

## Position Paper

---

# Children with disabilities in the United States and the COVID-19 pandemic

Amy Houtrow<sup>a,\*</sup>, Debbi Harris<sup>b</sup>, Ashli Molinero<sup>c</sup>, Tal Levin-Decanini<sup>d</sup> and Christopher Robichaud<sup>e</sup>

<sup>a</sup>*Departments of Physical Medicine and Rehabilitation and Pediatrics, University of Pittsburgh School of Medicine, Pittsburgh, PA, USA*

<sup>b</sup>*Family Voices of Minnesota, Minneapolis, MN, USA*

<sup>c</sup>*Disability Resource Center, UPMC, Pittsburgh, PA, USA*

<sup>d</sup>*Complex Care Center, UPMC Children's Hospital of Pittsburgh, Pittsburgh, PA, USA*

<sup>e</sup>*Kennedy School of Government, Harvard University, Cambridge, MA, USA*

**Abstract.** Children with disabilities are disproportionately impacted by COVID-19 and the containment response. Their caregivers must now adapt to increased stressors such as lack of access to needed therapies, medical supplies, and nursing care. Prior to COVID-19 these families were already marginalized, and this has only worsened during the pandemic. As a vulnerable population, children with disabilities have not been the focus of much discussion during the pandemic, likely because the disease disproportionately impacts older individuals. Nonetheless, children with disabilities should be a focus of evaluation and intervention to mitigate the negative consequences of COVID-19 and the resulting containment strategies. Their needs should be included in future crisis planning, as well. In order to raise awareness of pediatric rehabilitation professionals, health care administrators, policy makers, and advocates, this manuscript provides a discussion of the following topics: the immediate and ongoing impacts on children with disabilities and their families, the ethical concerns and implications of triage protocols for scarce resources that consider disability in their scoring systems, and optimizing medical care and educational needs in the time of COVID.

**Keywords:** Children with disabilities, COVID-19, health care inequities, Individualized Education Program, discrimination

## 1. Introduction

The COVID-19 pandemic is ravaging the bodies of some people infected, overwhelming hospitals and health care workers, and due to the need to physically distance to slow the spread, wreaking havoc upon the United States economy. “We are all in this together” is a common mantra used in the public scene. Although all Americans have been impacted by COVID-19 in some way, experiences are not universal, nor does there seem

to be a united approach to combating the pandemic [1]. Not only is there a cultural political battle for truth and trust in science, there has also been a sometimes violent collective disagreement about each individual's responsibility to other members of society with outright refusals by some to engage in recommended mitigation strategies. Further, the devastating impacts of structural racism, ableism, and health inequities have become apparent. The phrase, “we are all in this together,” should be modified to: “We are all weathering the storm together, but we are not all in the same boat.”

As a vulnerable population, children with disabilities have not been the focus of the discussion surrounding the pandemic, likely because the disease disproportionately impacts older individuals [2]. Nonetheless, children with disabilities should be a focus of evaluation

---

\*Corresponding author: Amy Houtrow, Children's Hospital of Pittsburgh, 4401 Penn Ave, FP 5113, Pittsburgh, PA, 15224, USA. Tel.: +1 412 692 6410; Fax: +1 412 692 6424; E-mail: houtrow@upmc.edu.

and intervention to address the negative consequences of COVID-19 and resulting containment and mitigation strategies used to reduce virus transmission [3]. To set the stage for a policy agenda and a clinical plan, the following topics are addressed: the immediate and ongoing impacts on children with disabilities and their families, the implications and ethical concerns of triage protocols for scarce resources that consider disability in their scoring systems, and optimizing care for these children while the pandemic continues. The experience of a mother of a child with disabilities (author DH) will be interwoven throughout this manuscript to bring the issues faced by families during this time into focus.

## 2. Children with disabilities

Children with disabilities are vulnerable, not just because of their underlying health conditions but because of the social circumstances in which they live. They are more likely to be poor, more commonly of minority race (and as such experience the negative impacts of structural and personally mediated racism more frequently than their non-disabled peers), and some have a higher risk of contracting COVID-19 [4–6]. Also, they and their families routinely face stigma and discrimination, often with multiple intersecting identities that are associated with exacerbated inequalities [7,8]. Children with a variety of different disabilities tend to be restricted in their social activities and have limited opportunities later in life [9–11]. Families of children with disabilities have higher rates of work loss and financially burdensome health care costs, even when covered by Medicaid [12–14]. Poor access to quality health care and high rates of unmet needs are pervasive and an area with recognized opportunities for improvement [15–19]. The COVID-19 pandemic has served to further challenge the already difficult situations experienced by children with disabilities and their families.

## 3. Impacts of the COVID-19 pandemic and the mitigation response

The need to isolate in order to protect themselves from COVID-19 and to help “flatten the curve” impacted families of children with disabilities immediately [20]. Families had to quickly organize to accommodate major shifts in access to supports, services, and supplies. Please see Box 1 for details about how one family adjusted when the COVID-19 containment strategies were initiated.

### Box 1: The initial impact of shelter-in-place

My baby, Jordan (name changed), had a grade IV intraventricular and subdural brain hemorrhage at birth. I had insisted that something was wrong seven months into my pregnancy and was ignored. This was another in a long list of unfortunate experiences of racial bias in the quality of my own medical care. After months in the NICU, Jordan was given two months to live, and came home with several diagnoses including tracheomalacia, laryngomalacia, bronchopulmonary dysplasia (which led to the need for a ventilator), hydrocephalus, microcephaly, visual impairment, and dysphasia. Later he would add cerebral palsy, spastic quadriplegia, severe scoliosis, and autonomic dysregulation to the list, exacerbated by issues of bowel motility as well as a host of associated orthopedic conditions requiring surgery, shunts, tubes, and pumps.

We have two full-time licensed nurses who work in our home – one four days per week and one four nights per week. In our area, this is remarkable staffing, given the nursing shortage. Immediate and extended family members fill in all other shifts, as our son requires 24-hour awake, hands-on care. We had just trained in a third nurse who was to start a mixture of day and night shifts on March 29, 2020. However, the full-time nurses expressed concern because the new part-time nurse also worked at a major hospital (with a newly established COVID unit), as well as at a long-term care facility. At the last moment, I asked him to hold off on his start date and assuaged the situation by paying him a bonus and promising to hold his hours until after the apocalypse.

Even though our governor called a shelter-in-place order, I have felt extremely anxious during this time. Do interactions occur outside of my watch that could ultimately be fatal for my family? I appreciate that others want to continue to work with us, and I do not want to control or pry inappropriately into their lives, but I am scared all of the time.

We have already asked all but immediate family to stop coming to the home, so my husband is doing about two night shifts a week, and I have about two 12- to 14-hour day shifts. We typically have no nursing on the weekends, so those are like marathons.

We have been told by our DME that we may receive only 3 boxes of gloves per month for 24/7 care – trach, peri care, gastrostomy – everything. The respiratory therapist’s monthly visit has been replaced by a modem that sends information about vent settings to the company. Vent circuitry, tubing, connectors, humidification chambers, and temp probes are being rationed. We were told that home care is not a priority.

Our home care agency has sent us nothing at all in the way of protocols or practical support. There has been no information about safety of staff, PPE, or safety for families and instead we have written our own COVID support plan.

The situation described is not unique. Children with disabilities and their families are dealing with the loss of home nursing, therapies, educational supports, personal protective equipment, other medical supplies, informal caregiving from extended family members, and safe access to medical providers. Delayed or forgone care during the pandemic is a source of concern in pediatrics, [3,21] and likely disproportionately impacts children with disabilities who historically have had more health care concerns and unmet needs [15]. Preliminary data during the pandemic from the Family Strengths Survey in the Western Pennsylvania area

identified that a majority of families of children with disabilities had reduced access to needed therapy services including Early Intervention, school-based therapies, and outpatient therapies [22]. Further, the economic toll from the response to the pandemic impacts those with limited resources the most [23,24]. Worsening food insecurity due to loss of financial resources to purchase food and loss of access to food are problems which disproportionately impact people with disabilities and their families [25]. During the pandemic many child welfare agencies have noted a drop in reports of child abuse/neglect, likely due to fewer opportunities for detection despite heightened risk [26]. Of note, at baseline, children with disabilities are at higher risk of abuse [27,28]. The closure of schools, child care centers, and other community organizations has limited community partners' abilities to detect and report abuse/neglect [29]. Additional vulnerabilities exist for children with disabilities living in skilled nursing or other congregate care facilities due to the high rate of transmission in these types of settings [30,31]. Families who have children residing in institutional settings have been worried about the risk of COVID-19 spreading through facilities and the loss of visitations, thus they are faced with the challenging decision to abruptly try to integrate their children with extensive needs into their homes without appropriate support to ensure well-being [32].

Perhaps one of the greatest challenges for families of children with disabilities has been the loss of schooling and the supports provided by the educational system, including meals for those living in poverty [33]. Utilizing virtual schooling instead can create stress for children with disabilities and their families, layered upon financial and emotional distress. These concerns can be exacerbated when access to technology is limited, a problem disproportionately experienced by families in poverty [33]. Other issues include the disruption of carefully developed routines; disintegration of support networks, and parents being required to do a job without training that even experienced teachers find challenging [34,35]. The unmet need for educational assistance has been staggering and challenging for families to navigate [36].

#### 4. Concern for disability discrimination during the pandemic

During the early phase of the pandemic, when hospitals were being overrun with cases and there was con-

cern that there would be widespread ventilator shortages across the country, numerous states and hospital systems developed, revisited or revised their crisis care protocols for the allocation of ventilators during a shortage. Some people with disabilities and their families worried that if they brought their ventilator-dependent loved one to the hospital that hospital officials would take their ventilator and use it for someone else if there was a shortage. This would lead to the certain death of their loved one in order to potentially save a non-disabled person's life. Unfortunately, this concern is not unfounded [37]. See Box 2 for the expression of one family's concerns

##### Box 2: Disability discrimination during the pandemic

At the beginning of the pandemic, when COVID-19 was just making headway in the US, my friend Joe Shapiro, a disability correspondent for NPR, wrote an article for their special series "The Coronavirus Crisis" about discrimination against people with disabilities in access to health care ("HHS Warns States Not to Put People With Disabilities at the Back of the Line for Care," The Coronavirus Crisis, March 28, 2020, 7: 23 PM ET). While reading the article, I was scared, definitely emotional, and wondering how Jordan might be treated should he present at the hospital with symptoms of this novel and deadly virus. His wide range of underlying conditions would most certainly complicate any treatment protocol, and his physical and intellectual disabilities could throw us back into dreaded quality-of-life and utilization-of-resources discussions that seem to follow families like ours at the most unfair times. I wondered if our neuro-atypical children and youth (those already marginalized because of their intellectual disabilities and yet far too visible because of their dependency on technology and high cost of care) could get fair and impartial treatment during a global pandemic. It seemed like in this pandemic powerful, multidimensional ventilators like Jordan's were scarce – and becoming more valuable to the general population daily, even hourly. Would they take this opportunity to attribute his decline to an underlying condition and take his ventilator?

People with disabilities, disability rights organizations, legal experts, health care professionals and ethicists have spoken out about their concerns that the protocols that would discriminate against people with disabilities [38]. Numerous organizations have filed complaints with states and the US Department of Health and Human Services over the crisis triage protocols that discriminated against people with disabilities [38]. A real concern is that biases against people with disabilities will lead to undertreatment of people with disabilities during this crisis [39]. Several states created policies that would do just that, according to the Disability Rights Education and Defense Fund [40]. In response to widespread concerns, the Health and Human Services Office for Civil Rights in Action released a bulletin which stated, "In this time of emergency, the laudable

goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else” [41].

When public health officials and hospitals develop triage protocols for the allocation of scarce resources, such as ventilators, the risk of disability discrimination is high [42]. The challenge is to create protocols that minimize instead of magnify the structural discrimination and the impacts of implicit biases that already operate in our health care systems [42]. Biases, stereotypes and inappropriate assumptions about the quality of life of people with disabilities are pervasive and can result in the devaluation and disparate assessments and treatment of people with disabilities [43]. Health care providers, such as physicians and nurses, are not exempt from deficit-based perspectives about people with disabilities, and when they make critical care decisions the results can be a deadly form of discrimination [43]. Although implicit biases are underrecognized, it is well documented that physicians misperceive quality of life for people with disabilities as poor and that medical judgments can be biased accordingly. Such was the case for Michael Hickson, a man with a history of severe traumatic brain injury who was not treated for COVID-19, in part because his physician deemed his quality of life too poor in a recorded conversation with Mr. Hickson’s wife [39,43–45]. Value judgments are routinely being made about what it means to have quality of life, or a life worth saving [46]. Consequently, necessary care can be withheld or withdrawn inappropriately [43]. Implicit biases easily permeate triage processes especially when not well implemented [42]. Because of this there is great debate over the use of quality-adjusted life years in policy making [46]. Even when purportedly “objective” criteria are used to allocate health care resources, subjective notions and ideas about the quality or desirability of life with disabilities may play an influential role [47].

Resource allocation protocols utilized in several states have explicit disability-based distinctions which have been identified as being in violation of the law [46]. The three major federal statutes that prohibit disability discrimination in medical treatment are the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act [46]. These statutes prohibit discrimination against people with disabilities due to those disabili-

ties [46]. Using the presence of a disability to deny or limit a person’s access to health care or to provide them a lower relative priority score in accessing scarce resources constitutes a clear violation of disability nondiscrimination law [48]. Thus, health care providers and hospitals should not limit care to people with disabilities because of their disabilities. Further, health care providers should not rely on judgements about the quality of life of people with disabilities when deciding to provide care [48].

Instead, resource allocations should be based on patient need, prognosis, and effectiveness [49]. Having a human rights-based strategy in place before catastrophic events happen is key for a disability inclusive response [50]. The core principles of dignity, nondiscrimination, equality of opportunity, and accessibility should be central during resource allocation protocol development [47]. To create successful disability inclusive community-based responses, planners need to ensure that people with disabilities have roles and responsibilities in the design and implementation of the responses [50].

In 2009, the Institute of Medicine (now the National Academy of Medicine) published a report outlining crisis standards of care that ensure that the response results in the best care possible given the resources at hand, that decisions are both fair and transparent, that there is consistency within and across states for policies and protocols, and that citizens and stakeholders are included and heard [51]. To ensure best possible care, the crisis standards should adhere to fairness, engage communities, be legally sound, and have equitable processes of transparency, consistency, proportionality, and accountability [51].

There are obvious ethical tensions at play when developing triage strategies. Equity from the perspective of public health requires maximizing the number of lives saved, while equity from the disability perspective means that everyone has an equal chance of receiving necessary health care [42]. People with disabilities face systemic long-standing barriers to equitable health care [42]. It should go without saying that the lives of people with disabilities are equally valuable to people without disabilities and people with disabilities are equally deserving of health care. Rooted in ableism, unequitable treatment is pervasive and worsened in times of crises This is often encoded in triage policies [37].

It is imperative that the distribution of the costs and benefits of any policy be addressed to ensure fairness. But as is true for equity, not all concepts of fairness are the same. The reasonable demand that scarce resources

be allocated fairly comes with the challenge of determining what fairness requires. Unfortunately, doing this is far from straightforward. Society has many different competing and sometimes incompatible conceptions of fairness [52]. Adopting a Rawlsian veil-of-ignorance reasoning [53], we are to imagine ourselves as rational human beings, not knowing many facts about ourselves – what our age is, or race, or religious views, or intelligence, or attractiveness, and so on. We are then invited, *as a matter of rational self-interest*, to select the institutions we would be willing to live under. From behind a veil of ignorance, we do not know whether we are healthy or not, or young or old. Thus as a matter of self-interest, we would only advocate for procedures that did not discriminate based on disability [54].

When developing crisis policies, it is imperative to recognize the ethical tensions and the competing interests of those involved because their implicit and explicit biases will reflect on the determination of goals, justifications for changes in protocol, and subsequent evaluation. For this reason, it is vital to have representation from individuals with disabilities, families, the health system, and the community engaged in order to create fair policies that minimize the risk of inequity. Moving through the pandemic, and eventually reflecting back will provide opportunities to review the unintended consequences of policies and provide guidance for improving them in the future.

## 5. Optimizing equitable care for children with disabilities during and after the pandemic

Each new day offers the opportunity to improve the delivery of care and services to children with disabilities and their families [55]. The World Health Organization offered guidance to governments regarding disability considerations during the pandemic which included assuring that public health information is accessible (captioning and sign language, for example), undertaking targeted strategies to meet the needs of those with disabilities and disability service providers, increasing attention to people with disabilities living in high-risk settings, and ensuring that emergency measures include the needs of people with disabilities (including non-discrimination) [56]. These measures are just a start. We need to firmly acknowledge, as Congress did in 2008 when it amended the ADA, that “historically society has tended to isolate and segregate individuals with disabilities and despite some improvements such forms of discrimination against individu-

als with disabilities continue to be a serious and pervasive social problem” [57]. Further, it is imperative to understand the intersectional forces (the forms of inequality that often operate together and exacerbate each other) that are at play [1,58]. The pandemic has worsened structural inequalities which have been hitting certain families, especially those of color who are also more likely to be poor, more so than others [59]. As noted by the United Nations Sustainable Development Group, the harmful effects and long-term impacts of the pandemic will not be distributed equally [60]. Children in our poorest neighborhoods and those who are already vulnerable, such as those with disabilities (who are also often poor) will experience the most damaging effects [60]. The complex stressors at play for families of children with disabilities during the pandemic also highlights how easily existing support structures collapse and how challenging it is to identify suitable replacements [36]. Moving forward, pediatric rehabilitation providers can engage with the families of the children they serve along with their health care systems to enhance the structure and processes of care delivery that can better withstand external catastrophic events. See Box 3 for the personal experience of one family navigating the daily challenges of the pandemic.

The way health care is delivered has always been inequitable. Pre-pandemic, children with disabilities were underserved by the health care system that wasn’t organized to meet their needs [15,17,55]. The pandemic brought forward the need to provide remote health care through telehealth which was rarely used pre-pandemic [61]. But access to telehealth is inequitable as some families don’t have reliable internet service or the devices needed to conduct a telehealth visit [62]. Although telehealth is an incredibly valuable tool to allow patients to see their health care providers when they cannot attend a face-to-face appointment, it has the potential to widen disparities and inequities [63]. In addition, telemedicine does not readily lend itself to use for some disciplines that are uniquely dependent on direct physical exam versus observation.

Any telehealth delivery system needs to be accessible, affordable, and inclusive according to the World Health Organization [56]. Quality of care and best practices need to be a priority. Children with disabilities see many types of health care providers beyond their routine wellness visits with pediatricians. A specialized care team can include any mix of physical and occupational therapists, orthotists, prosthetists, speech language pathologists, audiologists, nutritionists, and other healthcare professionals. The United States Of-

**Box 3: Living through the pandemic with intersectional identities**

The pandemic numbers did nothing to assuage our fears. As the virus raged, African American families like ours were dying from COVID-19 at rates much higher than the general population. Compounding race or ethnicity with disability did not help. Conflicts mounted in our home as to whether or not we should keep staff or let them go. As restrictions loosened around the country, Jordan's only night nurse announced he would take off at the end of the month to gather with friends from around the country for a week-long bachelor party at a rented lake house in Michigan. He would then assuage our fears by taking off another week in case he was exposed to the virus, as the large group would make no attempts to socially distance. Our hearts sank and the tension in our home became palpable as we sought solutions. I rushed to research incubation periods and testing sites. We were forced to re-call the nurse who works at the hospital to prepare to step in. One risky homecare nurse no longer outweighed the other.

Jordan requires 24-hour vigilant care, well-managed with astute assessment, to avoid hospitalization. My only remaining peer support is on Zoom now, a group of four of us mothers who have raised our boys with complex medical needs and disabilities together, grateful for every day that we have not lost one of them. We decided on our most recent call that if we could not be with them at the hospital – three of the four are nonverbal – we would simply keep them at home. Saying goodbye any other way would be unbearable.

The culture of our lives means that even multiple trips to the clinic each month for specialist visits, Baclofen pump refills, nutrition consults for pump feedings, pulmonary follow-ups, or scopes to assess Jordan's trachea are as much our social activity as they are his medical necessity. Since the quarantine, our main connection to the world has stopped, and we find ourselves sadly pining for even that bit of professional human interaction and social exchange. Instead, we sit and wait for the virus to come through our door, either with one of the nurses or, attached to one of the many boxes of supplies still delivered several times a week – diapers, gastrostomy tube formula, and sterile water bags – or on the people who deliver them.

Clinic visits with Jordan's primary physician and specialists have transitioned into phone calls or virtual visits. Jordan's otolaryngologist, who essentially gave him back to us through her brilliant surgical work with his airway many times throughout his life (the first when he was only three months old) retired during the pandemic. We said goodbye through tears and the video screen of a virtual clinic visit, a muted finale for a lifetime of gratitude. Three days ago, Jordan's nurse case manager from the home care agency sent a text revealing that he had been quiet for a couple of weeks because he had COVID-19. He was going to search his calendar to determine when he had last been in contact with us. Just days before that, George Floyd was killed here in the Twin Cities, and the world had erupted. Jordan's uncle, who had to pause his work here with Jordan because of his community risk of exposure early on, had to return to stay in our home because his street was burning. Protesters have assembled daily, often forced into medically compromising conditions, before Minnesota has even reached its peak of COVID-19 cases.

So, we accept that ultimately we have little real control, and we just wait.

Office of Civil Rights reminded the healthcare profession that that obligation to provide effective communication during the pandemic applied not only to the face to face visits, but also applied to telehealth visits [41]. They

loosened restrictions on types of communication technologies that could be used to include mainstream video conferencing platforms such as Skype for business, Microsoft Teams, Zoom, and others [64]. However, effective communication with patients and families with disabilities can look different in telehealth, requiring accessibility features that might not be readily available such as sign language interpretation.

As society moves through the various phases of the pandemic, we have the opportunity to examine the unintended consequences of the pandemic response on children with disabilities. With this knowledge, hospital policies can be created and clinical plans devised to make sure that actions taken do not disproportionately burden children with disabilities and their families. Comprehensive care plans that include emergency preparedness can be developed in coordination with families and the various sectors that serve them [65,66]. At all times, the planning needs to consider equity and access for all, regardless of disability status.

## 6. Educational equity

An important opportunity for advocacy is working with schools to address the needs of children with disabilities. It is helpful to be familiar with the laws that impact schooling for children with disabilities, especially the Individuals with Disabilities Education Act (IDEA). All children with disabilities, aged 3 to 21, must have available to them a free appropriate public education (FAPE) that emphasizes special education along with related services that are designed to meet their unique needs and prepare them for further education, employment, and independent living [57,67]. Related services can include transportation, speech therapy, audiology services, sign language interpreting services, psychology supports, physical and occupational therapy services, therapeutic recreation, social work supports, school nursing, and other services as described in the Individualized Education Program (IEP) [57]. The IEP must be developed in collaboration with the family and benefits from strong cooperation between the school and the family to best describe the child's abilities and needs. This way, a program can be designed that is appropriately tailored to that individual [57]. Children with disabilities are only to be removed from the regular educational environment if the nature or the severity of the disability is such that the education in a regular classroom with use of supplementary aids and services is not satisfactory [57].

The concept of the least restrictive environment has a presumption in favor of integration of children with disabilities [57].

Notably, not all children with disabilities are covered by IDEA because it only covers those who are *educationally* disabled. Section 504 of the Rehabilitation Act of 1973 prohibits discrimination against all school-age children with disabilities regardless of whether they require special education services or not [57]. 504 plans are utilized when the child's condition requires reasonable accommodations but not special education instruction [68,69]. In the early weeks of the pandemic, the United States Department of Education offered guidance to schools to reassure them that providing online instruction should not be withheld out of concern for non-compliance with IDEA and Section 504 of the Rehabilitation Act [70]. In all cases, the FAPE should be consistent with the need to protect the health and safety of students with disabilities [70]. During the pandemic, IEP teams should make individualized determinations and work with parents to creatively meet the needs of students with disabilities [70]. Special education can include classroom instruction or home instruction to meet the child's needs [57]. As such, the CDC recommends consideration of options for students that limit their exposure risk (e.g., virtual learning), but which could have the unintended consequence of segregation and isolation of children with disabilities [71]. Balancing the need for inclusive education and access to educational resources with risk mitigation will likely require the engagement of health professionals working with families and schools as described in the American Academy of Pediatrics Interim Guidance, Caring for Children and Youth with Special Health Care Needs During the COVID-19 Pandemic [72].

## 7. Conclusions

Children with disabilities are disproportionately impacted by COVID-19 and the containment response. Thus, their caregivers must now adapt to increased stressors such as lack of access to needed therapies, medical supplies, and nursing care. Prior to COVID-19 these families were already marginalized, and this has only worsened during the pandemic. As a society, we need to breakdown the ableist structures and policies that marginalize people with disabilities. Policy makers as well as medical and public health workers should be trained in disability competency. People in power should invite members of marginalized communities

to the table in an inclusive fashion when developing disaster response protocols. In addition to trying to reduce health service inequities, programs are needed to provide income and social supports to individuals and families of children with disabilities. During the ongoing pandemic and beyond, strategies must be developed to ensure the health of those living in group homes, nursing facilities, other congregate care arrangements, and those children who are suddenly transitioning into their family homes. When containment strategies require physical distancing and limiting contact with individuals outside of one's immediate family, plans need to be made to ensure that families who are isolating are not cut off from the supports and services their children need for optimal health. Development of such strategies must be done in a way that is transparent and allows for accountability and focuses on equity. The pandemic has shown the fault lines in health care delivery including the pervasive nature of inequities and racial disparities. With our heightened awareness to the problems faced by children with disabilities, their families, and their communities, pediatric rehabilitation providers and others can help advocate for system-level improvements and develop clinical strategies to assure children with disabilities get the care they need and deserve.

## Conflict of interest

The authors have no conflicts of interest to report.

## References

- [1] Bowleg L. We're Not All in This Together: On COVID-19, Intersectionality, and Structural Inequality. *Am J Public Health*. 2020 Jul; 110(7): 917. doi: 10.2105/AJPH.2020.305766.
- [2] Garg S, Kim L, Whitaker M, O'Halloran A, Cummings C, Holstein R, et al. Hospitalization Rates and Characteristics of Patients Hospitalized with Laboratory-Confirmed Coronavirus Disease 2019 – COVID-NET, 14 States, March 1–30, 2020. *MMWR Morb Mortal Wkly Rep*. 2020 Apr 17; 69(15): 458-464. doi: 10.15585/mmwr.mm6915e3.
- [3] Collins EM, Tam PI, Trehan I, Cartledge P, Bose A, Lanaspas M, et al. Strengthening Health Systems and Improving the Capacity of Pediatric Care Centers to Respond to Epidemics Such as COVID-19 in Resource-limited Settings. *J Trop Pediatr*. 2020 Aug 1; 66(4): 357-365. doi: 10.1093/tropej/fmaa028.
- [4] Houtrow AJ, Larson K, Olson LM, Newacheck PW, Halfon N. Changing trends of childhood disability, 2001–2011. *Pediatrics*. 2014 Sep; 134(3): 530-8. doi: 10.1542/peds.2014-0594.
- [5] Trent M, Dooley DG, Douge J. The Impact of Racism on Child and Adolescent Health. *Pediatrics*. 2019 Aug; 144(2): e20191765. doi: 10.1542/peds.2019-1765.
- [6] Bandi S, Nevid MZ, Mahdavinia M. African American children are at higher risk for COVID-19 infection. *Pediatr Allergy Immunol*. 2020 May 29; doi: 10.1111/pai.13298.

- [7] Perkins TS, Holburn S, Deaux K, Flory MJ, Vietze PM. Children of Mothers with Intellectual Disability: Stigma, Mother-Child Relationship and Self-esteem. *Journal of Applied Research in Intellectual Disabilities*. 2002; 15(4): 297-313.
- [8] Green S, Davis C, Karshmer E, Marsh P, Straight B. Living Stigma: The Impact of Labeling, Stereotyping, Separation, Status Loss, and Discrimination in the Lives of Individuals with Disabilities and Their Families. *Sociological Inquiry*. 2005; 75(2): 197-215.
- [9] Rosenberg L, Ratzon NZ, Jarus T, Bart O. Perceived environmental restrictions for the participation of children with mild developmental disabilities. *Child Care Health Dev*. 2012 Nov; 38(6): 836-43. doi: 10.1111/j.1365-2214.2011.01303.x.
- [10] Beckung E, Hagberg G. Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Dev Med Child Neurol*. 2002 May; 44(5): 309-16. doi: 10.1017/s0012162201002134.
- [11] Houtrow A, Jones J, Ghandour R, Strickland B, Newacheck P. Participation of children with special health care needs in school and the community. *Acad Pediatr*. Jul-Aug 2012; 12(4): 326-34. doi: 10.1016/j.acap.2012.03.004.
- [12] Okumura MJ, Van Cleave J, Gnanasekaran S, Houtrow A. Understanding factors associated with work loss for families caring for CSHCN. *Pediatrics*. 2009 Dec; 124(Suppl 4): S392-8. doi: 10.1542/peds.2009-1255J.
- [13] Houtrow AJ, Carle A, Perrin JM, Stein REK. Children With Special Health Care Needs on Supplemental Security Income for Disability Have More Health Impacts and Needs Than Other Children With Special Health Care Needs on Medicaid. *Acad Pediatr*. 2020 Mar; 20(2): 258-266. doi: 10.1016/j.acap.2019.10.014.
- [14] Wallander JL, Venters TL. Perceived role restriction and adjustment of mothers of children with chronic physical disability. *J Pediatr Psychol*. 1995 Oct; 20(5): 619-32. doi: 10.1093/jpepsy/20.5.619.
- [15] Houtrow AJ, Okumura MJ, Hilton JF, Rehm RS. Profiling health and health-related services for children with special health care needs with and without disabilities. *Acad Pediatr*. Nov-Dec 2011; 11(6): 508-16. doi: 10.1016/j.acap.2011.08.004.
- [16] Kuo DZ, Goudie A, Cohen E, Houtrow A, Agrawal R, Carle AC, et al. Inequities in health care needs for children with medical complexity. *Health Aff (Millwood)*. 2014 Dec; 33(12): 2190-8. doi: 10.1377/hlthaff.2014.0273.
- [17] Strickland BB, Jones JR, Newacheck PW, Bethell CD, Blumberg SJ, Kogan MD. Assessing systems quality in a changing health care environment: the 2009-10 national survey of children with special health care needs. *Matern Child Health J*. 2015 Feb; 19(2): 353-61. doi: 10.1007/s10995-014-1517-9.
- [18] US Department of Health and Human Services. *Healthy People 2020: Maternal, Infant, and Child Health Objectives 2011*. Available from: <http://healthypeople.gov/2020/topics/objectives/2020/objectiveslist.aspx?topicId=26>.
- [19] Parasuraman SR, Anglin TM, McLellan SE, Riley C, Mann MY. Health Care Utilization and Unmet Need Among Youth With Special Health Care Needs. *J Adolesc Health*. 2018 Oct; 63(4): 435-444. doi: 10.1016/j.jadohealth.2018.03.020.
- [20] Courtemanche C, Garuccio J, Le A, Pinkston J, Yelowitz A. Strong Social Distancing Measures In The United States Reduced The COVID-19 Growth Rate. *Health Aff (Millwood)*. 2020 Jul; 39(7): 1237-1246. doi: 10.1377/hlthaff.2020.00608.
- [21] Crawley E, Loades M, Feder G, Logan S, Redwood S, Macleod J. Wider collateral damage to children in the UK because of the social distancing measures designed to reduce the impact of COVID-19 in adults. *BMJ Paediatr Open*. 2020 May 4; 4(1): e000701. doi: 10.1136/bmjpo-2020-000701.
- [22] Ray K, Miller L. Children with Special Health Care Needs During COVID-19. Findings from the Family Strengths Research Study 2020. Available from: <https://www.pediatrics.pitt.edu/family-strengths-survey/> (Accessed May 25, 2020).
- [23] Perez-Escamilla R, Cunningham K, Moran VH. COVID-19, food and nutrition insecurity and the wellbeing of children, pregnant and lactating women: A complex syndemic. *Matern Child Nutr*. 2020 Jul; 16(3): e13036. doi: 10.1111/mcn.13036.
- [24] Patel JA, Nielsen FBH, Badiani AA, Assi S, Unadkat V, Patel B, et al. Poverty, Inequality & COVID-19: The Forgotten Vulnerable. *Public Health*. 2020 Jun; 183: 110-111. doi: 10.1016/j.puhe.2020.05.006.
- [25] Loopstra R. Vulnerability to food insecurity since the COVID-19 lockdown. The Food Foundation. 2020; Report (Accessed May 24, 2020).
- [26] Green P. Risks to children and young people during covid-19 pandemic. *BMJ*. 2020 Apr 28; 369: m1669. doi: 10.1136/bmj.m1669.
- [27] Seppala P, Vornanen R, Toikko T. Are Children With a Number of Disabilities and Long-Term Illnesses at Increased Risk of Mental Violence, Disciplinary Violence, and Serious Violence? *J Interpers Violence*. 2020 Jan 12; 886260519898440. doi: 10.1177/0886260519898440.
- [28] Spencer N, Wallace A, Sundrum R, Bacchus C, Logan S. Child abuse registration, fetal growth, and preterm birth: a population based study. *J Epidemiol Community Health*. 2006 Apr; 60(4): 337-40. doi: 10.1136/jech.2005.042085.
- [29] Campbell AM. An increasing risk of family violence during the COVID-19 pandemic: Strengthening community collaborations to save lives. *Forensic Science International: Reports*. 2020; 2. doi: 10.1016/j.fsir.2020.100089.
- [30] Davidson PM, Szanton SL. Nursing homes and COVID-19: We can and should do better. *J Clin Nurs*. 2020 Aug; 29(15-16): 2758-2759. doi: 10.1111/jocn.15297.
- [31] Arons MM, Hatfield KM, Reddy SC, Kimball A, James A, Jacobs JR, et al. Presymptomatic SARS-CoV-2 Infections and Transmission in a Skilled Nursing Facility. *N Engl J Med*. 2020 May 28; 382(22): 2081-2090. doi: 10.1056/NEJMoa2008457.
- [32] Goldman PS, van Ijzendoorn MH, Sonuga-Barke EJS. The implications of COVID-19 for the care of children living in residential institutions. *Lancet Child Adolesc Health*. 2020 Jun; 4(6): e12. doi: 10.1016/S2352-4642(20)30130-9.
- [33] van Lancker W, Parolin Z. COVID-19, school closures, and child poverty: a social crisis in the making. *Lancet Public Health*. 2020 May; 5(5): e243-e244. doi: 10.1016/S2468-2667(20)30084-0.
- [34] Asbury K, Fox L, Deniz E, Code A, Toseeb U. How is COVID-19 affecting the mental health of children with Special Educational Needs and Disabilities and their families? *PsyArXiv*. 2020; doi: 10.31234/osf.io/sevyd. (Accessed May 24, 2020).
- [35] Eshraghi AA, Li C, Alessandri M, Messinger DS, Eshraghi RS, Mittal R, et al. COVID-19: overcoming the challenges faced by individuals with autism and their families. *Lancet Psychiatry*. 2020 Jun; 7(6): 481-483. doi: 10.1016/S2215-0366(20)30197-8.
- [36] Rose J, Willner P, Cooper V, Landon PE, Murphy GH, Kroese BS. The effect on and experience of families with a member who has Intellectual and Developmental Disabilities of the COVID-19 pandemic in the UK: developing an investigation. *International Journal of Developmental Disabilities*. 2020; doi: 10.1080/20473869.2020.1764257.



- [37] New York State Task Force on Life and the Law. Ventilator allocation guidelines. Letter from the Commissioner of Health. 2015. Available from: [https://www.health.ny.gov/bmj.xforce/reports\\_publications/docs/ventilator\\_guidelines.pdf](https://www.health.ny.gov/bmj.xforce/reports_publications/docs/ventilator_guidelines.pdf). (Accessed on May 24, 2020)
- [38] Mello MM, Persad G, White DB. Respecting Disability Rights – Toward Improved Crisis Standards of Care. *N Engl J Med*. 2020 Jul 30; 383(5): e26. doi: 10.1056/NEJMp2011997.
- [39] Iezzoni L. Stemming the risk of disability bias during the COVID-19 pandemic. In: Hamblin A, editor. Center for Health Care Strategies, Inc. Available from: [https://www.chcs.org/stemming-the-risk-of-disability-bias-during-the-covid-19-pandemic/?utm\\_source=CHCS+Email+Updates&utm\\_campaign=93d6121db2-LIezzoni+blog+04%2F08%2F20&utm\\_medium=email&utm\\_term=0\\_bbc451bf-93d6121db2-1571913012020](https://www.chcs.org/stemming-the-risk-of-disability-bias-during-the-covid-19-pandemic/?utm_source=CHCS+Email+Updates&utm_campaign=93d6121db2-LIezzoni+blog+04%2F08%2F20&utm_medium=email&utm_term=0_bbc451bf-93d6121db2-1571913012020).
- [40] Disability Rights Education & Defense Fund. Letter From DREDF and Additional Organizations Opposing California's Health Care Rationing Guidelines; 2020 Available from: <https://dredf.org/letter-opposing-californias-health-care-rationing-guidelines/>. (Accessed May 20 2020)
- [41] Health and Human Services Office for Civil Rights in Action. Bulletin: Civil Rights, HIPAA, and the Coronavirus Disease 2019. sHealth and Human Services. 2020. Available from: <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>. (Accessed May 24, 2020).
- [42] Savin K, Guidry-Grimes L. Confronting Disability Discrimination During the Pandemic. *Chronic Conditions and End of Life Care*. 2020; Bioethics Forum Essay. Available from: [https://www.thehastingscenter.org/confronting-disability-discrimination-during-the-pandemic/?fbclid=IwAR2ssY8aVhxj5284prI9S2WqZUM3VZvtSjJGQ6DeX4cB\\_FhqmZ7vOv90msk](https://www.thehastingscenter.org/confronting-disability-discrimination-during-the-pandemic/?fbclid=IwAR2ssY8aVhxj5284prI9S2WqZUM3VZvtSjJGQ6DeX4cB_FhqmZ7vOv90msk). (Accessed May 24 2020).
- [43] National Council on Disability. Medical Futility and Disability Bias. *Bioethics and Disability Series* November 19 2019. Available from: [https://www.ncd.gov/sites/default/files/NCD\\_Medical\\_Futility\\_Report\\_508.pdf](https://www.ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf). (Accessed May 17 2020).
- [44] Fayed N, Cohen E, Houtrow A. Quality of life cannot be predicted from a brain scan. *Dev Med Child Neurol*. 2020 Apr; 62(4): 412. doi: 10.1111/dmcn.14484.
- [45] Powell RM. Applying the health justice framework to address health and health care inequities experienced by people with disabilities during and after COVID-19. *Washington Law Review*. 2021 forthcoming; Work-in-progress Accessed: September 14 2020.
- [46] Bagenstos SR. May Hospitals Withhold Ventilators from COVID-19 Patients with Pre- Existing Disabilities? *Yale Law Journal Forum*. 2020; 130. Available from: [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=3559926](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3559926). (Accessed May 24 2020).
- [47] Auriemma CL, Molinero AM, Houtrow AJ, Persad G, White DB, Halpern SD. Eliminating Categorical Exclusion Criteria in Crisis Standards of Care Frameworks. *Am J Bioeth*. 2020 Jul; 20(7): 28-36. doi: 10.1080/15265161.2020.1764141.
- [48] Disability Rights Education & Defense Fund. Preventing Discrimination in the Treatment of COVID-19 Patients: The Illegality of Medical Rationing on the Basis of Disability DREDF. 2020 March 25. Available from: <https://dredf.org/wp-content/uploads/2020/03/DREDF-Policy-Statement-on-COVID-19-and-Medical-Rationing-3-25-2020.pdf>:1-11. (Accessed April 25 2020).
- [49] American College of Physicians. Non-Discrimination in the Stewardship and Allocation of Resources During Health System Catastrophes Including COVID-19. Approved by the Executive Committee of the Board of Regents. 2020. Available from: [https://www.acponline.org/acp\\_policy/policies/acp\\_policy\\_on\\_non-discrimination\\_in\\_the\\_stewardship\\_of\\_healthcare\\_resources\\_in\\_health\\_system\\_catastrophes\\_including\\_covid-19\\_2020.pdf](https://www.acponline.org/acp_policy/policies/acp_policy_on_non-discrimination_in_the_stewardship_of_healthcare_resources_in_health_system_catastrophes_including_covid-19_2020.pdf). (Accessed May 22 2020).
- [50] Schiariti V. The human rights of children with disabilities during health emergencies: the challenge of COVID-19. *Dev Med Child Neurol*. 2020 Jun; 62(6): 661. doi: 10.1111/dmcn.14526.
- [51] In: Altevogt BM, Stroud C, Hanson SL, Hanfling D, Gostin LO, editors. *Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations: A Letter Report*. Washington (DC) 2009.
- [52] Rhodes R, Battin MP, Silvers A. *Medicine and social justice: essays on the distribution of health care*. 2nd ed. New York, NY: Oxford University Press; 2012. xvi, 560 p.
- [53] Rawls J. *A theory of justice*. Cambridge, Mass., Belknap Press of Harvard University Press; 1971; xv, 607 p.
- [54] Huang K, Greene JD, Bazerman M. Veil-of-ignorance reasoning favors the greater good. *Proc Natl Acad Sci U S A*. 2019 Nov 26; 116(48): 23989-23995. doi: 10.1073/pnas.1910125116.
- [55] National Academies of Sciences Engineering and Medicine (US.). Committee on Improving Health Outcomes for Children with Disabilities, Houtrow A, Valliere FR, Byers E, National Academies of Sciences Engineering and Medicine (US.). Board on Health Care Services. Opportunities for improving programs and services for children with disabilities. Washington, DC: National Academies Press; 2018. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK518927/>.
- [56] World Health Organization. Disability considerations during the COVID-19 outbreak. Technical Documentation. 2020; WHO/2019-nCoV/Disability/2020.1 Available from: <https://www.who.int/publications-detail/disability-considerations-during-the-covid-19-outbreak>: (Accessed May 26 2020).
- [57] Colker R. *Federal disability law in a nutshell*. Sixth edition. ed. St. Paul, MN: West Academic Publishing; 2019; xxxvi, 588 p.
- [58] Houtrow A. Becoming anti-racist for the benefit of our patients. *J Pediatr Rehabil Med*. 2020; 13(1): 1-2. doi: 10.3233/PRM-200680.
- [59] Huberfeld N, Gordon SH, Jones DK. Federalism Complicates the Response to the COVID-19 Health and Economic Crisis: What Can Be Done? *J Health Polit Policy Law*. 2020 May 28; 8641493. doi: 10.1215/03616878-8641493.
- [60] United Nations Sustainable Development Group. The impact of COVID-19 on children. Policy Brief. 2020; Available from: <https://unsdg.un.org/resources/policy-brief-impact-covid-19-children>.
- [61] Sisk B, Alexander J, Bodnar C, Curfman A, Garber K, McSwain SD, et al. Pediatrician attitudes toward and experiences with telehealth use: Results from a national survey. *Acad Pediatr*. 2020 Jul; 20(5): 628-635. doi: 10.1016/j.acap.2020.05.004.
- [62] Seah KM. COVID-19: Exposing digital poverty in a pandemic. *Int J Surg*. 2020 Jul; 79: 127-128. doi: 10.1016/j.ijssu.2020.05.057.
- [63] Crawford A, Serhal E. Digital Health Equity and COVID-19: The Innovation Curve Cannot Reinforce the Social Gradient of Health. *J Med Internet Res*. 2020 Jun 2; 22(6): e19361. doi: 10.2196/19361.
- [64] Health and Human Services, Office for Civil Rights. Notification of Enforcement Discretion for Telehealth Remote Communications During the COVID-19 Nationwide Public Health Emergency; March 30, 2020 Available from: <https://www.hhs.gov/hipaa/for-professionals/special-topics/emergency->

- preparedness/notification-enforcement-discretion-telehealth/indexhtml.
- [65] Adams S, Cohen E, Mahant S, Friedman JN, Macculloch R, Nicholas DB. Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): a qualitative study. *BMC Pediatr*. 2013 Jan 19; 13: 10. doi: 10.1186/1471-2431-13-10.
- [66] American Academy of Pediatrics Council on Children with Disabilities. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. *Pediatrics*. 2005 Nov; 116(5): 1238-44. doi: 10.1542/peds.2005-2070.
- [67] Lipkin PH, Okamoto J. The Individuals With Disabilities Education Act (IDEA) for Children With Special Educational Needs. *Pediatrics*. 2015 Dec; 136(6): e1650-62. doi: 10.1542/peds.2015-3409.
- [68] Korupolu R, Stampas A, Gibbons C, Hernandez Jimenez I, Skelton F, Verduzco-Gutierrez M. COVID-19: Screening and triage challenges in people with disability due to Spinal Cord Injury. *Spinal Cord Ser Cases*. 2020 May 11; 6(1): 35. doi: 10.1038/s41394-020-0284-7.
- [69] Betz CL. Use of 504 plans for children and youth with disabilities: nursing application. *Pediatr Nurs*. Jul-Aug 2001; 27(4): 347-52.
- [70] United States Department of Education, Office for Civil Rights, Office of Special Education and Rehabilitative Services. Addressing the Risk of COVID-19 in Preschool, Elementary and Secondary Schools While Serving Children with Disabilities. Supplemental Fact Sheet. 2020. Available from: <https://www2.ed.gov/about/offices/list/ocr/frontpage/faq/trr/policyguidance/Supple%20Fact%20Sheet%203.21.20%20FINAL.pdf>: (Accessed May 24 2020).
- [71] Sholas MG, Apkon SD, Houtrow AJ. Children with disabilities must be more than an afterthought in school reopening. *JAMA Pediatrics*. 2020 (in press).
- [72] American Academy of Pediatrics. Caring for children and youth with special health care needs during the COVID-19 pandemic. Critical Updates on COVID-19. 2020; Clinical Guidance (Issued September 3, 2020). Available from: <https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/caring-for-children-and-youth-with-special-health-care-needs-during-the-covid-19-pandemic/>.