negatively affect individuals with ASD.<sup>9–11</sup>

Two reviews of children's mental health of children during the pandemic suggested that an ASD diagnosis is a

risk factor for mental health difficulties due to the pandemic.<sup>8,12</sup> Two different studies of children with ASD reported increasing behavioral problems and the need for additional caregiver support,<sup>13</sup> emotional management difficulties, and anxiety in children with ASD.<sup>14</sup> Reviews that specifically focused on ASD found similar results,<sup>15–19</sup> with 1 review specifying conduct problems, aggression, and hyperactivity as the main behavioral issues.<sup>16</sup>

However, studies also unexpectedly found positive outcomes among individuals with ASD during the pandemic. A systematic review by Patel *et al.* found reports of greater participation in family routines, increased communication with parents, and greater autonomy, associated with the children being happier and calmer during the pandemic,<sup>17</sup> a finding replicated in another study.<sup>18</sup> A recent review concluded that, although there seems to have been a significant decrease in psychological well-being among children with ASD during the pandemic, there have also been reports of general stability in mood, problem behaviors,<sup>20</sup> sleep, and ASD symptoms,<sup>21</sup> as well as improvement in adaptive functioning.<sup>19</sup> Taken together, research suggests that the impact of the pandemic on individuals with ASD varies, depending on age, ASD severity, and family structure.<sup>18</sup>

Multiple recent studies have supported such heterogeneity in the pandemic's impact on individuals with ASD. Some studies continue to offer evidence of a harmful impact,<sup>22,23</sup> with observations of little clinical improvement<sup>24</sup> and feelings of social isolation.<sup>25,26</sup> Other studies reported stability and resilience in the ASD population.<sup>22,23,26–28</sup> Plak *et al.* found stability in emotional problems, decreased hyperactivity, fewer conduct and peer problems, and increased prosocial behavior in children with ASD during lockdown.<sup>27</sup> Toseeb *et al.* reported that youth with ASD did not get more depressed or anxious with the reopening of schools.<sup>22</sup> Two large studies clearly demonstrated the heterogeneous impact of the pandemic on youth with ASD, reporting that 38.7% ( $n = 265$ ) and 45.7% to 50.4% ( $n = 582$ ) did not have worsened ASD symptoms, behavior problems, anxiety, or mood.<sup>23,28</sup> Parent factors appear protective, including good parental mental health, lack of financial concerns,<sup>23</sup> and an agreeable personality.<sup>24</sup> Child factors include being allowed to organize their daily schedule,<sup>27</sup> lesser internalizing symptoms,<sup>23</sup> milder ASD symptoms,<sup>18</sup> and social isolation pre-pandemic.<sup>26</sup> Evidence is inconsistent regarding the effect of the child's age<sup>20,27,28</sup> or pre-pandemic special education.<sup>22,26</sup> Increased family contact, time to pursue hobbies, a self-paced daily life and learning,<sup>29–32</sup> and continued access to services<sup>23,28,33</sup> seem to have a protective effect.

Overall, it is likely that the effect of COVID-19, including social distancing, is complex rather than unidirectionally negative or positive for the ASD population. The

CoRoNaViruS Health Impact Survey—Adapted for Autism and Related neurodevelopmental conditions (CRISIS-AFAR)<sup>33</sup> is a parent/caregiver survey developed as an international collaborative effort to capture the impact across multiple domains and populations of individuals with ASD or other NDDs. Responses collected from 5 countries (15 samples,  $N = 1,275$ , mean age 11.0 years) found that 3 of the 4 clusters of clinical trajectories were clinically stable,<sup>33</sup> suggesting resilience in these youth. Because these data were collected only from European and North American samples, they may not be generalizable to other countries and cultures.

To address the sampling problem, we monitored the behavior and function of children with ASD by distributing the CRISIS-AFAR to caregivers of children with ASD recruited from an existing South Korean epidemiological sample. Unlike most other countries, the South Korean government implemented a stepwise system to determine each district's social distancing mandates separately, based on COVID-19 incidence and vaccination rates. Fluctuations in the severity of the pandemic were actively reflected by changes in local regulations. South Korea's inconsistency in strictly enforcing restrictions during COVID-19 provides a unique opportunity to assess the resilience of children with ASD in the face of the COVID pandemic. In this context, we hypothesized that children and adolescents with ASD would be negatively affected by the social isolation and stresses from frequent changes associated with the pandemic. As part of a prospective longitudinal study spanning 2 years, we present the results from our first 2 surveys distributed while changes in regulations were most frequent.

## METHOD

### Study Population

The initial representative population sample was ascertained as part of an incidence study, from 2012 to 2017 in, a stable, residential, suburban city in South Korea near Seoul (area: 102 km<sup>2</sup>; 2017 population: 1,005,102). Children and adolescents diagnosed with ASD in a previous study<sup>34</sup> were recruited. In the original study, individuals from 85 elementary schools in the district ( $n = 36,886$ , age range at screening 6–8 years) were screened with the Autism Spectrum Screening Questionnaire (ASSQ). Screen-positive youth were invited to complete a full clinical evaluation during which the best estimate clinical diagnosis of ASD was made using the Autism Diagnostic Observation Schedule—2 (ADOS-2), Autism Diagnostic Interview, Revised (ADI-R), cognitive testing (Leiter International Performance Scale, Wechsler Intelligence Scale for Children

(WISC-III or WISC-IV), or Wechsler Preschool and Primary Scale of Intelligence (WIPPSI-V)), and review of previous records. The performance intelligence quotient (PIQ) was used to assess cognitive function because the full-scale IQ or verbal IQ may not reflect the children's full cognitive capacity due to the language delays associated with autism. Of those previously diagnosed with ASD, 292 individuals with valid, current contact information constituted the target study population. This study was approved by the Institutional Review Boards of Yonsei University and the University of California, San Francisco.

### Data Collection

The CRISIS-AFAR has a total of 79 items addressing health/exposure statuses, worries, and life changes due to COVID-19, daily behaviors, psychiatric symptoms, and services of the participants.<sup>33</sup> The Korean translation was distributed to caregivers over a 6-month recruitment period from January to June 2021, when social distancing mandates were changed frequently. During most of this period, gatherings were limited to 4 people or fewer; masking was mandatory in all indoor and outdoor public spaces; and a maximum of one-third of all students were permitted on school grounds at any given time. The first follow-up survey was distributed 3 to 4 months later, at the time when the government declared a third wave of COVID-19. Caregivers were encouraged to maintain study engagement with gift cards for completion of each survey and educational webinars for parents with children with ASD that were accessible primarily to participants only, as well as interim phone calls and text messages.

With each survey, caregivers were requested to provide information about the preceding 30-day period. The initial questionnaire collected information about each participant from 3 months before the start of the pandemic (T0) and from the past 2 weeks (T1). The 3-month follow-up questionnaire inquired only about the past 2 weeks (T2). Caregivers of 146 children and adolescents with ASD consented to survey distribution. As 14 caregivers did not reply to the second survey, data from 132 caregivers who completed both surveys were included for analysis.

Among previously identified factors of the CRISIS-AFAR,<sup>33</sup> the current study focuses on adaptive living skills, RRBs, and co-occurring problem behavior domains. From the original study, only factor loadings 0.3 or greater in exploratory factor analyses were included in the subsequent confirmatory factor analyses. For theoretical plausibility, other items, such as factors with single items, were removed as needed to achieve a factor structure with more than 1 item meeting at least 2 of 4 goodness-of-fit criteria. One item ("deliberately injuring self" in the co-occurring

problem behaviors domain) was removed because of limited interpretability. The resulting factor structure remained consistent for responses corresponding to time points before and during the pandemic.

The study items for each of the domains are listed in Table S1, available online. For adaptive living skills, rating options ranged from: "independently" (without support, prompting, or supervision), "moderate supervision" (some verbal/visual reminders), "close supervision" (support including step-by-step instruction), or "not at all." Caretakers assessed RRBs by responding to items about the frequency of the described behaviors, with possible responses: "not at all," "rarely," "occasionally," "often," or "regularly." RRBs were further divided into lower- and higher-order RRBs according to results from the factor analysis. For each co-occurring problem behavior item, caregivers indicated whether the child exhibited the described behavior, and, if positive, a follow-up question was asked about the severity of the problem, with response options of "slightly," "moderately," "very much," or "a lot." As per the factor analysis results, co-occurring problem behaviors were further divided into activity/attention, oppositional, and anxiety/affect problem behaviors.

### Statistical Analysis

All analyses were performed using Python 3.12.4.

For adaptive living skills, ratings were transformed to a scale of 1 for "not at all" to 4 for "independently." Ratings for RRBs were transformed scores of 1 for "not at all" to 5 for "regularly." For co-occurring problem behaviors, the answers were transformed as follows: 0 for "unreported behaviors," 1 for "slightly," 2 for "moderately," 3 for "very much," and 4 for "a lot." Composite scores for adaptive living skills, lower-order RRBs, higher-order RRBs, activity/attention, oppositional, and anxiety/affect problem behaviors were obtained by calculating the weighted sum of their respective ratings, with factor loadings based on weights per Vibert *et al.*<sup>33</sup>

We calculated the baseline mean scores and the SDs for each of 6 domains using responses collected at T0. For each participant, composite scores for T1 and T2 were compared with the baseline mean to determine their function level or symptom severity compared to baseline (T0), leading to the assignment in 1 of 3 categories: low (below baseline SD from the baseline mean), within normal (within baseline SD from the baseline mean), and high (above baseline SD from the baseline mean). To assess the change in scores over time, we compared change in category membership between time points; for example, a "low" score at T0 and a "within normal" score at T1 is considered to be "improved." This resulted in 9 classes, each corresponding to participants who met the following criteria: class 1: worsened from T0 to T1 and from

T1 to T2; class 2: worsened from T0 to T1, but maintained the same level from T1 to T2; class 3: worsened from T0 to T1, but improved from T1 to T2; class 4: maintained the same level from T0 to T1, but worsened from T1 to T2; class 5: maintained the same level from T0 to T1 and T1 to T2; class 6: maintained the same level from T0 to T1, but improved from T1 to T2; class 7: improved from T0 to T1, but worsened from T1 to T2; class 8: improved from T0 to T1, but maintained the same level from T1 to T2; and class 9: improved from T0 to T1 and from T1 to T2.

For each time interval, pairwise  $Z$  tests for proportions were performed to compare the proportion of participants who remained stable in each domain.  $\chi^2$  Tests were performed to test significant differences among the 9 classes for each domain. Classes with fewer than 5 participants were excluded from the  $\chi^2$  test to preserve integrity.

Eight baseline characteristics (age, sex assigned at birth, diagnosis of ADHD, PIQ, whether the child attended general education without educational support pre-pandemic, caregiver's highest level of education, caregiver rating of overall physical health, and language level) were explored to identify characteristics of participants who remained stable or improved and those who worsened. First, the participants who worsened during both time intervals (class 1) for any of the domains were compared with their counterparts who were in classes 2 through 9 for all domains. This was followed by a comparison between participants who were in class 1 for more than 1 domain and participants who had only did so for 1 or none of the domains. Separately, for each domain, participants who had remained stable or improved for both T0 to T1 and T1 to T2 (classes 5, 6, 8, and 9) were compared to participants who had worsened during at least 1 time interval. Independent  $t$  tests and  $\chi^2$  tests were used to compare the characteristics between groups. All multiple comparisons were adjusted using the Benjamini–Hochberg procedure.<sup>35</sup>

## RESULTS

Among the 292 children with ASD in the target population, 235 (80.5%) were assigned male at birth; their mean age at T1 was  $13.1 \pm 1.76$  years. For present study, a subsample of 132 children agreed to join the study. Of these, 107 (81.1%) were assigned male at birth; their mean age was 12.6 years ( $SD = 1.88$ , median = 12). Those who responded to the survey at both T1 and T2 were enrolled in the study. Among the original 292 children, 200 (68.5%) had comorbid attention-deficit/hyperactivity disorder (ADHD). Four individuals with significant intellectual disability could not participate in cognitive testing. The mean PIQ of the other 288 children was 87.2 ( $SD = 22.4$ ).

**TABLE 1** Demographics and Baseline Characteristics of Participants

Characteristic	n (%) or Mean $\pm$ SD
Age	12.6 $\pm$ 1.88
Sex assigned at birth, male	107 (81.1)
DSM-5 <sup>36</sup> diagnosis	
ASD without ADHD	39 (29.5)
ASD with comorbid ADHD	93 (70.5)
PIQ (n = 131)	89.1 $\pm$ 23.43
Highest level of education attended by caregiver	
Elementary school	2 (1.5)
Middle school	1 (0.8)
High school	13 (9.8)
Some college or 2-y degree	23 (17.4)
4-y College or university graduate	78 (59.1)
Graduate or professional degree	15 (11.4)
Overall physical health of participants	
Excellent	12 (9.1)
Very good	24 (18.2)
Good	35 (26.5)
Fair	48 (36.4)
Poor	12 (9.1)
Education setting of participants before COVID-19	
General education program with support or services	38 (28.8)
Special education school program within a public school district	10 (7.6)
Special education school program at a private or nonpublic school	10 (7.6)
Home-based program	5 (3.8)
General education program without any individualized educational services	69 (52.3)
Language level (n = 112)	
No words	2 (1.8)
Single words meaningfully	11 (9.8)
Uses 3 word phrases	18 (16.1)
Uses sentences > 3 words	81 (72.3)

**Note:** ADHD = attention-deficit/hyperactivity disorder; ASD = autism spectrum disorder; IQ = intelligence quotient.

Demographics and baseline information for the study sample (n = 132) are shown in Table 1.<sup>36</sup> Among our sample of 132 children, 93 children (70.5%) had comorbid ADHD. One participant with significant intellectual disability could not undergo cognitive testing; the mean PIQ of the other 131 participants was 89.1 ( $SD = 23.43$ ). Comparison of age, ratio of sex assigned at birth (sex), ADHD comorbidity rate, and PIQ showed no statistically significant difference between our study

**TABLE 2** Numbers of Participants Who Worsened, Improved, or Maintained Stability in Each Composite Score From T0 to T1 and T1 to T2

	<b>Adaptive living skills</b>	<b>RRBs, lower-order</b>	<b>RRBs, higher-order</b>	<b>Activity/attention</b>	<b>Oppositional</b>	<b>Anxiety/affect</b>
From T0 to T1, n (%)						
Worsened	31 (23.5)	25 (18.9)	25 (18.9)	19 (14.4)	23 (17.4)	14 (10.6)
Maintained	77 (58.3)	86 (65.2)	78 (59.1)	113 (85.6)	109 (82.6)	118 (89.4)
Improved	24 (18.2)	21 (15.9)	29 (22.0)	0 (0.0)	0 (0.0)	0 (0.0)
From T1 to T2, n (%)						
Worsened	24 (18.2)	22 (16.7)	23 (17.4)	21 (15.9)	15 (11.4)	13 (9.8)
Maintained	86 (65.2)	85 (64.4)	82 (62.1)	111 (84.1)	117 (88.6)	119 (90.2)
Improved	22 (16.7)	25 (18.9)	27 (20.5)	0 (0.0)	0 (0.0)	0 (0.0)

**Note:** T0 = 3 months before COVID-19 outbreak; T1 = for past 2 weeks at distribution of first survey; T2 = for past 2 weeks at distribution of follow-up survey.

sample and the 160 children who did not participate in this study (age, independent  $t$  test  $p = .388$ ; sex ratio,  $\chi^2 p = .820$ ; ADHD comorbidity rate,  $\chi^2 p = .512$ ; PIQ, independent  $t$  test  $p = .587$ ).

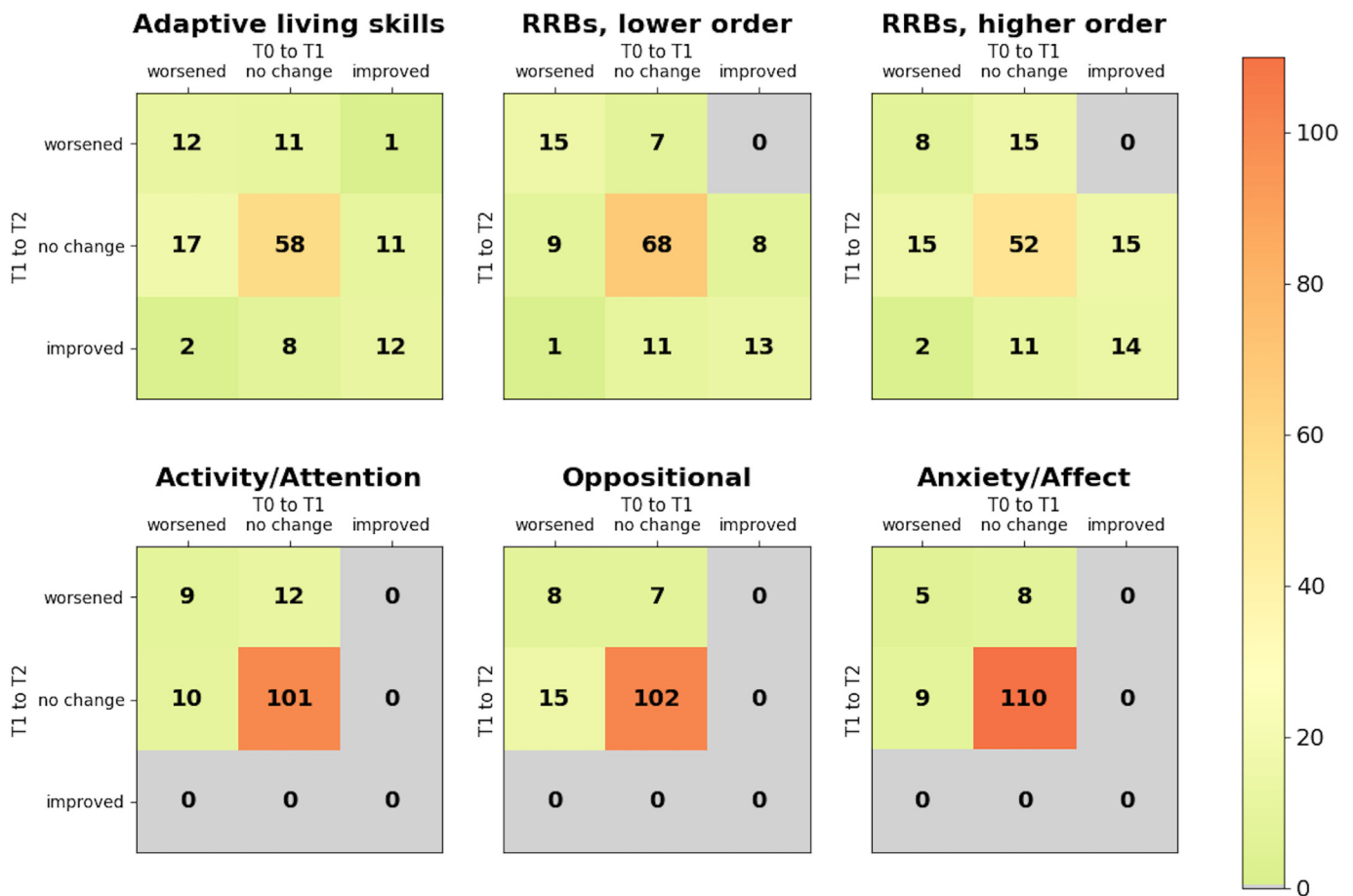
Based on the CRISIS-AFAR survey, 69 of the 132 children (52.3%) attended a general education school program without individualized educational services. Information on language level was collected for those with a past diagnosis of neurodevelopmental delay: "During the past month, how would you describe your child's unprompted speech throughout the day?" Reported reasons for delays included intellectual disability, ASD, learning disorder, ADHD, developmental delay, other problems requiring special education services, or other neurodevelopmental conditions ( $n = 112$ ; 84.8%). Among these individuals, at the time of the study, 72.3% (81 of 112) were able to use their own words to create sentences longer than 3 words to report on an event.

The numbers and percentages of children categorized to have worsened, improved, or remained stable in each composite score from T0 to T1 and from T1 to T2 are shown in Table 2. For all 6 domains and both time intervals, more than half of the participants maintained their level of function and symptom severity (58.3%-89.4% for T0 to T1; 62.1%-90.2% for T1 to T2). More participants demonstrated stability for co-occurring problem behaviors (82.6%-89.4% from T0 to T1, 84.1%-90.2% from T1 to T2) compared to the other 3 domains (58.3%-65.2% from T0 to T1, 62.1%-65.2% from T1 to T2) for both time intervals (all  $p < .001$  except oppositional problem behaviors vs lower-order RRBs [ $p = .001$ ]). The proportion of stable participants did not differ among the 3 co-occurring problem behaviors or among the adaptive living skills and RRB domains ( $p = .221$ -.505 from T0 to T1;  $p = .157$ -.905 from T1 to T2).

Figure 1 shows the number of individuals placed in each of the 9 classes based on the changes in symptom severity from T0 to T1 (column) and T1 to T2 (row) intervals ( $\chi^2$  for each domain  $p < .001$ ). For all domains, the number of participants who maintained stability from T0 to T1 and to T2 (center cells) was the largest among the 9 classes. This proportion was larger for co-occurring problem behaviors, with the largest being anxiety/affect problem behaviors ( $n = 110$ , 83.3%), followed by oppositional ( $n = 102$ , 77.2%) and activity/attention problem ( $n = 101$ , 76.5%) behaviors. Fewer participants remained stable for the other 3 domains, in decreasing order of lower-order RRBs ( $n = 68$ , 51.5%), adaptive living skills ( $n = 58$ , 43.9%), and higher-order RRBs ( $n = 52$ , 39.4%). Only a small portion of the participants continuously worsened from T0 through T2 (upper left cells), ranging from 5 participants (3.8%) for anxiety/affect problems to 15 participants (11.4%) for lower-order RRBs. Across all 6 symptom domains, only 1 participant worsened from T1 to T2 after improving from T0 to T1 (upper right cells), specifically in the adaptive living skills domain. Although none of the participants improved in co-occurring problem behaviors from T0 to T1 (right columns) or from T1 to T2 (bottom rows), 12 to 14 participants (9.1%-10.6%) showed continuous improvement throughout the entire study period for adaptive living skills or lower- or higher-order RRBs (bottom right cells).

Preliminary subgroup analyses were performed to identify associations between participants' baseline characteristics and the main findings. The 42 participants who worsened continuously during both time intervals in any of the domains did not show significant differences in baseline characteristics from the group that did not ( $n = 90$ ;  $p = 0.567$ -1.000) (Table 3). Those who worsened continuously in 2 or more of the domains had worse caregiver-perceived physical health (rated 1 [poor] to 5 [excellent]) than their counterparts (2 or more [ $n = 10$ ],  $0.9 \pm 0.74$ ; 1 or none



**FIGURE 1** Number of Participants for Each Direction of Change Among Three Ranges by Baseline Mean and Standard Deviation

**Note:** Color bar on the right shows the cell color corresponding to the number of participants in that cell. Cells with no respective participants are depicted in gray.  $\chi^2$  Test for each table,  $p < .001$ .

[ $n = 122$ ],  $1.9 \pm 1.11$ ;  $p = .036$ ). None of the other characteristics were significantly different.

Comparisons within each domain are summarized in Table 4. Participants who never worsened in their activity/attention problem behaviors had higher caregiver-rated physical health (never worsened [ $n = 101$ ],  $2.0 \pm 1.13$ ; worsened [ $n = 31$ ],  $1.3 \pm 0.94$ ;  $p = .032$ ). Higher PIQ ( $91.9 \pm 22.87$  vs  $79.4 \pm 23.35$ ;  $p = .027$ ), having attended general education pre-pandemic ( $n = 60$ , 60% vs  $n = 9$ , 28.1%;  $p = .027$ ), and having better language skills ( $3.7 \pm 0.66$  vs  $3.3 \pm 0.87$ ;  $p = .027$ ) characterized those who remained stable or improved in their severity of lower-order RRBs ( $n = 100$ ). Age, sex assigned at birth, diagnosis of ADHD, and caregiver's highest level of education did not differ in any comparisons. No baseline characteristics significantly differed for adaptive living skills, higher-order RRBs, oppositional problem behaviors, and anxiety or affect problem behavior.

## DISCUSSION

This study provides a longitudinal examination of 132 children with ASD ascertained from a previous large, representative, Korean community based ASD prevalence study. Using a caregiver survey, the CRISIS-AFAR, data were acquired for 3 time periods: 3 months before the pandemic; January to June 2021, and 3 to 4 months after, during South Korea's third wave of the pandemic. Six domains were examined: adaptive living skills, lower- and higher-order RRBs, and co-occurring problem behaviors including activity/attention, oppositional, and anxiety/affect problem behaviors.

For all domains, fewer than 25% of the 132 participants worsened in their level of symptom severity or adaptive daily function during the period of highest inconsistency in social distancing mandates. During the following 3 months, less than 20% worsened for any of the domains. The level of adaptive functioning or RRB symptom severity improved

**TABLE 3** Characteristics of Participants Who Worsened Continuously From T0 Through T2

	No. of domains in which participant worsened throughout both intervals		<i>p</i> <sup>a</sup>
	1 or More (n = 42)	None (n = 90)	
Age (mean ± SD)	12.6 ± 1.79	12.5 ± 1.93	.882
Sex at birth, male, n (%)	34 (81.0%)	73 (81.1%)	1.000
ADHD, n (%)	25 (59.5%)	58 (64.4%)	.882
PIQ, mean ± SD	84.6 ± 21.0	91.0 ± 24.4	.680
Attended general education <sup>a</sup> , n (%)	15 (35.7%)	54 (60.0%)	.567
Caregiver education <sup>b</sup> , mean ± SD	4.5 ± 0.89	4.7 ± 0.96	.770
Overall physical health <sup>c</sup> , mean ± SD	1.8 ± 1.21	1.8 ± 1.08	.882
Spoke in sentences <sup>d</sup> , mean ± SD	3.5 ± 0.82	3.6 ± 0.7	.770
	2 or More (n = 10)	1 or None (n = 122)	
Age, mean ± SD	12.2 ± 2.15	12.6 ± 1.87	.972
Sex at birth, male, n (%)	8 (80.0%)	99 (81.1%)	1.000
ADHD, n (%)	6 (60.0%)	77 (63.1%)	1.000
PIQ, mean ± SD	77.3 ± 21.94	90.0 ± 23.44	.306
Attended general education <sup>b</sup> , n (%)	2.0 (20.0%)	67 (54.9%)	.365
Caregiver education <sup>c</sup> , mean ± SD	4.7 ± 0.82	4.7 ± 0.95	1.000
Overall physical health <sup>d</sup> , mean ± SD	0.9 ± 0.74	1.9 ± 1.11	.036*
Spoke in sentences <sup>e</sup> , mean ± SD	3.5 ± 0.85	3.6 ± 0.73	1.000

**Note:** ADHD = attention-deficit/hyperactivity disorder; IQ = intelligence quotient.

<sup>a</sup>All *p* values have been adjusted for multiple comparisons using the Benjamini–Hochberg procedure.

<sup>b</sup>Whether each participant attended a general education program without any individualized educational services pre-pandemic.

<sup>c</sup>Caregiver's highest level of education, rated on an ordinal scale, from 1 = elementary school to 6 = graduate or professional degree.

<sup>d</sup>Overall physical health rated by the caregiver on an ordinal scale, with 1 = poor to 5 = excellent.

<sup>e</sup>Language level rated on an ordinal scale, from 1 = has no words to 4 = speaks in sentences.

\**p* (Adjusted) < .05.

during at least 1 interval in 15% to 22% of the participants. Among them, 10% advanced from a lower level of adaptive functioning or higher severity of RRBs, compared to baseline, to a level of improved functioning or symptom severity relative to baseline. No participants showed improvement from the higher than baseline average level to a lower level for co-occurring problem behaviors, but over 75% of participants maintained stable symptom severity throughout the study period. Although the participants showed some variability in their responses to the pandemic and its continuation, most remained stable over time despite the challenges associated with the pandemic.

Our findings contrast with reports suggesting that children with ASD are particularly vulnerable to adverse effects of COVID-19 and the accompanying social distancing rules.<sup>13,16,19,22,24,37</sup> Principal findings in prior studies included increased anxiety,<sup>22</sup> decline in mood,<sup>22,37</sup> increase in conduct problems, hyperactivity, and inattention,<sup>37</sup> and decreased adaptive living skills<sup>13</sup> in youth with ASD during the pandemic. However, it is difficult to directly compare our findings with many of the previous studies because most studies analyzed data obtained during

lockdown.<sup>13,22,24,37</sup> Avoiding indoor confinement and a sedentary lifestyle have a positive impact on social behavior, communication skills, aggressive behavior, stress levels, and behavioral problems in children with ASD.<sup>38</sup> As South Korea's social distancing measures allowed families to spend time outdoors, albeit with restrictions, it may have been easier to remain active then compared to during lockdown conditions. The study by Zhang *et al.* comparing clinical improvements during different durations of lockdown also illustrates that time under lockdown is associated with lesser improvement.<sup>24</sup>

Our findings are more consistent with reports indicating longitudinal outcomes with no overall decline in mental health following the COVID-19 outbreak.<sup>6,20,39</sup> They also align with findings during the development of the CRISIS-AFAR indicating that among 1,275 youth with NDDs (n = 1,004 [79%] with ASD), 80% maintained their composite scores for the 6 domains within 0.5 SDs from the mean.<sup>33</sup> The proportions of participants classified in each classification are largely in line with previously reports. A notable number of participants (18.2% from T0 to T1, 16.7% from T1 to T2) demonstrated improved

**TABLE 4** Characteristics of Participants Who Did Not Worsen in Their Level of Adaptive Skills or Symptom Severity

	Age, y, mean $\pm$ SD	Sex at birth, male, mean, n (%)	ADHD, n (%)	PIQ, mean $\pm$ SD	General education <sup>a</sup> , n (%)	Caregiver education <sup>b</sup> , mean $\pm$ SD	Physical health <sup>c</sup> , mean $\pm$ SD	Language level <sup>d</sup> , mean $\pm$ SD
Adaptive living skills								
Stable/improved (n = 89)	12.3 $\pm$ 1.94	72 (80.9)	56 (62.9)	87.4 $\pm$ 25.73	47 (52.8)	4.6 $\pm$ 0.95	1.7 $\pm$ 1.06	3.5 $\pm$ 0.76
Worsened (n = 43)	13.0 $\pm$ 1.7	35 (81.4)	27 (62.8)	92.2 $\pm$ 17.96	22 (51.2)	4.7 $\pm$ 0.93	2.0 $\pm$ 1.21	3.8 $\pm$ 0.66
<i>p</i> <sup>e</sup>	.220	1.000	1.000	.440	.220	.629	.220	.220
RRBs, lower-order								
Stable/improved (n = 100)	12.6 $\pm$ 1.84	80 (80.0)	63 (63.0)	91.9 $\pm$ 22.87	60 (60.0)	4.8 $\pm$ 0.82	1.9 $\pm$ 1.15	3.7 $\pm$ 0.66
Worsened (n = 32)	12.4 $\pm$ 2.05	27 (84.4)	20 (62.5)	79.4 $\pm$ 23.35	9 (28.1)	4.3 $\pm$ 1.21	1.6 $\pm$ 0.98	3.3 $\pm$ 0.87
<i>p</i> <sup>e</sup>	.881	.881	1.000	.027*	.027*	.058	.221	.027*
RRBs, higher-order								
Stable/improved (n = 92)	12.6 $\pm$ 1.83	76 (82.6)	60 (65.2)	91.6 $\pm$ 23.52	56 (60.9)	4.7 $\pm$ 0.9	1.9 $\pm$ 1.05	3.6 $\pm$ 0.77
Worsened (n = 40)	12.4 $\pm$ 2.01	31 (77.5)	23 (57.5)	83.0 $\pm$ 22.59	13 (32.5)	4.6 $\pm$ 1.03	1.6 $\pm$ 1.24	3.6 $\pm$ 0.69
<i>p</i> <sup>e</sup>	.749	.749	.749	.220	.192	.749	.264	.954
Activity/attention								
Stable/improved (n = 101)	12.6 $\pm$ 1.91	83 (82.2)	59 (58.4)	90.3 $\pm$ 23.57	60 (59.4)	4.7 $\pm$ 0.9	2.0 $\pm$ 1.13	3.6 $\pm$ 0.79
Worsened (n = 31)	12.5 $\pm$ 1.82	24 (77.4)	24 (77.4)	84.7 $\pm$ 23.06	9 (29.0)	4.7 $\pm$ 1.08	1.3 $\pm$ 0.94	3.7 $\pm$ 0.61
<i>p</i> <sup>e</sup>	.902	.902	.237	.488	.180	.902	.032*	.811
Oppositional								
Stable/improved (n = 102)	12.6 $\pm$ 1.89	83 (81.4)	61 (59.8)	89.9 $\pm$ 24.88	57 (55.9)	4.6 $\pm$ 0.99	1.9 $\pm$ 1.08	3.6 $\pm$ 0.8
Worsened (n = 30)	12.2 $\pm$ 1.85	24 (80.0)	22 (73.3)	85.8 $\pm$ 18.1	12 (40.0)	4.8 $\pm$ 0.76	1.6 $\pm$ 1.22	3.6 $\pm$ 0.56
<i>p</i> <sup>e</sup>	.648	1.000	.648	.648	.711	.648	.648	.755
Anxiety/affect								
Stable/improved (n = 110)	12.6 $\pm$ 1.88	90 (81.8)	70 (63.6)	90.2 $\pm$ 23.31	61 (55.5)	4.7 $\pm$ 0.98	1.9 $\pm$ 1.13	3.6 $\pm$ 0.74
Worsened (n = 22)	12.3 $\pm$ 1.91	17 (77.3)	13 (59.1)	82.4 $\pm$ 23.9	8 (36.4)	4.6 $\pm$ 0.73	1.3 $\pm$ 0.88	3.4 $\pm$ 0.77
<i>p</i> <sup>e</sup>	.838	.902	.902	.560	.560	.902	.096	.560

**Note:** ADHD = attention-deficit/hyperactivity disorder; IQ = intelligence quotient.

<sup>a</sup>Whether each participant attended to a general education program without any individualized educational services pre-pandemic.

<sup>b</sup>Caregiver's highest level of education, rated on an ordinal scale, from 1 = elementary school to 6 = graduate or professional degree.

<sup>c</sup>Overall physical health rated by the caregiver on an ordinal scale, with 1 = poor to 5 = excellent.

<sup>d</sup>Language level rated an ordinal scale, from 1 = has no words to 4 = speaks in sentences.

<sup>e</sup>All *p* values have been adjusted for multiple comparisons using the Benjamini–Hochberg procedure.

\**p* (Adjusted) < .05.



adaptive living skills in our study population, similar to a study that found increased parent-reported child autonomy in 14.9% of the their sample.<sup>40</sup> The proportion of individuals remaining stable in severity of RRBs (51.5% for lower-order RRBs, 39.4% for higher-order RRBs) were similar to the findings of Turner *et al.*<sup>28</sup> (45.7%-46.6%) and Berard *et al.*<sup>21</sup> (54.7%). The small proportion of participants with worsening of RRBs has also been previously demonstrated.<sup>30</sup>

The stability demonstrated by the majority of our participants in the 3 co-occurring problem behavior domains has been previously noted.<sup>20,27,33</sup> Research on typically developing children and adolescents during the pandemic identified an increase in externalizing and internalizing problems.<sup>41-43</sup> In contrast, social distancing resulting from pandemic public health precautions might have contributed positively to the mental health of children with ASD. The decreased effort required for socialization during COVID-19 restrictions may have actually lessened burdens for children with ASD. In previous studies, families of children with ASD reported benefiting from social distancing because they had more positive interactions with their children.<sup>32,40</sup>

The marked stability in symptoms suggested by our results, even amidst frequent changes in public health mandates, may be due to characteristics of our study population. Unlike clinical study populations, our epidemiologically ascertained study population included children with broad and comprehensive spectra of ASD symptoms, including both clinical (who already sought clinical and/or educational services before the study had begun) and nonclinical populations (who were not previously diagnosed and had not previously received clinical and/or educational services). Our study population's profile is in line with findings from a total population cohort in which children with ASD recruited from the general population had a higher PIQ than those recruited from the clinical population.<sup>34</sup> The large proportion of educated parents aligns with characteristics observed in the general Korean population, as 2020 and 2023 national statistics report that 57.9% and 66.7% of South Korean parents with children aged 9 years and older had a 4-year college degree or higher, respectively. In addition, over half of our sample attended general education programs, without any individualized educational services. Because many in our study population did not receive any services (32.6%) prior to the COVID-19 outbreak, many participants did not experience pandemic-related service disruptions. As prior studies have indicated that modification or discontinuation of treatment services predicts worse outcomes,<sup>23,28,33</sup> maintaining continuity may have benefited our study participants.

Preliminary subgroup analysis found lower ratings for the overall physical health of the participants to be associated with continued worsening in multiple domains. Better ratings of physical health were also a characteristic of participants who did not worsen in activity/attention problem behaviors at both time intervals. Our finding supports past observations that ASD children with nonpsychiatric comorbid disorders, such as neuromotor conditions, gastrointestinal conditions, or allergies, exhibited more severe behavior problems during the pandemic.<sup>13</sup> Furthermore, we found that the group of participants who did not worsen in their lower-order RRBs had higher PIQ, were more likely to attend general education without educational support, and had better language skills. The mean PIQ of the group that had worsened during at least 1 of the time intervals was 79.4, suggesting that presence of borderline intellectual functioning or more severe intellectual disability may be a risk factor for youth with ASD during the pandemic. Our results suggest that severe ASD symptoms may be a risk factor for further increase in RRBs, as demonstrated in prior studies.<sup>18</sup> As such, it is worth noting that youth with ASD who have poorer physical health, more severe ASD symptoms, and lower baseline IQ may benefit from additional support during similarly stressful periods.

Although this study provides a valuable snapshot of how children with ASD were affected by the early stages of the pandemic, it has limitations. We had a significant reduction in sample size from loss to follow-up; there is a possibility of sampling bias reflecting the willingness of the caregivers to participate in the survey. The decision may have been associated with parental stress, access to childcare and healthcare services, overall health of the child, or the compensation offered. However, a comparison of age, sex ratio, ADHD comorbidity rate, and PIQ between participants and nonparticipants among the children with ASD showed no statistically significant difference. Another limitation is that data on adaptive function and symptoms in children with ASD were collected from caregivers and were not verified by direct clinical observation and/or independent assessments. Finally, the small sample sizes per subgroup limited the subgroup analysis in terms of statistical power as well as the range of comparisons explored.

Strengths of our study include the prospective follow-up study design and the use of an epidemiologically ascertained sample of children with ASD, in contrast to studies ascertained from clinical settings. Clinical samples are likely to be affected by factors such as barriers to healthcare access, availability of resources, severity of ASD symptoms, and rates of comorbid conditions. In contrast, the present study provides insight into how the pandemic has affected a broad

and representative spectrum of children with ASD, including those not receiving services.

This ongoing study collected additional data during a planned 2-year follow-up. Follow-up responses have been collected in 6-month intervals until May 2023, when the World Health Organization (WHO) declared the end of the COVID-19 global health emergency. Further reports will be forthcoming to provide data on trajectories of symptoms and adaptive functioning, along with the factors contributing to variability in these trajectories during the longitudinal follow-up period with this study population.

### CRedit authorship contribution statement

**Yoon Jae Cho:** Writing – original draft, Visualization, Methodology, Formal analysis. **Eunjoo Kim:** Supervision, Project administration, Conceptualization. **Young-Shin Kim:** Writing – review & editing, Supervision, Project administration, Methodology, Funding acquisition, Conceptualization. **Hosanna H. Kim:** Project administration, Methodology, Data curation. **Jihyun Kim:** Project administration, Data curation. **Bokyoung Shin:** Project administration, Data curation. **Adriana Di Martino:**

Methodology, Conceptualization. **Bennett L. Leventhal:** Writing – review & editing, Supervision, Methodology, Conceptualization.

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Data Sharing: The dataset includes information that may breach confidentiality for the participants. De-identified data may be available upon reasonable request to the corresponding author.

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