

North Carolina Family Support ECHO™

*Amplifying the Connections Between Partners and
Resources Vital to Whole-Person Care*

September 2021

Objectives of Today's Presentation:

Identify the core elements of the Project ECHO model.

Identify a minimum of 3 outcomes from the NC Family Support ECHO programs that align with the mission of the LICC.

Learn how NC Family Support ECHO lays a foundation for family engagement, interagency collaboration, information sharing, and equity.

Identify opportunities for the expansion of NC Family Support ECHO programs.

Presenters

- Julie Davis, julie.davis@vayahealth.com
Family Partner, Member Engagement & Outreach,
Vaya Health
- Melinda Plue, mplue@arcnc.org
Director of Advocacy/Chapter Development
The Arc of North Carolina
- Kim Tizzard, ktizzard@autismsociety-nc.org
Director of Family Support
Autism Society of North Carolina

Development of NC Family Support ECHO

- ▶ Conversations around what is needed in North Carolina, given needs, gaps, current and future landscape
- ▶ Wyoming Project ECHO presentation at May 2018 Summit prompted discussion about the need for and feasibility of Family Support ECHO in NC
- ▶ Deciding on two organizations to spearhead a collective effort and securing funding support for pilot program from NC DHHS
- ▶ Deciding who should take the lead within those organizations
- ▶ Gathering a team from other partner organizations with shared mission
- ▶ Honing our focus: using ECHO to provide direct education and support to families, **OR** building a corps who provides that service and enhance their skills and connections

NC Family Support ECHO



Pilot Organizational Partners



Family Support Network™ of WNC



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NC DEPARTMENT OF HEALTH AND HUMAN SERVICES

Why Family Support?

- ▶ What we know:
 - ▶ Parents, siblings are often lifelong caregivers.
 - ▶ Primary caregivers are asking for support.
 - ▶ Keeping families supported puts less strain on multiple systems.
 - ▶ Medicaid Transformation and whole-person care on horizon.

Who Provides Family Support?

- ▶ Professionals and volunteers with or without lived experience.
- ▶ Many different titles: Family Partners, Practice Navigators, Family Navigators, Resource Specialists, Community Guides, Case Managers, Clinical Caseworkers, and Community Health Workers.
- ▶ Limited contact with peers.
- ▶ Rural communities face additional challenges.

NC Family Support Initiative: Where and Who?

Planning Team

***Kim Tizzard**, Autism Society of North Carolina

***Melinda Plue**, The Arc of North Carolina

*Julie Davis, VAYA Health

*Kerri Eaker, Family Support Network of WNC, Mission Children's Hospital

*Katie Holler, TEACCH

*Lisa Sullivan, First in Families NC

Karen Luken, Disability and Health Consultant

Dr. Gary Walby, External Evaluator

What is Project ECHO™?



- ▶ Guided practice model.
- ▶ Engages participants (SPOKES) via video conference.
- ▶ Connects participants to specialist mentors (HUB).
- ▶ Hub team members serve as teachers and mentors.
- ▶ Through tele-mentoring, ECHO™ creates access to local resources.
- ▶ ***ALL TEACH-ALL LEARN.***

What is Project ECHO?



Principles of the ECHO™ model: ABCD

Amplification (use technology to leverage scarce resources)

Best practices (to reduce disparity)

Case-based learning (to master complexity)

Data (to monitor outcomes)

Anatomy of an ECHO session

Part One: Brief Didactic

20-30 minutes, tops

Part Two: Family Presentation Review

1-2 per session, depending on complexity

- Prescriptive way to manage these sessions (facilitator role is critical)
 - Allows both Hub Team and Spokes to ask questions and share recommendations.
 - Each session followed with notes and recommendations for entire team.
 - Total time for an ECHO session was 90 minutes.

Setup of an ECHO session



NC Family Support ECHO PILOT

The Hub Team

- ❖ **Kim Tizzard**, Co-Facilitator, NC Family Support ECHO™
- ❖ **Melinda Plue**, Co-Facilitator, NC Family Support ECHO™

- ❖ **Julie Davis**
 - Family Partner, Vaya Health
- ❖ **Kerri Eaker**
 - Education Outreach Coordinator, FSN of WNC, Mission Children's Hospital
- ❖ **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

Pilot Spokes Team

❖ Recruitment of Spokes

❖ Incentives

▶ Cross-segment of community:

- ▶ Exceptional Children's Assistance Center, HCA Healthcare, Vaya Health, TEACCH, Community Care of NC, Pathways, McDowell Pediatrics, Youth Villages
- ▶ Ended up with a total of 9 spokes after recruitment.
- ▶ Represented 15 counties in Western NC - not just Buncombe.

Didactic presentation topics covered in NC Family Support ECHO pilot:

Housing Overview and Opportunities in WNC

Medicaid and How to Access Services

Guardianship, Alternatives to Guardianship, and Supported Decision-Making*

Self-Advocacy*

Health and Wellness*

The Basics of SSI & SSDI

The Basics of an IEP

ABLE Accounts*

Know Your WNC Resources

Self-Care

Family Presentation Review

NC Family Support ECHO



Family Presentation Review

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

Presentation Date:

Presenting Partner:

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

Family Background:

County of residence:

Number/relation(s) of people in household:

Strengths of individual/family needing assistance:

Needs of individual/family needing assistance:

Age of individual needing assistance:

Gender of individual needing assistance:

Diagnoses of individual needing assistance:

Family connection with community resources:

Present:

Past:

Services currently receiving *(educational, healthcare, disability, etc.)*

Family's Presenting Concern:

PRIMARY QUESTION(S) FOR THE ECHO HUB: What resources are available to help this Family survive?

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

1. Name
2. Birth Date
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

NC Family Support ECHO Pilot Evaluation Findings:

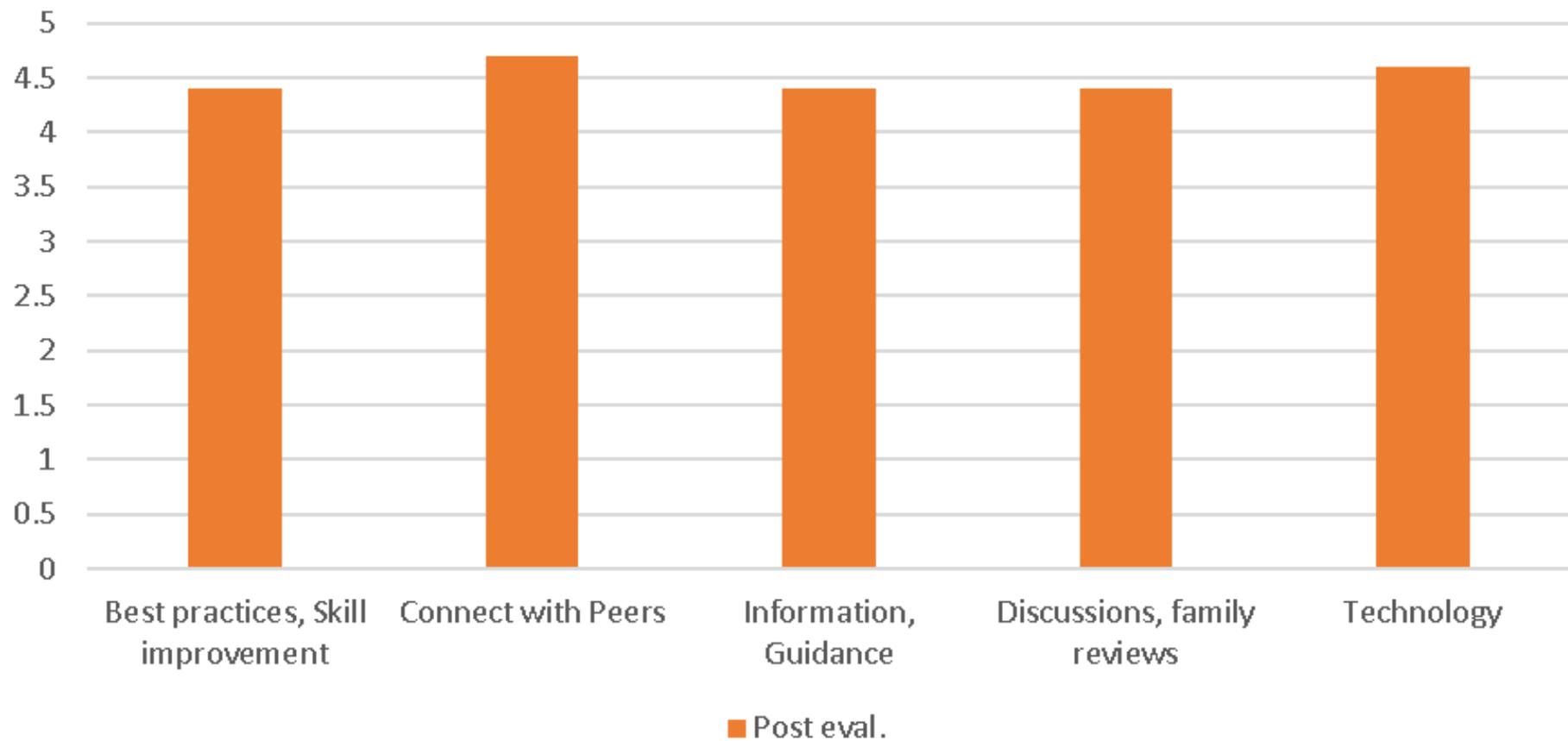
The following items showed the most improvement:

Ability to...

- ▶ Answer family questions about I/DD (including ASD) and know how to link them to the best resource.
- ▶ Connect a family to the LME/MCO for enrollment in services.
- ▶ Discuss the educational system and EC process with families.

Satisfaction Surveys

1 = strongly disagree 5 = strongly agree



Satisfaction Survey Feedback

*"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."*

*" ..realizing that **everybody had something to offer** even in their questions. It really became like a **safe haven** for people to have those **transparent, vulnerable conversations.**"*

*" A new role for me and a totally new area. I was able to hear **organic conversations about real people** during the family presentations and the 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."*

*"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."*

Expanding NC Family Support ECHO across the state and Ensuring a Regional Focus

- ▶ Western NC Family Support ECHO launched in October 2020 and ended May 2021
- ▶ Central/Triad Family Support ECHO launched in February 2021 and ended June 2021
- ▶ Western NC FS ECHO # 3 will launch in October 2021
- ▶ Eastern NC FS ECHO will launch in November 2021

Western NC Family Support ECHO 2.0

- ▶ 8 sessions
- ▶ 12 new spokes
- ▶ 2 former spokes became hub team members
- ▶ Covered 22 WNC counties
- ▶ Didactic topics
 - ▶ Professionalism-Boundaries
 - ▶ IEP, 504, Virtual learning
 - ▶ Navigating services without Medicaid
 - ▶ Supported Decision Making-Guardianship
 - ▶ IDD Medicaid Services: CAP-C, CAP-DA, NC PCS, Innovations, RUN
 - ▶ SSDI/Benefits
 - ▶ Sexuality*
 - ▶ Adult Living-Health

Central/Triad NC Family Support ECHO 2.0

- ▶ 8 sessions, February-May 2021
- ▶ 13 spokes
- ▶ Hub members included
- ▶ Covered 6 counties
- ▶ Didactic topics included
 - ▶ IEPs and 504 Plans
 - ▶ ABLE Accounts and Saving Money
 - ▶ Self-Advocacy
 - ▶ SSI/SSDI/Financial Stability
 - ▶ Sexuality for People with I/DD *
 - ▶ Know Your Regional Resources
 - ▶ Housing Overview
 - ▶ Guardianship Overview *

Satisfaction Survey 2021: NC Family Support ECHO Central



Self-Efficacy Survey 2021: NC Family Support ECHO Central

Items showing the **most improvement**:

Ability to:

- ▶ Connect a family to the Social Security Administration for benefits enrollment
- ▶ Connect families to crisis services and resources
- ▶ Identify additional financial support resources for families who are uninsured or under-insured
- ▶ Connect a family to appropriate healthcare providers and resources
- ▶ Discuss the educational system and EC process with families

Evaluation Across NC Family Support ECHO Programs

Positively influenced how they support families by **increasing their knowledge of available resources and connecting them with other professionals**

“It has been a total lifeline.”

“I have more resources now than I did before.”

“Participating in this program did help me to learn and think outside the box more.”

Benefits of Family Support ECHO

Connecting with other professionals and sharing resources

“I love that ECHO set a precedent that everyone is here to learn and has value to give.”

“It was nice to acknowledge that our systems are not perfect, but not to feel hopeless.”

“The biggest surprise was figuring out that through listening to other people during the case studies just sitting there and having aha! moments and using my real-life experiences...so eye-opening and gave me more confidence.”

Participant Feedback

- ▶ *“I didn’t expect it to be as **powerful** as it was. It did wow me. The expertise of the people participating was amazing. I think it **exceeded expectations.**”*
- ▶ *“ECHO helped me to see ... **you can always learn something new.** Things are constantly changing.”*
- ▶ *“Hearing from other people in this community that we all do share similar struggles when working with clients and that I am not alone.”*
- ▶ 100% said they would consider participating in another Family Support ECHO.
- ▶ 100% said they would consider participating in another ECHO program.

Things We Have Learned Along the Way

- ▶ Pick the right topic for your community.
- ▶ Pick the right champions and facilitators.
- ▶ Always focus on the needs of the learners and participants.
- ▶ Stay organized and follow up afterwards with notes and recommendations.
- ▶ Stay true to the fidelity of the Project ECHO model.

Alignment with LICC

- ▶ LICC brings parents, professionals and community members together with a common mission and vision.
- ▶ ECHO brings together subject matter experts (including families and individuals with disability) and community members to address a variety of issues relevant to the members and community.
- ▶ LICC members would be great Hub and / or Spoke participants in FS ECHO.
- ▶ LICC member ideas for topic specific ECHO programs, such as early intervention, others??

Alignment with Medicaid Transformation goals of:

- (1) Better Care Delivery;
- (2) Healthier People, Healthier Communities;
- (3) Smarter Spending.

Moving Forward: ECHO is ...

- A smart investment that supports a commitment to innovative, person and family centered systems of care that can address medical and non-medical drivers of health
- An innovative, evidence-based approach to improving access to quality services for children with special healthcare needs and their families
- Acknowledges the importance of technology-based and virtual learning and collaboration in today's world
- ▶ ECHO is growing and we want to make sure I/DD, families, and community members are intentionally included and represented.
- ▶ Working to establish a Project ECHO Network-NC

Resource List

- ▶ Project ECHO: <https://hsc.unm.edu/echo/about-us/>
 - ▶ <https://hsc.unm.edu/echo/>
- ▶ I/DD Medical Health Home Initiative:
 - ▶ Summary report on NC Family Support ECHO pilot, <http://iddhealthhomeinitiativenc.com/index.php>
 - ▶ **2021 Family Support and Navigation Summit**
http://www.iddmedicalhealthhomencinitiative.com/images/NCFamilySupportECHO_for_2021_Summit-FINAL-VERSION.pdf

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Mock Session

Questions?