

Intellectual and Developmental Disabilities

Family Support ECHO: Enabling Community Providers to Support Families of Individuals with Disabilities

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Abstract

Little funding is allocated to helping individuals provide lifelong support for their family members with intellectual and/or developmental disabilities (I/DD). The North Carolina (NC) Family Support ECHO™ program was created to help family support specialists ($n = 50$) meet the needs of this population. This evaluation used a mixed-methods approach and revealed that, on average, participants agreed that they were satisfied with the NC Family Support ECHO™ program and improved their self-efficacy from pre- to post-assessment. This evaluation demonstrates the positive impact that NC Family Support ECHO™ has had on providers who support this population. Future research should aim to understand how the NC Family Support ECHO™ program improves outcomes for individuals with I/DD and their families.

Key words: Family support, Project ECHO, developmental disabilities

Family Support ECHO: Enabling Community Providers to Support Families of Individuals with Disabilities

Approximately seven million people with intellectual and/or other developmental disabilities (I/DD) live in the United States (Larson et al., 2020). Families are often expected to provide lifelong support needed by their family member with I/DD (Anderson et al., 2018). More than half of individuals with I/DD who receive Medicaid-funded services live with their family, yet only a small percentage of total I/DD spending is allocated to supporting families (Larson et al., 2020). Health and human service systems are complex, and many families of children with I/DD report difficulty accessing needed services and support. According to the 2020-2021 Adult Family Survey, administered as part of the National Core Indicators Project, 39% of families said that they were able to receive the information necessary to plan services for their disabled family member (National Core Indicators, 2022). Additionally, when asked if the information about services and supports that they receive is easy to understand, 24% of families selected the options indicating that this information is 'sometimes' or 'seldom or never' easy to understand.

Keeping families informed and able to provide care and support is key to maintaining the health of the individual with I/DD and the family unit. Enhancing the strengths and abilities of family members can ultimately improve the support they provide the individual and foster opportunities within the community (Hecht et al., 2011). The Developmental Disabilities Assistance and Bill of Rights Act (2000) includes a focus on the family, emphasizing the importance of enabling families to nurture their children while preserving, strengthening, and maintaining the family. The joint position statement issued by the American Association of Intellectual and Developmental Disabilities and The Arc emphasizes the need for comprehensive and universally accessible family support to strengthen families across their lifetime (2020).

Supporting Families

The goal of family support is not to replace clinical services, but to promote family well-being through community-based programs that enable the family to better care for and support their family member with a disability (Moody et al., 2020). Key elements of family support include helping families access needed resources, increasing their knowledge about a wide array of topics and systems, connecting with other families who have experience caring for a family member with I/DD, and decreasing their isolation (Moody et al., 2020).

Family support is associated with a variety of positive outcomes for the family including improved family functioning (Factor et al., 2019), increased family involvement in care decisions and advocacy (Ashcraft et al., 2019), and decreased family stress (Peer & Hillman, 2014). Families demonstrate resilience when they are supported and feel competent in performing essential family functions such as daily care, education, socialization, and protection. Family services and support should be designed to enable the family to maintain a sense of control, manage their life situations, and preserve valued social identities (McConnell & Savage, 2015). A focus on the unique needs, interests, and circumstances of a family can enable the family to successfully address the everyday adaptive challenges they face (McConnell & Savage, 2015). Therefore, family health, education, and support should be a core element of a comprehensive healthcare delivery system and should be made available to families throughout the many stages of life, including birth, early childhood, school years, transition to adulthood, adulthood, and aging (Ervin et al., 2014). By strengthening the family's capacities to support their family member with I/DD, family support provides benefits to the person with I/DD, the family unit, the community, and the state.

State and Federal Service Systems

State and federal disability service systems provide a variety of services and supports to individuals with I/DD. Medicaid home and community-based services (HCBS) waiver programs provide important long-term benefits and supports for eligible individuals with I/DD. Firsing and colleagues (2016) documented an improvement in caregiver-perceived outcomes (e.g., community participation,

transportation) for individuals receiving a HCBS I/DD Waiver. In North Carolina (NC), behavioral health and I/DD services are delivered by locally Managed Care Organizations under a 1915(b)/(c) Medicaid waiver (NC I/DD Waiver), also referred to as the NC Innovations Waiver. This Waiver covers an array of services including community living and support, day and residential supports, respite, supported living, and supported employment. The Five-Year Plan (2017-2021) released by the NC Council on Developmental Disabilities (2016) stated there were 188,124 children and adults with I/DD living in NC. More than 12,000 individuals with I/DD receive services provided by the NC I/DD waiver. However, the average wait for the NC I/DD waiver is between 7 and 10 years and in 2021 there were 15,000 people on the Registry of Unmet Needs waitlist (Franklin et al., 2022; Autism Society of North Carolina, 2021). Lengthy waitlists for services increase the demands on families and highlight their need for knowledge about community resources and connections with other families.

The ECHO™ Model

One model that has demonstrated success in disseminating expertise into community settings is the Extension for Community Healthcare Outcomes (Project ECHO™) program. ECHO™ is a technology-enabled learning model that was originally developed to address the lack of access to specialized care for patients with hepatitis C in New Mexico (Arora et al., 2007; Arora et al., 2016).

Project ECHO™ uses a guided-practice, hub-and-spoke model that engages community participant learners interested in gaining knowledge and hands-on learning in their given field (i.e., spokes) via video technology (i.e., Zoom). Through this model, spokes are connected to subject matter experts (i.e., hub members) who serve as teachers and mentors (Katzman et al., 2016). The benefits of the ECHO™ virtual learning community include bringing expertise to rural and low resourced communities and providers, enabling rapid and coordinated responses to emerging issues, and facilitating implementation of evidence-based practices to address population-level health disparities and improve systems of care. Furthermore, videoconferencing technology allows spokes and hub members from geographically dispersed locations to learn from and teach each other through brief presentations, case-

based learning, and group discussion, which can decrease the isolation often experienced by providers (Struminger et al., 2017).

Over the past 15 years, ECHO™ has grown to address multiple health conditions and human service needs across medical, behavioral health, and educational disciplines. ECHO™ program topics are based on community and learner needs and cover a wide array of topics, including opioids and medication assisted treatment (Salvador et al., 2019), diagnosis of and supports provided to autistic people (Dreiling et al., 2022), chronic pain (Carlin et al., 2017), hepatitis C (Arora et al., 2011), diabetes (Cantor et al., 2022), COVID-19 (Thies et al., 2021), and behavioral health (Hager et al., 2018).

Development of NC Family Support ECHO™

In response to the needs of families and individuals with I/DD, an increasing number of healthcare providers, disability providers, and advocacy organizations now employ family members with lived experience of supporting an individual with a disability to provide various types of support to other families. Organizations use a range of position titles, such as family partners, navigators, liaisons, resource specialists and advocates. These positions are often the go-to person for information, advocacy, and helping families to navigate the complexities of medical, educational, disability, social, and legal systems. The individuals providing family support often have limited contact with other family support specialists across the broader developmental disability community. Those living in rural communities may face additional challenges engaging with other family partners and accessing subject matter experts and resources. The individuals providing these critical family support services need access to information, training, best practices, and colleagues within and outside of their usual sphere of operation. At this time, the availability of family support services is variable across NC, and funding dedicated to this service is a small portion of total state allocations for I/DD and autism services and supports.

Since 2013 the I/DD Medical Health Home Initiative (I/DD MHHI) has partnered with individuals with I/DD, families, advocates, providers, state government, managed care organizations, and

thought leaders across NC to develop policy and practice recommendations that promote family and person-centered care for children and adults with I/DD and their families (Intellectual and Developmental Disability Medical Health Home Initiative [I/DD MHHI], 2023).

In 2018, the I/DD MHHI hosted a summit focused on the role of consultation with subject matter experts in advancing integrated care (I/DD MHHI, 2020). A presentation by the University of Wyoming Institute of Disabilities entitled “Using the ECHO™ model to address diverse learning needs” included a discussion of their use of the ECHO™ model to address family support and education. This information, coupled with the success of the TEACCH Autism Program ECHO™ for primary care and mental health providers (Dreiling et al., 2022), generated interest in the development of a NC Family Support ECHO™ program. The current evaluation aims to determine whether the NC Family Support ECHO™ program was successful at achieving their goals of (1) creating a program that meets the needs of the spoke participants, and (2) improving self-efficacy of spoke participants from pre- to post-participation. This evaluation also sought to (3) identify the barriers that make it difficult for spoke participants to provide quality family support services.

Methods

Overview of NC Family Support ECHO™

In February 2019, a group of family members with lived experience working within the disability services system and others who worked as I/DD providers began discussing the development of a NC Family Support ECHO™ pilot. The Arc of North Carolina and the Autism Society of North Carolina submitted the partnership agreement to the University of New Mexico, and the core planning team attended the May 2019 ECHO™ Immersion training in Albuquerque, New Mexico to prepare to launch the NC Family Support ECHO™ pilot.

After attending Immersion training and prior to program development, 50 professionals who provided or authorized family support services in NC were surveyed about topic areas that could inform

didactic instruction within a Family Support ECHO™ program. Many of these providers were also family members with lived experience. Table 1 includes 10 session topics that emerged from the survey results and were prioritized during the pilot program. This approach to curriculum development guided all future Family Support ECHO™ programs in the state. If spoke participants identified a need or interest related to family support, then the facilitators could make the decision to revise curriculum topics.

Honoring the fidelity of the ECHO™ model, which continues to guide the NC Family Support program today, the pilot program was launched in January 2020. The program included 8 weekly sessions that each lasted 1.5 hours. The hub team that led this pilot program included six members who were employed in a variety of direct service and leadership roles (i.e., director of advocacy, family partner, director of family support, education and outreach coordinator, and regional director of services). The pilot hub team composition reflected the commitment to the lived experience of individuals with I/DD, as four were family members of individuals with I/DD. Additionally, four of these members attended the 2019 Immersion training and oriented the remaining two hub members to the ECHO model upon their return.

The format allocated time in the beginning of each session for an introduction to the topic. Next, an expert in the field (i.e., either a hub member or guest speaker) gave a 15- to 20-minute didactic presentation about a predetermined topic. Presenters were selected based on their expertise, availability, and willingness to follow the ECHO™ model. Third, a de-identified family presentation was introduced by a spoke participant, which gave them an opportunity to receive feedback from their peers on a family case that they were presently supporting or had previously supported. During family presentations, participants described the family, the issue of concern, and the context surrounding the case, while complying with HIPAA regulations. This allowed spoke participants to gain knowledge of resources available for families and receive advice from other providers on potential strategies that would best support the family. The goal of family presentations is to prioritize engagement between spoke participants by encouraging them to ask questions, offer suggestions, provide resources, and to learn from

the family case that was being presented. Upon completion of the family presentation, there was a follow-up period in which a hub member summarized the case and led a discussion that considered the variety of spoke perspectives. Finally, each session concluded with logistical announcements.

Recruitment

Hub members were responsible for recruitment strategies and identifying potential spoke members who might be interested in and eligible for participation in the program. Individuals who were eligible included people who 1) worked in a region of NC that was offering the NC Family Support ECHO™ program, and 2) had a role (paid or unpaid) in a community organization of helping families and individuals with I/DD navigate resources and services. Multiple methods (e.g., email correspondence, word of mouth, phone calls, and flyers) were used to recruit individuals with a range of experience delivering family support in a variety of settings (e.g., public schools, community-based disability non-profits, hospitals, and Local Management Entity-Managed Care Organizations (LME-MCO)). Potential spoke participants were asked to complete an application to confirm their eligibility for the program. These strategies resulted in 55 spoke participants recruited for the NC Family Support ECHO™ programs. Of the 55 recruited participants, 5 withdrew their participation in the program.

Procedure

The current evaluation focuses on 4 NC Family Support ECHO™ programs that launched in 2021 and 2022. Two weeks prior to participation in the NC Family Support ECHO™ program, program evaluation staff emailed spoke participants a link to an online pre-assessment survey. Upon completion of the NC Family Support ECHO™ program, evaluation staff emailed a link to an online post-assessment survey and conducted a 30-minute interview with spoke participants. All assessment surveys were administered through Qualtrics, a secure web-based platform. Interviews were conducted via Zoom and were audio recorded and transcribed verbatim by the evaluation staff.

Measures

Pre and Post Assessments

Demographic Information. Spoke participants completed a brief demographic questionnaire that included employment characteristics such as years providing services to families of individuals with I/DD, prior training in family support and navigation, participation in previous ECHO™ programs, and reasons for participating in the NC Family Support ECHO™ program.

Self-efficacy. Participant self-efficacy was measured at pre- ($\alpha = .92$) and post-participation ($\alpha = .94$) in the NC Family Support ECHO™ program. This measure was created by the evaluation team, who modified the University of New Mexico Project ECHO self-efficacy survey template to capture the construct of self-efficacy within the context of family support. Participants rated their confidence in their knowledge of family support services, ability to refer families of individuals with I/DD to appropriate services, and ability to connect families of individuals with I/DD to resources. For example, participants rated their ability to discuss funding sources, benefits enrollment, healthcare navigation, advocacy, and crisis resources with families of individuals with I/DD. Participants rated their confidence on a 6-point Likert scale, with 1 indicating ‘no confidence’ and 6 indicating ‘highly confident’.

Satisfaction. After completion of the program, participants rated their satisfaction ($\alpha = .95$) with the NC Family Support ECHO™ on a 5-point Likert scale, with 1 indicating ‘strongly disagree’ and 5 indicating ‘strongly agree’. Participants endorsed their level of satisfaction regarding program areas such as improving their ability to serve families of individuals with I/DD, learning best practices from hub and spoke members, connecting with peers and colleagues, and the format of the sessions.

Barriers and Supports. In the pre-assessment survey, participants were also asked to report the barriers encountered when providing family support services from a list of common barriers that support professionals face (e.g., lack of resources, lack of knowledge about the LME MCO system). Additionally, participants were asked to respond to an open-ended question about the supports that would enable them to provide better quality services to their clients.

Semi-Structured Interviews

The semi-structured interview guide was initially developed by the team that attended the ECHO™ Immersion training in 2019. The guide was revised and finalized with input from individuals involved in the NC Family Support ECHO™ pilot and the evaluation team. Semi-structured interviews prompted participants to discuss the impact that the NC Family Support ECHO™ program had on the supports they provided to families of individuals with I/DD and their knowledge of community and regional resources. Additionally, participants were asked to offer recommendations to improve the program and ideas for recruitment of professionals who provide support to families of people with I/DD. Spoke participant quotes will be presented throughout the results section to support the evaluation findings.

Data Analysis

The evaluation team implemented a mixed-methods approach to provide a more comprehensive picture of the spoke experience. The quantitative data collected provides a standardized measure of changes in participant knowledge and self-efficacy, while the qualitative data enriches our understanding of the spoke experience through interview responses. In other words, the quantitative data collected tells us what changed because of participation in the NC Family Support ECHO™ program and the qualitative data collected tells us why and how it changed.

Quantitative Data Analysis

All analyses were conducted using Statistical Package for the Social Sciences (SPSS) Version 28.0. Spoke participant demographics gathered in the form of categorical variables are reported as frequencies, and results from continuous variables are displayed as means and standard deviations. Similarly, the satisfaction ratings that were collected during the post-assessment are reported as means and standard deviations. Assumptions for normal distribution (i.e., normality, independence, and no

extreme outliers) were met; therefore, a paired samples t-test was used to compare spoke participants' mean self-efficacy ratings on the self-report self-efficacy survey from pre- to post-participation.

Qualitative Data Analysis

The evaluation team created a structured document that included each interview question and corresponding participant responses. One member from the evaluation team was assigned to each interview transcript for analysis. They engaged in a rapid assessment process (RAP), which has been defined in the literature as an “intensive, team-based qualitative inquiry using triangulation, iterative data analysis and additional data collection to quickly develop a preliminary understanding of a situation from the insider’s perspective” (Beebe, 2001, p. xv). This process included creating summaries of the episodes and collaboratively identifying potential themes generated from the participants.

Results

The initial pilot programs, which were developed in Western North Carolina, included a core group of 6 hub members and 9 spoke participants. However, this program has rapidly spread throughout the state to include Central, Central East, and Southern Piedmont regions of North Carolina. This evaluation represents data from 50 spoke participants that provide family support services across the state of North Carolina (see Table 2 for demographic information). Three spokes have advanced into hub member roles and additional spokes are pursuing this opportunity. This growth reflects the impact this program has had on individuals providing family support services, leading to the uptake throughout the state.

Satisfaction with the NC Family Support ECHO™

Spoke participants indicated that they agreed with items (e.g., the information I received from NC Family Support ECHO experts is useful to me in my work) on the satisfaction scale ($M = 4.37$, $SD = 0.10$), illustrating that they were pleased with the content and structure of the NC Family Support ECHO™ program. For example, an autism resource specialist reflected on how her participation in the

NC Family Support ECHO™ program has influenced the support she provides families of people with I/DD. She stated, “It [NC Family Support ECHO™] has been a total lifeline” (White, Female). Spoke participants indicated the highest levels of agreement with information received from NC Family Support ECHO™ experts being useful, discussions with other ECHO participants enhancing knowledge about family support, and comfort using technology associated with NC Family Support ECHO™. All items with corresponding means and standard deviations are included in Table 3. Spoke participants for three of the four cohorts ($n = 32$) were also asked about their interest in participating in another Family Support ECHO™ or another ECHO™ program that focused on different content. Most of the spoke participants indicated that they were interested in participating in another Family Support ECHO™ (81.25%) and other ECHO™ programs (81.25%), which demonstrates the value of engaging in the technology-enabled learning model.

Self-Efficacy

Spoke participants indicated an overall improvement in their self-efficacy from the pre- ($M = 3.89$, $SD = 0.76$) and post- assessment ($M = 4.63$, $SD = 0.62$), revealing significant gains in self-efficacy following their participation in the NC Family Support ECHO™ program. For example, during one of the semi-structured interviews an autism services coordinator stated, “I really, honestly felt it [NC Family Support ECHO™] was just very beneficial, not only to expand my knowledge, but to expand my confidence in sharing that information with families” (White, Female), supports the quantitative survey results. Ratings of each item are included in Table 4.

Barriers

Prior to engagement in the NC Family Support ECHO™ program, spoke participants were asked to identify barriers to providing family support that they experienced within their role. Participants most frequently identified the lack of community resources (42%), inadequate funding for these services (42%), and lack of knowledge about the LME-MCO system (38%) as barriers to providing family

support. Table 2 includes the number of participants who endorsed each item as a barrier within their work.

Discussion

The current evaluation used quantitative and qualitative methodologies to determine NC Family Support ECHO™ participants' perspective on the impact of this tele-mentoring program. Participants reported their satisfaction with various aspects of the program, self-efficacy before and after the program, and perceived barriers to providing family support. Evaluation findings from the NC Family Support ECHO™ suggest that it is an innovative and cost-effective approach to address family needs.

Satisfaction with the NC Family Support ECHO™

Post evaluation findings documented high satisfaction with the NC Family Support ECHO™, with the majority stating an interest in participating in another ECHO™ program. All satisfaction items, on average, ranked above 4 on a 5-point scale. Three of the highest ranked items documented the educational value (i.e., information is useful to my work, discussions with others enhanced my knowledge) and the accessibility (i.e., comfortable using technology associated with NC Family Support ECHO) of the ECHO™ sessions. Given that providers are faced with increasing staff training requirements, additional training opportunities must be considered relevant, engaging, and feasible. Didactic topics ranked of lesser value were generally described as not relevant for the specific participant's position or the learner had prior knowledge of the topic. For example, a participant responsible for employment services may not find early intervention topics as relevant to their daily work. The didactic topics have evolved beyond the initial pilot curriculum, demonstrating responsiveness to participant feedback and the potential to address an array of learner needs.

Workforce shortages are well-documented in the disability and human service sector (Wright et al., 2022; Hewitt et al., 2008) and require innovative and cost-effective ways to train and retain staff. The North Carolina Family Support ECHO™ Program offers a structured opportunity for providers to expand

their knowledge base and build connections with other providers in their communities, both essential elements of best practices in integrated care.

By connecting North Carolina Family Support ECHO™ spoke and hub members to other ECHO programs (e.g., chronic disease management, palliative care, social determinants of health) there is an opportunity to promote bi-directional learning and collaboration. Health and human service providers can learn from those with I/DD experience even when this may not be their primary patient or member population.

Self-Efficacy of Spoke Participants

Self-efficacy is an individual's belief that they can act and succeed in specific situations, which is believed to be a predictor of behavior changes (Bandura, 1977). Project ECHO™ programs have long incorporated self-efficacy measures into their evaluations to capture a potential shift in the behavior of health care professionals. Numerous published studies on Project ECHO™ programs have documented improved self-efficacy among professionals. Such studies included a variety of health topics, populations including autistic adults and children (Dreiling et al., 2022), and treatments, including treatments for HIV (Wood, 2016), chronic pain (Katzman et al., 2014), and diabetes (Colleran et al., 2012) as well as education related to palliative care interventions (White et al., 2019). Similarly, the NC Family Support ECHO™ survey showed positive change in overall self-efficacy of spoke participants.

The three items that participants indicated the greatest improvement from pre- to post-assessments were connecting families to appropriate healthcare providers and resources, identifying additional financial support resources for families who are uninsured or under-insured, and establishing family-to-family connections within the disability community. These items directly align with goals of the NC Family Support ECHO™: establishing meaningful relationships with families and helping families navigate complex service systems and the related funding requirements. Moreover, the program evaluation data from the Wyoming ECHO™ for Families reported similar findings, such that participants

identified improved skills and self-efficacy, as well as increased connections with families (Moody et al, 2020).

Most spoke participants gave family presentations and agreed that engaging in a family presentation increased knowledge about how to better serve families (i.e., rated 4.34 on a 5-point Likert scale). When asked about the value of family presentations, one participant stated, *“I think they are really good, and it puts a real-world scenario to the different topics we reviewed and opens up more resources and things on the different topics.”* (White, Female).

The qualitative interviews also illustrated the spoke participants’ increased confidence that resulted from participation in the NC Family Support ECHO™ program. For example, interview themes included comfort with the group process, increased confidence in referring families to community resources, and the importance of a collaborative approach to family support. When a participant was prompted to consider the biggest surprise she experienced during her participation, she reflected on how comfortable she felt throughout the program: *“Usually in group dynamics I feel shy to speak up, but [the] entire energy was like no wrong answers and that was surprising”* (White, Female). The interview responses related to self-efficacy document the value participants place on collaboration and relationships with peers, which creates a framework for the expansion of the NC Family Support ECHO™ program.

It is noteworthy that several spoke participants have built upon this confidence and knowledge by completing the University of New Mexico ECHO™ immersion/partner launch training, becoming hub members, and actively recruiting new spoke participants from their organizations and communities. The self-efficacy and knowledge gains reported by spoke participants in the NC Family Support ECHO™ program illustrates the “All Teach, All Learn” mission that guides Project ECHO™ programs, such that hub and spoke participants learn from one another as they share experiences, ideas, and resources while engaging in collaborative problem solving. This learning loop enables community members to learn from each other and from subject area experts. Furthermore, experts can learn from those in the community. This interactive approach promotes peer-to-peer learning and real time sharing of best practice models,

strategies, and resources. Additionally, the knowledge and self-efficacy gains has facilitated the transition of several spokes into a hub role.

Barriers

Participants noted barriers to offering family support services were the lack of community resources, inadequate funding for community services, and limited knowledge about the evolving state Medicaid managed care system. Although NC Family Support ECHO™ alone cannot mitigate these barriers, hub members and spoke participants can advocate for policy and resource allocation changes at a local, state, and federal level. For example, service definitions are often narrow, rigid, and based on “out-of-date” service delivery models and best practices. It would be beneficial to families and providers alike if policies were to allow for flexible funding, such as the use of voucher payments, so that families can address their needs in a timely manner. Additionally, family support should be more accessible by being available in multiple contexts and settings, such as schools, communities of faith, and medical practices as well as across the lifespan.

Over the course of four years, the NC Family Support ECHO™ program has grown from a pilot to an established program that is offered twice each year. Keys to building a successful Family Support ECHO™ include focusing on the needs of the learners and engaging knowledgeable hub members: families with lived experience, professionals who are responsible for family support services, and organizations responsible for policies and resource allocation that impact families. The participants’ positive response to the didactic topics, family presentations, and peer connections demonstrates the potential of the NC Family Support ECHO™ to educate those who provide services to families and to foster a multidisciplinary and inclusive community of learners.

Evaluation Strengths and Limitations

Although ECHO™ programs were originally designed for medical providers, they have evolved to address the needs of a wide range of learners and community health priorities. The NC Family Support

ECHO™ brings together participants from multiple health and human service systems, including disability, healthcare, education, social services, and employment. It was designed to ensure leadership by family members with lived experience of caring for someone with I/DD. This is in response to the growing body of evidence on the value of lived experience for outreach to and engagement with specific populations, and the positive effect peers can have on individuals and service systems (Skelton-Wilson et al., 2022).

Although the NC Family Support ECHO™ program has its strengths, the evaluation is not without limitations. The participant demographics reflect the program's appeal to a wide age range (20 to 69 years) of family support specialists. However, 92% of participants identified as female, slightly higher than the US Bureau of Labor Statistics 2021 finding that 78% of employees in the healthcare and social assistance workforce are female (U.S. Bureau of Labor Statistics, 2022). Furthermore, a majority of participants indicated their racial identity to be White or Caucasian (67%). Although this matches the US Census Bureau North Carolina population racial demographics, the NC Family Support ECHO programs recognize the importance of continued outreach to diverse communities, providers, subject matter excerpts and guest speakers (U.S. Census Bureau, 2022). Hispanic or Latino participant representation was 6%, below the state population average of 10.5%. This is an area of concern given the Hispanic population is the fastest growing population demographic in the state (Tippett, 2021). Comprehensive outreach and recruitment strategies are needed to ensure a diverse and inclusive program that provides equitable access to ECHO™ programs. Recruitment has successfully expanded statewide, indicating that this educational, tele-mentoring program is meeting a statewide need and there are opportunities for expansion.

In addition to recruitment challenges, another limitation of the current evaluation was the choice to assess only the barriers that existed for spoke participants prior to the NC Family Support ECHO program. Without assessing barriers that exist for spoke participants at post-assessment, we cannot

determine whether the NC Family Support ECHO program addressed the issues that were identified by program participants.

Lastly, it is well documented that self-report measures have the potential to be vulnerable to response bias (Donaldson & Grant Vallone, 2002); thus, an additional limitation to the present evaluation is that all data was collected through self-report surveys.

Recommendations for Future Evaluations and Practice

Future studies are needed to evaluate the impact of the NC Family Support ECHO™ program on the families served by the providers who participate in the ECHO™ program. Future evaluations should explore how the NC Family Support ECHO™ addresses health disparities experienced by families and individuals with I/DD, within a framework that considers both medical outcomes and social drivers of health. An increased focus on recruitment and engagement of diverse hub and spoke participants is critical given changing state and national demographics. Furthermore, efforts to evaluate the extent to which demographic characteristics (e.g., age, gender, race) impact the satisfaction and self-efficacy of ECHO members may inform future adaptations to the curriculum to be more inclusive. ECHO™ programs need to increase engagement with funders and organizations responsible for policies, programs, and resource allocation to ensure sustainability and expansion of programs. Building a network of ECHO™ programs focused on family support can add to the evidence and efficiency of Family Support programs.

To maintain and expand the NC Family Support Program, it is imperative that program managers and policy makers recognize the value of the program and actively engage in advocacy efforts. For example, program managers can identify the NC Family Support ECHO™ as a valued staff training resource and ensure staff are able to participate, and state Medicaid can authorize the funding of ECHO™ programs in MCO contracts. Furthermore, policymakers can also encourage MCOs and health plans to utilize community investment funds to support ECHO™ programs and family support services.

Collaboration with academic programs to document the value proposition of the NC Family Support ECHO™ program will strengthen the rationale for expanded funding.

Conclusion

Despite increasing numbers of people with I/DD living with family for longer periods of time, the availability of services varies, and those in rural communities face additional challenges in accessing services and qualified providers. Family support services can promote healthier families and communities by emphasizing collaboration with community partners and enabling families to navigate the complexities of disability, health, and human service systems. Although provider agencies are responding to this need by increasing the focus on family support services, staff often work in isolation and face challenges with making connections to resources outside of their service domain.

There is a need for comprehensive, accessible, and effective family support services that meet the needs of families of children and adults with I/DD and align with the goals of Medicaid managed care and integrated care. Family support provides benefits to the person with I/DD, the family unit, the community, and the state. The ECHO™ model promotes a person- and family-centered philosophy with an emphasis on shared learning and connections. Evaluation findings document the efficacy of the NC Family Support ECHO™ program and offer an innovative approach to engaging those who support families in urban and rural communities. The NC Family Support ECHO™ has demonstrated that program growth and sustainability can occur when programs use evidence-based models, are built on strong partnerships with the community, and measure and document outcomes.

References

- American Association on Intellectual and Developmental Disabilities & The Arc. (2020). *Family support* [Position statement]. <https://www.aaid.org/news-policy/policy/position-statements/family-support>
- Anderson, L., Hewitt, A., Pettingell, S., Lulinski, A., Taylor, M., & Reagan, J. (2018). *Family and individual needs for disability supports (v.2) community report 2017*. Minnesota: ---Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. https://thearc.org/wp-content/uploads/2019/07/FINDS_report-2017-FINAL-VERSION.pdf
- Arora, S., Kalishman, S., Thornton, K., Komaromy, M., Katzman, J., Struminger, B., & Rayburn, W. F. (2016). Project ECHO (Project Extension for Community Healthcare Outcomes): A national and global model for continuing professional development. *Journal of Continuing Education in Health Professions, 36*, S48-49.
- Arora, S., Thornton, K., Jenkusky S. M., Parish, B., & Scaletti, J. V. (2007). Project ECHO: Linking university specialists with rural and prison-based clinicians to improve care for people with chronic hepatitis C in New Mexico. *Public Health Reports, 122*(Suppl. 2), 74-77.
- Arora, S., Thornton, K., Murata, G., Deming, P., Kalishman, S., Dion, D., Parish, B., Burke, T., Pak, W., Dunkelberg, J., Kistin, M., Brown, J., Jenkusky, S., Komaromy, M., & Qualls, C. (2011). Outcomes of treatment for hepatitis C virus infection by primary care providers. *New England Journal of Medicine, 364*(23), 2199-2207.
- Ashcraft L. E., Asato, M., Houtrow, A. J., Kavalieratos, D., Miller, E., & Ray, K. N. (2019). Parent empowerment in pediatric healthcare settings: a systematic review of observational studies. *The Patient-Patient-Centered Outcomes Research, 12*, 199-212.

- Autism Society of North Carolina. (2021). *The Innovations Waiver and Registry of Unmet Needs*.
https://www.autismsociety-nc.org/wp-content/uploads/Innovation-Waiver-and-Registry-of-Unmet-Needs_June2021.pdf
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, 84(2), 191–215.
- Beebe, J. (2001). *Rapid Assessment Process: An introduction*. AltaMira Press.
- Cantor, J. C., Chakravarty, S., Farnham, J., Nova, J., Ahmad, S., & Flory, J. H. (2022). Impact of a provider tele-mentoring learning model on the care of Medicaid-enrolled patients with diabetes. *Medical Care*, 60(7), 481-487.
- Carlin, L., Zhao, J., Dubin, R., Taenzer, P., Sidrak, H., & Furlan, A. (2018). Project ECHO tele-mentoring intervention for managing chronic pain in primary care: Insights from a qualitative study. *Pain Medicine*, 19(6), 1140-1146.
- Colleran, K., Harding, E., Kipp, B. J., Zurawski, A., MacMillan, B., Jelinkova, L., Kalishman, S., Dion, D., Som, D., & Arora, S. (2012). Building capacity to reduce disparities in diabetes: Training community health workers using an integrated distance learning model. *The Diabetes Educator*, 38(3), 386–396.
- Donaldson, S. I., & Grant-Vallone, E. J. (2002). Understanding self-report bias in organizational behavior research. *Journal of Business and Psychology*, 17(2), 245-260.
- Dreiling, N. G., Cook, M. L., Lamarche, E., & Klinger L. G. (2022). Mental health Project ECHO Autism: Increasing access to community mental health services for autistic individuals. *Autism*, 26(2), 434-445.
- Ervin D. A., Hennen, B., Merrick, J., & Morad, M. (2014). Healthcare for persons with intellectual and developmental disability in the community. *Frontiers in Public Health*, 2.
- Factor, R. S., Ollendick, T. H., Cooper, L. D., Dunsmore, J. C., Rea, H. M., & Scarpa, A. (2019). All in the family: A systematic review of the effect of caregiver-administered autism spectrum disorder

- interventions on family functioning and relationships. *Clinical Child and Family Psychology Review*, 22, 433-457.
- Firsing, S. L., Dantzler, J. A., Hackman, C., Rush, S. E., Borkovich, R. A., & Delpont, J. (2016). Exploration of the effects of Medicaid home and community-based services waiver services on outcomes for people with intellectual disability. *Inclusion*, 4(2), 120-132.
- Fisher, E., Madondo, K., Weiss, L., & Pagan, J. A. (2017). Project ECHO Evaluation 101: A practical guide for evaluating your program. The New York Academy of Medicine. Available at: <http://nyshealthfoundation.org/resourcesand-reports/resource/project-echo-evaluation-101>.
- Franklin, M. S., Bush, C., Jones, K. A., Davis, N. O., French, A., Howard, J., Greiner, M.A., & Maslow, G. R. (2022). Inequities in receipt of the North Carolina Medicaid waiver among individuals with intellectual disability or autism spectrum disorder. *Journal of Developmental & Behavioral Pediatrics*, 43(7), 393-401.
- Hager, B., Hasselberg, M., Arzubi, E., Betlinski, J., Duncan, M., Richman, J., & Raney, L. E. (2018). Leveraging behavioral health expertise: Practices and potential of the Project ECHO approach to virtually integrating care in underserved areas. *Psychiatric Services*, 69(4), 366-369.
- Hecht, E., Reynolds, M., Agosta, J., McGinley, K., & Moseley, C. (2011). *Building a national agenda for supporting families with a member with intellectual and developmental disabilities* [Report of the Wingspread Summit]. Racine, WI: Johnson Foundation. <https://dzp4370ojv4q1.cloudfront.net/wp-content/uploads/sites/74/2017/05/Wingspread.pdf>
- Hewitt, A., Larson, S., Edelstein, S., Seavey, D., Hoge, M. A., & Morris, J. (2008) A synthesis of direct service workforce demographics and challenges across intellectual/developmental disabilities, aging, physical disabilities, and behavioral health. *National Direct Service Workforce Resource Center*. <https://rtc.umn.edu/docs/Cross-DisabilitySynthesisWhitePaperFINAL.pdf>
- Intellectual and Developmental Disability Medical Health Home Initiative. (2020). *North Carolina Family Support ECHO Pilot: A Summary of Planning, Implementation, Evaluation, and Recommendations*.

[http://www.iddmedicalhealthhomencinitiative.com/images/NC Family Support ECHO Pilot-Final-Report-November-2020.pdf](http://www.iddmedicalhealthhomencinitiative.com/images/NC_Family_Support_ECHO_Pilot-Final-Report-November-2020.pdf)

Intellectual and Developmental Disability Medical Health Home Initiative. (2023). *North Carolina Medical Health Home Initiative*. Retrieved April 25, 2023 from

<http://www.iddmedicalhealthhomencinitiative.com/>

Katzman, J. G., Comerci, G., Jr, Boyle, J. F., Duhigg, D., Shelley, B., Olivas, C., Daitz, B., Carroll, C., Som, D., Monette, R., Kalishman, S., & Arora, S. (2014). Innovative telementoring for pain management: Project ECHO pain. *The Journal of Continuing Education in the Health Professions*, 34(1), 68–75.

Katzman, J. G., Galloway, K., Olivas, C., McCoy-Stafford, K., Duhigg, D., Comerci, G., Kalishman, S., Buckenmaier, C.C., McGhee, L., Joltes, K., Bradford, A., Shelley, B., Hernandez, J., & Arora, S. (2016). Expanding health care access through education: Dissemination and implementation of the ECHO model. *Military Medicine*, 181(3), 227-235.

Larson, S. A., Eschenbacher, H. J., Taylor, B., Pettingell, S., Sowers, M., & Bourne, M. L. (2020). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2017*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. https://ici-s.umn.edu/files/aCHyYaFjMi/risp_2017.pdf?preferredLocale=en-US

McConnell, D., & Savage, A. (2015). Stress and resilience among families caring for children with intellectual disability: expanding the research agenda. *Current Developmental Disorders Reports*, 2, 100-109.

Moody, E. J., Sturges, H. A., Zlatkovic, S., Dahl, E., Root-Elledge, S., & Hardesty, C. (2020). A public health approach to family supports: Empowering families of children with autism through the ECHO model. *International Review of Research in Developmental Disabilities*, 59, 163-193.

National Core Indicators. *Adult Family Survey, 2020-2021 Final Report*. (2022). National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute.

https://legacy.nationalcoreindicators.org/upload/core-indicators/2020-2021_AFS_National_Report.pdf

North Carolina Council on Developmental Disabilities. (2016). *2017-2021: Five Year State Plan*.

<https://nccdd.org/five-year-plan.html>

North Carolina Department of Health and Human Services. (2022). *Medicaid Delivery Reform and Value-Based Payment Update*. <https://medicaid.ncdhhs.gov/medicaid-delivery-reform-and-value-based-payment-update/download?attachment>

Peer, J. W., & Hillman, S. B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 92-98.

Salvador, J., Bhatt, S., Fowler, R., Ritz, J., James, R., Jacobsohn, V., Brakey, H.R., & Sussman, A. L. (2019). Engagement with Project ECHO to increase medication-assisted treatment in rural primary care. *Psychiatric Services, 70*(12), 1157-1160.

Skelton-Wilson, S., Sandoval-Lunn, M., Zhang, X., Stern, F., & Kendall, J. (2022). *Methods and Emerging Strategies to Engage People with Lived Experience*. Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. <https://aspe.hhs.gov/reports/lived-experience-brief>

S.1809 - 106th Congress (1999-2000): Developmental Disabilities Assistance and Bill of Rights Act of 2000. (2000, October 30). <https://www.congress.gov/bill/106th-congress/senate-bill/1809>

Struminger, B., Arora, S., Zalud-Cerrato, S., Lowrance, D., & Ellerbrock, T. (2017). Building virtual communities of practice for health. *Lancet, 390*(10095), 632–634.

Tippett, R. (2021). *North Carolina's Hispanic Community: 2021 Snapshot*. Carolina Population Center, University of North Carolina at Chapel Hill. <https://www.ncdemography.org/2021/10/18/north-carolinas-hispanic-community-2021-snapshot/>

- Thies, K. M., Gonzalez, M., Porto, A., Ashley, K. L., Korman, S., & Lamb, M. (2021). Project ECHO COVID-19: vulnerable populations and telehealth early in the pandemic. *Journal of Primary Care & Community Health, 12*.
- U.S. Bureau of Labor Statistics (2022). Over 16 million women worked in health care and social assistance in 2021. *The Economics Daily*. <https://www.bls.gov/opub/ted/2022/over-16-million-women-worked-in-health-care-and-social-assistance-in-2021.htm>
- U.S. Census Bureau. (2022). *Quick facts: North Carolina*. U.S. Department of Commerce. <https://www.census.gov/quickfacts/fact/table/NC/PST045222#PST045222>
- White, C., McIlfatrick, S., Dunwoody, L., & Watson, M. (2019). Supporting and improving community health services—a prospective evaluation of ECHO technology in community palliative care nursing teams. *BMJ Supportive & Palliative Care, 9*(2), 202–208.
- Wood, B. R., Unruh, K. T., Martinez-Paz, N., Annese, M., Ramers, C. B., Harrington, R. D., Dhanireddy, S., Kimmerly, L., Scott, J. D., & Spach, D. H. (2016). Impact of a telehealth program that delivers remote consultation and longitudinal mentorship to community HIV providers. *Open Forum Infectious Diseases, 3*(3):ofw123.
- Wright, C., Hensley, V., Emery, N., & Swanson, P. (2022). The where and the how: Ensuring those with disabilities have the people power for healthy living. *Delaware Journal of Public Health, 8*(3), 90–92.

Table 1
2019 Pilot Curriculum

Week	Topic
Week 1	Self-Care
Week 2	Housing Overview
Week 3	Medicaid and Accessing Services
Week 4	Guardianship
Week 5	Self-advocates
Week 6	Health and wellness
Week 7	SSI & SSDI
Week 8	IEP basics
Week 9	ABLE accounts
Week 10	Know your regional resources

Note. ABLÉ = Achieving a Better Life Experience; IEP = Individualized Education Program; SSDI = Social Security Disability Insurance; SSI = Supplemental Security Income

Table 2
Spoke Participant Characteristics (n = 50)

Variable	n	%
Age (years)		
20-29	9	18
30-39	10	20
40-49	18	36
50-59	5	10
60-69	8	16
Gender		
Female	46	92
Male	3	6
Non-binary	1	2
Race ^a		
American Indian or Alaska Native	1	2.04
Asian	1	2.04
Black or African American	11	22.45
Multi-racial	1	2.04
White or Caucasian	33	67.35
Prefer not to answer	2	4.08
Ethnicity		
Not Hispanic or Latino	46	92
Hispanic or Latino	3	6
Prefer not to answer	1	2
Barriers to providing family support ^b		
Lack of time	15	30
Lack of support from management	0	0
Lack of community resources	21	42
Inadequate funding for this service	21	42
Lack of support from community	2	4
Lack of knowledge about the LME-MCO system	19	38
Lack of knowledge about community services and resources	17	34
Lack of confidence in my ability to support families dealing with complex situations	9	18
Lack of confidence in my ability to advocate with healthcare, human service, and education systems	8	16
Lack of training in family support and navigation	7	14
Lack of appropriate supervision	0	0

Lack of contact with others who provide family support services	9	18
Other ^c	13	26
<hr/>		
Variable	<i>M (SD)</i>	
<hr/>		
Year(s) providing services	9.56 (7.97)	
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Note. LME-MCO = Local Management Entity/Managed Care Organizations; *M* = mean; *SD* = standard deviation; Participants were not required to respond to all questions.

^a variable contains missing data. 49 participants reported their race.

^b response categories were not mutually exclusive.

^c examples of barriers provided by participants include “more comprehensive trainings” and “state-wide resource connections.”

Table 3*Spoke Satisfaction Ratings (n= 44)*

Variable	<i>M (SD)</i>
Participation in NC Family Support ECHO improved my ability to provide quality services to families.	4.30 (0.76)
I learned best practices in family navigation and support through participation in NC Family Support ECHO.	4.20 (0.85)
I was able to connect with peers and colleagues through my participation in NC Family Support ECHO.	4.30 (0.82)
NC Family Support ECHO experts provided guidance in supporting families across the lifespan.	4.32 (0.77)
The information I received from NC Family Support ECHO experts is useful to me in my work.	4.48 (0.70)
Didactic presentations enhanced my knowledge about family navigation, support, and resources.	4.41 (0.76)
Discussions with other ECHO participants enhanced my knowledge about family support.	4.43 (0.79)
The family presentation review increased my knowledge about how to better serve families.	4.34 (0.81)
I have been comfortable using the technology associated with NC Family Support ECHO.	4.52 (0.51)
Technology for NC Family Support ECHO functioned smoothly.	4.41 (0.79)

Note. M = mean; SD = standard deviation

Table 4*Spoke Self-Efficacy Ratings (n = 44)*

Variable	Pre-Assessment <i>M (SD)</i>	Post-Assessment <i>M (SD)</i>
Establish a professional partnership with families.	4.86 (2.34)	5.14 (0.65)
Explain the variety of federal and state funding sources that may be available to families.	3.42 (1.84)	4.20 (0.93)
Answer family questions about I/DD (including ASD) and know how to link them to available resources.	4.17 (2.11)	4.98 (0.81)
Connect a family to the LME-MCO for eligibility and enrollment in services.	4.00 (2.21)	4.76 (1.00)
Connect a family to appropriate healthcare providers and resources.	3.56 (1.93)	4.80 (0.84)
Partner with families to facilitate supported decision-making/restoration of rights with their family member.	3.78 (2.07)	4.75 (0.83)
Connect a family to the Social Security Administration for benefits enrollment.	3.44 (2.00)	4.52 (0.99)
Discuss the educational system and the Exceptional Children process with families.	3.69 (2.02)	4.73 (0.92)
Establish family to family connections within the disability community.	3.64 (1.91)	4.75 (0.91)
Guide families through the appeal/grievance process if services/supports are denied.	3.03 (1.78)	3.95 (1.28)
Know how to take care of myself to prevent burnout.	4.06 (2.07)	4.27 (0.81)
Identify community resources that can address social determinants of health (essential community living needs such as housing, transportation, food).	3.72 (1.93)	4.52 (0.89)
Educate families on the importance of family self-care.	4.25 (2.07)	4.89 (0.79)
Provide information on guardianship, alternatives to guardianship, and supported decision-making to families.	3.58 (1.99)	4.50 (0.89)
Identify additional financial support resources for families who are uninsured or under-insured.	2.81 (1.54)	4.02 (1.03)
Teach families how to advocate for their family member.	4.5 (2.18)	4.95 (0.76)
Connect families to supportive parenting education resources.	3.81 (1.97)	4.57 (0.91)
Connect families to crisis services and resources.	3.75 (2.00)	4.59 (0.91)
Maintain appropriate boundaries with family members.	4.78 (2.37)	5.05 (0.82)

Note. ASD = autism spectrum disorder; I/DD = intellectual and developmental disabilities; LME-MCO = Local Management Entity/Managed Care Organizations; M = mean; SD = standard deviation