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Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions

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Abstract

Background COVID-19 restrictions have significantly limited access to in-person educational and healthcare services for all, including individuals with intellectual and developmental disabilities (IDDs). The objectives of this online survey that included both national and international families were to capture changes in access to healthcare and educational services for individuals with IDDs that occurred shortly after restrictions were initiated and to survey families on resources that could improve services for these individuals.

Methods This was an online survey for caregivers of individuals with (1) a genetic diagnosis and (2) a neurodevelopmental diagnosis, including developmental delay, intellectual disability, autism spectrum disorder or epilepsy. The survey assessed (1) demographics, (2) changes in access to educational and healthcare services and (3) available and preferred resources to help families navigate the changes in service allocation.

Results Of the 818 responses (669 within the USA and 149 outside of the USA), most families reported a loss of at least some educational or healthcare services. Seventy-four per cent of parents reported that their child lost access to at least one therapy or education service, and 36% of respondents lost access to a healthcare provider. Only 56% reported that their child received at least some continued services through tele-education. Those that needed to access healthcare providers did so primarily through telemedicine. Telehealth (both tele-education and telemedicine) was reported to be helpful when available, and caregivers most often endorsed a need for an augmentation of these remote delivery services, such as 1:1 videoconference sessions, as well as increased access to 1:1 aides in the home.

Conclusions COVID-19 restrictions have greatly affected access to services for individuals with syndromic IDDs. Telehealth may provide opportunities for delivery of care and education in a sustainable way, not only as restrictions endure but also after they have been lifted.

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Keywords Autism, COVID-19, Genetics, Intellectual disability, Parents

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Introduction

The COVID-19 stay-at-home orders have led to considerable and unique challenges for families of children and adults with genetic conditions associated with intellectual and developmental disabilities ('syndromic IDDs'), with loss of in-person educational and medical services (Eshraghi *et al.* 2020). The majority of individuals with syndromic IDDs receive not only special education services (either in a separate special education classroom or embedded within the general education classroom) but also behavioural supports and interventions (such as speech therapy, occupational therapy and behavioural support) both through and outside of the school setting (Liptak *et al.* 2006; Boulet *et al.* 2009). Medically, children with syndromic IDDs often have co-morbidities such as epilepsy, psychiatric disorders, sleep impairments and gastrointestinal issues that require careful supervision from physicians (Jeste 2011; Jeste & Tuchman 2015; Tye *et al.* 2019). The implications of losing these in-person educational and medical supports are profound, adding substantially to caregiver burden and also compromising the child's overall health and well-being. To begin to understand the changes in access to services for individuals with syndromic IDDs caused by COVID-19 stay-at-home restrictions early in the pandemic, we distributed an online international survey called 'CARING through COVID' in partnership with a digital health community (The Mighty 2020) and national rare disorder patient advocacy groups. We focused this project on genetic syndromes, rather than the broader IDD spectrum, because individuals with these conditions often experience more severe developmental disabilities and have complex co-morbid medical needs, representing a subset of the IDD population particularly dependent on both educational and healthcare resources. Caregivers were asked about their experiences with service delivery, healthcare utilisation and desired resources (Muhle *et al.* 2004; Fernandez & Scherer 2017). Here, we describe the results from the survey and consider the next steps to optimally support these families.

Objective

The objectives of this online survey were to understand the changes in access to services caused by COVID-19 restrictions for individuals with genetic syndromes associated with IDDs and to survey caregivers about helpful resources in both education and health care.

Methods

The online questionnaire required 10–12 min to complete and was administered in English to caregivers of individuals with syndromic IDDs. Using Qualtrics, the survey was distributed widely by The Mighty and patient advocacy groups over a 2-week period, 15 April through 4 May 2020. Caregivers consented online, and no participant identifiers were retained. This study was approved by the University of California, Los Angeles Institutional Review Board (IRB#20-000568).

Participants

Inclusion criteria, based on caregiver report, included being the caregiver of an individual with a (1) genetic diagnosis and (2) neurodevelopmental disorder, including developmental delay (DD), intellectual disability (ID), autism spectrum disorder (ASD) or epilepsy. Caregivers were not required to provide the exact genetic diagnosis of their child.

Procedures

The survey itself included the following sections: (1) demographics, (2) changes to educational services, (3) changes to healthcare services and (4) resources that caregivers found most helpful. Item non-responses were omitted from the denominator of individual questions. Open-ended responses were coded using a qualitative response rubric. Satisfaction reports were averaged and correlated with variables using SPSS.

Results

Participants

A total of 1106 caregivers opened the survey, 984 consented to participate, and 818 qualified.

Descriptive data

The majority of respondents lived in the USA (669), representing all but four states; 149 respondents lived

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outside of the USA (Fig. 1). Of the total sample, DD was the neurodevelopmental disorder most commonly reported (89%). A wide range of genetic diagnoses were reported, with the largest representation from those with Angelman syndrome ($n = 103$, 13%), tuberous sclerosis complex ($n = 32$, 4%), Rett syndrome ($n = 20$, 2%), Dup15q syndrome ($n = 19$, 2%), Sanfilippo syndrome ($n = 19$, 2%) and Phelan–McDermid syndrome ($n = 18$, 2%). Additional participant demographic details are found in Table 1.

Educational services

At the time the survey was taken, 74% of caregivers within the USA and 78% outside of the USA reported that their child was no longer receiving at least one therapy or educational service (Table 2). Thirty per cent within the USA and 50% outside of the USA lost all therapy and educational services. Changes in service modality were also reported, such that 56% within the USA and 32% outside of the USA reported that their child received at least one continued service through tele-education.

Caregivers whose children received some tele-education services were asked how helpful they found these services on a 1–4 scale ('not at all helpful', 'a little helpful', 'somewhat helpful' or 'extremely helpful'). Overall, only 14% (52/374) of respondents within the USA and 9% (4/47) outside of the USA found the tele-education services 'not at all helpful', while the remaining caregivers rated the services as helpful to some extent. There were no significant differences in the overall rating of tele-education based on the type of neurodevelopmental diagnosis (ASD, DD and ID). Individuals receiving more services through tele-education had a higher average rating of their tele-education services (Pearson correlation = 0.185, $P < .001$). Of those receiving combined video and email services, 34% found the video more helpful, 12% found email more helpful, and 54% found video and email equally helpful.

Educational resources

Caregivers both within and outside of the USA reported the most helpful resources to be (1) expanded tele-education services, $n = 82$; (2) written materials such as educational articles or lists of tips,

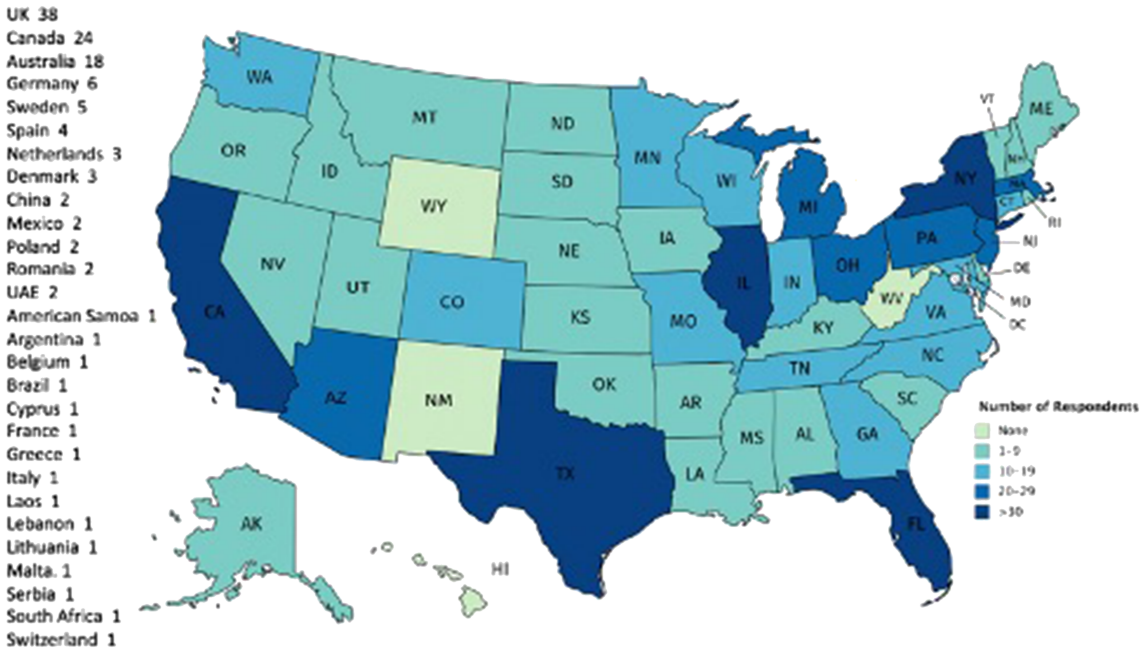

Figure 1. Respondent location within the USA by state (total = 669) and outside of the USA by country (total = 149). [Colour figure can be viewed at wileyonlinelibrary.com]

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Table 1 Demographics of survey respondents (caregivers) and children of respondents

	In the USA (total = 669) No. (% of total)	Outside of the USA (total = 149) No. (% of total)
Caregiver		
Female	593 (88.6)	127 (85.2)
Urban	168 (20.5)	57 (38.2)
Suburban	423 (51.7)	55 (36.9)
Rural	175 (21.4)	30 (20.1)
Child		
Female	397 (48.5)	74 (49.7)
<1 year old	8 (1.0)	1 (0.7)
1–3 years old	109 (13.3)	22 (14.8)
4–9 years old	262 (32.0)	60 (40.3)
10–15 years old	179 (21.9)	25 (16.8)
16–18 years old	63 (7.7)	12 (8.1)
19–21 years old	60 (7.3)	11 (7.4)
>22 years old	137 (16.7)	18 (11.4)
General education programme with support/services	106 (15.8)	40 (26.8)
Special education programme in public school district	241 (36.0)	50 (33.6)
Special education programme at private school	50 (7.8)	14 (9.4)
Centre-based programme	24 (3.6)	6 (4.0)
Home-based programme	52 (7.8)	2 (1.3)
Residential placement	23 (3.4)	7 (4.7)
Day programme/supervised employment	57 (8.5)	7 (4.7)
None of these education placements apply	116 (17.3)	23 (15.4)
Autism spectrum disorder	282 (42.2)	67 (45.0)
Developmental delay	602 (90.0)	150 (85.9)
Intellectual disability	535 (80.0)	114 (76.5)
Epilepsy	381 (57.0)	80 (53.7)

$n = 71$; and (3) tool kits with visual schedules, activities and videos, $n = 60$. Qualitatively, caregivers suggested the following accommodations and enhancements to improve school programmes and interventions: (1) more tele-education (integrated video learning, more 1:1 sessions and more frequent sessions), $n = 143$; (2) continuation of previously provided therapy and intervention, $n = 110$; (3) in-person services (1:1 sessions in the home; reopening programmes, including statements such as 'screens don't work for my child'), $n = 103$; (4) better programming and planning (clearer objectives/targets, consolidation of materials, consistent scheduling, time to collect materials, smaller group size and shorter sessions), $n = 52$; (5) social interactions (face-to-face time with peers, teachers and friends), $n = 39$; (6) support for parents (trainings/explanations/demonstrations, parent-to-parent advice and more available caseworkers), $n = 32$; (7) less demand on parents (including statements such as 'I am not a teacher/therapist', 'I am stretched too thin'; flexible/evening hours), $n = 19$; (8) development-specific programmes (acknowledgement of special needs, appropriate expectations and recommendations to address impairment), $n = 16$; and (9) provision of specific equipment (therapy tools, playground and physical support tools for children with mobility challenges), $n = 14$.

Health care

Seventy per cent of respondents in the USA and 58% outside of the USA reported needing to visit with a healthcare provider during this period (Table 3). Of these, 67% in the USA and 53% outside of the USA were able to meet with at least one provider through telemedicine, with the highest telemedicine rates among neurologists and general practitioners. Fifty-one per cent of respondents in the USA and 56% outside of the USA reported that they were unable to see at least one of their healthcare providers when needed during this period.

Caregivers identified aspects of their child's medical care that needed to be prioritised during restrictions, including (1) larger supplies of medication, $n = 212$; (2) reminders to administer/refill medication, $n = 47$; (3) continuation of delayed/cancelled clinical trial, $n = 37$; (4) assistance with monitoring of new medications (access to physicians and safe lab work), $n = 17$; (5) home delivery of medication, $n = 12$; (6) respite care (in-home medication administration and home nurses), $n = 6$; (7) medical supplies (distilled water, oxygen and personal hygiene products), $n = 6$; and (8) expedited insurance processing (referrals to specialists, genetic testing and medication coverage), $n = 5$.

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Table 2 Lost and continued access to educational and therapy services by type for respondents within the USA (total = 669) and outside of the USA (total = 149) who received services prior to COVID-19

Type of service Group (number of respondents who received service prior to COVID, % of total)	Lost access No. (%)	Accessed in-person No. (%)	Accessed via video No. (%)	Accessed via email No. (%)	Accessed via combined email and video No. (%)
Academic					
In the USA (426, 63.7%)	184 (43.2)	7 (1.6)	58 (13.6)	52 (12.2)	125 (29.3)
Outside of the USA (86, 57.7%)	57 (66.3)	2 (2.3)	7 (8.1)	12 (14.0)	8 (9.3)
Speech therapy					
In the USA (468, 70.0%)	245 (52.3)	11 (2.4)	121 (25.9)	39 (8.3)	62 (13.2)
Outside of the USA (100, 67.1)	75 (75.0)	3 (3.0)	15 (15.0)	2 (2.0)	5 (5.0)
Occupational therapy					
In the USA (451, 67.4%)	258 (57.2)	14 (3.1)	100 (22.2)	35 (7.8)	44 (9.8)
Outside of the USA (97, 65.1%)	73 (75.3)	3 (3.1)	11 (11.3)	6 (6.2)	4 (4.1)
Physical therapy					
In the USA (400, 59.8%)	240 (60.0)	16 (4.0)	83 (20.8)	27 (6.8)	34 (8.5)
Outside of the USA (94, 63.1%)	79 (84.0)	4 (4.3)	8 (8.5)	1 (1.1)	2 (2.1)
Applied behavioural analysis					
In the USA (178, 26.6%)	112 (62.9)	30 (16.9)	27 (15.2)	4 (2.2)	5 (2.8)
Outside of the USA (41, 27.5%)	34 (82.9)	1 (2.4)	3 (7.3)	0 (0.0)	3 (7.3)
Social skills					
In the USA (284, 42.5%)	209 (73.6)	14 (4.9)	36 (12.7)	16 (5.6)	17 (6.0)
Outside of the USA (62, 41.6%)	51 (82.2)	1 (1.6)	4 (6.5)	3 (4.8)	3 (4.8)
General counselling					
In the USA (149, 22.3%)	97 (65.1)	4 (2.7)	33 (22.1)	5 (3.4)	10 (6.7)
Outside of the USA (41, 27.5%)	29 (70.7)	2 (4.9)	5 (12.2)	1 (2.0)	4 (9.8)
Psychiatry					
In the USA (87, 13.0%)	46 (52.9)	2 (2.3)	34 (39.1)	3 (3.4)	2 (2.3)
Outside of the USA (21, 14.1%)	14 (66.7)	0 (0.0)	6 (28.6)	0 (0.0)	1 (4.8)
Recreation					
In the USA (201, 30.0%)	179 (89.0)	5 (2.5)	13 (6.5)	3 (1.5)	1 (0.1)
Outside of the USA (54, 36.2%)	47 (87.0)	1 (1.9)	2 (3.7)	3 (5.6)	1 (1.9)
Summary (≥1 service)					
In the USA (669)	495 (74.0)	61 (9.1)	267 (39.9)	110 (16.4)	158 (23.6)
Outside of the USA (149)	116 (77.9)	8 (5.4)	26 (17.4)	21 (14.1)	12 (8.1)
			Any type of tele-education		
			In the USA (669)		372 (55.6)
			Outside of the USA (149)		47 (31.5)
Summary (all services)					
In the USA (669)	199 (29.7)	3 (0.4)	26 (3.9)	12 (0.2)	29 (4.3)
Outside of the USA (149)	75 (50.3)	2 (1.3)	4 (2.7)	1 (0.7)	5 (3.4)

Discussion

To our knowledge, this is the largest survey assessing the experiences of COVID-19 restrictions on caregivers and individuals with syndromic IDDs, a population that is not only significantly dependent on educational and behavioural intervention services for overall development but also particularly medically vulnerable due to complex medical co-morbidities (Center for Disease Control and Prevention 2020). The heterogeneous sample included multiple genetic conditions associated with a range of IDDs, providing a breadth of information across rare disorders. Although individually rare, taken together, these genetic disorders account for up to 15–20% of cases of ASD and other IDDs (Neale *et al.* 2012; Sanders

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Table 3 Lost and continued access to healthcare services by provider type for respondents within the USA (total = 669) and outside of the USA (total = 149) who reported needing physician contact; summary of data for respondents who reported needing access to at least one type of provider

Type of service Group (number of respondents who needed to access this service during COVID-19, % of total)	Accessed through telemedicine No. (%)	Accessed in-person No. (%)	Could not access No. (%)
General practitioner			
In the USA (229, 34.2%)	140 (61.1)	55 (24.0)	34 (14.8)
Outside of the USA (50, 33.5%)	23 (46.0)	16 (32.0)	11 (22.0)
Psychiatry			
In the USA (117, 17.5%)	57 (48.7)	1 (0.9)	59 (50.4)
Outside of the USA (24, 16.1%)	7 (29.2)	2 (8.3)	15 (62.5)
Neurology			
In the USA (255, 38.1%)	174 (68.2)	17 (6.7)	64 (25.1)
Outside of the USA (49, 32.9%)	26 (53.1)	5 (10.2)	18 (36.7)
Gastroenterology			
In the USA (111, 16.6%)	57 (60.0)	8 (4.0)	46 (20.8)
Outside of the USA (19, 12.8%)	7 (36.8)	1 (5.3)	11 (57.9)
Psychology			
In the USA (81, 12.1%)	41 (50.6)	2 (2.5)	38 (46.9)
Outside of the USA (18, 12.1%)	5 (27.8)	1 (5.6)	12 (6.7)
Other subspecialty (dentistry and optometry)			
In the USA (282, 42.2%)	78 (27.7)	24 (8.5)	180 (63.8)
Outside of the USA (45, 30.2%)	9 (20.0)	6 (13.3)	30 (66.7)
Summary (≥1 service)			
In the USA (471, 70.4%)	319 (67.7)	91 (19.3)	243 (51.6)
Outside of the USA (86, 57.7%)	46 (53.5)	25 (29.1)	49 (56.9)

et al. 2012). This survey provides a unique snapshot of the experience of families with syndromic IDDs both in and outside of the USA early in the pandemic stay-at-home orders.

The results indicate that these individuals lost a substantial number of educational and medical supports, potentially adding to caregiver burden while also compromising both the child's and caregiver's overall health and well-being (Aman & Pearson 2020). In a recent report designed to provide guidance on school reopenings during the COVID-19 pandemic, the National Academies of Sciences, Engineering, and Medicine task force called for the prioritisation of re-entry of children with special needs, emphasising that they were 'best served' by in-person instruction (Dibner *et al.* 2020). However, as evidenced through this survey, remote delivery of services has become a reality for many individuals with IDDs.

At the time of this survey, a large majority of families had lost at least one of their educational or behavioural intervention services, with some having lost all of their services. Very few families continued to receive services in-person. While many families expressed a motivation to resume their in-person services, most families requested an expansion of tele-education services. Many families reported that they feared sending their immunocompromised children into an unknown and potentially unsafe environment and preferred to enhance the quality and availability of at-home services through tele-education and 1:1 home aides. Importantly, many families reported that the needs of their children had not been considered in the implementation of existing tele-education structures and suggested that their children would benefit from careful adaptations and modified expectations from their school districts. Also notable was the relationship between satisfaction with and availability of tele-education services. Families provided with more remote services expressed higher average satisfaction, suggesting that simply the dose of exposure to tele-education

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improved the perception of quality. This association may also reflect disparities in resource allocation, with some families receiving more comprehensive high-quality care, while others receive less overall quality and quantity of support. The absence of association between the type of IDD and satisfaction rating suggests that successful tele-education may not depend on child characteristics as much as on the ability of the service to adequately address the specific needs of the child.

With regard to health care, families were able to connect with providers through telemedicine, particularly neurologists and general practitioners, though some specialties were less available overall. Telemedicine resources and guidelines for remote neurological examinations have been disseminated through the American Academy of Neurology and the Child Neurology Society in an effort to maximise the effectiveness of the remote neurological visit. A recent survey of telemedicine use in a child neurology clinic showed a high satisfaction rate among both patients and caregivers. Racial disparities in the delivery of remote health care were also identified, with minorities more likely to use telephone rather than video services (Rametta *et al.* 2020). With time, iteration, and revision, telemedicine delivery will likely improve substantially and may, in fact, sustain even after restrictions have been lifted to replace in-person visits for those families who live remotely or are distanced from expert medical centres. Remote delivery becomes particularly relevant for patients with these rare disorders that are geographically dispersed and require expert care. Finally, caregivers also reported barriers to obtaining medical supplies, medications and respite care, highlighting the need for healthcare providers to survey patients about and then support these specific areas, as comprehensive health care includes more than just the physician visit.

Findings from this study reinforce the need to further develop partnerships between service providers and families to enhance the effectiveness of telehealth delivery for children with syndromic IDDs, as we will likely be facing lasting restrictions to in-person clinical visits, school and therapeutic services. Telehealth may improve the accessibility of health care and education in a sustainable way even after the restrictions have been lifted. Creative methods for tele-mentoring through peer-to-peer consultations also have been effective in expanding the reach of medical care across conditions, as evidenced by the ECHO model (Extension for Community Healthcare Outcomes) that was created to improve treatment of hepatitis C in rural New Mexico and now has been applied to diagnosis and care of autism as well as a for specific syndromic forms of IDD. In this model, an expert 'hub' provides consultation about patients to providers ('spokes') through videoconferencing, empowering the local physicians to effectively care for complex patients (Arora *et al.* 2011; Mazurek *et al.* 2016). Efforts to provide targeted guidance for professionals working under these conditions are now being developed (Rodriguez 2020).

Some additional critical next steps include improving delivery and quality of telehealth, particularly to under-resourced and diverse communities, and continuing to educate providers on the most effective strategies to deliver care remotely. Even as regions slowly resume in-person educational and behavioural therapy, those unable to safely provide these services may consider enhancing programmes that support in-home 1:1 aides or designing telehealth delivery models better suited to educate and support children with IDDs, such as shorter, more frequent sessions or direct coaching of caregivers.

Limitations

Although the questionnaire used in this study was developed by a team of experts in IDDs, with guidance from a survey development team, it was not validated against a clinical gold standard, nor did we include any validated clinical measures or assessments alongside the survey. Our goal was to capture data about the pandemic experience in a timely manner without placing additional burdens on the families as part of this study. We also did not collect specific phenotypic data about the participants, including severity of impairment; rather, we relied on caregiver report of diagnoses. However, many conditions in this sample have known clinical profiles, with those most frequently reported diagnoses characterised by ID and high rates of epilepsy. Therefore, a significant level of need is presumed. Moreover, all diagnoses were based on parent report, and we did not directly gather genetic reports from families.

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The survey captured a cross-sectional snapshot of families' responses early in the stay-at-home orders in most states in the USA and many countries outside of the USA, but they do not reflect the experience of continued restrictions and changes that have occurred since, nor do they account for pre-COVID-19 experiences. Since the survey was conducted, parents may have developed new strategies for mitigating the challenges around remote delivery of care, or the providers may have improved their approaches to caring for or educating children with IDDs. We might find an improvement in the quantity or quality of remote services or identification of new resources that becomes more helpful over time. A questionnaire that included items based on this study's survey is now being administered longitudinally to other samples of IDD (CRISIS AFAR 2020).

Finally, many demographic factors, including race, socio-economic status and parental income, were not included in the survey, and access to telehealth most certainly is affected by family resources. Although the reported genetic diversity and general consistency of findings both within and outside of the USA indicate that results from this cohort can be generalised to the larger population of individuals with syndromic IDD, the telehealth experience is widely variable and dependent on a range of factors not collected as part of this study (e.g. parent education, income or insurance). However, the experiences with telehealth described in this large cohort can be informative for education and healthcare stakeholders. As these stakeholders launch plans for resuming educational services in the upcoming school year, it is critical to consider the experiences of those who are both medically vulnerable and also particularly reliant on therapies and interventions.

Conclusions

This large-scale survey of syndromic IDDs offered an opportunity to gain insight into the considerable educational and medical needs of these families. The loss of critical services post-COVID-19 restrictions evidenced across the sample reinforces the need for close monitoring, creativity in delivery of care and optimisation of strategies in order to improve delivery of all resources that promote optimal medical and developmental outcomes for children with syndromic IDDs during this pandemic. Further, efforts to consider the experiences of families during this challenging time and adjust care plans accordingly could lead to improvements in long-term care and support for these families.

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Conflict of interest

No conflicts of interest have been declared.

References

Aman M. G. & Pearson D. A. (2020) Challenges for child and adolescent psychiatric research in the era of COVID-19. *Journal of Child and Adolescent Psychopharmacology* 280–4.

Arora S., Thornton K., Murata G., Deming P., Kalishman S., Dion D. *et al.* (2011) Outcomes of treatment for hepatitis c virus infection by primary care providers. *New England Journal of Medicine* **364**, 2199–207.

Boulet S. L., Boyle C. A. & Schieve L. A. (2009) Health care use and health and functional impact of developmental disabilities among US children, 1997–2005. *Archives of Pediatrics and Adolescent Medicine* **163**, 19–26.

Centers for Disease Control and Prevention (2020) Coronavirus disease: people with developmental and behavioral disorders. Centers for Disease Control and Prevention. Available at: https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-developmental-behavioral-disabilities.html. (retrieved 16 August 2020).

CRISIS AFAR (2020) The CoRonavIruS Health Impact Survey (CRISIS)–adapted for Autism and Related Neurodevelopmental conditions (AFAR). CRISIS Survey. Available at: http://www.crisissurvey.org/crisis-afar/ (retrieved 16 August 2020).

Dibner K. A., Schweingruber H. A. & Christakin D. A. (2020) Reopening K-12 schools during the COVID-19 pandemic. *Journal of the American Medical Association* 833–44.

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Eshraghi A. A., Li C., Alessandri M., Messinger D. S., Eshraghi R. S., Mittal R. *et al*. (2020) COVID-19: overcoming the challenges faced by individuals with autism and their families. *The Lancet Psychiatry* **7**, 481–3.

Fernandez B. & Scherer S. W. (2017) Syndromic autism spectrum disorders: moving from a clinically defined to a molecularly defined approach. *Dialogues in Clinical Neuroscience* **19**, 353–71.

Jeste S. S. (2011) The neurology of autism spectrum disorders. *Current Opinion in Neurology* **24**, 132–9.

Jeste S. S. & Tuchman R. (2015) Autism spectrum disorder and epilepsy. *Journal of Child Neurology* **30**, 1963–71.

Liptak G. S., Stuart T. & Auinger P. (2006) Health care utilization and expenditures for children with autism: data from U.S. national samples. *Journal of Autism and Developmental Disorders* **36**, 871–9.

Mazurek M. O., Brown R., Curran A. & Sohl K. (2016) ECHO autism: a new model for training primary care providers in best-practice care for children with autism. *Clinical Pediatrics* **56**, 247–56.

Muhle R., Trentacoste S. V. & Rapin I. (2004) The genetics of autism. *Pediatrics* **113**, 472–86.

Neale B. M., Kou Y., Liu L., Ma'Ayan A., Samocha K. E., Sabo A. *et al*. (2012) Patterns and rates of exonic de novo mutations in autism spectrum disorders. *Nature* **485**, 242–5.

Rametta S., Fridinger S., Gonzalez A. K., Xian J., Galer P. D., Kaufman M. *et al*. (2020) Analyzing 2,589 child neurology telehealth encounters necessitated by the COVID-19 pandemic. *Neurology* 1257–66.

Rodriguez K. (2020) Maintaining treatment integrity in the Face of crisis: a treatment selection model for transitioning direct ABA services to telehealth. *Behavior Analysis in Practice* 291–8.

Sanders S., Murtha M., Gupta A., Murdoch J. D., Raubeson M. J., Willsey A. J. *et al*. (2012) De novo mutations revealed by whole-exome sequencing are strongly associated with autism. *Nature* **485**, 237–41.

The Mighty (2020) Making health about people. The Mighty. Available at: https://themighty.com/ (retrieved 17 June 2020).

Tye C., Runicles A., Whitehouse A. J. & Alvares G. A. (2019) Corrigendum: characterizing the interplay between autism spectrum disorder and comorbid medical conditions: an integrative review. *Frontiers in Psychiatry* **10**, 438.

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