


Essay

“Nothing about Us without Us” Meets the “All Teach, All Learn” Model: Autistic Self-Advocates as Leaders and Collaborators in Project ECHO

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Abstract: Those with intellectual and developmental disabilities (I/DD), especially autism, represent an often misunderstood and underserved population. In order to address health disparities faced by those with I/DD in Washington state, the Extension for Community Healthcare Outcomes (Project ECHO) model was implemented to build capacity to serve these individuals and their families in their home communities. Through this year-long telementorship and learning community, expert teams lead clinics based on interdisciplinary case-based discussion and knowledge sharing with medical, behavioral, and mental healthcare providers. A cornerstone of these expert teams are autistic self-advocates, who provide insight into lived experience. In this paper, we will discuss how the inclusion of six autistic self-advocates across four different ECHO programs has allowed ECHO participants to broaden their horizons and gain new insight into supports for their I/DD clients across multiple aspects of care. In addition to the unique knowledge provided by self-advocates, their participation illustrates the potential for all people with I/DD to live rich and fulfilling lives. The initial implementation and on-going success of including lived experience within the ECHO model can be used as an example of how to create partnerships that meaningfully inform decisions and improve equitable outcomes in service provision.

Keywords: Project ECHO; autistic self-advocates; healthcare disparities; lived experience; learning collaboratives



Citation: Casagrande, K.A.; Davis, S.; Moore, B.S.; Dahiya, A.V.; Smith, I.; Krebsbach, S.; Mancini, J. “Nothing about Us without Us” Meets the “All Teach, All Learn” Model: Autistic Self-Advocates as Leaders and Collaborators in Project ECHO. *Educ. Sci.* **2024**, *14*, 910. <https://doi.org/10.3390/educsci14080910>

Academic Editors: Charlotte Brownlow, Yosheen Pillay and Emma Goodall

Received: 30 April 2024

Revised: 17 July 2024

Accepted: 2 August 2024

Published: 20 August 2024



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1. Introduction

Intellectual and developmental disabilities (I/DD), also sometimes called neurodevelopmental disabilities, describe a broad range of biological and/or brain-based differences with complex etiologies that manifest early in development. Examples of these disorders include autism spectrum disorder (ASD), attention-deficit/hyperactivity disorder (ADHD), intellectual disability (ID), fetal alcohol spectrum disorders (FASD), and genetic syndromes such as Fragile X and Trisomy 21. Although there are many different diagnoses under this umbrella, these disorders are all considered lifelong and affect the trajectory of an individual’s physical, intellectual, adaptive, social, and/or emotional development. Furthermore, these conditions often co-occur with each other and can be difficult to disentangle [1,2].

With such a diverse range of symptoms and co-occurring needs, it is not surprising that individuals with neurodevelopmental disabilities have a higher rate of healthcare service

utilization compared to their neurotypical peers [3,4]. However, there is a significantly limited workforce of professionals in the United States trained to support these individuals across the continuum of care from initial screening and diagnosis, routine and specialty medical care, case management, resource navigation, and behavioral health services [5]. As such, it is important to build a competent workforce and identify ways to improve access to and quality of services for individuals with I/DD across their lifespans, while ensuring that those with lived experience are a part of the conversation to ensure those needs are being met in a person- and family-centered way.

In this paper, we focus primarily on the challenges faced by the Autistic community as there are greater barriers to care for this population compared to other I/DD groups [6,7], acknowledging that co-occurring disabilities are common and much of this information applies to intellectual and developmental disabilities more broadly [8]. We will provide an overview of the common challenges in accessing services for individuals with autism in the United States, introduce adaptations to the Extension for Community Healthcare Outcomes (Project ECHO) model [9] to address those challenges by increasing community capacity to care for people with autism across the continuum of care, and discuss the role of Autistic self-advocates in the development, implementation, and outcomes associated with Project ECHO in Washington state.

1.1. Barriers to Care

Autistic people, as well as those with other developmental disabilities, have increased service needs and they are, as such, are more likely to interface with medical and behavioral health professionals than their neurotypical counterparts [3,4]. However, this increased use of services does not mean that people with autism and IDD can find providers with the appropriate specialty training to support them. Individuals with I/DD, especially those diagnosed with autism, experience a greater level of unmet healthcare needs and report lower quality of services than their neurotypical peers. For example, caregivers of autistic children report challenges with service access including reduced insurance coverage, long waitlists, limited specialists, poorly coordinated care, and overall low satisfaction with care [10]. These barriers are especially pronounced for those from marginalized backgrounds and autistic adults [11–13].

Barriers to care in the United States exist across a continuum of services, from initial screening and diagnosis to finding specialized and routine care providers. Parents report significant delays and difficulty in accessing a timely diagnosis for their child, both in terms of systemic barriers such as transportation, insurance coverage, and waitlists, as well as interacting with providers who are dismissive of their concerns about autism [14]. Providers also express barriers in their ability to diagnose autism, such as inadequate training, limited time to provide services, and concerns about family readiness and support following an autism diagnosis [15]. Following a diagnosis, families continue to struggle with accessing recommended developmental, educational, and medical supports due to similar systemic and relational barriers [6,10,16]. Transition age youth and autistic adults also experience challenges related to aging out of a pediatric support system into a system that has not been built to serve the complex needs of autistic adults [11,17,18].

In addition, there are increased complexities with supporting the behavioral healthcare needs of autistic individuals. Autistic people experience a greater prevalence of many mental health diagnoses, such as anxiety, depression, and suicidality [19], and present more frequently to the emergency rooms for mental health emergencies than those without autism [20]. However, many autism-specific services are often unable to support these co-occurring mental health needs [21], despite many autistic individuals and families identifying mental health challenges as the most impactful [22]. For example, autistic individuals and their families share stories of being excluded from traditional mental health services due to the diagnosis of autism and that providers' lack of knowledge about autism has led them to encounter misunderstandings and negative experiences [23].

Despite growing awareness and education around autism for many medical and behavioral healthcare providers, there are still significant limitations in developing a well-trained workforce that can support this unique and complex population across their lifespans and across systems [5]. Many healthcare providers report not receiving appropriate training in autism and other developmental disabilities during their medical education or lacked confidence in their ability to support patients with autism or related conditions [24,25]. However, while training in the identification and diagnosis of autism or other neurodevelopmental disabilities can be helpful in finding interventions or supports, it can also lead to a biased view of disabled people, wherein they are only seen for their deficits and considered as lesser or in need of fixing [26,27]. It is important to work toward changing providers' perspectives and improving their understanding of autism and other neurodevelopmental disabilities to address common myths and misconceptions, as these misconceptions relate to negative attitudes about autistic individuals [28]. Taken together, the combination of barriers across the continuum of services related to both systemic issues and provider readiness culminates in a United States healthcare system that fails to serve those most in need of specialized support.

1.2. Project ECHO

To address the health disparities faced by those with I/DD in Washington state and build capacity to care for individuals with I/DD and their families in their home communities, we implemented the Extension for Community Healthcare Outcomes (Project ECHO) model. Project ECHO was initially developed at the University of New Mexico to improve Hepatitis C healthcare for medically underserved populations (e.g., those living in rural areas, prison populations, un- or under-insured individuals [9]) and was quickly adapted to address a wide variety of chronic health conditions [29]. The ECHO model aims to bring high-quality care to rural and underserved communities by using videoconferencing to connect community-based providers with an interdisciplinary team of specialists for networking, mentorship, and knowledge sharing through regularly occurring meetings. In addition to short didactics by subject matter experts, each ECHO session utilizes case-based learning to apply knowledge, engage in discussion, and develop recommendations from both the specialist team and participants. While the ECHO model is not a direct telehealth service or consultation as all case discussions are anonymized, it provides a space for respectful co-learning wherein community professionals can collaborate with each other and a team of experts to disseminate and implement the best practices.

The ECHO model has been successfully implemented in the United States and internationally to improve care for autistic individuals in a variety of ways [30], such as improving screening and diagnosis [31–33], early intervention [34], mental healthcare [35], and adult healthcare [36,37]; models have also been adapted to support parents or caregivers of children with autism [38]. The cornerstone of these expert teams includes those with lived experience. However, this lived experience has often come from family members rather than autistic individuals [30]. We will focus here on the involvement of Autistic self-advocates, most of whom have additional mental health and neurodevelopmental diagnoses aside from autism, within programs supported by the Washington INCLUDE collaborative. This includes four distinct ECHO tracks to support various aspects of care, including navigating healthcare policies and resources specific to Washington state:

- *ECHO Autism Washington* is designed to assist medical and psychiatric practitioners in diagnosing and managing both core and secondary challenges associated with autism. This includes identifying individuals at risk for autism, conducting autism evaluations, developing care plans for autistic patients, providing ongoing care management for related conditions, and referring patients for appropriate treatment or further evaluation as needed. There are two cohorts within *ECHO Autism Washington*—one focusing on younger or more unambiguous cases and another focusing on lifespan and/or more complex cases. There are three Autistic self-advocates who support these two cohorts.

- *ECHO I/DD Wraparound* supports professionals working with those at the intersection of I/DD and mental health. Many of the cases discussed have multiple diagnoses including autism and co-occurring mental health conditions. This highly interdisciplinary ECHO brings together behavioral healthcare providers, clinical supervisors, case managers, family navigators, educational representatives, and healthcare and insurance administrators, with a hub team of medical and behavioral health experts and three Autistic self-advocates, to enhance care for children and young adults with dual diagnosis and their families. Sessions focus on the evaluation and treatment of mental health conditions in neurodiverse youth, coordination of care across systems, and navigation of local and state resources.
- *ECHO I/DD Resources and Resource Navigation*, which benefits from the insight of two Autistic self-advocates, focuses on supporting care coordinators, family navigators, healthcare providers, parents, peers, and self-advocates by providing consultations around evidence-based resources and information to address the complex needs of the autistic and I/DD community. This includes a focus on state and federal resources, psychoeducation, behavioral health services, and crisis intervention.
- *ECHO I/DD Psychiatric Care*, supported by one Autistic self-advocate, provides medical professionals with specialized training and support in diagnostics, evidence-based practices, and psychopharmacology. This group provides a lifespan approach to caring for those with I/DD and various medical, psychiatric, and neurodevelopmental co-morbidities.

2. Self-Advocate Engagement in ECHO

2.1. Program Development and Outreach

Autistic self-advocates have been involved in Washington INCLUDE ECHO programs since the ECHO Autism Washington group was launched in our community in 2019. Our first Washington state ECHO program was launched after ongoing needs were identified by community primary care providers (PCPs) following an initiative from the Washington Healthcare Authority to train and certify such providers to diagnose autism and write prescriptions for Applied Behavioral Analysis (ABA) where appropriate. During initial planning for the launch of ECHO, a self-advocate faculty member affiliated with the University of Washington Leadership Education in Neurodevelopmental and related Disorders (LEND) program provided a connection to another Autistic self-advocate who was interested and able to support the initial pilot of the program along with an interdisciplinary team that also included family advocates. Including the perspectives of those with lived experience from the onset helped the team use a neurodiverse-affirming approach to program development. This Autistic self-advocate was a part of decision making, including structural organization, content development, and communication about the program.

Following the initial launch of ECHO Autism Washington, a second cohort for ECHO Autism Washington was launched, and an Autistic self-advocate from the LEND program was recruited to participate on the hub team. Additional programs were added to support other professionals across the state of Washington through ECHO I/DD Wraparound, starting in 2020, as well as ECHO I/DD Resources & Resource Navigation and ECHO I/DD Psychiatric Care, which were initiated in 2022. As the Washington INCLUDE ECHO program expanded, additional Autistic self-advocates were hired to support new programs, including three new hires in early 2022 (see more details about supporting equitable and accessible hiring below). During each of these additional programs' development, a self-advocate was recruited onto the hub team to support program development. Autistic hub team members have played a role in ensuring that online content and communications about ECHO were accessible in terms of using respectful language to discuss I/DD, ensuring appropriate font size and choice for those with visual impairments, and having information portrayed in plain language with supporting visuals to increase readability for those with intellectual disabilities.

2.2. Creating an Accessible Hiring Process

Self-advocates were hired into their roles as paid subject matter experts on the hub team in a similar way to other professionals, uncovering challenges with traditional university hiring practices. Two self-advocates and the director of the ECHO programs worked collaboratively to identify challenges, communicate them with human resources, and provide accessible alternatives for future hiring of neurodiverse self-advocates. Challenges identified included the requirement for a post-secondary degree to apply for posted positions, lack of transparency on available disability accommodations for faculty and staff, available accommodations not being appropriate for those with substantial needs, and strict requirements for written materials and use of the online portal as the basis of the application process. While some applicants were able to navigate the system, others needed help with the organizational tasks that simply applying for the position required. Similar barriers with hiring and accessibility have been noted by other groups collaborating with autistic individuals in providing education within a university setting [39,40].

Following the changes made by human resources to the application process, adjustments were made within the interview process by the ECHO team. Self-advocates were and are now involved in all parts of the process—from initial recruitment to reviewing applications, interviewing candidates, introducing the roles and expectations of being a hub team member, and training all new hub team members. Additionally, support was provided throughout the hiring process as needed, including regular communication, with different options being provided for the interview process, such as in-person, remote, and asynchronous video and/or written responses. Lastly, all candidates were encouraged to join and observe an ECHO session as part of the process, and meetings were scheduled afterwards to allow participants to ask questions and discuss the session with the team.

2.3. Hub Team Leadership

Autistic self-advocates are full hub team members and participate in all aspects of ECHO programs, including attending organizational meetings to inform the structure and content of future sessions; developing, reviewing, and presenting didactics; mentoring and supporting participants; serving as subject matter experts during case presentations by asking questions and providing recommendations; and disseminating information at scientific and educational conferences. The current paper also represents our work to include Autistic self-advocates in co-authoring academic papers, which required a substantial number of adjustments to the traditional collaborative writing process.

The initial idea for this paper was proposed by Autistic self-advocates based on previous conference presentations and the lack of published articles regarding self-advocate involvement in professional trainings on autism and neurodevelopmental disabilities. As none of the Autistic self-advocates had previously contributed to writing a journal article, initial meetings were scheduled to share information about peer-reviewed articles, discuss authorship responsibilities, identify desired paper contributions, and refine the paper topic. After obtaining a consensus on the overall scope of this paper, two monthly meetings were held to work on this paper and various adjustments were made to the writing process. These accommodations were made to make the academic writing process accessible for individuals with intellectual and/or learning disabilities. For example, the initial outline of this paper was developed collaboratively during these meetings, with edits and reorganization carried out live rather than via back-and-forth email communications. Portions of the outline were then assigned to specific co-authors based on their interest and knowledge of the topic area. Based on individual preferences, a subset of co-authors participated in one-on-one meeting with another author to discuss their ideas and content for a specific section of this paper; that conversation then guided the writing of their portion.

Self-advocates uniquely contribute their lived experience perspective and emphasis on disability empowerment, increasing the representation of those that the ECHO programs are intended to support. Autistic self-advocates describe their individual roles on the hub team in several different ways. For example, one member describes their role as

“challenging the status quo” by asking questions that push providers to rethink their beliefs about I/DD and autism, as well as changing how they approach their work to be more inclusive, respectful, and accessible. Another self-advocate shared that a major part of their role is “addressing the adult experience” and ensuring that providers “not [deny] opportunities based on an assumed mental age” by respecting the autonomy, experience, and values of individuals with disabilities regardless of their intellectual abilities. Another Autistic hub team member reported that it was important to “share my experiences, both struggles and successes, as a person with autism”. Furthermore, the inclusion of self-advocates has helped to bridge the gap in representation of the autistic experience, which has often been held by the caregivers and/or family members of autistic people. In our ECHO programs, both types of advocates learn alongside one another, challenge each other’s perspectives, and find common ground through communication, interaction, and sometimes tough conversations.

2.4. Personal and Professional Development

Given the “all teach, all learn” model of Project ECHO, self-advocates grow and learn alongside ECHO participants, making strides toward their own personal and professional goals. The open discussion of barriers and challenges providers face has allowed self-advocates to better understand why there are gaps in services and how policies can be used to redirect resources towards populations in need. ECHO participants often cite a lack of accessible services for themselves and/or their clients, especially when seeking services in languages other than English, in rural areas of Washington state, or for those who are unable to access services through the public school system. This awareness of the importance of policies is key in facilitating productive discussions with elected officials, insurance providers, and other healthcare decision makers to push for a more accessible and equitable future for all people with disabilities. Many Autistic self-advocates serve on state advisory councils and legislative advocacy committees, where they can share their own experiences of navigating the United States healthcare systems as an autistic person and the experiences of ECHO participants to advance change at the policy level.

Additionally, participation in the ECHO program allows self-advocates to engage in professional development and work towards their career goals. Many advocates sit on both regional and state advisory boards to address local policy development and the implementation of services for those with I/DD, as well as taking leadership roles in developing networks of self-advocates. For example, one self-advocate states that “being a part of the hub team has increased my advocacy role. These positions do not come around very much so being a part of the hub team has been rewarding for me”. They commented that being involved as an ECHO hub team member has helped develop their communication skills and provided additional experience that helped them successfully apply for disability advisory positions; they now work with three different advocacy and advisory committees. Another self-advocate has a leadership role in three different disability self-advocacy and support groups with a large focus on supporting Autistic and intellectual disability communities.

Self-advocates also work with other hub team members to build their knowledge base and explore areas of interest through didactics and participation in different ECHO sessions. As self-advocates find new areas of interest or expertise, they can move between different ECHOs and broaden their horizons. Being part of the hub team also provides self-advocates with the opportunity to attend various conferences to communicate with key stakeholders about I/DD and the ECHO model. Self-advocates have been able to share their experiences and insights with the state and national councils for developmental disability policies, as well as at scientific research conferences. Through these experiences, self-advocates build their confidence and communication skills, which they can carry forward into their future work.

3. Participant Experiences in ECHO

Participants and hub team leaders across the four ECHO programs were informally asked to share their perspectives on how involvement from self-advocates has impacted them and their practice. These perspectives were provided as part of an ongoing program evaluation and quality improvement through direct emails or conversations, comments made during ECHO sessions, or anonymous post-session survey responses. Their comments generally fell into three areas, as described below.

3.1. *Shifting the Lens*

ECHO participants have reflected that self-advocate voice during sessions, shifting their understanding of and perspective around autism and I/DD. One significant shift was in mental age theory. Mental age theory is the practice of referring to individuals by their estimated mental age, typically based on a summary score from intellectual ability testing, rather than their chronological age. This is a common practice among professionals, which often devalues the lived experience and the distinct developmental profiles of individuals with autism across their lifespans, resulting in infantilization, discrimination, and removal of human rights [41]. Several ECHO participants shared that they no longer use an overall estimate of mental age to talk about their clients, instead paying more attention to the unique profile of the strengths and challenges that an individual might experience. For example, one participant shared that they learned how important “using the right words, using the term non-speaking instead of non-verbal. Also, how offensive the mental age approach can be”. A step away from mental age theory has also reinforced among participants the importance of providing sexual health and substance use education and engaging individuals in treatment planning, despite a diagnosis of an intellectual disability or language disorder. These topics were previously avoided based on assumed mental age and limited competence to understand or engage in such conversations.

Participants also shared that hearing self-advocates discuss the importance of sensory interests and aversions provided greater insights into the autistic experience—for example, recognizing that exposure and desensitization to aversive sensory experiences can be distressing, or even painful, for autistic individuals. They also appreciated learning about how integrating sensory preferences and needs into their daily routines can improve independence and support emotion regulation throughout the day. Regarding self-advocates talking about their experiences with sensory sensitivities, one participant shared, “I love that self-advocates remind everyone about the normality of different behaviors. They give more ideas of what might work and ‘out of the box’ information and ideas”.

Overall, participants shared that self-advocate involvement in ECHO has broadened their understanding of the autistic experience and “provides an appreciation of the challenges faced, fears, frustration, celebrations, etc.”. Another provider shared that self-advocate involvement “has helped a lot, especially with helping the understanding of various types of challenges and disabilities (e.g., I/DD, blindness, sleep problems)”. Furthermore, a participant reflected that “understanding the personal, lived experiences in an environment that allows asking questions interactively is so valuable!”.

3.2. *Adjusting Communication*

There has also been a significant shift in how participants communicate about and with the individuals and families they serve. As one participant stated, “having Autistic self-advocates has provided insight into how my clients may view various communication approaches, resources, and interventions”. Another participant shared that “working with the self-advocates through our Project ECHO programs has significantly impacted the language I use when talking to patients and their families. I believe my communication has significantly improved as a direct result of this collaborative work”.

In addition to shifting away from the use of mental age theory, as described in the prior section, ECHO participants have been empowered to use more neurodiversity-affirming and strength-based language. Research and interventions for autistic individuals have

largely focused on deficits, based on the idea that changing core autistic characteristics will improve functioning. While acknowledging the difficulties that autistic individuals face is necessary in creating supportive interventions, a continual focus on deficits contributes to the devaluation and dehumanization of autistic individuals by failing to understand and honor their strengths [42].

Self-advocates have been able to educate participants on why deficit-focused language is harmful and encourage the use of strength-based and disability-affirming perspectives. Using strength-based and disability-affirming language and perspective helps ensure that autistic individuals have their unique strengths and challenges understood, have agency over their care, and can identify the goals and supports that are meaningful to them, which fosters self-confidence and empowers them to live fulfilling, authentic lives [43]. Through participation in ECHO, providers have been able to recognize “the need to share diagnostic information and symptoms”, and tailor their “communication style based on the client’s unique needs”.

3.3. Changing the Approach

Having self-advocate voices within ECHO has given participants insights and new ideas about how to approach their work that they had not previously considered. For example, providers have shared various ways in which they changed their approach, such as engaging in more collaborative care, adjusting to accommodate different learning styles, and creating sensory friendly environments to make people feel more welcome in their spaces.

As previously mentioned, self-advocates have been able to educate ECHO participants on the importance of strength-based, person-centered, and individualized care for autistic individuals. This allows for a more collaborative model of care, wherein providers engage the individual in support that is personally meaningful. An important part of this more collaborative model of care includes involving caregivers and other key stakeholders in an individual’s life in the conversation about support and intervention. Having a trust-based partnership between providers and families is particularly important for those who are historically underserved, such as for Black, Indigenous, and other people of color, low-income, and/or non-English speaking clients [44]. An authentic partnership between providers and families, which includes providers advocating for the individual’s needs and supporting the family’s access to care, is an essential part of providing person-centered care.

Through a greater understanding of and collaboration with clients, providers have also been able to engage with clients’ learning styles and discover new methods for sharing information. As one provider described, “many clients often are given a diagnosis and not told what that truly means in a way they can understand. . . I have learned to provide clients with space to update their treatment plan with me with their own language used”. A fundamental aspect of disability-affirming care that self-advocates have shared is the need for providers to presume that all clients can engage and grow, given the proper support. Under this presumption, providers must determine how clients process and take in information; then, they should adjust their practices to meet clients’ needs. ECHO participants have shared that through their involvement, they have become more familiar with the different learning styles.

As providers have been better able to understand the importance of sensory interests and aversions, they have also been able to adjust their physical environments to be more sensory friendly. Sensory aversive experiences cause distress for autistic individuals and can have cascading effects on communicative or social functions, which directly impacts clients’ abilities to have successful healthcare interactions [45]. Self-advocates have shared insights into strategies to help minimize sensory discomfort or overwhelm during office visits, such as turning down overhead lights or having alternative lighting options, providing options for sensory input/fidgeting, alternative seating options, and encouraging clients to use accommodations like sunglasses and headphones/ear plugs, as needed. The contributions of self-advocates have been “invaluable” for participants, with one provider

noting that “many of the experiences and suggestions offered by my autistic colleagues were new perspectives or considerations that I had not considered previously. I greatly value the opportunity to learn from others and work with a team of different specialists”.

4. Discussion

Given the barriers to accessing comprehensive and high-quality healthcare for autistic individuals living in the United States [46], especially for adults and marginalized populations [17,47], it is important to expand access to continuing education and support for professionals working with the Autistic community across service settings. Providers have numerous concerns regarding their ability to care for autistic individuals due to systemic barriers such as insurance and visit time limitations, lack of formal training in autism and co-occurring conditions, and difficulty navigating or coordinating care across systems [24,25]. Project ECHO [9] is a capacity-building model that connects participants with a diverse, interdisciplinary team of subject matter experts with the goal of improving healthcare for underserved and/or complex populations. This model has been successfully adapted and implemented to address healthcare needs for autistic individuals and their families across their lifespans and across various systems of care, both locally and globally [30]. The ECHO model is also especially well suited to support low-income countries and rural communities given its ability to be adapted to the local context, its low cost of implementation, and its utilization of technology to create connections across communities [48,49].

An area where the ECHO model has been less commonly applied is to the field of education [50]. A pioneer in this area is the University of Wyoming’s ECHO for Education network, which has been shown to be a feasible, effective, and cost-saving method for improving the education of students with disabilities [51,52]. However, individuals with lived experience, such as Autistic self-advocates, are not listed as members of the specialist team for these networks [50] p. 44, indicating a need to further explore how autistic voices can be integrated into ECHOs for educators.

We have focused here on sharing our process of including Autistic self-advocate voices within ECHO programs in Washington state focusing on autism and I/DD—from initial hiring and program development through implementation and presenting at conferences—in the hopes of providing other groups with ideas for more fully integrating self-advocate voices into their own educational activities. Having autistic people, not just parents or caregivers, at the table is a critical component of creating meaningful changes in both the systems that provide education and the target audience of those education opportunities. For example, by hiring Autistic self-advocates through the same mechanisms as other hub team members, inequitable hiring processes were uncovered, and accessible alternatives were implemented in collaboration with Autistic self-advocates. If compensations were provided in the form of small stipends or gift certificates, as is often the case for advisory roles, such hiring practices would remain unchanged.

The ECHO model relies on an “all teach, all learn” philosophy, where all individuals are present to listen and learn from each other. Autistic self-advocates have benefited from being engaged in such programs to further their own career goals and experiences. For example, a better understanding of healthcare systems and conversations with professionals has increased their ability to effectively advocate for changes within these systems through their roles on legislative and advisory councils across the state. Collaboration with self-advocates around the development and the delivery of ECHO session content also provides exposure to a greater diversity in perspectives and knowledge for participants. Through the unique contributions of Autistic self-advocates and their voice, ECHO participants discussed shifting their understanding of the autistic experience, utilizing more disability-affirming and strength-based communication, and engaging in more shared decision making and collaborative care for patients with I/DD.

Through more conversations and increased engagement between autistic individuals and the professionals who seek to support them, it is our hope to continue increasing respect for persons with disabilities and promoting autonomy, dignity, and inclusion. Having

Autistic self-advocates as part of the interdisciplinary team during ECHO sessions provides an opportunity for professionals to practice engaging in conversations about healthcare and systems barriers with autistic people rather than only listening to their voices and continuing to discuss the implications in groups solely with other healthcare providers. This engagement and integration between stigmatized communities and the majority group is a core component of reducing prejudice and bias [53,54].

The voices of autistic people have often been ignored in favor of the voices of neurotypical professionals and academics. Social norms, stereotypes, and ableist attitudes frequently exclude or discount autistic voices and marginalize them in ways neurotypical people may not notice. Our work to include and amplify autistic voices is part of the nascent but intellectually rich fields of neurodiversity and critical autism studies, which embrace identity, embodied knowledge, lived experience, disability studies, disability justice, and the social model of disability [55]. Scholarship and inquiries led by autistic people, in collaboration with non-autistic allies, offer previously unacknowledged possibilities to continue to seek the emancipation of autistic people. Through focusing attention to the power relations that shape the field of autism, concern to advance enabling narratives of autism challenging the predominant deficit-focused constructions, and commitment to developing analytical frameworks using inclusive and nonreductive approaches, it is possible to create emancipation and empowerment for autistic people [56].

Even within the disabled community, there is a hierarchy of whose voices and needs are centered, wherein people with intellectual disabilities or those who are non-speaking are excluded. This again highlights the need for more equitable and affirming understandings of disability, wherein each disabled person is seen as an individual who is an expert regarding their own life, experiences, needs, and strengths. All disabled people are not the same and deserve to have people in solidarity with them to acknowledge their differences, collaborate and network, and work toward common goals. We hope that interdisciplinary learning collaboratives like ECHO continue to be utilized to create a greater collaboration between all parties involved, contributing to appropriate changes being made in currently utilized systems.

Author Contributions: Conceptualization, all authors; data curation, K.A.C. and A.V.D.; writing—first draft preparation, K.A.C. and S.D.; writing—review and editing, all authors; project administration, J.M.; funding acquisition, J.M. All authors have read and agreed to the published version of the manuscript.

Funding: Project ECHO programming through the Washington INCLUDE collaborative is funded by the Washington State Health Care Authority.

Acknowledgments: Thank you to all our Project ECHO staff and participants who contributed their time, knowledge, and perspectives on this process of understanding the influence of Autistic self-advocate voice on the ECHO experience.

Conflicts of Interest: The authors declare no conflict of interest.

Position Statement: The authors of this paper include autistic individuals and their allies. Authors S. Davis, B. Moore, I. Moore, and S. Krebsbach identify as autistic. Authors K. Casagrande, A. Dahiya, and J. Mancini identify as allies to the neurodivergent community. This paper is a collaboration among the authors, and, as such, the writing style changes throughout to represent different voices and perspectives. We center the voices and lived experiences of autistic individuals, including those with co-occurring intellectual disabilities, mental health challenges, and physical disabilities. We acknowledge the important history of both person-first and identity-first language in the disability community [57,58] and use both in this paper. We use person-first language when referring to the broad category of intellectual and developmental disabilities but prioritize identify-first language when referring to autistic people based on the preferences of the Autistic community [59,60].

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