North Carolina Family Support ECHO™ Pilot:

A Summary of Planning, Implementation, Evaluation, and Recommendations

January 2019 through June 2020

Autism Society of North Carolina

The Arc. North Carolina

Project ECHO®

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What is Project ECHO™?

The goal of Project ECHO™ (Extension of Community Health Outcomes) is to spread knowledge, expand capacity and accelerate collective wisdom. ECHO™ uses a guided-practice model that engages participant spokes via video conferences and connects them with specialist mentors at a hub. Through tele-mentoring, ECHO™ creates access to high quality care in local communities. The experts serve as teachers and mentors who share their expertise in a virtual learning community.

Principles of the ECHO™ Model

1. Amplification: Use technology to leverage scarce resources
2. Share best practices to reduce disparity
3. Case-based learning

ECHO™ is *all teach; all learn.*

ECHO™ format:

- Didactic presentations and discussions of evidence-based practices
- 1-2 in-depth case discussions led by participants
- Consultation from the experts and group discussion
- Follow up after the initial case discussion

Strengths of the ECHO™ Model:

- Addresses the needs of rural and low resourced communities and providers
- Rapid dissemination of best practices and promising practices
- Promotes consistency of care within the medical home
- Decrease in professional isolation experienced by providers
- Patients can access quality care in their community.

"Collaboration is at the heart of the ECHO™ model."

Dr. Sanjeev Arora, MD, Founder

Project ECHO™ has rapidly grown to address multiple health conditions and human service needs across the world in numerous medical, behavioral health and educational disciplines: opioids and medication-assisted treatment, diagnosis and treatment of Autism Spectrum Disorder, pain management, and palliative care, for example.

Why Family Support ECHO™?

Families are frequently the primary caregivers and a life-long support for children and adults with intellectual and other developmental disabilities. Keeping families healthy, informed, and able to provide care and support is key to maintaining the health of the individual and family and the state's health and human service system.

The *2011 Wingspread Summit[1]* defined family support as "a set of strategies directed to the family but that ultimately benefit the individual with I/DD. Family Support strategies are intended to assist family members, who have a key role in the provision of support and guidance to their family member with I/DD. These strategies are designed, implemented and funded in a flexible manner that addresses the emotional, physical and material well-being of the entire family."

An increasing number of healthcare, disability provider, and advocacy organizations employ family members with the lived experience of parenting and supporting a child with a disability to provide a variety of support to families. Sometimes these individuals are volunteers. Many of these family partners, advocates, navigators, and liaisons (every organization titles them differently) function with limited contact with other family support specialists across the broader developmental disability community. Those living in rural communities may face additional challenges trying to engage with other family partners.

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) includes a focus on the family and the importance of enabling families to nurture and enjoy their children at home, and preserving, strengthening, and maintaining the family. Although the research within the developmental disability community is limited, it has documented that family support was associated with a positive effect on family quality of life, family functioning, family satisfaction, and lowered family stress.

Family support is an approved Medicaid billable service for families with children with serious emotional, behavioral, and/or mental health challenges and their families. In North Carolina family support is not currently a billable service within the I/DD community.

We believe that families caring for their children with intellectual and other developmental disabilities are also deserving of and in need of a comprehensive and robust array of family support services.

By increasing the knowledge, competence, confidence, and connections of those engaged in family support services, we aim to:
- support families as they help their children of all ages with disabilities achieve their full potential;
- promote individualized, family-driven support that respects family culture, values, and preference;
- improve community capacity to serve families with children of all ages who have disabilities; and
- encourage parent and professional collaboration in the design and delivery of services for these families and individuals with a disability.

[1] Hecht, E., Reynolds, M., Agosta, J., & McGinley, K. (2011). Building an agenda for supporting families with a member with intellectual and developmental disabilities. Report of the Wingspread Conference on building a family support agenda, March 6-8, 2011. Racine, Wisconsin: Johnson Foundation

[2] Developmental Disabilities Act Public Law 106–402, 106th Congress, https://acl.gov/about-acl/authorizing-statutes/developmental-disabilities-assistance-and-bill-rights-act-2000

Family Support ECHO™ Planning Activities

At the 2018 Summit, sponsored by the I/DD Medical Health Home Initiative, the University of Wyoming Institute of Disabilities made a presentation entitled "Using the ECHO™ model to address diverse learning needs" that included a discussion of family support and education services. This information, coupled with the success of the TEACCH Autism ECHO™ programs offered to primary care and mental health providers, generated interest in how a NC Family Support ECHO™ program could be developed. In the winter of 2019, a group of family members with lived experience working within the disability services system and others who work as I/DD providers began meeting to discuss the development of a Family Support ECHO™ pilot.

Prior to implementing an ECHO™ program, the ECHO™ Institute requires submission of a partnership agreement, participation in the three-day immersion training program, and completion of a launch readiness assessment and planning worksheet. The Arc of NC and the Autism Society of NC submitted the partnership agreement and the planning team attended the May 2019 ECHO™ Immersion in Albuquerque, New Mexico. There was no registration cost for the training. Participants were responsible for travel costs. See attachments: launch readiness assessment and planning worksheet. Additional information on ECHO™ training events can be found at *ECHO.unm.edu/join-the-movement/outreach-training/*

Immersion Training Participants and Organizations:

Julie Davis, *Family Partner, Vaya Health*

Kerri Eaker, *Education Outreach Coordinator, Mission Hospital's Family Support Network of WNC*

Benita Hathaway, *Transition Manager-Clinical Operations, Trillium Health Resources*

Katie Holler, *Resource and Referral Specialist, TEACCH*

Karen Luken, *Disability and Health Consultant, I/DD Medical Health Home Initiative*

Melinda Plue, *Director of Advocacy and Chapter Development, The Arc of NC*

Megan Roberson, *Manager Clinical Operations Transition Team, Trillium Health Resources*

Lisa Sullivan, *Chapter Director, First In Families of NC, Five County Chapter*

Kim Tizzard, *Director of Family Support, Autism Society of NC*

Planning sessions continued through December 2019 with the goal of:

- surveying stakeholders to determine learning interests of potential participants;
- development of Family Support ECHO™ didactic topics based on survey and hub expertise;
- confirmation of hub members including recruitment of two new hub members;
- development of evaluation survey tools;
- identification and recruitment of spoke participants;
- format for Family Presentation Reviews.

The decision was made to conduct the pilot NC Family Support ECHO™ in a specific region of the state to allow for a focused recruitment of hub and spokes, to lay a foundation for the expansion of a regional Family Support ECHO™, and to build on established relationships and connections across organizations.

Family Support ECHO™ Pilot Hub Team Members:

- **Melinda Plue**, *Co-Facilitator, NC Family Support ECHO™, Director of Advocacy and Chapter Development, The Arc of North Carolina*
- **Kim Tizzard,** *Co-Facilitator, NC Family Support ECHO™, Director of Family Support, Autism Society of North Carolina*
- **Julie Davis**, *Family Partner, VAYA Health*
- **Kerri Eaker**, *Education Outreach Coordinator, Mission Hospital's Family Support Network of Western NC*
- **Michael LePage**, *Western Regional Director, Autism Society of North Carolina*
- **Duncan Reid,** *Regional Director, The Arc of North Carolina*

Hub Support Staff:

- **Elena Lamarche**, *Coordinator/Administrator*
- **Andre Perkins**, *IT Specialist, The Arc of North Carolina*

One hub member had participated in the TEACCH Autism ECHO™ for primary care. Several hub and spokes had participated in other technology-based learning experiences or learning collaboratives. Four of the six hub members attended the UNM ECHO™ Immersion training in May 2019.

ECHO™ Curriculum Development

To ensure the didactic presentations would meet the needs of potential learners, a survey was sent to over fifty people engaged in the delivery, supervision, or payment of family support services across NC. Potential categories and topics are noted below:

Potential learning topics and categories identified by the planning group:

Funding Sources: What are the federal and state funding sources and how can families navigate the system?

- Social Security, Medicaid, benefits counseling
- SSI, SSDI, & Medicaid
- NC Waivers (Innovations, CAP-C, TBI)
- State-funded services: respite, personal care
- Accessing grants/ alternative funding sources through LME/MCOs (like the Choose Independence Grant via Trillium)
- ABLE accounts

Education: what services are available in elementary, high school and post-secondary and how can families navigate the system?

- Educational Services: IEP, 504 plans, transition plans, IFSPs
- Parenting: Triple P-Stepping Stones
- Post-Secondary options
- Negotiating accommodations

Available Services and Resources: what state services are available and how can families navigate the system?

- Services-I/DD specific (is this part of funding??) example??
- I/DD and Mental Illness- dual diagnosis: NC START
- What resources can a family access when their family member (child or adult) is experiencing a behavioral crisis?
- Family Medical Leave Act and other resources available through work

Social determinants of health: how can we support families to meet their community living needs?

- Housing (Shared Living, Section 8)
- Transportation
- Employment Options
- Food

Health and Wellness, Life Transitions and Ethics: (somewhat of a catch-all category)

- Person-centered principles and self-determination
- Medical and dental health homes, care notebooks
- The importance of self-care
- Guardianship, alternatives to guardianship, and supported decision making
- Creating positive outcomes in challenging situations
- Ethics and boundaries, especially in crisis situations

The survey results then informed the development of the ECHO™ didactic presentations and session calendar. See attachment for survey results.

Recruitment

The responsibility for outreach to potential spoke participants was shared by all hub members. The planning group brainstormed a list of potential individuals, sent an email invitation, and announcement flyer the week of December 2019 (see attachment). The goal for the pilot was to have a mix of participants who had experience in family support with those newer to the field.

Fifteen people were initially identified, twelve people were contacted, and nine people completed the application (see attachment).

Spoke Participants:
- **Hannah Bridges** *(Exceptional Children's Assistance Center)*
- **Jessica Edwards** *(HCA Healthcare)*
- **MaryAnn Haskel** *(Vaya Health)*
- **Austin Holder** *(TEACCH)*
- **Jennifer Jones** *(Community Care of NC)*
- **Lee Kube***, community volunteer*
- **Mikaila Mills** *(Pathways)*
- **Samantha Parrow** *(Family Support Network, McDowell Pediatrics)*
- **Melissa Zenz** *(Youth Villages)*

Demographic profile of hub and spokes
- Gender: majority females and 3 males
- Age range: mid 20s to mid-50s
- Race: all white
- Lived experience: 6 participants are family members
- Training: mix of on-the-job, webinars, limited conference
- Reasons for participation: networking, increased knowledge, increased comfort in role, being effective with families

Planning Activity Timelines:

11/05/19	Learning Topic Survey with personalized emails sent to people engaged in delivery, supervision, or payment of family support services across NC
11/14/19	Requested survey return
11/19/19	Survey results reviewed by team and evaluator
12/03/19	Team conference call to review survey results, develop topic survey for spoke recruitment
12/09/19	Topic survey sent to potential Spokes
12/20/19	Due date for recruitment confirmation paperwork from spokes
01/15/20	Launch date for session one

Family Support ECHO™ Pilot Launch

The pilot was launched on January 15, 2020 and 10 sessions were completed by June 2020. The sixth session, scheduled for March 25, was postponed due to the COVID-19 outbreak and disruptions to people's work and personal schedules.

Didactic Presentations

The ECHO™ model emphasizes time limited (15 to 20 minute) didactic presentations so that most of the ECHO™ session is spent on case presentations and group discussion. This approach prevents the ECHO™ session from becoming a webinar with passive participation. The didactic presentations were selected based on the survey results. Presenters were selected based on their expertise, willingness to follow the ECHO™ model, and availability.

ECHO™ Calendar, Learning Topics and Didactic Presenters

Jan 15	Self-Care: Julie Davis, in partnership with Lisa Sullivan
Jan 29	Housing Overview and Opportunities in NC: Sara Grignon, The Arc of North Carolina
Feb 12	Medicaid/Accessing Services: Julie Davis
Feb 26	Guardianship, Alternatives to Guardianship, and Supported Decision Making: Jean Farmer-Butterfield, The Arc of North Carolina
March 11	Self-Advocates: What Parents and Guardians Need to Know: Kayla Davis, Maudeb Maybin, Lindy Monteleone
March 25	Health and Wellness: Michael LePage (rescheduled to June 10 due to COVID-19 disruption)
April 8	SSI & SSDI: Amy Upham, Owl Eye Consulting
April 22	IEP Basics: Amy Perry, Autism Resource Specialist, ASNC
May 13	ABLE Accounts: Mary Buonfiglio, NC Treasurer's Office
May 27	Know Your Regional Resources: Kerri Eaker

Two sample presentations are included as attachments:

ABLE Accounts and Know Your Regional Resources

Family Support ECHO™ Logistics

To ensure fidelity to the ECHO™ model the hub team developed an outline for ECHO™ sessions beginning with an opening script:

- "ECHO™ is a lifelong learning and guided practice model with the goal of spreading knowledge, expanding capacity, and accelerating collective wisdom.
- We are a learning community.
- We represent a group diverse in experience and knowledge; everyone's input is important, and we are learning from each other.
- Each of your contributions is valued and we appreciate you making the effort to join us during this time.
- We will recognize you by name when you have a question or comment. This is helpful as we get to know one another and for those that may not have the video picture option today.
- The ECHO™ format is brief presentation and then a Family Presentation Review.
- Please put yourself on mute at this time."

Sessions were offered during lunch hours and members were encouraged to eat and drink.

Detailed Outline of an ECHO™ Session

Introductions: Hub and spoke participants and guests

Opening script

Announcements

a) Updates

b) Spoke questions and concerns

c) Question and answers from last ECHO™ session

d) If required, reminders to face camera, how to mute and unmute and minimize external noise.

Educational Presentation

a) Hub facilitator introduces didactic presenter; presentation viewed on shared screen.

Case Presentation

a) Hub facilitator introduces spoke member responsible for today's Family Presentation Review: "Please present your FPR at this time."

b) Presenter reviews the family presentation.

c) Participant or facilitator summarizes family presentation.

d) Hub facilitator clarifies with family presenter the summary is accurate: "Did I summarize this info correctly?"

Hub Facilitator asks spokes for questions/comments.

a) Facilitator reminds all that this is not the time for recommendations for diagnosis or treatment, but to ask clarifying questions.

b) Spoke participants ask questions first.

c) Hub team follows with clarifying questions.

d) If a member on the Hub team is particularly qualified to address the case, they can begin discussion.

Hub Facilitator summarizes and asks for comments & discussions.

a) Ask case presenter if his or her questions have been adequately addressed.

b) Invites case presenter to represent in the future and to liaise ECHO™ Admin Co-coordinator.

Closing Announcements

Confirm topic for next session and family review presenter.

Post-ECHO™ Session Debrief

Hub team reviews and comments on the flow and facilitation of the session, self-reflection, and issues that may not have been obvious in the moment.

ECHO™ Model and Case-Based Learning

ECHO™ is based on adult learning techniques with sessions designed around case-based learning and mentorship.

The six principles of adult learning identified by Knowles are:

1. Adults are internally motivated and self-directed.
2. Adults bring life experiences and knowledge to learning experiences.
3. Adults are goal oriented.
4. Adults are relevancy oriented.
5. Adults are practical.
6. Adult learners like to be respected.

https://thepeakperformancecenter.com/educational-learning/teaching-training/principles-of-learning/adult-learning-principles/

Case-based learning enables participants to bring a real case of concern for discussion with their peers and hub members. This collaborative learning approach is designed to encourage reflection and the integration of knowledge with skills and real-world practice.

The hub team developed a Family Presentation Review Form that served as the outline for the weekly presentations and discussions. The review document is also included as an attachment.

The majority of family presentations were made by the spoke participants but hub members also contributed. It may be helpful to develop a family presentation schedule within the first few weeks of ECHO and for the hub team or administrator to provide specific support to spokes in the development of their family case presentations.

ECHO™ Hub Roles

Subject matter experts: knowledgeable about family support, the disability service system and their communities, champions of family support services, and committed to lifelong learning and collaboration.

ECHO™ facilitator(s): Hub team member(s); provides a neutral perspective and manages the process; helps facilitate an open and non-threatening environment.

- Provides a neutral perspective and manage the ECHO™ process.
- Keeps the ECHO™ session agenda on track in an efficient and relaxed manner.
- Help facilitate an open, non-threatening environment.
- Encourages video-conference etiquette.
- Ensures all spoke participants receive certificate of completion and thank you.

ECHO™ administrator: responsible for the administrative and organizational components of ECHO™. Track recruitment commitment.

- Distribute pre- and post- evaluation surveys; assign ECHO™ ID number to each spoke for evaluation.
- Send weekly announcement to spokes re: upcoming session.
- Follow-up with spoke that is doing the case presentation; offer to assist with template
- Sends thank you note to presenter (didactic and case presentation)
- Ensures PHI and HIPAA removed before document sent to spokes.
- Takes notes during ECHO™ sessions, shares notes with HUB team members.
- Identify items needing follow-up after ECHO™ session, develop recommendations summary
- Keeps track of forms: case presentation, pre- and post- evaluations, session notes and follow-up recommendations, didactic presentation
- If spoke is absent, ensures they receive session materials.
- If participant misses a second session, checks in with individual.

IT support ensures IT is working so hub members can focus on presentations, case reviews, group discussion. They provide support to spokes re: answering questions about necessary equipment to effectively participate in ECHO™ sessions and assist with practice sessions prior to an ECHO™ launch. It was suggested that a Zoom (preferred platform) practice session be offered to the spokes prior to the first ECHO session.

ECHO™ didactic presentations: can be hub member or invited subject matter experts; presenters have appropriate knowledge of the topic and seasoned presenting skills, receive orientation to ECHO™ model so they understand the goal is a brief presentation of 15 minutes that is followed by a family presentation for group discussion. Guest speakers are invited to observe the entire ECHO™ session.

Observers

Selected partners and stakeholders were offered the opportunity to observe a session with these guidelines:

- Observers were sent the Zoom link for a specific session, which allowed them to observe the Zoom meeting in progress.
- Observers were asked to be silent observers after their introduction to the group.
- Observers were asked to honor the confidentiality protocols established by Family Support ECHO™.
- Observers were asked to review some basic ECHO™ information prior to the session if they were unfamiliar with the ECHO™ model and format.
- Observers were limited ,so as not to overwhelm the hub or spoke participants.

Family Presentation Reviews

Evaluation Summary

Attendance:

	Spokes (9 members)	Hub (6 members)
Ten sessions	1	4
Nine sessions	3	2
Eight sessions	3	
Four sessions	2 ***Two members had to drop out due to COVID-19 disruptions to work and family life**	

Post-ECHO™ Interview Summary (conducted by Complex Systems Innovations)

Abbreviated highlights from ten interviews conducted with four (4) spokes and six (6) hub members.

Has the Family Support ECHO™ influenced how you support families?

- 8 out of 10 stated it was a positive influence by exposing them to a larger group other professionals and knowledge.
- 9 out of 10 stated it had increased their knowledge of community resources.

"It's allowed me to take a more 30,000-foot view of supporting a family instead of diving right into what their particular issues are. Listening to the questions that were asked in the family presentation is allowing me to help frame how I support families in my work."

Most important benefit to you:

- Process of collaboration and the development of relationships
- Passion, creativity, and developing a learning community
- Brainstorming during the family presentation reviews
- Resource sharing and learning about new resources

"I just started this job in October and I moved from across the state. It was a new role for me and a totally new area. This was great, because I was able to hear organic conversations about real people during the family presentations and then resources for them. There was a lot of stuff I wasn't aware of. A lot of little stuff that wouldn't be easy to find online or wouldn't be obvious. Second to that, as someone who is new to this role in this field, it was really helpful for me to hear experienced professionals discuss how they handle these situations in professional meetings."

Positive surprises that emerged during implementation or developed over time

The collaboration and resiliency of more seasoned members encouraged those newer to this work, as they were already experiencing some level of stress and burnout due to the emotional demands of the position.

"I would go back to the resiliency of this team. We've all been in it for years. That's what really surprised me, because I didn't quite know what I was getting into. I was really surprised to see the resiliency of the people who have been doing this for years, that are still passionate, that are still trying, that are still helping, supporting and doing as much as they can."

The power of connection was a consistent theme.

Family Presentation Reviews:

- Appreciated the diversity of the family presentation reviews and the number of different ways modeled to ask questions about parents and to parents;
- Team approach to presenting, commenting, and asking questions;
- ECHO™ has a specific presentation and discussion format that some participants did not like, while others felt the structure kept the discussion on track.

Most relevant didactic presentation:

- Financial and entitlements with specific mention of ABLE accounts
- Self-advocacy
- Health and wellness
- Guardianship and alternatives to guardianship.
- Housing was viewed as relevant but in need of additional time and specificity.

Least helpful didactic presentation: participants stated the sessions were all helpful in some way.

- The self-care session was viewed as helpful but not specific enough.
- Housing was noted as good information in general, but with the lack of housing resources in western NC it was difficult to operationalize.
- Self-advocacy was noted by one respondent as not relevant to where spoke participants were in their professional development.

Additional Topics for Consideration

Entitlements, especially after age 18	Medically fragile children
Collaborating with medical professionals	COVID-19 impact
Accessing mental health and substance abuse services	Survival resources: housing, food, transportation
Employment and post-secondary education	Diversity
Boundary setting	Cultural bias
Accessing services when not eligible for Medicaid	

Challenges that emerged during implementation or developed over time:

- Getting all participants to actively engage
- Zoom experience was difficult for some as they were unfamiliar with the technology or they experienced it as distant and somewhat impersonal. Some participants prefer in-person meetings.
- Wide range of professional and personal experience
- COVID-19 disruptions: two members had to drop out; hub and spoke members dealing with evolving work demands and schedules
- Youth 18-19 years of age that have never been connected to services
- Families in need of services that did not have health insurance coverage or were on the Registry of Unmet Needs.
- Maintaining fidelity to the ECHO™ model and structure
- Acknowledging the importance of and time demands required for planning activities

Evaluation

Satisfaction Survey *(see attachment)*

The satisfaction survey documents a high degree of satisfaction with the Family Support ECHO™ pilot across all five categories:

Satisfaction Surveys
1 = strongly disagree   5 = strongly agree

Category	Post eval.
Best practices, Skill improvement	4.4
Connect with Peers	4.7
Information, Guidance	4.4
Discussions, family reviews	4.4
Technology	4.6

■ Post eval.

Perceived Barriers Survey *(See attachment)*

The perceived barriers survey was intended to measure the barriers participants encounter when providing services and supports to families. The top two barriers identified were a lack of funding for this service and a lack of community support. Additional barriers were the lack of time, knowledge, and support from management. When asked what is needed to provide better family navigation and support services the replies included:

- support to address social determinants of health (transportation, housing, food insecurity)
- strategies and resources to address language barriers
- quick follow up to family requests
- better communication across agencies
- shared database for tracking referrals and outcomes
- services for those not on Medicaid

The expansion of family support services and the Family Support ECHO™ program across North Carolina will require a focus on policy, resource allocation, and education.

Self-Efficacy Survey (see attachment):

The Family Support ECHO™ self-efficacy survey, modeled after the self-efficacy surveys developed by Project ECHO™ , measures participants' degree of confidence to effectively support families across four ability areas: establishing a partnership with families, explaining multiple funding sources and services, helping families connect to services and resources, and connecting with their peers. Overall self-efficacy improved by 10.71%. Sixteen of nineteen items showed improved scores.

The following items showed the most improvement:

Item 3: Answering family questions about I/DD (including ASD) and know how to link to the best resource
Item 4: Connecting a family to the LME/MCO for enrollment in services
Item 8: Discussing the educational system and EC process with families

The Value of Connection: One of the reasons the I/DD Medical Health Home initiative invested in the development of a Family Support ECHO™ model was the reality that many individuals who serve as family navigators and liaisons work with limited connections to other family support specialists across the developmental disability community. OF note is that the ability to connect with peers received the highest score in both the satisfaction survey and self-efficacy survey. The interview responses also emphasized the power of connection and value of collaboration and relationships with peers.

Funding Support: The NC DHHS provided funding support for the Family Support ECHO™ pilot:

- travel support for six of the eight planning group members to attend the immersion training at the ECHO™ Institute (Trillium funded travel costs for their staff);
- staff time for ECHO™ co-facilitators (Kim Tizzard and Melinda Plue);
- purchase of technology equipment.

Hub members were given approval from their organizations to participate. Spokes were not paid for their participation but did receive a certificate of completion for their professional portfolio. See attachment. The guest speakers donated their time and expertise. There was no cost for use of the Zoom technology. The initial equipment costs were approximately $1,000. However, it is possible to launch a Project ECHO™ with very minimal technology and equipment costs. The UNM ECHO™ partnership agreement allows ECHO™ partners to utilize the ECHO™ Institute license agreement.

Recommendations & Next Steps for Family Support ECHO™

The pilot group unanimously agreed that NC Family Support ECHO™ should be expanded across the state, while maintaining a regional focus. Suggestions include:

- each Local Management Entity/Managed Care Organization (LME/MCO) catchment area in North Carolina should offer a Family Support ECHO™;
- be mindful of other learning collaboratives to avoid duplication and competition;
- develop implementation tools, such as a handbook;
- develop a mentoring process that enables experienced spoke participants to become hub members;
- balance the needs of entry level members with more experienced members;
- ensure at least two organizations share the implementation workload; and
- connect NC Family Support ECHO™ with other ECHO™ programs across the state.

Expanding Recruitment:

The pilot participants offered several recommendations for expanded spoke recruitment:

- inviting other disciplines and professional groups, such as physicians new to the area, mental health counselors, school system representatives;
- increased focus on diversity of the hub and spoke participants;
- expanding membership to those who have authority to make decisions about meeting family needs;
- connect with existing groups, that provide family support services to those with behavioral health needs, such as Families United;
- The Family Support ECHO™ pilot hub group has continued to meet and is discussing plans for a WNC Family Support ECHO™ #2 to be launched in late 2020.

Keys to Success

- Pick the right topic *(we know family support is the right topic!)*.
- Pick the right champions and facilitators *(families with lived experience, professionals who are responsible for family support services, and organizations responsible for policies and resource allocation that impact families)*.
- Always focus on the needs of the learners and participants (*survey potential learners, recruit knowledgeable presenters, ensure there is time for family presentation reviews and robust discussion*).

Policy Implications and Opportunities for North Carolina

North Carolina is in the midst of Medicaid Transformation that is intended to "build an innovative, whole-person, well-coordinated system of care, which addresses both medical and non-medical drivers of health and promotes health equity." There are three central aims: (1) better care delivery; (2) healthier people, healthier communities; and (3) smarter spending.

We believe that **family support services** are in alignment with the goals of Medicaid Transformation and the needs of families and children and adults with I/DD. Better care can be achieved through the

provision of family support services that are person and family-centered and accessible to the family and individual within their community. Family support services do promote <u>healthier people and healthier communities</u> by emphasizing the need to work collaboratively with community partners to address unmet resource needs and reduce health disparities. <u>Smarter spending</u> means paying for value and innovation that results in access to appropriate care and promoting quality of life for people with I/DD and their families.

The NC Institute of Medicine Healthy North Carolina 2030 report, the NC Child and Family Services Plan 2020-2024, and published white papers and priorities of the NC DHHS under *Healthy Opportunities* and NC Medicaid Transformation have identified a number of concerns and disparities that must be addressed from a statewide population health perspective, person and family centered philosophy, and in a locally responsive manner.

At this time, the availability of family support services is variable across the state and funding dedicated to this service is a small portion of total state allocations for I/DD and ASD services and supports. Family support services and Family Support Project ECHO™ are a wise investment of public and private funds and demonstrate a commitment to an innovative, person and family-centered system of care that can address medical and non-medical drivers of health.

Thank Yous

The Family Support ECHO™ pilot would not have been possible without the contributions of our funders, supporters, spoke participants, and hub members.

Funder: NC DHHS, Division of MHDDSAS

Supporters:

- Members of the planning group, noted on page 5-6
- NC Council on Developmental Disabilities for support of the I/DD Medical Health Home initiative since 2013.
- Organizations who supported their staff's participation as hub and spokes
- The Arc of NC and the Autism Society of NC for their shared leadership of the ECHO™ partnership agreement and pilot implementation
- Elena Lamarche, administrator

The values of ECHO™ are applicable to Family Support:

https://ECHO.unm.edu/about-ECHO/values

Service to the underserved: committing our efforts to building a better society, one that is more just and more loving.

Trust and respect: working from a place where we give the best of ourselves, we assume the best of others, and we communicate openly, honestly, and with regard for others.

Excellence and accountability: maximizing our individual and organizational potential, contributing to the best of our ability, seeking to be better, and owning our mistakes.

Joy of work: nurturing an environment that allows us each to do what we do best and balance our energy.

Demonopolize knowledge: sharing resources, knowledge, time, and talents freely across the organization, the movement, and the world.

Teamwork: recognizing that achieving our ambitions requires collective contribution and collaborative effort and cultivating a culture where we support each other, pitch in, and work together.

Innovation and learning: fostering continuous evolution and new creative ideas that have the power to change the world through learning and experimentation.

Attachments

- ECHO™ immersion training:
    - Launch Readiness Assessment
    - Planning Worksheet
- Recruitment Flyer
- Recruitment- Information and Intent Form
- Invitation email/letter for participants
- Survey to inform development of didactic presentations
- Family Presentation Review
- Didactic presentations: ABLE accounts and Know Your Local Resources
- Evaluation: demographic profile, perceived barriers and needs, self-efficacy, satisfaction survey
- Certificate of Completion

NC Family Support ECHO

Self-Efficacy Survey

Knowledge/Referral/Resources

Please rate your confidence in in your ability to effectively…	No confidence	Very little confidence	Slight confidence	Confident	Very confident	Highly confident/ expert
1. Establish a professional partnership with families.	1	2	3	4	5	6
2. Explain the variety of federal and state funding sources that may be available families.	1	2	3	4	5	6
3. Answer family questions about I/DD (including ASD) and know how to link them to the best resource.	1	2	3	4	5	6
4. Connect a family to the LME/MCO for enrollment in services.	1	2	3	4	5	6
5. Connect a family to appropriate healthcare providers and resources.	1	2	3	4	5	6
6. Partner with families to facilitate supported decision-making with the family member with I/DD.	1	2	3	4	5	6
7. Connect a family to the Social Security Administration for benefits enrollment.	1	2	3	4	5	6
8. Discuss the educational system and EC process with families.	1	2	3	4	5	6
9. Connect a family to other families with family members with a disability.	1	2	3	4	5	6
10. Explain the appeal process if the family is denied services.	1	2	3	4	5	6
11. Know how to take care of yourself to prevent burnout.	1	2	3	4	5	6
12. Identify community resources that can address social determinants of health (essential community living needs such as housing, transportation, food)	1	2	3	4	5	6

13. Educate families on the importance of family self-care.	1	2	3	4	5	6
Please rate your confidence in in your ability to effectively…	**No confidence**	**Very little confidence**	**Slight confidence**	**Confident**	**Very confident**	**Highly confident/ expert**
14. Provide information on guardianship, alternatives to guardianship, and supported decision-making to families.	1	2	3	4	5	6
15. Identify additional financial support resources for families who are uninsured or under-insured.	1	2	3	4	5	6
16. Teach families how to advocate for their family member with I/DD.	1	2	3	4	5	6
17. Connect families to supportive parenting education resources.	1	2	3	4	5	6
18. Connect families to crisis services and resources.	1	2	3	4	5	6
19. Maintain appropriate boundaries with family members.	1	2	3	4	5	6

Navigating Community Resource in WNC

Know Your Local Resources!

Kerri Eaker, Family Support Outreach Coordinator

MISSION Children's Hospital | **Family Support Network™ of WNC**

NC Family Support ECHO

Autism Society of NORTH CAROLINA   Project ECHO®   The Arc. North Carolina

Your Most Important Job:
Know Your Resources

❖ Develop your Personal Community Resource Guide

❖ Network with other Community Family Support Providers

❖ https://nccare360.org/ is the first statewide coordinated care network to electronically connect those with identified needs to community resources and allow for a feedback loop on the outcome of that connection.

❖ https://www.nc211.org/ is an information and referral service provided by United Way of North Carolina. Accessible via an easy-to-remember, three-digit number, families and individuals can call to obtain free and confidential information on health and human services and resources within their community.

Get To Know The Family

Take the Time to Gather All the Information:

It will save you time and the family frustration on the back end!

▶ Type of Insurance

▶ Any Assessments ie. Psychological

▶ Disability Determination- Social Security

▶ All Services Family is Already Provided

▪ *Care Notebook, Child & Family Team*

Transitioning Through A Child's Life

Hint: Make a check list for each stage of childhood

Birth to Three Years of Age

▶ [Children's Developmental Services of Western North Carolina](#)
Office: 828-251-6091 Fax: 828-251-6911 maggie.panther@dhhs.nc.gov

CDSA is accepting referrals and offering eligibility determination via teleconference. Face-to-face visits have been suspended until further notice. We are providing the following services via tele therapy: PT, OT, Speech, Nutrition, Social-Emotional/Counseling, Medical and Specialized Instruction (CBRS). Service coordinators are continuing to support families remotely and offering consultation with CDSA therapists for families unable to access tele therapy. (Individual Family Service Plan, IFSP)

▶ **The Community Alternatives Program for Children (CAP/C)** provides home- and community-based services to children at risk for institutionalization in a nursing home. https://medicaid.ncdhhs.gov/beneficiaries/get-started/find-programs-and-services-right-you/community-alternatives-program

▶ **WIC is the Special Supplemental Nutrition Program** for **W**omen, **I**nfants, and **C**hildren funded by the United States Department of Agriculture. It is commonly referred to as the **WIC** Program. County health departments, community and rural health centers, and community action agencies provide WIC Program services - [find the WIC Program in your county](#).

Three to Five Years of Age

▶ North Carolina Department of Public Instruction, Exceptional Children Division, Office of School Readiness- Preschool Program https://www.dpi.nc.gov/districts-schools/classroom-resources/early-learning-read-achieve/preschool-exceptional-children-program, Local NC Pre-K contract administrators can provide specific information about the enrollment process, available programs that meet NC Pre-K Program Requirements, and other specific information related to participation in NC Pre-K in your county, as well as other options for early childhood education services (e.g., Child Care Subsidy, Child Care Resource and Referral, Head Start, Preschool Exceptional Children, Smart Start, Title I Preschool).

Five Years of Age To Graduation from High School

- North Carolina Department of Public Instruction, Exceptional Children Division, https://ec.ncpublicschools.gov/ Exceptional Children Division is to ensure that students with disabilities develop intellectually, physically, emotionally, and vocationally through the provision of an appropriate individualized education program in the least restrictive environment. All service's are delivered through and Individual Education Program (IEP)

- No specialized instruction needed consider Section 504 https://ec.ncpublicschools.gov/policies/nc-policies-governing-services-for-children-with-disabilities/ncdpi-communication/2016-2017/federal-programs-Updates/parent-and-educator-resource-guide-to-section-504-in-public-elementary-and-secondary-schools-12-28-16/view?searchterm=504 and/or Individual Health Plan (School Health Nurse)

- Transition to Adulthood Planning Begins at age 14 ie. Vocational Training, Community Living Options, Secondary Educational Options, Guardianship or Alternatives https://ec.ncpublicschools.gov/disability-resources/intellectual-disabilities/secondary-transitions

Education System
Local and State Resources

▶ Exceptional Children's Resource Center (ECAC)- ECAC is the state's designated Parent Training and Information Center (PTI) and receives funding from the federal Department of Education Office of Special Education Programs https://www.ecac-parentcenter.org/

▶ FIRST Resource Center- FIRST has been funded as a Community Parent Resource Center by US Department of Education, Office of Special Education offering free parent training related to educational issues and rights under IDEA and Section 504. https://firstwnc.org/cprc/

▶ Family Support Network's of the Western Region- Service System Navigation Support

▶ Assistance navigating complex service systems to increase access to needed supports and services for children and their families

  ▶ WNC- https://missionhealth.org/member-hospitals/childrens/family-support-network/

  ▶ HOPE- https://www.fsnhope.org/

  ▶ High County- https://parent2parent.appstate.edu/

  ▶ Region A- https://rapc.org/

Where to Start in Finding Services

The Department of Health and Human Services manages the delivery of health- and human-related services for all North Carolinians, especially our most vulnerable citizens – children, elderly, disabled and low-income families.

https://www.ncdhhs.gov/about/overview

Assistance Services

- **Aging And Adult Services**
- **Children's Services**
- **Deaf-Blind Services**
- **Disability Services**
- **Disaster Preparation And Recovery**
- **Guardianship**
- **Hearing Loss**
- **Low-Income Services**
- **Medicaid**
- **Medicaid Transformation**
- **Mental Health And Substance Abuse**
- **NC Assistive Technology**
- **Pregnancy Services**
- **Veteran's Services**
- **Vision Loss**
- **Vital Records**

Divisions

- **Aging And Adult Services**
- **Child Development And Early Education**
- **Disability Determination Services**
- **Health Benefits (NC Medicaid)**
- **Health Service Regulation**
- **Mental Health, Developmental Disabilities, And Substance Abuse**
- **Office Of Economic Opportunity**
- **Office Of Minority Health And Health Disparities**
- **Office Of Rural Health**
- **Public Health**
- **Services For The Blind**
- **Services For The Deaf And The Hard Of Hearing**
- **Social Services**
- **State Operated Healthcare Facilities**
- **Vocational Rehabilitation Services**

Mental Health, Developmental Disabilities and Substance Abuse Services

- **Adult Mental Health Services**
- **Certified Community Behavioral Health Clinics**
- **Chief Medical Office for Behavioral Health and IDD**
- **Crisis Services**
- **Customer Service and Community Rights**
- **Consumer Empowerment and Community Engagement**
- **Deaf and Hard of Hearing Mental Health and Substance Use Disorder Services**
- **Down Syndrome**
- **Discounted Medications**
- **Driving While Impaired**
- **Frequently Used Acronyms**
- **Gambling**

- **Intellectual and Developmental Disabilities**
- **Involuntary Commitments**
- **Jail Diversion**
- **North Carolina Drug Control Unit**
- **NC START**
- **Psychiatric Advance Directives (PAD) forms**
- **State Operated Healthcare Facilities**
- **Substance Use Disorders**
- **Supported Housing**
- **Traumatic Brain Injury**

Home and Community Living Service Options

Services begin with your Local Management Entity/Managed Care Organization (LME/MCO)

▶ The NC Innovations Waiver is a Federally approved 1915 C Medicaid Home and Community-Based Services Waiver (HCBS Waiver) designed to meet the needs of Individuals with Intellectual or Development Disabilities (I/DD) who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting. The Medicaid Innovations Waiver supports Individuals with I/DD to live the life they choose. Waiver services are administered by a local management entity/managed care organization (LME/MCO) . **https://medicaid.ncdhhs.gov/providers/programs-and-services/behavioral-health-idd/nc-innovations-waiver/waiver-services**

▶ **Vaya Health**
Counties Served: Alexander, Alleghany, Ashe, Avery, Buncombe, Caldwell, Cherokee, Clay, Graham, Haywood, Henderson, Jackson, Macon, Madison, McDowell, Mitchell, Polk, Swain, Transylvania, Watauga, Wilkes, Yancey

▶ **Partners Behavioral Health Management Office**
Counties Served: Burke, Catawba, Cleveland, Gaston, Iredell, Lincoln, Rutherford, Surry, Yadkin

Medical/Dental Access to Care

▶ Medicaid or Health Choice-https://medicaid.ncdhhs.gov/beneficiaries/get-started/apply-medicaid-or-health-choice

▶ EARLY AND PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT (EPSDT)- Is a comprehensive healthcare plan focused on prevention and early treatment. A flexible plan with a menu of benefits available to be tailored to children's individual and developmental needs. https://medicaid.ncdhhs.gov/beneficiaries/get-started/find-programs-and-services/medicaid-benefit-children-and-adolescents-under

▶ Private Insurance Policies- Most policies have care manages to support families to navigate medical services.

▶ NC Family Health Information Center-Access Family Support Health Information Center is the family to family health information for the state of North Carolina. https://f2fsupport.org/contact-us/

Medical/Dental Access to Care

▶ NC Children with Special Health Care Needs Helpline: 1-800-737-3028

▶ Community Care of Western North Carolina (CCWNC) provides is care management services to Carolina Access II patients (Medicaid) assigned to our participating primary care practices (PCP). (Jennifer Jones) - http://ccwnc.org/programs-services/care-management

▶ Healthcare Passports- My Health Passport is a health advocacy document that describes the unique supports and preferences of an individual. It is designed to be shared with many types of healthcare providers, in clinic and hospital settings, especially for those who are not very familiar in providing care to individuals with intellectual/developmental disabilities. http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

Financial Assistance

▶ Social Security Benefits- Apply online https://www.ssa.gov/benefits/forms/

▶ First in Families of NC- To respond to a particular need, First In Families partners with local businesses, citizens, and agencies. Sometimes we work to get the lowest possible price, or we might barter or exchange something. Other times we simply make a referral to an appropriate agency.
http://fifnc.org/programs/chapters.html

Blue Ridge
Counties served: Alexander, Alleghany, Ashe, Avery, Buncombe, Caldwell, Cherokee, Clay, Graham, Haywood, Henderson, Jackson, Macon, Madison, McDowell, Mitchell, Polk, Swain, Transylvania, Watauga, Wilkes, Yancey
36-955-7140 or email BlueRidge@fifnc.org

▶ Check with your local programs some programs have funding options for certain items and counties in a WNC. The Arc Chapters, Eblen Foundation, United Way

▶ Able Accounts- https://savewithable.com/nc/home.html

▶ Special Needs Trust- http://www.ncestateplanningblog.com/blog-92-Permitted+Distributions+for+Special+Needs+Trusts

Legal Resources

- Disability Rights of NC- Is the Protection and Advocacy agency for North Carolina, who serve the whole state. They offer information and referral to residents with disabilities. They also offer free legal services. These services are provided to people who need help because of their disability. https://disabilityrightsnc.org/what-we-do/continuum-of-services

- Guardianship https://www.ssa.gov/benefits/forms/

- Alternative Options https://www.ssa.gov/benefits/forms/, https://www.ncleg.gov/enactedlegislation/statutes/pdf/bysection/chapter_32c/gs_32c-3-301.pdf

- Legal Aid- https://www.legalaidnc.org/

Questions -Thoughts Moving Forward

- Reach out to each other for Support
- Build a Team Email Listserv
- Google doc. Option- Mikaila Mills

Kerri Eaker
Contact Information:
Kerri.eaker@hcahealthcare.com
828-213-0047

NC Family Support ECHO

Partners

NC ABLE Accounts: Eligibility, Features and Benefits

NC ABLE
National ABLE Alliance Member

Dale T. Folwell, CPA
STATE TREASURER OF NORTH CAROLINA
DALE R. FOLWELL, CPA

Understanding NC ABLE Benefits

Understanding NC ABLE Benefits

NC ABLE allows people living with disabilities to save and invest their money in a tax-advantaged account for qualified disability expenses, without jeopardizing SSI or Medicaid benefits.

Eligibility and Certification

Eligibility and Certification

Two criteria must be met to qualify for NC ABLE

At least ONE of the following is true:

Disability occurred before the age of 26

+

Have a disability or blindness with a written diagnosis from a licensed physician

OR

Eligible for SSI or SSDI because of a disability

Note: Self-certification is required at the time of application and every year thereafter.

Opening an NC ABLE Account

Opening an ABLE Account

Enroll online
NC.SaveWithABLE.com

Download, print and mail
in application

For help opening an account, call NC ABLE at (888) 627-7503
Monday – Friday, 8:00 am – 5:00 pm ET

Authorized Agents

Account Owner and Authorized Agents

While the person who qualifies for an ABLE account is considered the owner, they can get help from an "Authorized Agent." There are four levels of agent status.

1 LEVEL 1

Can access information about the account

2 LEVEL 2

Can access information, receive duplicate statements, and move money within the account

3 LEVEL 3

Can access information, receive duplicate statements, move money within the account, and withdraw money

4 LEVEL 4

Can do everything the account owner can do – full access

Why NC ABLE?

- Unlike most states, NC ABLE allows parents to open an account on behalf of their disabled child who is an adult.

- Membership in the National ABLE Alliance (NAA) consortium of states provides the negotiation and buying power of 18 members states.

- Partner in advocacy in the North Carolina General Assembly.

Contribution Sources and Limits

Contribution Sources

Account Owner

Family and Friends

Rollovers from a 529 Plan

CARES Act benefit checks can be used to open and fund an NC ABLE account.

Contributions Limits

$15K

$15,000 per year contribution and rollover limit

$100K

Up to $100,000 is excluded from the calculation of the resource limit for SSI

$450K

Maximum Account Balance of $450,000

13

Contributions Limits-ABLE to Work

$15K

$15,000 per year contribution and rollover limit

Contribution limit may increase by the lesser of the amount of the account owner's earned income or the one-person poverty level for the prior year

How to contribute

Contributions to the ABLE account can be made by either:

Check

Electronic Funds Transfer (EFT)

Payroll Deductions

Ugift ugiftable.com

Now SSI payments can be direct deposited into NC ABLE accounts.

Investment Options

Investment Options

Checking account option

- **Interest bearing**
- **FDIC insurance up to $250,000**
- **Debit card with no card issuance fees**
- **Check writing**
- **Use of 53,000+ fee-free ATMs nationwide**
- **No overdraft fees**

Investment Options

- **Range of investment options**
- **Options based on risk level/comfort**
- **Money could grow over time**
- **NOT insured and it's possible to lose money**
- **Performance is not guaranteed**
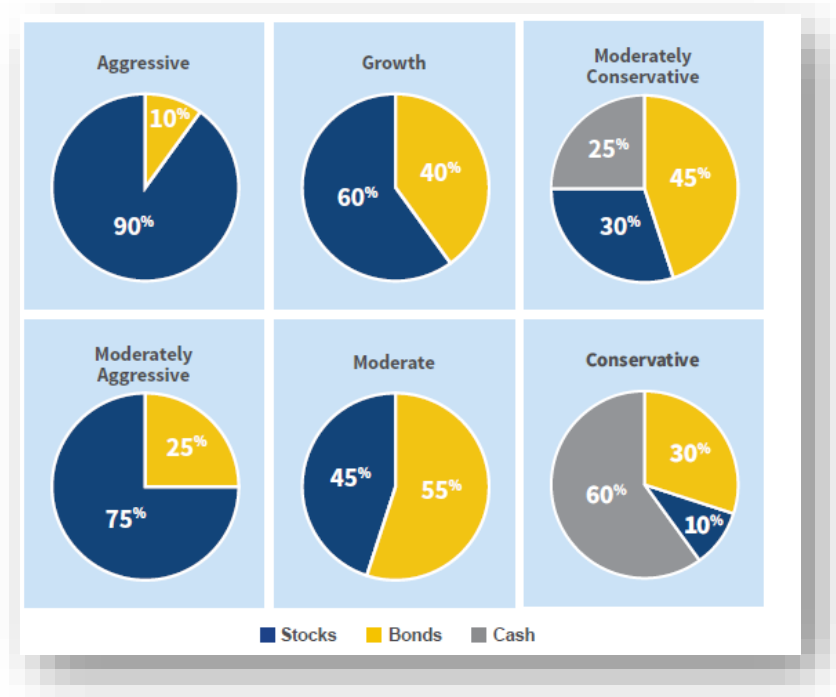
Investment options

Qualifying Expenses

Qualifying Expenses

The ABLE Act allows account owners to withdraw their money, tax-free, when it is used for a Qualifying Disability Expense (QDE).

A QDE is any expense related to the account owner's disability that can be used for the benefit of the account owner in maintaining or improving their health, independence or quality of life, such as:

Housing   **Transportation**   **Medical**   **Legal Fees**
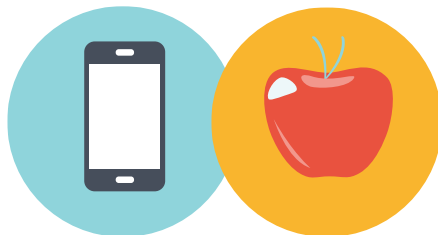
Food and cellphones may also considered QDEs.

Withdrawal Options

Withdrawal Options

Withdrawals from the ABLE account can be made by either:

ATM withdrawals

Check

Electronic funds transfer (EFT)

Debit card

Account Fees

Understanding Account Fees

- **Annual account maintenance flat fee** of $45 – regardless of the size of the account balance. ($60 for paper statements)

$45 → $40 goes to the program manager

$45 → $5 goes to the state of North Carolina to help pay for some of the costs to administer NC ABLE
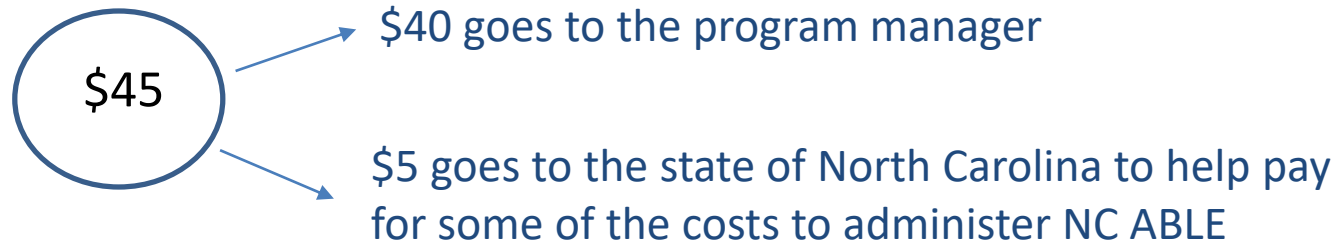
- **Checking Account option** - Fifth Third charges $2 per month. _Waived_ if average daily account balance is $250 or more, OR if electronic delivery of statements is elected

- **Annual asset-based fees for investment options** between .34% and .37% depending on investment options chosen (i.e. $3.40 - $3.70 per $1,000, annually)

ABLE and Special Needs Trust

ABLE and Special Needs Trusts

- Can be used in conjunction with a Special Needs Trusts (SNTs)

- Choice depends upon the beneficiary's specific needs and financial goals

- Encourage meeting with a SNT attorney for further information

For more information about the NC ABLE program

NC.SaveWithABLE.com

(888) 627-7503

@NCABLEProgram

NCABLEProgram

http://www.ablenrc.org/

info@ablenrc.org

1667 K Street, NW - Suite 480
Washington, DC 20006

(202) 683-6094

Questions

Thank you

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NC ABLE

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Longleaf Building
Raleigh, NC 27604

North Carolina
Total Retirement Plans

DALE R. FOLWELL, CPA

NC Family Support ECHO Pilot

Potential Didactic Topics (survey electronically)

Funding Sources: What are some of the federal and state funding sources and how can families navigate these system's?

- Social Security, Medicaid, Benefits Counseling
- SSI, SSDI & Medicaid
- NC Waivers (Innovations, CAP-C, TBI)
- State-funded services: Respite, Personal Care Services
- Alternative funding sources
- ABLE accounts

Education: What services are available in elementary, high school and post-secondary and how can families navigate the system?

- Individual Education Programs (IEPs) VS 504 Plans
- Transition Process
- Post-Secondary Options
- Parenting Education: eg. Triple P-Stepping Stones

Available Services and Resources: What state services are available and how can families navigate the system?

- Intellectual and Developmental Disability Services- eg. Innovations Waiver, B3, Registry of Unmet Needs
- Behavioral health needs and services
- Resources available for the uninsured and under insured
- Family Medical Leave Act and other resources available thru work

Social Determinants of Health: How can we support families to meet their community living needs?

- Housing (Shared Living, Section 8)
- Transportation
- Employment Options
- Food

Health and Wellness, Life Transitions and Ethics:

- Person-Centered principles and self-determination
- Medical and Dental Health Homes, Care Notebook
- The Importance of Family Self Care
- Guardianship, Alternatives to Guardianship and Supported Decision Making
- Creating Positive Outcomes in Challenging Situations
- Ethics, Boundaries especially in crisis situations

Name: _____ Group: _____

Planning Worksheet for Project ECHO for_____:

<div align="center">(your organization)</div>

This can serve as a planning guide, which might also be useful for preparing a proposal for funding. Filling in this sheet will also provide you with information on next steps, possible challenges, and help you focus on extracting relevant information from the different sessions you attend during immersion.

Part 1: Analysis and history   Focus Area: Pre-work
(you should answer these questions before coming to immersion, if not, we will help you find these answers)

1. What challenge/issue do you want to address? What will be the focus of your ECHO?
    _____
    _____
    _____
    _____

2. Why?
    _____
    _____
    _____
    _____

3. How does lack of access to this specialty knowledge result in poor outcomes?
- An analysis of _____ *(the topic or reason for your ECHO)*
    indicates that the problem has been linked to *(check the boxes that apply)*
    - ❏ Increased _____
    - ❏ Unnecessary _____
    - ❏ Longer _____
    - ❏ Poor outcomes in terms of _____
    - ❏ Poor follow-up
    - ❏ Other _____

4. What is your special expertise you want to share in order to amplify your impact? What can others learn from you that would be valuable to them?
- Tell us about your organization's expertise or role in this arena:
    _____
    _____
    _____
    _____

5. What gap or need in the community will your ECHO address? How has the gap been documented?

- A "gap analysis" shows inadequate expertise exists in _____ *(area)*, based on:
  - *National data*
  - *Flow of referrals to specialists*
  - *Government, academic or reports from professional organizations*
  - _____
    _____
    _____

> **ECHO is a model that demonopolizes specialty knowledge and expands access to critical care or services. The "sweet spot" for ECHO is to target issues of complexity, which require guided practice and ongoing mentoring, particularly areas where other forms of training or capacity-building fall short.**

6. What makes your target problem a "good fit" for the ECHO model?
   _____
   _____
   _____
   _____

7. What other partner organizations are you working with or do you plan to engage?
   _____
   _____
   _____
   _____

Part 2: Hubs and spokes   Focus Area: Replication Step-by-Step
(you should try to answer these questions during this session)

> **ECHO is a "hub" and "spoke" model creating multi-directional knowledge networks.**

8. What will your multidisciplinary (hub) look like? In this visioning, don't be constrained, create your "fantasy football" team… what kinds of expertise contribute to "best practice" in this field?

❑ Specialist/Subject Matter Expert(s)
_____
_____
_____

❑ Specialists/Subject Matter Experts from related disciplines
_____

❑ Specialists, Subject Matter Experts with interest in this area
_____

❑ Quality Improvement Expert
❑ Case Manager
❑ Social Worker
❑ Preventionist
❑ Financial Expert
❑ Legal Expert
❑ Others_____
_____
_____
_____

9. Who will be part of your staff team for administrative tasks and technical assistance?

❑ Clinic Coordinator   ❑ Program/Project Manager

❑ IT Staff   ❑ Others _____

10. Who are your likely learners/participants or "spokes"?

_____
_____
_____
_____

11. Will your initial ECHO be closed (invitation only) or open to anyone who wants to join?

_____
_____
_____

12. Do you already have a well-established network of learners? If yes, explain:

_____
_____
_____
_____

13. If not, you will need to recruit these participants or spokes:

- How many spoke participants in how many places do you want to include in the initial ECHO?

_____

- How many spoke participants in how many places do you want to include over time (we recommend 25 as a good target)?

_____
_____

- Where will your spoke sites be located?

❑ Public schools   ❑ Non-Profits

❑ Training Facilities/Professional Schools   ❑ Hospitals

❑ Professional Organizations   ❑ Medical schools

❑ Business or Service Centers   ❑ University clinics

❑ Private providers   ❑ Correctional facilities

❑ Governmental organizations   ❑ Federally Qualified Health Centers

❑ Non-Profits   ❑ Rehab facilities

❑ Community health clinics   ❑ Other_____

_____

Potential Spoke Site	What do you know about site? *(# of patients/participants, challenges, strengths, etc.)*	What is your relationship?	Who do you know? *(any potential champions?)*
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			

- What is the status of the internet capacity to support Zoom videoconferencing [>1 Mbps] at these sites?
  (Use letter codes: a – reliable, b – don't know, c – unstable, d – no internet)

Part 3: Curriculum Design
Focus Area: Curriculum & Case Presentation Template Development
(you should try to answer these questions during this session)
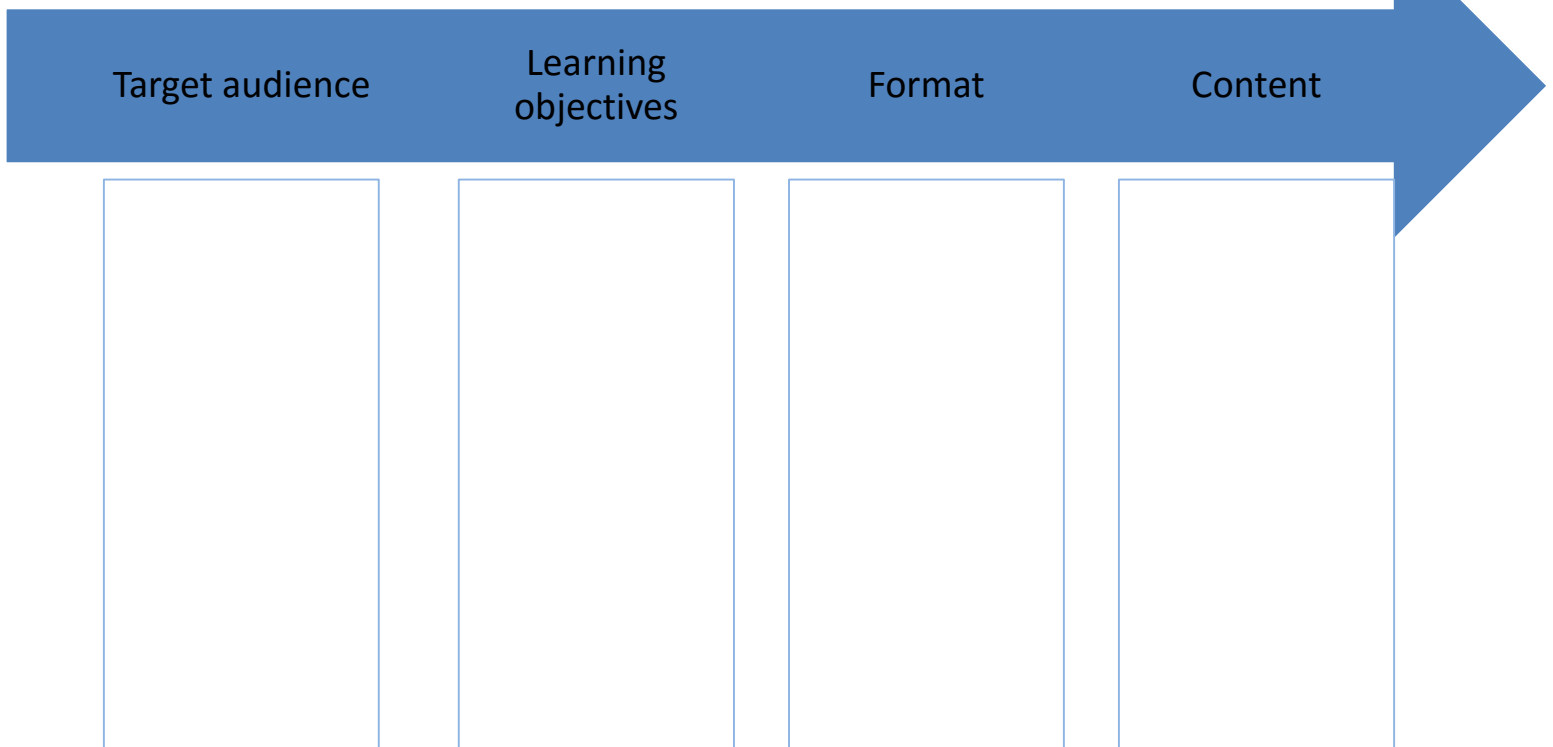
> **Besides case presentations, your targeted learners should be given the opportunity each week to benefit from didactics presented by experts in the field supported by references and contain at least three main learning objectives.   We recommend didactics to be between 15-20 minutes in length with time for questions. An ideal didactic curriculum should be inter-professional in scope and might follow these steps for its creation:**

Target audience	Learning objectives	Format	Content
• Conduct needs assessment • Invite representatives from your audience	• What do you want your audience to learn? • Are there any national standards available?	• Add a face-to-face component? • Majority of the time focuses on case-based learning	• What are some potential topics you want to cover?
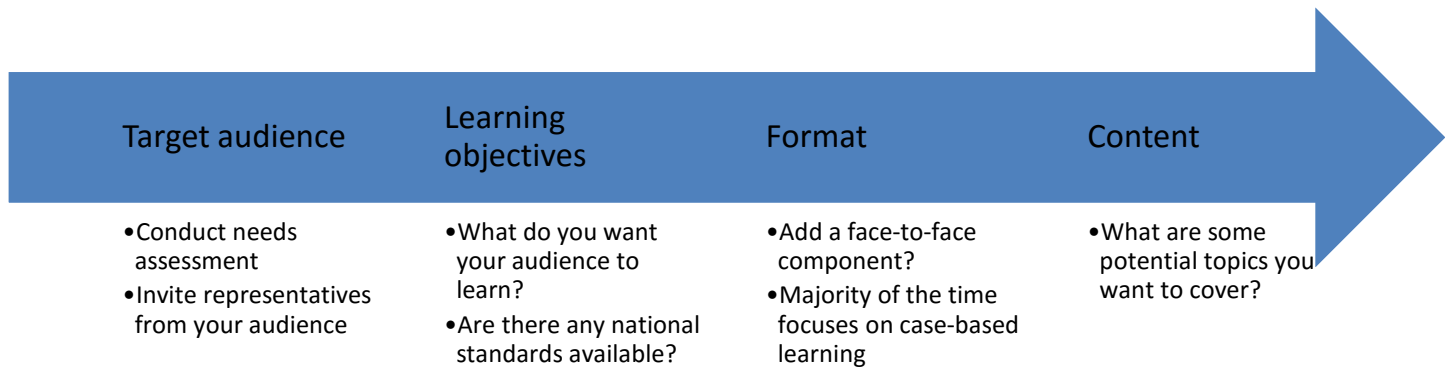
14. What will YOUR curriculum cover? Do you have a curriculum already? Will it need to be modified and adapted to optimize adult learning? [e.g. 15-20 min didactics, team –based learning, etc.]

Target audience	Learning objectives	Format	Content

15. Based on the idea you outlined above and through the process of ECHO telementoring, what are some of the potential competencies that participants will demonstrate?

a. _____

b. _____

c. _____

d. _____

e. _____

f. _____

Part 4: Evaluation   Focus Area: Evaluation Strategies and Resources
(you should try to answer these questions during this session)

16. How will you measure improvement in the above competencies? Consider outcomes and as well as training. How do you get data on the problem you are addressing?

_____
_____
_____
_____
_____

17. How will you know if your program is successful? To what degree do you expect the problem to be solved or lessened as a result of ECHO??

_____
_____
_____
_____
_____

18. What kinds of educational credits, certificates, or other incentives for participation will you offer and who will provide them (which institution)?

_____
_____
_____
_____
_____

Part 5: Funding   Focus Area: Strategic Planning

(you should try to brainstorm about these questions during this session)

> **In our experience, funding follows the creation or implementation of successful ECHOs, not the other way around. Often, organizations have funding (grants, contracts, department funds, etc.) to do the work that you want to amplify with ECHO. ECHO can often help you deliver on this work more effectively and efficiently, without requiring additional funding to begin.**

19. What funding do you already have that you can leverage to support your ECHO?

_____
_____
_____
_____
_____
_____

20. What additional funding do you think you will require?

_____
_____
_____
_____
_____
_____

21. What ideas do you have regarding funding sources (immediate and longer term)?

_____
_____
_____
_____
_____
_____

Part 6: Next Steps

Focus Area: Post-work

(you should answer these questions after Immersion with the help of your RPC)

```
┌────────────────────────┐     ┌────────────────────────┐     ┌────────────────────────┐
│ Send other team members│     │ Structure a learner-   │     │ Build support and buy-in│
│ to attend Introduction,│ ──▶ │ centric ECHO concept   │ ──▶ │ with leadership, other  │
│ Orientation and/or     │     │ and project plan (with │     │ hub experts, funders,   │
│ Immersion. Register at │     │ timeline and budget)   │     │ policy makers, etc.     │
│ http://echo.unm.edu/   │     │                        │     │                         │
│ start-an-echo/         │     │                        │     │                         │
│ orientation-events/    │     │                        │     │                         │
└────────────────────────┘     └────────────────────────┘     └────────────────────────┘
            │
            ▼
┌────────────────────────┐     ┌────────────────────────┐     ┌────────────────────────┐
│                        │     │ Develop a curriculum,  │     │                         │
│ Develop Hub team of    │ ──▶ │ learning objectives    │ ──▶ │ Create evaluation plan  │
│ experts and staff      │     │ and find didactic      │     │ and strategies          │
│                        │     │ presenters, develop    │     │                         │
│                        │     │ educational credits    │     │                         │
│                        │     │ and other participation│     │                         │
│                        │     │ incentives             │     │                         │
└────────────────────────┘     └────────────────────────┘     └────────────────────────┘
            │
            ▼
┌────────────────────────┐     ┌────────────────────────┐     ┌────────────────────────┐
│ Recruit Spoke          │     │ Train all hub members  │     │ Conduct 2 or 3 practice │
│ participants, set      │ ──▶ │ in their roles,        │ ──▶ │ sessions with open      │
│ session agenda and     │     │ establish protocols    │     │ feedback from all hub   │
│ time                   │     │ for all needed         │     │ and spoke participants  │
│                        │     │ processes              │     │ (and ECHO Institute),   │
│                        │     │                        │     │ then LAUNCH!            │
│                        │     │                        │     │ Congratulations.        │
└────────────────────────┘     └────────────────────────┘     └────────────────────────┘
```

22. What Challenges do you foresee?

_____
_____
_____
_____
_____
_____

23. How can we assist you in next steps or in overcoming challenges?

_____
_____
_____
_____
_____
_____

Project ECHO® (Extension for Community Healthcare Outcomes)

ECHO HUB
LAUNCH READINESS ASSESSMENT

Organization Name:_____

Contact Name (first and last):_____

Contact Email Address:_____

Contact Phone Number:_____

How did you learn about ECHO?_____

Have you been in contact with any ECHO Institute staff? If so, who?_____

Pre-Assessment Checklist

ℹ️ *Before you begin your assessment, please complete the checklist below.*

☐ Attend a monthly Introduction call
   (https://echo.unm.edu/join-the-movement/outreach-training/#Introduction)

☐ Review the What You Need to Know About ECHO page on our website
   (https://echo.unm.edu/need-to-know/)

☐ Review the Launch Readiness Assessment Guide

   (https://echo.unm.edu/wp-content/uploads/2019/02/Launch-Readiness-Assessment-Guide-Final.pdf)

Project ECHO® (Extension for Community Healthcare Outcomes)

Launch Readiness Assessment

Please answer each question as fully as possible. Do not exceed 500 words for each question.

1 *Please briefly describe your organization (include the type, size, and mission of your organization at a minimum).*

2 *How do you plan to use ECHO to address an issue/solve a problem in your community? Who will your ECHO learners ("spokes") be?*

3 *Do you have funding to support your anticipated ECHO project? If not, what resources do you have available to support your ECHO efforts?*

4 *Do you have your ECHO team identified (typical roles include an ECHO Lead, Clinic Coordinator, Program Manager, IT Support, and Subject Matter Expert; please note, these titles refer to roles, not individuals, so there may be overlap)?*

Project ECHO® (Extension for Community Healthcare Outcomes)

| 5 | *When are you hoping to launch your ECHO project(s)?* |

| 6 | *Do you have any questions for us? Anything else you'd like us to know?* |

Perceived Barriers Survey

1. **What are the barriers you face when providing support and/or services to families who are caregivers of children and adults with I/DD (including autism)?**
    Check all that apply:

    ☐ Lack of time.

    ☐ Lack of support from management.

    ☐ Lack of support from the community.

    ☐ Inadequate funding.

    ☐ Lack of knowledge about the LME MCO system.

    ☐ Lack of knowledge about community services and resources.

    ☐ Lack of confidence in my ability to support families dealing with complex situations.

    ☐ Lack of confidence in my ability to advocate with healthcare, human service and education systems.

    ☐ Lack of prior training in family navigation and support.

    ☐ Lack of supervision.

    ☐ Lack of peer contact.

    ☐ Other *(please specify):*

    _____

    _____

    _____

    _____

2. **What do you need to provide better family navigation and support services in your work?**

    _____

    _____

    _____

    _____

    _____

<u>Didactic Sessions</u>

Jan 15   Self-Care (Julie Davis)
Jan 29   Housing Opportunities and Funding Basics (Duncan Reid)
Feb 12   Medicaid/Accessing Services (Julie Davis)
Feb 26   Guardianship, Alternatives to Guardianship, and SDM (Duncan Reid)
March 11   Self-Advocates – Dream Big (Lindsey M.)
March 25   Health and Wellness (Michael LePage)
April 8   SSI & SSDI (Amy Upham) note: noon start for her presentation
April 22   IEP Basics (Kathy Dolbee, ASNC Autism Resource Specialist)
May 13   ABLE Accounts (Mary Buonfiglio, NCABLE/NC Treasurer's Office)
May 27   Know Your Regional Resources (Kerri Eaker)

<u>Meet Your Hub Team Members</u>

Kim Tizzard
Co-Facilitator, NC Family Support ECHO
Director of Family Support, Autism Society of North Carolina

Melinda Plue, MSW, LCSW
Co-Facilitator, NC Family Support ECHO
Director of Advocacy and Chapter Development, The Arc of North Carolina

Elena Lamarche
Coordinator/Administrator, NC Family Support ECHO

Kerri Eaker
Education Outreach Coordinator, Family Support Network of Western NC

Julie Davis, NCPSS
Family Partner, VAYA Health

Duncan Reid
Regional Director, The Arc of North Carolina

Michael LePage
Western Regional Director, Autism Society of North Carolina

Andre Perkins
IT Specialist, The Arc of North Carolina

We are excited to announce that we are developing a **NC Family Support ECHO** project in North Carolina. Our state pilot will launch in January 2020 and will focus on family support in western North Carolina, but it is our hope that with continued funding we can expand to other parts of the state. This is a joint venture supported by DHHS and co-led by The Arc of North Carolina and Autism Society of North Carolina, and we appreciate the help from our partner organizations: First in Families of North Carolina, Family Support Network of Western North Carolina, TEACCH, and Vaya Health.

NC Family Support ECHO will be offered as a ninety-minute interactive webinar. It includes a live presentation and discussion about the needs of a family, and it is followed by a short but deeper dive into a topic of interest for the entire group. This is where we need your help.

We want to know about which topics you think are most important for people who provide family support to understand as they assist families with accessing comprehensive information and navigating multiple complex systems in western North Carolina.

The survey is located at this link:

http://sgiz.mobi/s3/NC-Family-Support-ECHO-Content-Survey

This survey closes on November 12, 2019. Please take time to fill it out this week- it is very short and will not take very much of your time.

Thank you so much.

NC FS ECHO Planning Team

SATISFACTION SURVEY

Please rate the extent to which you agree with the following:	Strongly Disagree	Disagree	Neutral or No Opinion	Agree	Strongly Agree
1. Participation in NC Family Support ECHO improved my ability to provide quality services to families.	1	2	3	4	5
2. I learned best practices in family navigation and support through participation in NC Family Support ECHO.	1	2	3	4	5
3. I was able to connect with peers and colleagues through my participation in NC Family Support ECHO.	1	2	3	4	5
4. NC Family Support ECHO experts provided guidance in supporting families across the lifespan.	1	2	3	4	5
5. The information I received from NC Family Support ECHO experts is useful to me in my work.	1	2	3	4	5
6. Didactic presentations enhanced my knowledge about family navigation, support, and resources.	1	2	3	4	5
7. Discussions with other ECHO participants enhanced my knowledge about family support.	1	2	3	4	5
8. The family presentation review increased my knowledge about how to better serve families.	1	2	3	4	5
9. I have been comfortable using the technology associated with NC Family Support ECHO.	1	2	3	4	5
10. Technology for NC Family Support ECHO functioned smoothly.	1	2	3	4	5

11. Please share your thoughts about NC Family Support ECHO.

_____
_____
_____

12. Please share any suggestions for improvement for NC Family Support ECHO.

_____

_____

DEMOGRAPHIC FORM

1. What is your age? (in years) ____

2. What is your gender?

   ☐ Male
   ☐ Female

3. What is your ethnicity? (check the one with which you most closely identify):

   ☐ Hispanic or Latino
   ☐ Not Hispanic or Latino

4. What is your race? (check all that apply):

   ☐ American Indian or Alaska Native
   ☐ Asian
   ☐ Black or African American
   ☐ Native Hawaiian or other Pacific Islander
   ☐ White or Caucasian

5. In what county or counties do you provide family support services? _____

6. For what organization do you provide family support services?

7. What is your job title?

8. How long have you been in this position? _____

9. Please estimate the number of families for whom you provided services during the 2019 calendar year. ____

10. Have you had specific training in family support and navigation?
    ☐ No
    ☐ Yes

    IF YES, please indicate the type of training you have received and an estimate of the number of hours (check all that apply):

    ☐ Workshop ____
    ☐ Conference presentation . ____
    ☐ Webinar . ____
    ☐ On-the-job training . ____

☐ Lived Experience
☐   Other . ____

11. Why are you interested in participating in the NC Family Support ECHO?
    ☐ Increased networking with colleagues
    ☐ Increased knowledge about resources
    ☐ Learning how to be more effective in providing family support and navigation
    ☐ Desire to be more comfortable when providing services to families
    ☐ Other (please list)

    ☐   _____
         _____
         _____
         _____
         _____
         _____

12. What is your primary reason for participating?
    _____
    _____
    _____

Information & Intent Form
(deadline is December 20, 2019)

Families with loved ones with I/DD (including Autism Spectrum Disorder) ofte n struggle to access comprehe nsive, updated information while navigating multiple complex systems in our state. We know that keeping families healthy and informed is key to their family member's future.

We are pleased to announce a new initiative beginning in January 2020. **NC Family Support ECHO** is piloting a statewide approach to training and mentoring for those who provide family support and navigation services in a variety of settings.

Who Should Attend?

Individuals who provide family support to children and adults with I/DD and ASD in **western NC** and who would like to enhance their knowledge, expertise and connections as they help individuals of all ages with disabilities achieve their full potential.

The NC Family Support ECHO Team:

Specialists from Autism Society of NC, The Arc of NC, Family Support Network of Western NC, First in Families NC, Vaya Health, TEACCH, and others will share their expertise with a community of providers who support families across western North Carolina.

Intent Form:

Deadline: December 20, 2019 by emailing completed intent form to NCFSECHO@arcnc.org.

You will be contacted with more information by someone from the team. Applicants will be asked to complete a brief survey describing your work with families and topics about which you would be interested in learning more. NCFS ECHO reserves the right to approve or deny all applicants.

Requirements to Participate:

NC Family Support ECHO sessions are ninety-minutes long and are held twice per month (see schedule on right). NC FS ECHO sessions begin January 15, 2020 and end on May 27, 2020. We ask that participants commit to attending at least eight sessions in their entirety as a requirement for participation.

All participants will need access to a computer or mobile device with internet access to a working webcam.

Please note: Participants will be asked to present a real-world family presentation to the hub and peers for group discussion and shared learning.

ECHO Sessions:
Wednesdays, 11:45am-1:15pm

January 15
January 29
February 12
February 26
March 11
March 25
April 8
April 22
May 13
May 27

No cost to participate. You must have the approval of your agency and be able to attend a minimum of eight (8) of the ten sessions.

Project ECHO®

Project ECHO (click **here** for more info) is an online learning and guided practice model that is revolutionizing health and human services and education. Sessions link subject matter experts and mentors serving in a local community (the "hub") with people providing family navigation (the "spokes") across Western NC.

ECHO sessions are hosted via Zoom and involve brief lectures and discussion followed by a family presentation from the participants.

This video teleconferencing series, guided by experts, takes place twice monthly (90 minutes each) and will cover topics specific to family support and navigation services, including:

Funding sources: state and federal
Educational systems and options
Navigating complex systems
Social determinants of health
Health and wellness
Guardianship/Alternatives/SDM
Ethics and boundaries

Intent Form

NAME _____

EMAIL ADDRESS_____

HOME ADDRESS _____

CITY _____ STATE _____ ZIP_____

HOME COUNTY_____

CONTACT NUMBER _____

EMPLOYER_____

JOB TITLE_____

EMPLOYER'S ADDRESS _____

CITY _____ STATE _____ ZIP_____

WORK COUNTY_____

NC Family Support ECHO

NC FS ECHO is happy to provide free professional development for individuals in Western NC who are providing support, resources, and/or referrals to individuals and self-advocates who have intellectual disabilities (including Autism Spectrum Disorder).

The Arc of North Carolina and Autism Society of North Carolina and our partner organizations (First in Families of North Carolina, Family Support Network of Western North Carolina, TEACCH, and Vaya Health) would like to invite you to an exciting initiative.

We are conducting an ECHO pilot (NC FS ECHO) from January-June of 2020; it is designed to address the comfort level and professional development needs of people providing support to families and selfadvocates in Western North Carolina.

What is Project ECHO?

Project ECHO (https://ECHO.umn.edu) is an online learning and guided practice model that is revolutionizing professional education. The program will link subject matter experts and mentors serving in your local community (the "hub") with volunteers and professionals providing family navigation (the "spokes"). NC Family Support ECHO will be offered as a ninety-minute interactive webinar involving a brief lecture, discussion, family presentation and consultation. Individuals representing The Arc of NC, Autism Society of NC, Vaya Health and Family Support Network of Western NC will be serving as both mentors and colleagues (the Hub Team), sharing their knowledge and expertise with a community of those in a variety of family navigation roles (the Spokes) across Western North Carolina.

Requirements?

Our pilot project will consist of ten (10) ninety-minute sessions held on the second and fourth Wednesdays of the month (11:45am-1:15 pm). ECHO sessions begin January 15th and end on May 27. We ask that participants fully commit to attending eight sessions at a minimum. All participants will need access to a computer or smartphone with working internet and functioning webcam.

Who is eligible?

People in Western NC who have the professional role (paid or unpaid, but as a part of an organization) of helping caregivers and individuals navigate resources and services and who would like to enhance their knowledge and skill to better serve people with I/DD (including Autism Spectrum Disorder).

Want to hear more?
For questions, please reach out to us at NCFSECHO@arcnc.org and we will be in touch.

CERTIFICATE
OF APPRECIATION

THIS CERTIFICATE IS PRESENTED TO:

Name Surname

in recognition of your contributions and participation
as a Hub Team member of the NC Family Support ECHO pilot
January – June 2020

Presented July 2020

NC Family Support ECHO

Autism Society
of NORTH CAROLINA

Project
ECHO®

The Arc.
North Carolina

NC Family Support ECHO

Autism Society of NORTH CAROLINA   Project ECHO   The Arc. North Carolina

Family Presentation Review

Out of respect for the ECHO participants, individuals and families,
do not share presentations outside the NC Family Support ECHO setting.
See HIPAA identifiers to the right.

Presentation Date:

Presenting Partner:

NC FS ECHO ID Number:
(to ensure compliance with protected health information
and allow form to be filed)

Family Background:

Some HIPAA Identifiers:
(REMINDER – the below listed identifiers should NOT appear anywhere in this document.)

1. Name
2. Date of Birth
3. Street Address
4. Phone number
5. Email Address
6. SSN
7. Insurance provider & number
8. Photos *(unless consent is obtained)*
9. Unique or other identifying characteristics

Diagnosis/Diagnoses of individual:

County of residence:

Number/relation(s) of people in household:

Family's connection to available community resources (special education services, healthcare, etc.)- include past and present.

Strengths of individual/family needing assistance:

Needs of individual/family needing assistance:

Questions for the Hub Team:

Age of individual needing assistance:

Gender of individual needing assistance: