American Journal on Intellectual and Developmental Disabilities

Caregiver ECHO: A Model for Delivering Virtual Behavior Management Education to Families of Children with Neurodevelopmental Disorders

--Manuscript Draft--

Manuscript Number:	AJIDD-D-24-00036R1
Article Type:	Research Report
Keywords:	Intervention; mental health disorders; parent education; social support; telehealth
Corresponding Author:	Rose Nevill University of Virginia School of Education and Human Development Charlottesville, VA UNITED STATES
First Author:	Rose Nevill
Order of Authors:	Rose Nevill
	Gail Lovette
	Katherine Bateman
	Natalie Badgett
	Genevieve Lyons
	Emily Fuhrmann
	Genevieve Bohac
	Karen Orlando
	Keith Page
Manuscript Region of Origin:	UNITED STATES
Abstract:	Children with neurodevelopmental disorders (NDD) are at high risk of challenging behavior, yet families experience consistent barriers to affordable parent education in behavior management. This study tested the efficacy of a caregiver-focused Extensions of Community Health Outcomes (ECHO) program in delivering behavior management education and support to caregivers of children with NDD. A pre-post design was used to evaluate impact on 30 caregivers' behavioral knowledge, self-efficacy in managing challenging behavior, empowerment, and negative emotional reactions to challenging behavior. Participation resulted in significant improvements across outcomes and high satisfaction. The Caregiver ECHO model offers advantages in that it emphasizes peer learning, active problem-solving, and community building as core components of its approach while using low-cost methodologies.

RUNNING HEAD: Caregiver ECHO

Caregiver ECHO: A Model for Delivering Virtual Behavior Management Education to Families of Children with Neurodevelopmental Disorders

Abstract

Children with neurodevelopmental disorders (NDD) are at high risk of challenging behavior, yet families experience consistent barriers to affordable parent education in behavior management. This study tested the efficacy of a caregiver-focused Extensions of Community Health Outcomes (ECHO) program in delivering behavior management education and support to caregivers of children with NDD. A pre-post design was used to evaluate impact on 30 caregivers' behavioral knowledge, self-efficacy in managing challenging behavior, empowerment, and negative emotional reactions to challenging behavior. Participation resulted in significant improvements across outcomes and high satisfaction. The Caregiver ECHO model offers advantages in that it emphasizes peer learning, active problem-solving, and community building as core components of its approach while using low-cost methodologies.

Keywords: Neurodevelopmental disorders, intervention, mental health disorders, parent education, social support, telehealth, virtual

Children with NDD display higher rates of challenging behavior (CB) – behaviors that risk harm to self or others, negatively impact learning, or reduce community inclusion – than children without DD (Emerson et al., 2014; Nicholls et al., 2020). While evidence-based models for addressing CB have been developed, such as positive behavior supports and applied behavior analysis, these treatments remain difficult for families of children with NDD to access. Many states only mandate insurance coverage of behavioral therapy for people with an autism diagnosis, despite ample evidence of behavioral principles being effective across behaviors and diagnoses (Heinicke & Carr, 2014; LaRue et al., 2015; Salloum et al., 2016). Affordable access to behavioral therapies is also limited by the number of providers, long waitlists, age discrimination, and disparities in diagnostic access (Trump & Ayres, 2019). Lacking access to behavioral and related supports disempowers families of children with NDD; from a theoretical perspective, disempowerment reduces caregivers' strength to make decisions and create positive change (Israel et al., 1994). This in turn increases families' social isolation (Halstead et al., 2018) and parenting stress (Barroso et al., 2018), and reduces quality of life (Zeng et al., 2020). As such, further research identifying inexpensive and accessible methods for delivering behavior supports to a broad range of NDD is critical (Zeng et al., 2020).

Parent education in evidence-based interventions has been established as an effective method for increasing families' capacities to address child CB. Parent education in behavioral interventions, specifically, has been shown to effectively reduce CB (Machalicek et al., 2016; Pennefather et al., 2018; Vismara et al., 2018) and increase parents' self-efficacy in behavior management (Bearss et al., 2018). One key benefit of parent education programs is that they are typically delivered in a group format, providing valuable education and access to a peer network. Social support has been identified as a key predictor of resilience among parents of children with

NDD (Peer & Hillman, 2014).

The ECHO Model

The ECHO model is an innovative telehealth-based model that provides education and opportunities for community building. The four core ingredients of the ECHO model are a) using technology to leverage scarce resources, b) disseminating best practices to reduce disparities, c) using case-based learning to build expertise, and d) outcomes monitoring through data collection (Project ECHO, 2021). ECHOs virtually connect an interdisciplinary “hub” team of experts, typically university-based clinicians, with community-based practitioners or “spokes”, over a free teleconferencing platform such as Zoom® for regular ECHO sessions to provide education and support around a condition (e.g., autism) or problem (e.g., burnout amongst healthcare workers). In each session, a hub team member delivers a short 15-20-minute workshop on a relevant topic, and a spoke presents the case of a deidentified patient or client with a guiding question (e.g., “should my patient be evaluated for autism?”) for peer consultation. The deidentification of patients is essential for facilitating cross-region consultation from licensed healthcare professionals. All attendees engage in group-based problem solving to generate recommendations for the spoke, which in turn facilitates learning in spokes and hub members and community building (Arora et al., 2011).

Previous empirical evaluations of the ECHO model have demonstrated its efficacy, particularly in disseminating knowledge to providers on how to address rare healthcare conditions about which they had limited to no expertise. While it was originally developed to increase medical practitioners’ capacity to treat Hepatitis C (Arora et al., 2014), it has been expanded for use with NDD populations, such as autism (e.g., Mazurek et al., 2017), and practitioners in allied healthcare settings (Project ECHO, University of New Mexico School of

Medicine, 2021), and special educators in schools (Root-Elledge et al., 2018).

There has been a call to use the ECHO model for empowering and supporting caregivers of children with autism, specifically (Moody et al., 2020). Use of ECHO with caregivers has the potential to offer advantages for children with autism and other NDD above and beyond other parent education models such as parent-focused group therapy, given that it focuses on parenting skills, peer-to-peer learning, resource connection, and social support, rather than parent education or parent outcomes in isolation. To date, there has been only one empirical evaluation of an ECHO application with caregivers (Bateman et al., 2023). Seventeen parents of children with NDDs received education on addressing CB using applied behavior analytic techniques through a 16-week program. Results from pre-post testing found significant improvements on some, but not all subscales of the Family Empowerment Scale and the Parenting Sense of Competence Scale. Authors posited that the non-significant findings for some subscales assessing parenting values, comfort with parenting, and parenting self-efficacy may have been due to measurement error and called for further investigation into the efficacy of ECHO with caregivers. Given the multitude of advantages and low costs of the ECHO model, the significant waitlists that children with NDDs face in accessing parent education and behavioral intervention, and previous mixed findings into its effectiveness with caregivers (Bateman et al., 2023), there is a need to further explore the efficacy of this approach using larger sample sizes and a broader evaluation of impact.

Current Study Aims

This study evaluated the effects of participating in an innovative ECHO program to receive free, accessible parent behavior management education and peer support on caregivers of children with NDD. Specifically, it evaluated effects on caregivers’ knowledge, self-efficacy, confidence, and empowerment using a quasi-experimental, pre-post design in a statistically powered sample. The following primary hypotheses were tested: participating in the Caregiver ECHO program would increase caregivers' knowledge of CB intervention strategies, empowerment to support children with NDD, and self-efficacy in managing CB. The secondary hypothesis was that this study explored whether participating would lead to decreased negative emotional reactions (sadness or anxiety). Finally, the ECHO model's social validity with caregivers was assessed.

Method

Participants

Participants were the primary caregivers of a child with NDD exhibiting CB at home. This study was conducted during the COVID-19 pandemic given the major service loss families of children with NDD experienced, while recognizing that barriers to service access would persist even after the resumption of in-person services. Participants were recruited through social media, email listservs, pediatrics offices, support groups, and word-of-mouth. Inclusion criteria were being the primary caregiver of a child who was: 1) enrolled in K-12th grade, 2) had a NDD diagnosis, 3) received or was seeking school-based special education services, 4) engaged in at least one form of CB (e.g., aggression) on a weekly basis, and 5) did not have other supports addressing the CB for which they were pursuing ECHO support.

Thirty caregivers (90% female, 10% male) participated in this study, each reporting on one child with NDD. Most participants were White and had completed a bachelor's degree (see Table 1). Fifty-three percent of participants lived in rural (57%), 27% urban (27%), and suburban (20%) areas. Participants lived across the United States along the East Coast, West Coast, and in the Midwest. Ninety percent of participants were biological and 10% were adoptive parents. No participants had previously participated in an ECHO program.

<<Insert Table 1 here>>

Measures

Child Demographic Measures

Caregivers completed a survey to provide information on their child's age, community diagnoses (i.e., conferred by a medical or educational professional) of NDD and mental health disorders, current educational supports, and support format (e.g., virtual, hybrid, in person). To adhere to the ECHO model of keeping children deidentified, diagnostic information was taken based on caregiver report alone.

Child Challenging Behavior Measure

Researchers developed a survey of CB frequency and severity, which participants completed before starting the ECHO program. Participants were asked to report on the types of CB displayed at home from a comprehensive pre-written list. For each topography of CB, definitions and examples were provided in parentheses (e.g., ripping, throwing, or swiping objects for property destruction). Frequencies were rated on a four-point Likert scale from 1 (not currently) to 6 (multiples times a day).

Behavioral Knowledge Test

This was a 20-item multiple choice questionnaire developed by the research team that assessed participants' abilities to operationally define behavior, identify behavioral functions (e.g., attention, escape/avoidance), select appropriate intervention techniques based on behavioral function, define basic behavioral strategies (e.g., negative reinforcement), evidence-based strategies for measuring behavior change, and select intervention targets (Cooper et al., 2007). Tests were scored based on total correct items. This assessment was completed at pre and post-test ECHO participation.

Difficult Behavior Self-Efficacy Scale

This self-report tool included five items rated from 1 (not at all confident) to 7 (very confident) to evaluate participants' perceived confidence in their ability to effectively address CB (Hastings & Brown, 2002). The original instructions referenced CB displayed by a child with ASD – for this study, instructions were modified to replace "autism" with "disability". Independent psychometric evaluations in US and Korean samples confirmed good internal consistency (Cronbach's α = .88) and excellent factor structure (Comparative Fit Index = 0.98) (Oh & Kozub, 2010).

Family Empowerment Scale (FES)

The FES was a 34-item questionnaire designed to measure caregivers' self-reported empowerment to care for a child with disabilities (Koren et al., 1992). Each item was rated using a five-point Likert scale (0 = not true at all to 4 = very true). Originally developed as a two-subscale measure, psychometric analyses demonstrated substantial internal consistency (Cronbach's α = .87 - .88), stable test-retest reliability (r = .77 - .85), substantial validity (overall *Kappa* = .77), and good factor structure. The FES is scored by summing all items to yield one overall score (Koren et al., 1992).

Emotional Reactions to Challenging Behavior Scale (ER-CB)

This self-report measure was completed at pre and post-test to evaluate the extent to which participants experienced negative emotional reactions to CB (Mitchell & Hastings, 1998). It included 23 items, each listing a different emotional reaction (e.g., shocked), and prompted respondents to rate how frequently they typically experienced each emotion when observing CB from their child. Each item was rated using a four-point Likert scale ranging from “no, never” to “yes, very frequently”. Items were summed to yield two subscale scores: Depression/Anger (range = 0 – 30), and Fear/Anxiety (range = 0-15). The Depression/Anger (Cronbach’s α = .83) and Fear/Anxiety (Cronbach’s α = .85) subscales had good internal consistency and test-retest reliability (Depression/Anger: r = .74; Fear/Anxiety: r = .81) and did not demonstrate susceptibility to social desirability response bias (Mitchell & Hastings, 1998).

Social Validity

A six-item measure of social validity was created and administered at post-test. It surveyed participants on whether they believed that participating in the ECHO program increased their knowledge of behavior management strategies and ability to support children with NDD, provided valuable access to expertise and a community of caregivers, increased their confidence in school-based special education supports by providing education around these services, and reinforced lessons learned through handouts that were disseminated at the end of each session. Items were rated using a five-point Likert scale (1 = Ineffective, 5 = Effective). The questionnaire also included an open-ended question following each quantitative question for participants to provide qualitative feedback.

Procedure

This study had institutional review board approval from [BLINDED FOR REVIEW]. The Caregiver ECHO program was offered from October 2020 to May 2021 to three cohorts to maintain small group sizes of 6-12 participants. Sessions were 1.25 hours, held in the evenings once a week for an eight-week period over Zoom® to accommodate families’ daily routines of dinner and bedtime. All sessions were video recorded with participant consent.

Hub Team Composition

The hub team consisted of a session facilitator, special educator, clinical psychologist, school psychologist, family navigator, and ECHO coordinator who provided technical support. All hub team members had attended an ECHO immersion training through the ECHO Institute. Because each workshop discussed behavioral supports, the special educator and clinical psychologist, who were doctoral-level board certified behavior analysts (BCBA-D) and had extensive parent education experience, presented all workshops. The family navigator and facilitator provided the lived experience perspective as the mothers of children with NDD. The school psychologist provided recommendations regarding eligibility testing within schools, school-based behavioral and social support (e.g., a lunch bunch), and families' educational rights.

ECHO Session Structure

Consistent with the original ECHO model, each session began with approximately five minutes of introductions, followed by a 15–20-minute workshop and a question-and-answer period. The eight-session series covered the following topics: 1) introduction to ECHO, reinforcement; 2) antecedent-behavior-consequence relationships of behavior; 3) antecedent-based intervention strategies, 4) understanding the functions of behavior; 5) consequence-based intervention strategies; 6) strategies for reducing CB and teaching replacement skills; 7) data collection; and 8) a review. A one-page workshop summary handout was provided after each workshop.

Case Presentations. After the workshop, one participant presented on a CB their child was demonstrating for group-based problem solving. If participants endorsed observing multiple CBs at home at study enrollment, they were asked to focus on the most interfering behavior. All participants provided qualitative information on the child's background, strengths, what the targeted CB looked like and environment in which it occurred, previous strategies used to address the CB, and any additional pertinent information. One participant was asked to present each week on a voluntary basis, with the goal of giving each participant the chance to present during their ECHO participation. When the number of participants in a cohort exceeded opportunities to present, the ECHO facilitator grouped cases based on similar presentations and needs and invited one participant from subgroups of similar needs to present, whose case discussion would likely yield greatest learning opportunities for the entire cohort. Presentations were 5-10 minutes long, followed by clarifying questions. The ECHO facilitator prepared a single lecture slide of the child's information that was collected during registration, which caregivers then used to present.

As is consistent with the original ECHO model, during the remainder of the session, participants and hub members provided recommendations. Participants were requested but not required to make recommendations, and each hub team member shared at least one recommendation from their respective discipline, based on their expert judgement and the degree of relevance to the CB (e.g., prioritizing safety recommendations for dangerous self-injury). If a participant provided a non-evidence-based recommendation (e.g., inaccurate explanation of special education law), the hub team member from the most relevant discipline provided gentle corrective feedback. Following ECHO sessions, the hub team completed a written form that summarized all recommendations shared by the hub and spokes and any additional recommendations from hub team members that were not shared during the discussion due to limited time. All participants received access to all case recommendation forms and an online resources library that contained links to any recommended resources.

Modifications to the original ECHO model

The ECHO model is designed so that it can be flexibly applied across various audiences. Beyond the four core ingredients of the ECHO model, the structure of an ECHO (e.g., duration, frequency, hub team structure) can be flexibly arranged while maintaining adherence to the original model (ECHO Institute, 2021). The primary modification in this application pertained to treating familial caregivers as spokes, whereas ECHO was originally designed for applications with professionals (e.g., physicians). Given that caregivers of children with NDD regularly fill in for the roles of therapists, teachers, and aides, and that this was particularly the case due to the school and clinic closures during the COVID-19 pandemic, the ECHO Institute approved the application of the ECHO model with familial caregivers. A second minor modification to traditional ECHO procedures was that, due to the emotional strain of experiencing CB at home, the hub team regularly provided participants with encouragement and validation during their case presentations, above and beyond what is typically necessary within a professionally focused ECHO. A third modification was that full participation was incentivized with a $100 gift card. Full participation was defined as attending at least seven out of eight sessions and completing all pre and post-test measures. Traditionally, ECHO programs do not provide financial incentives to participants, given that participants receive the inherent benefit of free education and peer support. In this instance, financial incentives were provided to help alleviate the burden of participation, given the increased strain caregivers were facing during the COVID-19 pandemic and cover the costs of increase bandwidth subscriptions if needed to access the ECHO program.

ECHO Fidelity Ratings. Fidelity measures were completed for each session using a scorecard developed by the ECHO institute (Project ECHO, 2021). Scorecards included 12 items, each rated as observed, not observed or not applicable. Examples of content assessed included whether core components of the ECHO model were implemented (i.e., use of technology, case-based learning, and evidence-based practices), whether the session schedule was followed, sessions started on time, and participants were engaged throughout the session. A study team member who did not participate in the ECHO program completed ratings for each session by watching session recordings. Across sessions, fidelity ratings were 100%.

Analysis Plan

First, descriptive analyses were performed to characterize participant and child demographics, child diagnoses, and CB frequencies. As there were three cohorts of participants, and 22 out of 30 total participants presented a case during their ECHO participation, participants were compared on demographic variables, pre-test scores, and post-test scores based on their cohort and whether they presented a case. After confirming that there were no differences between cohorts nor groups based on these variables, hypothesis testing was performed using outcomes data for all 30 caregiver participants.

To test the first hypothesis, participating in the Caregiver ECHO program would increase caregivers' knowledge of behavioral strategies for addressing CB, empowerment to support children with NDD, and self-efficacy in managing CB, Wilcoxon signed-rank tests was used to compare pre- and post-ECHO total scores for the ABA Knowledge Test, FES, and Difficult Behavior Self-Efficacy Scale. A Wilcoxon signed-rank test was selected as Kolmogorov-Smirnov tests for homogeneity of variance demonstrated that three scores were non-normally distributed when examined by timepoint: Behavioral Knowledge (post), ER-CB: Depression/Anger (pre, post), and ER-CB: Fear/Anxiety (post). To account for multiple comparisons, a Bonferroni correction was applied to all p-values such that only values below $p = 0.01$ were considered statistically significant ($p = 0.05/5$). Treatment effect sizes (r) were calculated for all pre-post-test changes (Rosenthal, 1994). Secondary hypothesis testing, participating would lead to decreased negative emotional reactions (depression/anger and fear/anxiety) to CB, pre-post ECHO scores on the ER-CB: Depression/Anger and ER-CB: Fear/Anxiety subscale scores, implemented the same approach to determine the ECHO model's social validity, mean and standard deviations were calculated for each item.

Power. An a priori power analysis found that, with three main hypotheses and one secondary hypothesis, a minimum sample of 27 was needed to detect a medium effect of the intervention with a power of .80 ($\alpha = 0.05$) based on the initial analysis plan of using repeated measures t-tests (Faul et al., 2007). After data collection had completed and non-normal variability had been found, the more robust statistical approach of Wilcoxon signed-rank tests was selected for determining whether the intervention resulted in significant improvement in dependent variables from pre- to post-ECHO. Authors conducted a second power analysis prior to hypothesis testing to confirm that the collected sample size continued to be large enough for this approach. This power analysis indicated that a minimum sample size of 28 would be needed to detect a medium effect with a power of .80 ($\alpha = 0.05$) (Faul et al., 2007).

Results

Child Demographics and Needs

Of 30 represented children, 100% had one NDD diagnosis and 43% had multiple NDD diagnoses. In addition to a NDD diagnosis, 27% had one co-occurring mental health disorder and 50% had multiple co-occurring mental health disorders (see Table 2).

<<Insert Table 2 here>>

The most frequent CB observed occurring multiple times per day, were inattention (83%), hyperactivity (70%), noncompliance (60%), interfering stereotypical behavior (50%) and verbal aggression (43%). The least frequently endorsed CB was self-injury, which only 33.7% of the sample were reported to display. Greater detail regarding frequencies of CB across all children represented, as well as median frequencies, can be found in Table 3.

<<Insert Table 3 about here>>

Case Presentations

The CB of 22 of the 30 represented children were presented for case consultation. See Table 2 for demographic information of the subset of presented children and the full sample of children. Presented children were 8.90 years old on average (SD = 4.15, range = 5-21) and primarily male (76%). Most common reported behaviors of concern for which participants requested case consultation were tantrums (19%), noncompliance (19%), anxiety (14%), aggression (14%), interfering restricted and repetitive behavior (14%), loud vocalizations (5%), frequent lying (5%), self-injurious behavior (5%), and difficulties transitioning (5%). Common diagnoses included disruptive disorders (e.g., oppositional defiant disorder). Genetic disorders included Down and Duane syndromes. Children were enrolled in kindergarten through 12th grade at the time of the study, and 52% were receiving special education services outlined by a formalized individualized education plan (IEP), , and 19% were receiving partial special education supports through a 504 plan. Children were receiving schooling through general education (52%), special education (33%), home school (5%), private school (5%), or general education with a resource room (5%). Most children were attending school virtually (48%), followed by in-person four days per week (24%), in-person full-time (14%), and through a hybrid format (14%).

Pre-Post ECHO Change

Analyses of changes from pre to post-test across all participants supported all three main hypotheses: participating in the ECHO program had a very large effect on Behavioral Knowledge (*r=0.80*), FES scores (*r*=0.71), and Difficult Behavior Self-Efficacy scores (*r*=0.67). Concerning the secondary hypothesis, participating in the ECHO program resulted in significant decreases with large treatment effects on ER-CB: Depression/Anger (r=0.54). While significant improvements with medium effects were observed in ER-CB: Anxiety/Fear (*r*=0.46) scores, these improvements were not statistically significant after applying Bonferroni corrections (see Table 4).

<<Insert Table 4 about here>>

Social Validity

Participants strongly agreed that participation increased their knowledge of behavior management strategies (M = 4.80, SD = 0.61), was effective in increasing their ability to support children with NDD (M = 4.73, SD = 0.58), the hub team provided valuable expertise on NDD (M = 4.97, SD = 0.18), ECHO built a community of support (M = 4.73, SD = 0.52), and handouts effectively summarized each session's workshop (M = 4.87, SD = 0.35). No participants provided “somewhat ineffective” or “ineffective” ratings on any questions.

Examining qualitative feedback, participants most frequently reported that access to a community of other caregivers decreased their isolation (e.g., “I was so happy to find other parents like me. I feel like I am on an island by myself sometimes”), they learned about behavior management strategies (e.g., “I have learned so much from the hub and the network”), lessons learned from the interdisciplinary expert team and their peers was helpful (e.g., “It was encouraging and informative to hear the stories of others and to learn along with everyone. It felt like a positive community to be a part of”) and that they saw improvements in their child’s behavior after implementing recommended strategies (e.g., “We have implemented suggestions and seen changes”).

Participants also made recommendations for improving the program, specifically by keeping group sizes to eight or fewer to increase everyone’s opportunities to speak, opening the network to a mix of special education teachers and parents to build a larger community, including a self-advocate with NDD on the hub team, and offering specific ECHO networks to families within the same communities (e.g., geographic area, racial/ethnic groups).

Discussion

This study explored the efficacy of the ECHO model as an approach for delivering virtual parent education in behavior management to caregivers of children with NDD. Results showed that it was very effective for increasing caregivers’ knowledge of behavioral approaches for addressing CB, empowerment as caregivers of children with NDD, and self-efficacy in managing CB. The program was also effective in reducing caregivers’ self-reported negative emotional reactions to CB. Finally, participants reported high satisfaction with and social validity of the ECHO program. These findings expand upon previous evidence found by Bateman and colleagues (2023) for ECHO use with caregivers, by showing increased significant outcomes in a larger, statistically powered sample.

Caregiver ECHO participation showed important impacts on caregivers’ sense of empowerment, which is of note given that caregiver empowerment is less frequently a focus of parent education programs. Empowerment has been shown to be negatively impacted by family functioning (Wakimizu et al., 2017), and plays an important role in advocacy skills. It is less frequently an outcome targeted through parent education programs (Jackson et al., 2016), though it is an essential skill for parents of children with NDD who often have to serve as advocates for their children to receive appropriate services and supports. The inclusion of a network of peers encouraging one another, along with an interdisciplinary hub team that provided guidance on special education rights, self-care, and resources, likely strengthened the impact of ECHO participation on empowerment. Given that participation in Caregiver ECHO was associated with very large effects on caregiver empowerment, using the ECHO model to disseminate support to caregivers may be a particularly effective and relevant approach to parent education.

Participation in the Caregiver ECHO program was associated with major increases in participants' self-efficacy in managing CB. Caregiver self-efficacy has implications for children's adjustment, overall caregiver competence, and caregiver psychological functioning. Caregiver self-efficacy in managing CB has a great impact on daily life and functioning of both caregivers and children (Breitenstein et al., 2010; Jones & Prinz, 2005). Research has also shown that when caregivers feel confident and knowledgeable in implementing behavior strategies, fidelity of implementation increased (Casagrande & Ingersoll, 2017), which further translated into better treatment outcomes. Thus, increasing parenting self-efficacy is an essential target of parent education, and the Caregiver ECHO program successfully demonstrated increased self-efficacy.

Free or low-cost avenues for accessing parent education such as an ECHO program were particularly important for children with NDD and their families who experienced service loss during the COVID-19 pandemic (Masi et al., 2021; Shorey et al., 2021). Even after the conclusion of the COVID-19 pandemic, continued access for families of children with NDD remains imperative. Many children with NDD demonstrate high rates of co-occurring CB (Nicholls et al., 2020) that warrant access to behavioral therapies and supports. Yet, even beyond the COVID-10 pandemic, children with NDD struggle to access these supports due to their geographic location, scheduling limitations, the deficit of qualified providers, or the costs of attending appointments (Vohra et al., 2014). Effective, evidence-based approaches to parent education and support that can be implemented for free or at low costs therefore needed.

This adaptation of the ECHO model holds great promise for making a positive impact on families of children with NDD by connecting them with peer emotional and social support. As was demonstrated by qualitative feedback, participants most frequently reported valuing access to a network of peers to reduce their social isolation and normalize their experiences as caregivers of neurodivergent children. While families of children with NDD experienced significant anxiety, depression, and caregiver burden associated with the social isolation experienced during the COVID-19 pandemic (Iovino et al., 2021), caregivers also experience poorer mental health and social isolation outside of the pandemic (Peer & Hillman, 2014). Providing parent education in group formats that is easily accessible to families, such as virtually and at low-cost, therefore also promotes long-term family functioning and well-being.

More research is needed to evaluate how participation in ECHO networks directly impacts outcomes of participants and the students or children they represent (Hardesty et al., 2020). Future evaluation of the Caregiver ECHO program should capture direct and standardized measures of behavior change amongst children served. Further, additional randomized group design studies are needed to establish causal relationships between participation in a Caregiver ECHO program and targeted outcomes. Future ECHO programs should include strategic recruitment approaches to increase representation within their samples. A snowballing approach, for example, may be effective in recruiting families from racial or ethnic minority backgrounds (Hughes et al., 1995). Finally, studies can investigate how the ECHO model builds capacity among other populations that support children with NDD, such as special education teachers.

Strengths and Limitations

Strengths included having a sufficiently powered sample size, the diversity of child behaviors and diagnoses represented in the sample, and the recruitment of families from across the United States representing homes from urban, suburban, and rural areas. Concerning limitations, a control group was not included as this study was a preliminary efficacy study. Further, while participants were surveyed on child frequency and topographies of CB at pre-test, a standardized measure of CB was not used at pre or post-test to facilitate more objective measures of behavioral change. Participants were not surveyed on their age, and we therefore cannot speak to the diversity of parenting ability across the sample based on years of experience. There was limited diversity across the sample based on race, ethnicity, and socioeconomic status. Nonetheless, the low-cost and accessible nature of the Caregiver ECHO program means that it can likely be used as a method for increasing equity in education and support to culturally and linguistically diverse families who may ordinarily struggle to access center-based parent education.

Conclusion

This study demonstrated preliminary evidence that the ECHO model, can serve as an inexpensive, effective approach for providing parent education around behavior management to caregivers of children with NDD. The added benefits of increasing caregivers' sense of empowerment and self-efficacy and community building for caregivers, demonstrated the social validity of this approach for supporting families. It additionally added to the existing literature demonstrating the efficacy of delivering parent education virtually, which is significant for families of children with NDD who experience high amounts of isolation due to the complexities of their child's needs. Future research examining the impact of the ECHO model versus a comparison treatment on caregivers, such as a general parent education program, and that includes standardized measures of child behavioral change, would help elucidate the extent to which unique components of the ECHO model impact caregiver and family outcomes above and beyond traditional parent education. Such discoveries would continue to drive the establishment of best practice approaches to delivering parent education at low cost.

References

Arora, S., Thornton, K., Komaromy, M., Kalishman, S., Katzman, J., & Duhigg, D. (2014). Demonopolizing medical knowledge: *Academic Medicine*, *89*(1), 30–32. https://doi.org/10.1097/ACM.0000000000000051

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. https://doi.org/10.1056/NEJMoa1009370

Barroso, N. E., Mendez, L., Graziano, P. A., & Bagner, D. M. (2018). Parenting stress through the lens of different clinical groups: A systematic review & meta-analysis. *Journal of Abnormal Child Psychology*, *46*(3), 449–461. https://doi.org/10.1007/s10802-017-0313-6

Bateman, K. J., Schwartz, I. S., & Grimm, R. P. (2023). Project ECHO: Supporting parents of children with disabilities using an online, telementoring service delivery model. *Infants & Young Children*, *36*(2), 130. https://doi.org/10.1097/IYC.0000000000000236

Bearss, K., Burrell, T. L., Challa, S. A., Postorino, V., Gillespie, S. E., Crooks, C., & Scahill, L. (2018). Feasibility of parent training via telehealth for children with autism spectrum disorder and disruptive behavior: A demonstration pilot. *Journal of Autism and Developmental Disorders*, *48*(4), 1020–1030. https://doi.org/10.1007/s10803-017-3363-2

Breitenstein, S. M., Fogg, L., Garvey, C., Hill, C., Resnick, B., & Gross, D. (2010). Measuring implementation fidelity in a community-based parenting intervention. *Nursing Research*, *59*(3), 158–165. https://doi.org/10.1097/NNR.0b013e3181dbb2e2

Casagrande, K. A., & Ingersoll, B. R. (2017). Parent-mediated interventions for social communication in young children with ASD. In *Handbook of social skills and autism spectrum disorder: Assessment, curricula, and intervention* (pp. 285–312). Springer International Publishing AG. https://doi.org/10.1007/978-3-319-62995-7_17

Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied Behavior Analysis* (2nd ed.). Pearson.

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*(2), 175–191. https://doi.org/10.3758/BF03193146

Halstead, E. J., Griffith, G. M., & Hastings, R. P. (2018). Social support, coping, and positive perceptions as potential protective factors for the well-being of mothers of children with intellectual and developmental disabilities. *International Journal of Developmental Disabilities*, *64*(4–5), 288–296. https://doi.org/10.1080/20473869.2017.1329192

Hardesty, C., Moody, E. J., Kern, S., Warren, W., Cooley Hidecker, M. J., Wagner, S., Arora, S., & Root-Elledge, S. (2020). Enhancing professional development for educators: Adapting Project ECHO from health care to education. *Rural Special Education Quarterly*, *40*(1), 42–52. https://doi.org/10.1177/8756870520960448

Hastings, R. P., & Brown, T. (2002). Behavioural knowledge, causal beliefs and self-efficacy as predictors of special educators' emotional reactions to challenging behaviours. *Journal of Intellectual Disability Research*, *46*(2), 144–150. https://doi.org/10.1046/j.1365-2788.2002.00378.x

Heinicke, M. R., & Carr, J. E. (2014). Applied behavior analysis in acquired brain injury rehabilitation: A meta-analysis of single-case design intervention research. *Behavioral Interventions*, *29*(2), 77–105. https://doi.org/10.1002/bin.1380

Hughes, A. O., Fenton, S., Hine, C. E., Pilgrim, S., & Tibbs, N. (1995). Strategies for sampling black and ethnic minority populations. *Journal of Public Health Medicine*, *17*(2), 187–192. https://doi.org/10.1093/oxfordjournals.pubmed.a043091

Iovino, E. A., Caemmerer, J., & Chafouleas, S. M. (2021). Psychological distress and burden among family caregivers of children with and without developmental disabilities six months into the COVID-19 pandemic. *Research in Developmental Disabilities*, *114*, 103983. https://doi.org/10.1016/j.ridd.2021.103983

Israel, B.A., Checkoway, B., Schultz, A., & Zimmerman, M. (1994). Health education and community empowerment: Conceptualizing and measuring perceptions of individual, organizational and community control. *Health Education Quarterly*, *21*(2), 149–170. https://doi.org/10.1177/109019819402100203

Jackson, A. C., Liang, R. P.-T., Frydenberg, E., Higgins, R. O., & Murphy, B. M. (2016). Parent education programmes for special health care needs children: A systematic review. *Journal of Clinical Nursing*, *25*(11–12), 1528–1547. https://doi.org/10.1111/jocn.13178

Jones, T. L., & Prinz, R. J. (2005a). Potential roles of parental self-efficacy in parent and child adjustment: A review. *Clinical Psychology Review*, *25*(3), 341–363. https://doi.org/10.1016/j.cpr.2004.12.004

Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, *37*(4), 305–321. https://doi.org/10.1037/h0079106

LaRue, R. H., Sloman, K. N., Dashow, E., & Isenhower, R. W. (2015). Assessment and intervention for individuals with attention deficit hyperactivity disorder. In H. Roane, J. E. Ringdahl, & T. Falcomata (Eds.), *Clinical and Organizational Applications of Applied Behavior Analysis* (1st ed.). Elsevier.

Machalicek, W., Lequia, J., Pinkelman, S., Knowles, C., Raulston, T., Davis, T., & Alresheed, F. (2016). Behavioral telehealth consultation with families of children with autism spectrum disorder. *Behavioral Interventions*, *31*(3), 223–250. https://doi.org/10.1002/bin.1450

Masi, A., Mendoza Diaz, A., Tully, L., Azim, S. I., Woolfenden, S., Efron, D., & Eapen, V. (2021). Impact of the COVID-19 pandemic on the well-being of children with neurodevelopmental disabilities and their parents. *Journal of Paediatrics and Child Health*, *57*(5), 631–636. https://doi.org/10.1111/jpc.15285

Mazurek, M. O., Brown, R., Curran, A., & Sohl, K. (2017). ECHO Autism: A n model for training primary care providers in best-practice care for children with autism. *Clinical Pediatrics*, *56*(3), 247–256. https://doi.org/10.1177/0009922816648288

Mitchell, G., & Hastings, R. P. (1998). Learning disability care staff's emotional reactions to aggressive challenging behaviours: Development of a measurement tool. *The British Journal of Clinical Psychology*, *37*(4), 441–449. https://doi.org/10.1111/j.2044-8260.1998.tb01401.x

Moody, E. J., Sturges, H. A., Zlatkovic, S., Dahl, E., Root-Elledge, S., & Hardesty, C. (2020). Chapter Six - A public health approach to family supports: Empowering families of children with autism through the ECHO model. In S. Hepburn (Ed.), *International Review of Research in Developmental Disabilities* (Vol. 59, pp. 163–193). Academic Press. https://doi.org/10.1016/bs.irrdd.2020.07.006

Nicholls, G., Hastings, R. P., & Grindle, C. (2020). Prevalence and correlates of challenging behaviour in children and young people in a special school setting. *European Journal of Special Needs Education*, *35*(1), 40–54. https://doi.org/10.1080/08856257.2019.1607659

Oh, H.-K., & Kozub, F. M. (2010). The psychometric properties of the Difficult Behavior Self-Efficacy Scale. *Adapted Physical Activity Quarterly*, *27*(3), 191–207. https://doi.org/10.1123/apaq.27.3.191

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. https://doi.org/10.1111/jppi.12072

Pennefather, J., Hieneman, M., Raulston, T. J., & Caraway, N. (2018). Evaluation of an online training program to improve family routines, parental well-being, and the behavior of children with autism. *Research in Autism Spectrum Disorders*, *54*, 21–26. https://doi.org/10.1016/j.rasd.2018.06.006

Project ECHO, University of New Mexico School of Medicine. (2021). *Project ECHO, (2021). Education. Project ECHO.* https://hsc.unm.edu/echo/

Root-Elledge, S., Ed, M., & Leki, E. (2018). The ECHO Model® for enhancing assistive technology implementation in schools. *Assistive Technology Outcomes and Benefits, 12,* 37–55.

Rosnow, R. L., & Rosenthal, R. (2003). Effect sizes for experimenting psychologists. *Canadian Journal of Experimental Psychology/Revue Canadienne de Psychologie Expérimentale,* *57*(3), 221–237. https://doi.org/10.1037/h0087427

Salloum, A., Johnco, C., Lewin, A. B., McBride, N. M., & Storch, E. A. (2016). Barriers to access and participation in community mental health treatment for anxious children. *Journal of Affective Disorders*, *196*, 54–61. https://doi.org/10.1016/j.jad.2016.02.026

Shorey, S., Lau, L. S. T., Tan, J. X., Ng, E. D., & Aishworiya, R. (2021). Families with children with neurodevelopmental disorders during COVID-19: A scoping review. *Journal of Pediatric Psychology*, *46*(5), 514–525. https://doi.org/10.1093/jpepsy/jsab029

Trump, C. E., & Ayres, K. M. (2019). Autism, insurance, and discrimination: The effect of an autism diagnosis on behavior-analytic services. *Behavior Analysis in Practice*, *13*(1), 282–289. https://doi.org/10.1007/s40617-018-00327-0

Vismara, L. A., McCormick, C. E. B., Wagner, A. L., Monlux, K., Nadhan, A., & Young, G. S. (2018). Telehealth parent training in the Early Start Denver Model: Results from a randomized controlled study. *Focus on Autism and Other Developmental Disabilities*, *33*(2), 67–79. https://doi.org/10.1177/1088357616651064

Vohra, R., Madhavan, S., Sambamoorthi, U., & St Peter, C. (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism*, *18*(7), 815–826. https://doi.org/10.1177/1362361313512902

Wakimizu, R., Yamaguchi, K., & Fujioka, H. (2017). Family empowerment and quality of life of parents raising children with developmental disabilities in 78 Japanese families. *International Journal of Nursing Sciences*, *4*(1), 38–45. https://doi.org/10.1016/j.ijnss.2016.12.004

Zeng, S., Hu, X., Zhao, H., & Stone-MacDonald, A. K. (2020). Examining the relationships of parental stress, family support and family quality of life: A structural equation modeling approach. *Research in Developmental Disabilities*, *96*, 103523. https://doi.org/10.1016/j.ridd.2019.103523

Table 1.
Caregiver Participant (n = 30) Demographic Characteristics

Participant Characteristics	n(%)
Race/Ethnicity	
Asian	1(3)
Black	1(3)
Hispanic/Latinx	1(3)
White	25(83)
More than one	2(7)
No response	1(3)
Highest education level	
High school graduate	2(7)
Some college	5(17)
Undergraduate degree	1(3)
Master's degree	11(37)
Doctoral degree	3(10)
Employment status before COVID-19	
Part-time	7(23)
Full-time	16(53)
Unemployed	7(23)
Employment change since COVID-19	
No change	16(53)
Still employed, increased work hours	6(2)
Still employed, but hours reduced due to personal/family obligations	5(17)
Still employed, but hours reduced by employer	5(17)
No longer employed	5(17)
Furloughed	5(17)

Table 2

Demographic Characteristics of Children from the Full Sample and the Subset of Children Presented for ECHO Network Consultation

Demographic Characteristic		% Presented Children (n = 22)	% Total Children (n = 30)
Child Gender (M:F)		76:24	
Child NDD Diagnoses	Attention Deficit Hyperactivity Disorder	43	57
	Auditory Processing Disorder	5	ǂ
	Autism spectrum disorder	38	40
	Genetic syndromes	19	ǂ
	Learning Disability	10	10
	Intellectual Disability	10	17
	Language Disorder	5	13
	Sensory Processing Disorder	19	ǂ
Child MH Diagnoses	Anxiety Disorder	24	57
	Behavioral disorders	23	23
	Depression or mood disorder	10	17
	Other mental health or DD diagnosis	36	27

Note. ǂ Conditions were not surveyed as part of baseline assessment but were independently reported by participants during their case reviews

Table 3

Child Challenging Behavior Frequency at Pre-Test

	Overall Frequencies (%)					
Challenging Behavior	Not Currently	A Few Times a Month	Once a Week	A Few Times a Week	Once a Day	Multiples Times per Day
Hyperactivity	10	-0	-0	7	13	70*
Inattention	7	-0	-0	-0	10	83*
Noncompliance	3	3	3	10	20	60*
Verbal Aggression	7	-0	7	27	17*	43
Physical Aggression	17	13	13	23*	7	27
Property Destruction	30	20*	13	20	10	7
Self-Injury	67*	20	3	7	-0	3
Interfering Stereotypies	17	3	-0	20	10*	50
Elopement	53*	17	3	17	7	3
Other CB	77*	7	-0	3	-0	13

Key. * indicates median response for each topography of behavior.

Formatted Table

Table 4

Effects of ECHO Participation on Main and Secondary Outcomes

	Pre (n = 30)		Post (n = 30)				
	Med	IQR	Med	IQR	*Z*	*p*	*r*
Behavioral Knowledge	14.50	12.00-16.00	16.50	15.75-18.00	4.41	<.001*	0.80
Empowerment	121.50	107.75-130.00	132.00	122.75-143.50	3.91	<.001*	0.71
CB Self-Efficacy	18.13	12.53-21.96	22.44	18.97-25.15	3.66	<.001*	0.67
Depression/Anger	13.00	9.00-19.00	9.50	6.75-12.25	-2.98	<.01*	0.54
Fear/Anxiety	5.00	4.00-8.00	4.00	3.00-6.00	-2.52	<.05	0.46

Key. IQR = Interquartile range; r effect size ranges: |r|<0.1: no effect; |r|=0.1: small effect; |r|=0.3: medium effect; |r|=0.5: large effect. **p*-value is significant using threshold of $p = 0.01$ (Bonferroni correction)