

# Developmental Disabilities Network Journal

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Volume 1  
Issue 2 *COVID-19 Pandemic and Developmental  
Disabilities*

Article 4

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2020

## Virtual Advocacy: Lived Experience Takes Center Stage During and After Pandemic

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### Recommended Citation

Burks-Abbott, Gyasi; Gannaway, Amanda V.; Szarkowski, Amy; Fogler, Jason M.; and Helm, David T. (2020) "Virtual Advocacy: Lived Experience Takes Center Stage During and After Pandemic," *Developmental Disabilities Network Journal*: Vol. 1 : Iss. 2 , Article 4.

DOI: <https://doi.org/10.26077/ee71-6d0f>

Available at: <https://digitalcommons.usu.edu/ddnj/vol1/iss2/4>

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## Virtual Advocacy: Lived Experience Takes Center Stage During and After Pandemic

### Cover Page Footnote

Gyasi Burks-Abbott, MS1\* Amanda V. Gannaway, PhD1\* Amy Szarkowski, PhD1,2 Jason M. Fogler, PhD1 David T. Helm, PhD1 \*Indicates co-primary authorship 1 LEND Program (Leadership Education in Neurodevelopmental and related Disabilities), Institute for Community Inclusion/University Centers for Excellence in Developmental Disabilities (UCEDD), Division of Developmental Medicine, Boston Children's Hospital 2 Children's Center for Communication/Beverly School for the Deaf Author Note: This work is partially funded by MCHB grant #T73MC0020. The authors have no conflicts of interest to disclose. Correspondence concerning this article should be addressed to Amy Szarkowski. Address: Boston Children's Hospital, 300 Longwood Ave. Boston MA 02115. Email: Amy.Szarkowski@childrens.harvard.edu Authors' ORCID numbers: Amy Szarkowski: 0000-0002-3856-7761; Jason M. Fogler 0000-0002-5566-8783; David T. Helm 0000-0002-6484-5585

# Virtual Advocacy: Lived Experience Takes Center Stage During and After Pandemic

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## Plain Language Summary

*An autistic self-advocate, a mother of a child with a disability, and three graduate and medical schoolteachers wrote this paper. They described meeting with government leaders to discuss disability issues. This paper includes ideas for advocating for disability policy and working together.*

Self-advocate Jim Charlton (2000) famously titled his book, *Nothing About Us Without Us*, and disability advocates have long embraced the slogan. While advocacy has, at least in theory, been embraced, civic engagement for individuals with disabilities continues to face substantial barriers across intrapersonal, interpersonal, and organizational levels (Foster-Fishman et al., 2007). Insufficient opportunities have been afforded to self-advocates to develop skills and competencies needed for effective advocacy work. Interpersonal factors such as team dynamics can also make advocacy challenging. Organizationally, decision-making processes too often do not include the perspectives of individuals with disabilities and their families, and limited resources may be allocated elsewhere, leaving important potential improvements for those impacted by disability unfunded.

## An Emancipatory Perspective

Involvement of persons with disabilities in advocacy is not novel but is also not widespread. Activist leaders like Judith Heumann, author of *Being Heumann* (2019), have had enormous impacts on the disability rights movement, yet too often processes intended to reduce barriers to fully inclusive participation are ad hoc and lack intentionality. In order to increase meaningful involvement of individuals with disabilities, systemic processes need to enable and

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This work is partially funded by MCHB grant #T73MC0020.

The authors have no conflicts of interest to disclose.

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support participation rather than place that onus on individuals. For example, the processes should not be alienating—either by requiring independent mobility to access legislators or being structured in a way that does not accommodate for variability in communication modes (Radermacher et al., 2010). Further, the advocacy itself should emphasize topics that individuals with disabilities determine to be important and about which they desire change (Moriña, 2020).

In the fields of research design and implementation, it has been recognized that involvement in the research process by those “being studied” can have a transformative effect, not only in addressing the necessary complexities of understanding others’ experiences, but also as a mechanism for promoting social change (Mertens, 2007). In health sciences research, stakeholder participation is increasingly becoming the norm, wherein funding for health-related research is generally contingent upon including the viewpoints and honoring the wishes of patients with relevant conditions and their families (Denegri et al., 2015). Meta-analyses of community-based research and involvement of participants shows a positive impact on the participants and better-informed science (Ortiz et al., 2020). Shifting toward “researching with” and away from “researching on” (Moriña, 2020) has shown to be valuable in terms of understanding the research—and the types of outcomes—that self-advocates perceive to be useful. There is growing recognition that involvement of individuals with disabilities, even those who are young (Liddiard et al., 2019), can contribute valuable information to the understanding of a particular experience. Community-based participatory research methods/approaches are increasingly used in research that involves individuals with disabilities and have had a powerful impact in shaping this field (Wallerstein, 2020).

There have been a number of frameworks posited for meaningfully including people with disabilities and family members of individuals with disabilities in research—not only as “subjects” but as co-investigators. These include the participatory and emancipatory frameworks, subtly distinguished by: (a) the degree to which co-investigators with disabilities are included in the crafting of methodologies and hypotheses (with the emancipatory framework assuming full egalitarian partnership); and (b) how “agenda-forward” the research is, with emancipatory research implying a more explicit and *a priori* leaning toward advancing the public good for people with disabilities through research (Kramer-Roy, 2015).

Questions have been raised about the true benefit of emancipatory research to self-advocates, in particular those with intellectual disabilities. Scholars have explored the limitations of emancipatory research, in practical as well as ethical terms (e.g., Barnes, 2008). It is true that the nature of one’s disability can influence how an individual with a disability might engage in advocacy efforts. Naturally, the classification of “individuals with disabilities” encompasses a wide variety of individuals with divergent life experiences. For example, the experiences of a person with an acquired physical disability can be substantially different from those of a person with a congenital developmental disability. An important consideration is that “self-advocacy” can take different forms. For some individuals with intellectual disabilities, speaking to their peers about issues of concern to them and developing the ability to protect themselves are among the ways that they have self-identified their activism (Petri et al., 2020). Yet amongst individuals with intellectual disability, there has also been a demonstrated positive impact of inclusion as

participants in studies (Schwartz et al., 2020). Individuals with intellectual disability have been found to value the direct and indirect benefits of research and see value in participating (McDonald et al., 2016).

### **From Research to Activism**

Shifting from research to advocacy, on the individual level, policy-related activism promotes self-advocates' social integration, enhances feelings of self-efficacy, and contributes to the development of personal interest in policy (Petri et al., 2020). As groups of marginalized individuals engage in disability advocacy, they increase their awareness of their rights and responsibilities as citizens, experience "being a part of something," and feel empowered to use their collective experiences to inform the public discourse.

Through our collective advocacy efforts, we aimed not only to educate policy makers about specific topics of concern relevant to individuals with disabilities and their families, but also to highlight the importance of understanding the lived experiences of self-advocates and parents of children with developmental disabilities. It is in alignment with this notion that the authors of the present paper embrace the emancipatory perspective, believing that advocacy efforts are important not only to effect positive social change, but also to empower the change-makers as well.

### **Emancipatory Nature of Co-Authorship**

Co-authorship is a natural extension of a collaboration undertaken from an emancipatory perspective. Creating space in academic publishing and incorporating multiple perspectives, including self-advocates and family members, and centering the writing on their experiences, should be prioritized. However, a review of published literature on co-authorship found projects that adopted the label of "inclusive research" held no set standards for transparency regarding the extent and form in which self-advocates' voices were reflected in the presentation of published results (Strnadová & Wamsley, 2018). To address this issue, guidelines have been proposed for increasing transparency in the publications produced by "inclusive projects," which may help discourage tokenism and provide clear examples of how meaningful co-authorship can occur. The guidelines written by Strnadová and Wamsley suggest including an explicit description of how co-authored articles are written.

Prior to writing this article, the co-authors worked together as members of a Leadership Education in Neurodevelopmental and related Disabilities (LEND) cohort for a year during which time they came to know each other's specific skill sets. The co-primary authors of this article, a self-advocate and a mother of a child with a developmental disability, both hold graduate degrees and have previous experience with academic writing. Over the course of the year, after having been moved and impressed by the other co-primary author's life story, one co-primary author (Amanda) suggested that the voice of the other (Gyasi) be highlighted through publication. After collaborating together through the COVID-19 pandemic on an unprecedented advocacy effort, a third co-author (Amy) suggested writing together about this shared experience, and interest

emerged within the group. Building substantial relationships over time, understanding each co-author's strengths and interests, and being afforded a certain level of institutional flexibility throughout the early stages of the pandemic allowed for an organically inclusive collaboration from inception to completion that both responded to and was facilitated by the larger context of a global health crisis. For the present paper, the structure and content were decided by group consensus. Each co-author contributed to the conceptualization of the work and wrote about his/her/their own reflections. All authors were involved in editing the complete text. The co-authors actively participated in the virtual advocacy that is one focus of the present paper and engaged in the co-creation of this reflective piece.

### Disability Policy Seminar

The annual Disability Policy Seminar (DPS)<sup>1</sup> has historically been a valuable opportunity to meet face-to-face with policy makers and to foster understanding among LEND fellows about educating their legislators regarding specific legislation. The DPS had traditionally consisted of two days of talking and learning about disability policy, followed by a day "on the Hill" speaking with legislators and their aides—which invariably helped to demystify Washington, D.C., and the policy-making process. In the past, the journey to Washington, D.C., has united the cohort of LEND fellows and faculty, as they collectively learned to work with and support legislators to advance policies favorable to the disability community. Visiting one's legislative representatives allowed LEND fellows, alongside faculty, to formulate and practice how best to educate their legislators regarding specific policy. This has been an invaluable way to enhance these future leaders' confidence that they can channel their educational, clinical, or life experiences in new ways to impact policy effectively.

Former LEND fellows' comments on the end-of-year survey regarding their Hill visits suggest this has been a positive learning experience: (1) *"The DPS in DC reassured me that we can influence policy on issues related to disability and disparity in health care issues"* (licensed clinical social worker); (2) *"I have a newfound appreciation for the unique and positive role we in the field can play in the care of and advocacy for the children that we see"* (developmental-behavioral pediatrician); (3) *"...the DPS and Hill visits...increased my confidence to voice my thoughts and concerns to legislators in order to advocate for disability rights and make a difference on a systemic level for all citizens with disabilities"* (clinical psychologist); (4) *"I learned more about Supplemental Security Income (SSI) and how important it is for people with disabilities to live more independent and meaningful lives in the community, I also learned about how to reach out to people using personal stories"* (self-advocate); (5) *"This has allowed me to become a better advocate. I want to bring our voice to the community and teach the parents a new way to advocate and a new way to engage"* (parent of child with a developmental disability).

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<sup>1</sup> The Disability Policy Seminar (DPS) is a three-day annual federal legislative conference co-sponsored by The Arc, Autism Society, American Association on Intellectual and Developmental Disabilities, Association of University Centers on Disabilities, National Association of Councils on Developmental Disabilities, National Down Syndrome Congress, United Cerebral Palsy, and Self Advocates Becoming Empowered (the partners).

## Impact of Shifting to a Virtual Disability Policy Seminar

When the pandemic arrived, the opportunity to participate in-person at DPS disappeared; LEND faculty were faced with the dilemma of how to provide a meaningful disability policy advocacy experience for fellows, without anyone needing to leave their homes. The logistics of this decision turned out to be easier in some ways than shifting our mindsets. Although uncertain of the outcome—and the new technology that would soon become a staple of our daily lives—we contacted the legislators' aides and schedulers and proposed virtual Hill visits. The meetings were set, yet faculty and fellows alike grappled with our own doubts about how effectively we could communicate in a virtual space undergirded by a video conference call that we feared could “drop” at any moment.

The change in preparing for an in-person Hill visit compared to the virtual visit with legislators presented us with the need for a quick turn-around. For in-person sessions, we had the advantage of close proximity to each other for support and the ability to quickly clarify any misperception that might arise. The nonverbal cues of the meeting, coupled with the feel of the office space and nearness to the source of policy making, is difficult to replicate in a virtual meeting. Traditionally, one prepares for the possibility of both an unexpectedly “hurried” in-person appointment as well as a more drawn-out meeting lasting up to 30 minutes or more. In the virtual setting, we had a firm time commitment in which to present and discuss our issues and priorities. Still, preparation for both modes persisted as each participant had practiced their “elevator speech” as well as rehearsed a more leisurely but focused discussion of the various topics. The attention originally directed toward our preparations for travel logistics including air, hotel, and ground transportation aligned with everyone's needs (e.g., wheel-chair accessibility), turned to worries of secure and dependable internet connectivity and timing of a coordinated approach to our policy concerns. We lost the comradery and team-building experiences of traveling together and managing the logistics of the 3-day excursion. This was replaced with opportunities to visit with more legislators, observe more meetings and, thus, learn from a broader array of experiences.

One of the LEND fellows who participated in the virtual advocacy visits is deaf. Short notice of the shift to a virtual format left the group unable to secure an American Sign Language (ASL)/English interpreter in time for the visit. One of the faculty members who can communicate in ASL agreed to serve in the “interpreter role” to support this fellow’s involvement. Importantly, the faculty and fellow had worked together over the year and knew each other’s communication styles. The faculty member is fluent in ASL, yet is not a certified interpreter; however, the fellow agreed to this arrangement and expressed a desire to be a part of the “virtual visit to the Hill.” Wearing the dual hats of LEND faculty and “interpreter” provided interesting insights: (1) legislative aids needed to be reminded of attending to constituents’ communication needs (e.g., allowing each person to finish talking – and the interpreter an opportunity to “catch up” at times – before the next person spoke); (2) there is benefit to having the person in the interpreter role be savvy about the topics in order to convey a full understanding of the content being discussed (e.g., numerous acronyms were used by the legislative aids; while some of the fellows in the group took notes about those acronyms in order to look them up later, a Deaf advocate relying

on ASL would generally find note-taking and watching the interpreter quite difficult. Being able to “add in” information, such as providing an explanation of the acronym in real-time proved useful); and (3) the legislative aides, initially seemingly surprised or perhaps uncomfortable adjusting the communication to allow for access to information through interpretation, did appear to relax and become more natural over the course of the visits. Had these meetings been held at “the Hill” without an ASL interpreter present, the perspective of that fellow/self-advocate/emerging professional would have been lost. At the conclusion of the session, one legislative assistant reported that the experience of adjusting the communication taught her as much about the need for communication access for individuals with disabilities as did the advocacy conversations that were held. This drove home the importance of representation (for advocates, by advocates—but also by a variety of advocates with different lived experiences) and provided greater insight into the “other burdens” that can be placed on self-advocates who desire to engage in advocacy efforts.

The congressional aides with whom we met during the virtual DPS meetings acknowledged that they truly had not considered the information or perspectives that were being shared with them by self-advocates and family members of individuals with developmental disabilities. Given the timing of these visits, the congressional aides were highly focused on the impact of COVID-19 on their constituents, yet they acknowledged that they had not realized what the impacts might be for their constituents with physical or developmental disabilities. As a group, the LEND fellows and faculty were assured that the legislative aides would be bringing these concerns directly to the legislators. The facts about developmental disability conveyed to the legislators had a minor impact compared to the personal stories shared during the advocacy conversations. Allowing the lived experience of self-advocates and family members to determine the agenda for our virtual meetings proved to be the most effective strategy for educating legislators.

### **Virtual Disability Advocacy: Honoring Agency through Personal Narratives**

Centering the voices of people with disabilities and their families in policy advocacy is an important tool in the effective education of legislators. Personal stories humanize and add dimension to issues that risk being reduced to legalese for those not personally impacted. Allowing lived experiences to direct discussions about policy also underscores for lawmakers two aspects of the disability community that are important to acknowledge: (1) the needs and priorities of people with disabilities and their families are diverse and intersectional (Kattari et al., 2017); and (2) these needs and priorities, like life with a disability, are dynamic, changing over time (Roebroek et al., 2009). The complexity and urgency of the challenges posed by the COVID-19 pandemic that were revealed by the personal stories shared during the virtual Hill visits served to underscore these points in a concrete way.

Individual stories, snapshot “portraits” of life with a disability at the onset of a global health emergency told first-hand by self-advocates and family members, were the centerpiece of our Hill visits and also serve as the backbone of this article, subverting long-entrenched academic power structures and aligning our collaboration with the emancipatory perspective



(Oliver, 1992). As a group, we embraced the “hyper-specific” and “hyper-localized” situations that were of great importance to the self-advocates and family members of individuals with developmental disabilities, believing that as policy makers listened to and began to better comprehend the nuances of the challenges that COVID-19 was posing for individuals with developmental disabilities, they would better comprehend the big picture as well. Inclusion of these various perspectives were neither superficially perceived by the group as a “nice thing to include” nor as a tokenistic opportunity to “promote inclusion”; rather, there was a recognition that centering the messages of the collective group (LEND fellows and faculty) around the lived experiences of self-advocates and family members had the potential to deepen legislators’ understanding about the support needs of individuals with developmental disabilities, particularly in the context of the COVID-19 pandemic. What follows are reflections written by a self-advocate and a parent of a child with a developmental disability about the experience of sharing their stories during the virtual Hill visits in the early days of the COVID-19 pandemic.

### ***Reflections from an Autistic Self-Advocate***

COVID-19 completely upended my life. Conferences I had been looking forward to (one of which was in Ghana and I was to be a speaker) were cancelled or postponed. The conferences that did go forward, like the DPS, were conducted in a completely virtual format. In many ways, the actual disruption to my schedule was minimal. I was creating a website of autism and adulthood resources<sup>2</sup> as part of my fellowship at the Institute for Community Inclusion at the University of Massachusetts Boston. Most of my business could be completed from home, and I was only required to be in the office 20 hours a week. The Hill visits going virtual also did not fundamentally change my work. My task was still to talk about legislation that I felt was important. The major challenge I faced was the fact that the Hill visits were taking place in the context of a national emergency.

One of my takeaways from the LEND Program was the importance of telling my story. Legislators no doubt go to Congress with their own priorities, but they are supposed to represent their constituents, and they want to be re-elected. Caught in a storm of competing obligations, demands, and requests coming from all sides, it is not easy for Congresspeople to know the right way to go. My story could be their compass. In preparation for the Hill visits, I put together a packet of materials to distribute concerning pending legislation. But I knew the most important information I had to convey was my personal experience. A piece of legislation I was particularly excited about was the SSI Restoration Act, which would raise the asset limit on SSI beneficiaries from \$2,000 to \$10,000. I saw this bill as a game changer and was looking forward to telling the story about the dilemma I had been caught in for most of my adult life; not making enough money to be self-supporting but making just enough to jeopardize my benefits.

Then COVID-19 happened, and Congress’ focus was understandably on dealing with this public health emergency. In the scheme of things, the SSI Restoration Act now seemed rather insignificant. How could I justify talking about it in the midst of a global pandemic? Then, the plan

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<sup>2</sup> <https://autismadulthood.net/>

was set in motion to send every American a \$1,200 stimulus check—immediately raising the specter of the negative impact those checks would have on public benefits. As it would turn out, the situation with the stimulus checks would be resolved by not counting them as income for a year. However, the underlying issue remained of asset limits that placed an undue financial burden on people with disabilities. Indeed, as I pointed out during the Hill visits, the overly restrictive asset limits were among a number of problems that already existed but were magnified by the current crisis. Instead of waiting for things to get back to normal, I thought now was the perfect opportunity to address some of the systemic flaws being highlighted by coming up with long-term solutions.

There is something transformative about having your story take center stage—a phenomenon I experienced when my mother wrote an article about my life with autism long before I had ever heard of participatory or emancipatory perspectives. My mother was an English professor who specialized in African American Literature and Film. Towards the end of her life, she shifted some of her focus towards the field of Disability Studies. While a student at the Harvard Graduate School of Education, my mother took a class in a qualitative research method called Portraiture. As Sara Lawrence-Lightfoot, a noted Portraitist and my mother’s professor, explains in *The Art and Science of Portraiture*:

*Portraiture is a method of qualitative research that blurs the boundaries of aesthetics and empiricism in an effort to capture the complexity, dynamics, and subtlety of human experience and organizational life. Portraitists seek to record and interpret the perspectives and experience of the people they are studying, documenting their voices and their visions -- their authority, knowledge, and wisdom. (p. XV)*

In that spirit, my mother chose me as the subject of her Portrait, and what she wanted to capture was what being autistic meant to me. We sat down for a series of interviews in which my mother asked me questions covering a range of topics from my earliest memories of being different, to my experiences in special education, to my current struggles in the world of work. My mother also recorded her own observations of me.

The final product was a biographical sketch called “A Brief Portrait of an Autistic as a Young Man,” a version of which was published in an anthology called, *Illness in the Academy: A Collection of Pathographies by Academics* (Myers, 2007). My mother and I also started co-presenting at conferences both domestically and abroad. One of the things our audiences said they appreciated the most was hearing the perspectives of both a parent and a self-advocate. For me, having my story put front and center was validating and empowering. It gave me the sense that I was part of a larger conversation. I was being listened to. What I had to say mattered.

My mother hoped that her Portrait of me would do more than just give me an avenue for self-expression, she also wanted to draw attention to the needs of “high-functioning” autistics, needs that are all too often overlooked. Like my mother’s Portrait, the Hill visits gave me a platform from which to speak, and, in a way, carry forth her message—my ability to understand the issues and articulate my thoughts did not translate into me needing no help. In fact, the assistance I required was what I was bringing to the legislators’ attention. And, by having me

choose what legislation to discuss, the structure of the Hill visits made me an equal partner in determining the course of the conversation, which is very much in keeping with an emancipatory framework.

### ***Reflections from a Parent of a Child with a Rare Genetic Disorder***

Because of the last-minute changes instituted in response to the COVID-19 pandemic, my experience of the Hill visit significantly diverged from my expectations for the event in two ways: (1) I shifted the content of my conversations in anticipation of newly developing issues, and (2) the format in which those conversations took place was dramatically altered.

For me personally, the burgeoning pandemic made the issue of policy advocacy more urgent and less abstract. It also shifted my focus from preexisting policy proposals to potential future pitfalls. In the weeks leading up to the Hill visits, I had not yet identified the policies that I felt resonated most strongly with my family's story. As the parent of a toddler with a rare genetic condition, I lived very much in the moment, addressing new challenges as they arose with little ability to anticipate what the needs of my child might be in either the near or distant future. While I understood policy advocacy to be an important tool for advancing and protecting the rights of the disability community, how my family's immediate concerns might translate into broad, long-term solutions still felt vague to me in the weeks before our visits. This changed, however, with the onset of the pandemic.

Our virtual Hill visits took place one and a half weeks after my state of residence, Massachusetts, instituted a "stay-at-home advisory." At this time, general emergency preparedness advice was to have a 3-month supply of prescription medications on hand in the event that supply chains were disrupted or visits to the pharmacy were deemed unsafe. My child held five prescriptions for a combination of maintenance and rescue medications, though even with the privilege of comprehensive private health insurance I could not acquire a 3-month supply of these medications without paying several hundred dollars for them out of pocket because of where they were in their various refill cycles. For me, insurance coverage for 90-day supplies of medication and more flexibility for refilling recurring prescriptions suddenly became an urgent topic for legislative discussion.

My child turned 3 the day before our virtual Hill visits, making the date of our meetings his official entrance into the public-school system. Until that point, his therapeutic services were delivered by an Early Intervention program. Remote instruction and the perceived threat of school districts potentially seeking waivers for providing special education services put protections for the Individuals with Disability Education Act, which until that point I had largely taken for granted, on my agenda for the Hill visit. Before the start of the pandemic, my family felt well prepared as we had spent nearly a year planning for my child's entrance into public school. Having a child who was now moving between systems during a moment of crisis, however, highlighted for me the particular vulnerabilities associated with major transitions throughout the lifespan. The new challenges and uncertainties that my child suddenly faced allowed me to raise awareness of these weak points in our systems of care, which if not properly addressed can lead

to the needs of those with disabilities being lost in the administrative fray of moving from one major life stage to the next.

Before the DPS shifted to an online format, my family had planned to travel together to the event. Among the logistical details attended to during planning were time off from work and therapies, funding the trip, finding accommodations that allowed us to prepare meals that met dietary restrictions, and the transportation of medications and equipment. Were the format established in advance, virtual meetings would have alleviated scheduling complications associated with care taking and negated the stress and expense of traveling.

In the shift to a virtual DPS, our LEND cohort missed opportunities for teambuilding and insight into the physical spaces and governmental processes that we would have been exposed to by moving through professional offices on Capitol Hill. The shift to a virtual format also, however, allowed my colleagues and I to listen in on and learn from more conversations than would have been possible if the meetings had been held in person as originally planned. There were up to as many as 32 of us on calls to senators' offices and 15 on calls to representatives' offices, affording us more experience and collegial support as we shared our stories. I attended our virtual Hill visits from my child's room, which in hindsight seems an appropriate venue. It was a comfortable space for me and as a reflection of my child's identity, marked his presence in our discussion with legislators.

### ***Implications of Virtual Advocacy for Centering the Experiences of Self-Advocates and Family Members***

The experience of being in Washington, walking the halls of Congress, and meeting Representatives and Senators (and/or their aides) in their offices has had a significant impact on DPS attendees—yet involves a great deal of effort, organization, and planning, which invariably limits some participation. Not everyone can attend (e.g., family responsibilities may limit travel options) and attendees who have ambulation challenges (such as wheelchair users or those who use walkers) recognize that the accessibility is difficult and requires considerable planning and time-consuming execution. The cost of travel to and accommodation in Washington is substantial, thus limiting many. Benefits of virtual advocacy for self-advocates and families include reducing the burdens associated with travel including the direct costs involved, as well as the opportunity costs, such as having to miss work and/or having to leave children at home and the many necessary arrangements that being away demands. Thus, a greater number of people from a variety of backgrounds can participate in virtual advocacy efforts.

Virtual engagement can offer legislators greater insight into the lives of people with disabilities by welcoming them into the homes of advocates. This may simultaneously “level the playing field” by shifting focus away from the power differences between advocates and those holding elected office, which are inherently emphasized by being on the Hill during in-person visits. The virtual experience reduces the angst that some self-advocates or family members, particularly those who are new to disability advocacy, may feel when face-to-face in engaging with policy makers. Being in the comfort of one's home may make it easier to tell the emotional

aspects of one's own story, or that of one's family. Advocates can convey their stories as they wish through either telling or showing, using their surroundings as a complementary mode of communication (e.g., by keeping their camera off if they feel more comfortable doing so, or by joining in from their child's bedroom, to emphasize the durable medical equipment that is a part of their daily lives).

The flexibility that virtual advocacy permits can also facilitate engagement of individuals with disabilities who have a variety of learning styles or communication needs. It is possible, for example, to "screen share" a pre-prepared message crafted by an individual with a disability (perhaps with support, if necessary or useful to the self-advocate) with a legislative representative. Such a strategy can allow emphasis on points that may otherwise not be shared by self-advocates who have difficulty conveying messages in real-time, as might be the case for self-advocates who experience cognitive challenges or who rely on communication devices that require time and effort to "program" specific statements. There is also a need to ensure that self-advocates can receive information from the legislative representatives, which can also require specific technology (e.g., speech-to-text) or the support of a sign language interpreter. While some of the necessary supports can be arranged for in-person Hill visits, the burden of ensuring accessibility often falls to the individuals with disabilities and their family members. Virtual participation in an advocacy meeting that is pre-planned can help to mitigate some of those structural barriers, improve accessibility for disability self-advocates in both giving and receiving messages with their representatives, and foster broader participation in advocacy efforts along with more authentic inclusion in the process.

Aligning with notable lessons from inclusion models for disability advocacy (Ife, 1995; Radermacher et al., 2010), our engagement in the virtual Hill visits were broad in scope, making space for self-advocates and family members to emphasize topics of importance to them, while also fostering a sense that their involvement mattered. Different forms and degrees of participation were acknowledged, valued, and supported, with efforts made to reduce the potentially alienating processes inherent in the advocacy structure.

### **Discussion: Lived Experience Takes Center Stage through Authentic Collaboration**

The present paper examines the impact—for a self-advocate, a parent of a child with a developmental disability, and professionals working in the disability space—of centering lived narratives in advocacy during the early stages of the COVID-19 pandemic. What is described is a collaborative advocacy project undertaken from an emancipatory perspective, which was informed by recent advances in research. The emancipatory nature of this collaboration, from virtual Hill visits to co-authorship, was facilitated in part by the flexibility demanded by the context of a global health emergency, which may be crucial for generalizing our experience of working within an emancipatory perspective to similar collaborative efforts. In particular, the ways in which the shift to a virtual format for advocacy events and expanded opportunities in publishing created more accessible spaces for self-advocates and family members to share their personal stories may offer valuable insight into how authentic collaborations can be supported in the future.

As previously outlined, the shift to a virtual format has the potential for making several aspects of advocacy events more inclusive, thereby increasing direct communication between self-advocates, family members and legislators. This is of particular importance in times of crisis when people with developmental disabilities are disproportionately affected—as has been the case during the COVID-19 pandemic. Preliminary data suggests that people with intellectual disabilities and developmental disorders may be three times more likely than the general population to die as a result of COVID-19 infection (Rabin, 2020). In addition, the challenges for individuals with disabilities and their families regarding accessing healthcare (Hall et al., 2019), reduced economic opportunities (Andresen & Nord, 2020), and social isolation (Singleton & Darcy, 2013), particularly as they age (Bradley et al., 2020), have been exacerbated by the COVID-19 pandemic. In times of such urgent concern, hierarchical settings and processes risk slowing the exchange of information between individuals with disabilities and their families—whose needs during an emergency are immediate and dynamic—and those in power who are responsible for addressing their concerns. Positioning self-advocates and family members as leaders of our group, which also included faculty, professionals, and trainees, benefitted our virtual advocacy efforts by providing legislators insight into these complex problems as they unfolded in real time.

### Conclusion

An emancipatory perspective to collaboration requires that the involvement of all contributors be meaningful and authentic throughout the process, including in co-authorship. The rigidity of the academic publishing process, however, can present challenges to co-authorship for individuals with developmental disabilities who comprise an enormously heterogeneous demographic that may, in contrast to the typical hierarchical structure, thrive in flexible inclusive research settings that respond to diversity (Stevenson, 2010). For our group, the context of COVID-19 may have eased some of the difficulty associated with highlighting the voices of self-advocates and family members in academic publishing. Recognition of the need to collect and share anecdotal experiences during this unprecedented time created a unique opportunity to widen the impact of our collaborative advocacy effort through co-authorship. Extrapolating upon lessons learned from this collaborative endeavor, the authorial team posits that academic writing could be made a more accessible platform for people with developmental disabilities by broadening the types of submissions and article formats accepted. This would allow collaborators to share the work generated by projects that, while related to common research interests, fall outside of the purview of formally designed research studies. More importantly, expanding the ways in which disability self-advocates and family members of individuals with disabilities can be meaningfully engaged in research and writing projects can advance the understanding and appreciation of the expertise contributed by those with lived experience.

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