

Experiences of Students with Intellectual and Developmental Disabilities and their Caregivers during Covid-19

Purpose

The education of all students, including those with intellectual and developmental disabilities (IDD), was disrupted by the Covid-19 pandemic. We conducted a national survey to understand how the pandemic impacted both students with IDD and their caregivers by comparing experiences before Covid-19 to those between March-June 2020, and during Fall of 2020.

Background and Context

The Covid-19 pandemic amplified the existing vulnerability of students with intellectual and developmental disabilities (IDD), a historically marginalized group with chronically poor in- and post-school outcomes (National Technical Assistance Center on Transition, 2018). When the Covid-19 pandemic caused nationwide school closures in March 2020, the specially designed instruction and critical therapies students with intellectual and developmental disabilities (IDD) rely on receiving from school were no longer safe to continue in person.

It is not surprising that when asked about the ease with which they were able to provide services to students with disabilities between mid-May and September 2020, 73% of districts reported it was more or substantially more difficult to provide appropriate instructional accommodations than pre-Covid, and 58% said it was more or substantially more challenging to comply with requirements of the Individuals with Disabilities Education Act (IDEA) to provide specially designed instruction (Jackson & Bowdon, 2020). After all, they had minimal to no research-based models to follow for providing interventions in an online or remote setting (White et al., 2021). Elementary children with IDD fall into the category of students considered most at-risk for learning loss (Kuhfeld et al., 2020). High-poverty districts (who serve students with disabilities in higher proportions) reported greater challenges than low-poverty districts. Further distressing to students of color with IDD and those from low-income families is the “substantially unequal burden of Covid-19” (Chen & Kriger, 2021, p. S45) reflected in higher positivity and death rates in their communities.

Caregivers of students with IDD have reported various effects of the challenges districts faced to provide their children with the services and supports outlined in their IEPs in initial surveys (Jeste et al., 2020; ParentsTogether, 2020; White et al., 2021). These initial surveys captured the educational experiences of students with IDD across the United States in spring of 2020 as perceived by their caregivers. To understand the impact of the Covid-19 pandemic on instruction for students with IDD, a baseline understanding of instructional experiences for individuals with IDD is needed. Therefore, our purpose was to survey caregivers of students with IDD in the United States about their student’s instructional experiences before Covid-19, in Spring of 2020, and during Fall of 2020, addressing the following research questions:

1. What was the impact of the Covid-19 pandemic on the educational experiences of school-age (K-21) students with IDD as perceived by their caregivers?
2. What were the effects of these impacts on students with IDD as perceived by their caregivers?
3. Is there a relationship between caregiver perception of students’ school enjoyment, frequency of one-on-one instruction, and number of areas of regression?

Method

Participants

Participants included 66 caregivers of school-age students with IDD in the United States who completed an online survey about their student's educational experiences prior to and during Covid-19. The participants represented 25 states across all six geographic regions of the United States. See Table 1 for detailed student demographics. Participants were recruited using social media posts and emailed flyers sent to targeted professional and parent organizations.

Survey Instrument

Participants were asked to complete an online survey through a secure, web-based platform (Qualtrics). We first asked participants to report demographic information about themselves, their child with IDD, and their household. If participants had more than one child with IDD, they were asked to select one to focus on for the purpose of the survey and only complete the survey once. Next, participants completed questions about their child's educational experiences prior to March 2020 (Wave 1), from March to June 2020 (Spring 2020; Wave 2), and during Fall 2020 (Wave 3) to understand a) participants' experiences during Covid-19, and b) how these experiences differed from those prior to the pandemic. Each section prompted caregivers to recall the specified time periods or "waves" when answering that specific section's questions. In each wave, the survey evaluated the context of where students received instruction and services, the specific instructional content students received, and the supports available.

The instrument included a range of response formats such as multiple-choice, rating and ranking scale, Likert scale, matrix, drop-down, and open-ended questions. We asked questions related to instructional context, (e.g., where students were enrolled and learning formats offered by their schools), content, and supports (e.g., on average how much time they spent with their child on weekdays across seven instructional areas, what school-based supports and services students received). We also asked about their students' attitudes toward school and caregivers' perceived areas of regression using a four-point Likert scale and to what degree, if any, their students exhibited regressions across seven instructional areas: literacy (reading, writing), science/social studies, mathematics, life skills, social skills, job skills, and motor skills. At the end of the survey participants had an opportunity to provide additional information with researchers through open-ended responses.

We piloted the survey instrument twice. The initial pilot survey included four caregivers of children with IDD of diverse ages, backgrounds, and geographic locations. Next, doctoral students in special education who were not members of the research team piloted the revised survey. None of the pilot responses were included in the final sample.

Data Analysis

We used IBM SPSS Statistics (Version 26) analytic software for all descriptive analyses. When possible, we calculated responses for each question across three time periods: prior to Covid-19, Spring 2020, and Fall 2020. Two members of the research team double-checked all survey items requiring coding and calculated interrater reliability at 98.2%; discrepancies were addressed and resolved to consensus. We calculated descriptive statistics (e.g., mean, percentages) to summarize responses from items using rating scales. To explore associations between ordinal variables, we calculated Spearman's rank order correlations.

Findings or Results

Findings from this survey, as expected, revealed variability among participants regarding educational experiences of students with IDD during COVID.

RQ1: Changes in Instruction

To understand how the Covid-19 pandemic changed instruction for students with IDD, we analyzed reported instructional context, content, and support prior to and during the Covid-19

pandemic. Regarding where students were enrolled, 81.8% ($n=54$) of respondents reported that their students attended traditional public schools prior to March 2020, 15.2% ($n=10$) were enrolled in private schools, and 3% ($n=2$) had students enrolled in another setting (unspecified). No respondents reported that their students' schools offered hybrid or fully remote instruction prior to March 2020. In Spring 2020, 80.3% ($n=53$) began remote learning, 4.5% ($n=3$) continued attending school in person, and 15.2% ($n=10$) reported their student did not receive any instruction. By Fall 2020, 71% of respondents' ($n=44$) schools offered various instructional formats (hybrid, fully in person, etc.) for students to choose from; 19.3% of respondents' ($n=12$) schools provided a single hybrid model in which all students received both virtual and in-person instruction, and 9.7% of respondents ($n=6$) reported their schools only offered in-person instruction. In Fall 2020, 30.6% ($n=19$) attended school in-person, 17.8% ($n=11$) attended in a hybrid model, and 51% ($n=32$) were learning remotely. Finally, responses varied regarding access to extended school year (ESY).

Table 2 displays the estimated time students spent with caregivers on weekdays across instructional areas prior to March 2020, in Spring 2020, and in Fall 2020. Whereas prior to March 2020, only 18.6% of caregivers reported spending 30 min or more on literacy instruction with their student on weekdays, 52.4% of respondents were spending over 30 min on literacy in Spring 2020, with 22.2% spending over 60 min on this topic. Prolonged home literacy support continued into Fall 2020, as 63.3% of respondents reported spending over 30 min on weekdays in this area. Likewise, home instruction in mathematics increased for much of the sample, with 62.5% reporting spending less than 15 min on weekdays supporting math to almost half of the sample (45.2%) spending more than 30 min in Spring 2020 and to 51% spending more than 30 min on weekdays on math in Fall 2020.

We assumed that prior to Covid-19 all students received one on one specially designed instruction to some degree. All respondents reported that their students with IDD also received related services from school prior to March 2020, with the majority of respondents reporting that this included speech/language therapy (73.4%; $n=47$) and occupational therapy (68.8%; $n=44$), followed by paraeducator support (60.9%; $n=39$) and behavior plans (54.7%; $n=35$). Fewer students were reported to receive physical therapy (29.7%; $n=19$) or use AAC devices (21.9%; $n=14$) at school. Responses ranged from 0 to 6 related services and supports per student ($M = 3$; $SD = 1.6$) prior to Spring 2020.

Almost one-third of respondents (32.1%; $n=17$) reported that their students never received any one-on-one instruction in Spring 2020. Only 39 respondents (59.1% of the total sample) reported that their students received related services and supports, a 39% reduction from the time period prior to Spring 2020. Although responses ranged from 0 to 6 related services and supports per student as they did before Spring 2020, respondents reported fewer supports per student, on average ($M = 1.23$; $SD = 1.5$) and all related service areas were reduced.

In Fall 2020, only 9.5% of respondents ($n=4$) reported not receiving any one-on-one instruction and reported receipt of related services increased over spring 2020 levels, as 90% ($n=60$) respondents reported their students received related services and supports from school during this time. As in the two previous waves, parents reported a range of 0 to 6 related services and supports per student ($M=2.39$, $SD=1.7$). Again, the most common areas for related supports during Fall 2020 were speech/language and occupational therapy (each 68.3%; $n=41$), followed by paraeducator support (46.7%; $n=28$), behavior plans (40%; $n=24$), physical therapy (26.7%; $n=16$), AAC (13.3%; $n=8$), and "other" related services (unspecified, 11.7%; $n=7$).

RQ2: Perceived Effects on Students

To understand the effects of the Covid-19 pandemic and schooling changes on students with IDD, we asked caregivers about their perceptions of their student's attitude toward school during each of these time periods and whether they had observed regression in skills. Prior to March 2020, 43.9% ($n=29$) of students were reported by caregivers to strongly like school, followed by 33% ($n=22$) somewhat liking school, only 16.7% ($n=11$) somewhat disliking school, and 6.1% ($n=4$) strongly disliking school. Caregiver perception of students' attitudes toward school strongly shifted in Spring 2020, as 43.4% ($n=26$) reported their student strongly disliking school, 23.3% ($n=14$) somewhat disliking school, 23% ($n=14$) somewhat liking school, and only 10% ($n=6$) strongly liking school. Caregiver reports of student attitudes toward school in Fall 2020 were more similar to pre-Covid than Spring 2020, with 40.3% ($n=25$) somewhat liking school, 27.4% ($n=17$) strongly liking school, 17.8% ($n=11$) somewhat disliking school, and 14.5% ($n=9$) strongly disliking school.

When asked about possible regressions exhibited by students during Spring 2020, 81.7% ($n=49$) of respondents reported regressions in at least one of the following areas: academics, language, adaptive behavior, life skills, social skills, job skills, motor skills, or other. Responses ranged from 0 to seven regression areas ($M=2.2$, $SD=1.9$) per student during this time period. Most common were regressions in social ($n=33$, 55%), academic ($n=32$, 53.3%), and adaptive skills ($n=29$, 48.3%), followed by language ($n=20$, 33.3%), life- ($n=15$, 25%), motor- ($n=14$; 23.3%), and job skills ($n=3$; 4.5%). In Fall 2020, the number of respondents who reported one or more areas of regression dropped slightly to 72.2% ($n=39$).

RQ 3: Relationship Between Changes in Instruction and Perceived Effects

To explore the relation between changes in instruction and caregivers' perceived effects on students with IDD, we calculated Spearman's correlations among the following variables: school enjoyment (Pre-COVID, Spring 2020, Fall 2020), frequency of one-on-one instruction (Spring 2020, Fall 2020), and number of areas of regression (Spring 2020, Fall 2020). Data met assumptions of ordinality, paired data, and monotonicity required for such calculations. Results are displayed in Table 3.

Conclusions and Implications

Our findings generally align with those reported by the National Survey of Public Education's Response to Covid-19 (AIR, 2020), marginalized students who entered the pandemic most vulnerable to loss of instruction. Districts serving mostly students of color, with high percentages of English learners, and low-achieving districts were less likely to report their teachers covered all content they normally would (Rickles et al., 2021). Furthermore, most districts surveyed reported it was substantially more difficult to comply with IDEA requirements to provide specially designed instruction (58%), related services (55%), and the least restrictive environment (52%). Participants in our sample mirror reported characteristics of the larger population of students with IDD in the United States, in that most received related services in addition to specially designed instruction in order to access the general curriculum (Monz et al., 2019; Zuckerman et al., 2016). Echoing findings of prior surveys, most of our respondents reported their students lost access to the related services and supports they are entitled to receive. Our findings are encouraging though, as they show that while the experiences of students with IDD were inexcusably poor from March-June 2020, they did show improvement with the start of the new school year in Fall 2020.

This loss of access to necessary services was a specific concern of leaders in special education at the onset of the pandemic. In their commentary published in May 2020, Thompson and Nygren insisted children with disabilities have full access to educational opportunities no

matter the mode of instruction. Acknowledging the “growing pains” experienced by the educational system in this historic move to a new way of educating students, authors warned of false dichotomies between meeting the needs of some or all students and use of the pandemic to justify anything less than continued provision of FAPE. Given that the majority of our respondents reported their students attending traditional public schools, the complete lack of instruction reported by some respondents in Spring 2020 and dramatic decrease in provision of school-based supports and services during Spring and Fall of 2020 compared to before Covid-19 is concerning.

One perhaps unsurprising finding is that none of the respondents reported their students had engaged in remote learning prior to Spring of 2020. This necessary shift in mode of instructional delivery was also difficult for teachers, who reported students needing support from caregivers to engage in remote learning (Schuck & Lambert, 2020). This need for additional support may help to explain the sharp increase in time spent with caregivers on instructional areas during weekdays, as online formats require different skill repertoire related to attending, digital literacy, and remaining engaged with limited reinforcers (Stenhoff et al., 2020). Though the descriptive nature of our study precludes causal inferences, the reported change in caregiver perception of students’ attitudes toward school during Spring 2020 and student skill regressions are striking and concerning. Almost the same percent of students who were reported to strongly like school (43.9%) pre-Covid were reported to strongly dislike school in spring 2020 (43.6%). Also concerning is that 81% of caregivers reported perceived regression in at least one domain during Spring 2020, most commonly social skills (55%), followed by academic skills (53%).

We want to point out two important limitations to consider when interpreting results of the survey. The first is the survey length. Authors made an a priori decision to gather in-depth information on experiences from caregivers, resulting in a longer survey and average response time. This may have been the reason for attrition/non completers. Relatedly, the participant demographics should not be considered lightly. Our participants were not unique, as with other surveys they were primarily identified as mothers of individuals with ASD (70%; Neece et al., 2020), and white, older, and identified as female (White et al., 2020). Therefore we cannot claim that these results speak for the experience of all caregivers of students with IDD. Yet if these well educated white mothers with self-identified social capital, privilege, access to training or background in education, and the time to answer a 30 minute survey were experiencing high levels of stress, significant regression in their children’s skills, and 1 in 5 of their children were not receiving any instruction during initial school closures, we would estimate that the true picture is far more dire.

Unfortunately, teaching and learning during a pandemic is no longer unprecedented. Whereas schools, students, and caregivers all abruptly changed their way of teaching, learning, and living in Spring of 2020, the Covid-19 pandemic is ongoing as it is nearing 2 years since schools shut down. There are implications for multiple stakeholders as the pandemic has made irreversible changes to our way of teaching and learning. For teacher educators, we can no longer prepare future teachers for the classrooms and schools we remember, as that is not the environment they will be working in. Instead, they must be prepared to continue providing high-quality specially designed instruction using non-traditional methods. Collaboration and communication with families is critical; our previous textbooks, lectures, activities, and syllabi are insufficient because there is an entirely new level of communication and collaboration needed between teachers and caregivers of students with IDD.

Appendix A - References

Not included in page count.

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Appendix B - Tables and Figures

Table 1.

Student Demographics (n=66)

Variable	n=	%
Number of Adults Per Household		
1	6	9.1
2	53	80.3
3	7	10.6
Gender Identity		
Female	15	22.7
Male	51	77.3
Race		
Asian	1	1.5
Black or African American	1	1.5
White	58	87.9
Multiracial	4	6
Other	1	1.5
Prefer not to disclose	1	1.5
Ethnicity		
Hispanic or Latino	10	15.2
Not Hispanic or Latino	56	84.8
Primary Language		
English	66	100
Secondary Language		
AAC Device	1	1.5
American Sign Language	1	1.5
French	1	1.5
Hebrew	1	1.5
Portugese	1	1.5
Spanish	3	4.5
Student Grade		
K-2	12	18.2
3 rd to 5 th	22	33.3
6 th to 8 th	14	21.2
9 th to 12 th	14	21.2
Post-12 th Grade Transition	4	6.1
Disability		
ASD	37	56.1
ID	7	10.6
ASD and ID	7	10.6
MD	12	18.2
Other	3	4.5

Table 2.***Minutes spent with caregiver on instructional areas during weekdays***

	Pre-Covid (N range 62-66)					Spring 2020 (N range 60-63)					Fall 2020 (N range 59-61)				
	0	<15	15-30	30-60	>60	0	<15	15-30	30-60	>60	0	<15	15-30	30-60	>60 min
Literacy	4.6%	46.2%	30.8%	15.4%	3.2%	1.6%	23.8%	22.2%	30.2%	22.2%	1.7%	13.3%	21.7%	45%	18.3%
Math	1.6%	60.9%	25%	7.8%	4.7%	1.6%	22.6%	30.6%	30.6%	14.6%	1.7%	15%	33.3%	38.3%	11.7%
Science/ Social Studies	11.3%	67.7%	11.3%	4.7%	4.7%	8.2%	41%	19.7%	21.3%	9.8%	10.2%	20.3%	35.6%	28.9%	5%
Life Skills	12.3%	24.6%	27.8%	21.5%	13.8%	21%	27.4%	13%	24.2%	14.4%	26.7%	20%	25%	16.6%	11.7%
Social Skills	6%	28.8%	40.9%	16.7%	7.6%	9.9%	47.5%	16.4%	13.1%	13.1%	11.7%	30%	30%	23.3%	5%
Job skills	44.6%	40%	10.8%	3.1%	1.5%	60%	26.7%	5%	5%	3.3%	52.5%	16.4%	11.5%	4.9%	14.7%
Motor Skills	21.5%	40%	18.5%	13.8%	6.2%	26.6%	31.7%	18.3%	16.7%	6.7%	30%	23.3%	25%	16.7%	5%

Table 3.
Correlations between school enjoyment, frequency of one-on-one instruction, and number of areas of regression.

Variable	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7
<i>Pre-COVID</i>									
1. School enjoyment	3.16	0.90	-						
2. Number of supports received									
<i>Spring 2020</i>									
School enjoyment									
Number of supports received									
2. One-on-one instruction	3.25	1.68	.16	-					
3. Areas of regression	2.27	1.93	-.17	.10	-				
4. School enjoyment	1.98	1.02	.34**	-.01	-.36**	-			
<i>Fall 2020</i>									
Number of supports received									
5. One-on-one instruction	3.98	1.37	-.01	.38*	.14	.31*	-		