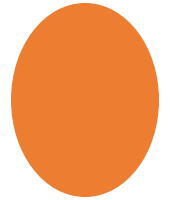


Supporting Families and Healthcare Providers to Provide Quality Care to Persons with Down Syndrome Across the Lifespan

Karen Luken

Cheri Howell

April 2023



Our Presentation



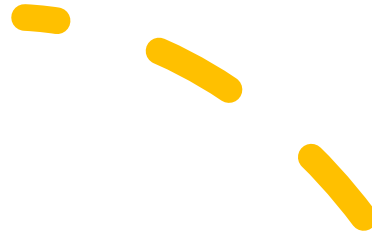
Health and a medical home

Resources for families that support access and continuity of healthcare

Resources for Healthcare providers

Opportunities for collaboration and education that support the mission of NCDSA

Health



More than absence of disease

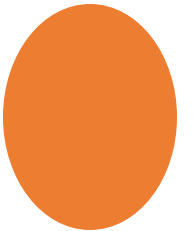
Disability is NOT an illness

Shifts back and forth on a continuum during our lifetime

Maintaining good health requires access to quality healthcare services

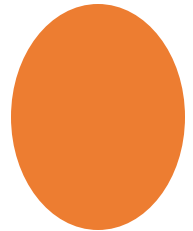
Having access to routine primary health care, health promotion services and necessary specialty care

Having access to services from competent, caring professionals



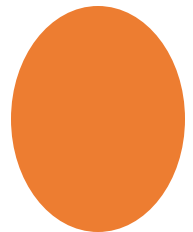
Perceptions of Good Health by People With I/DD in Medicaid Managed Care (Heller)


- ability to perform the activities one wants to do
- absence of pain, disease, and symptoms
- being able to follow treatment or not needing treatment
- physical self-care
- mental or spiritual self-care



Perceptions of Good Healthcare by People With I/DD in Medicaid Managed Care **(Heller)**

- ensuring needs are met through timely access to services
- continuity
- quality services
- navigating the healthcare system successfully
- receiving humanizing healthcare

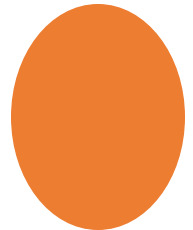




"Staying healthy requires a **collective effort, social support, and environments** where healthy choices are made available and easy to make."



Dr. Beth Marks

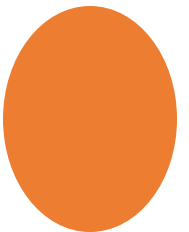


Patient Centered Medical Home

Everyone should have a Medical Home where many of their health needs can be met

Providers, individuals, and families **work together** as partners

Doctors and others know how to help the person **get the care and services they need to be healthy**



Benefits of a Medical Home



Knowing where to go for care

More organized care

Support from a team of informed health-care professionals who know their patients and take responsibility for their ongoing care

More efficient communication – not continually repeating information to multiple providers

Appointments scheduled in a coordinated, efficient way to avoid duplicated services

Comprehensive, central health record that contains all pertinent information

Reduced stress

Increased satisfaction with health care



Choosing Your Healthcare Provider

QUALIFICATIONS

EXPERIENCE

PHILOSOPHY

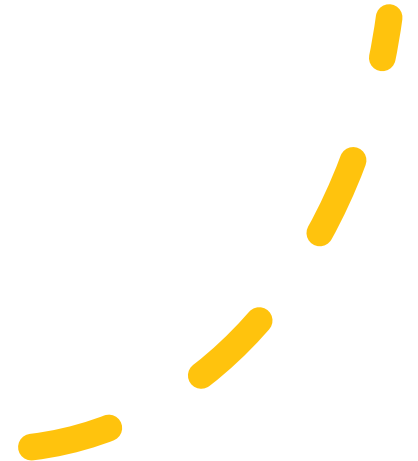
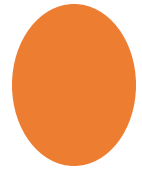
ACCESSIBILITY

AVAILABILITY FOR
APPOINTMENTS

OFF HOURS ACCESS

COMMUNICATION

REFERRALS



Preparing for Appointments: Ask Me Three

Every time you talk with a health care provider

ASK THESE 3 QUESTIONS

1

**What is
my main
problem?**

2

**What do
I need
to do?**

3

**Why is it
important
for me to
do this?**

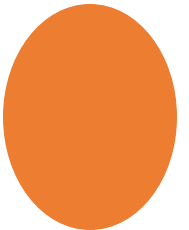
Adults with Down syndrome

Living longer than ever before

- Providers need to learn about common conditions and issues encountered in adulthood so they can help individuals prepare for a healthy future

Experience “accelerated aging”

- Providers need to be aware that adults in their 40s and 50s may experience certain conditions that are more commonly seen in elderly adults in the general population



Diagnostic Overshadowing: All is Not Down syndrome

Misdiagnosis or underdiagnosis of co-occurring conditions

Physical health and mental health problems can be missed, misdiagnosed or not treated effectively

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Health Issues to watch for include



Being Overweight

Sensory Changes

High Cholesterol

Obstructive Sleep Apnea

Celiac Disease

Increased Risk of leukemia

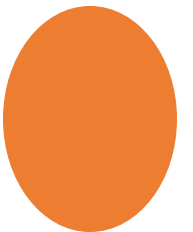
Early menopause

Hypothyroidism

Osteoarthritis

Osteoporosis

Cervical Spine concerns



What Do Families & Individuals Want & Need from their Medical Home

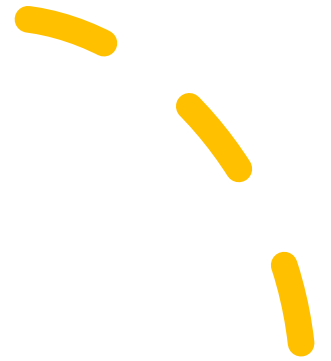
- Recommendations that avoid complex terminology and provide concrete, actionable steps
- Background information and evidence for recommendations
- Toolkits and resources in user friendly language





 publicdomainvectors.org

Bridging the Gaps



“Collaboration
is at the heart
of the ECHO™
model.”

Dr.
Sanjeev Arora,
MD, Founder

NC Family Support ECHO

www.iddmedicalhealthhomencinitiative.com/project/nc-family-support-echo

TEACCH Autism ECHO - Primary Care

TEACCH Autism ECHO -Mental Health

www.Teacch.com/trainings/project-echo-autism

Down Syndrome

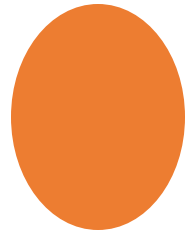
Medical Interest Group ECHO

Project ECHO Network-NC



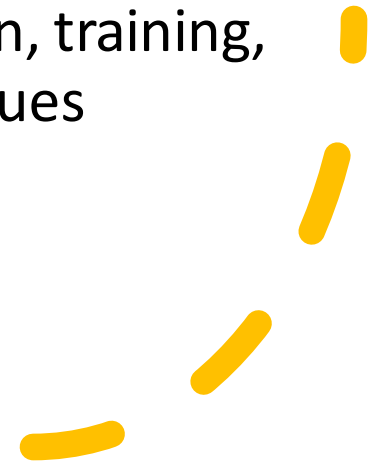
Project ECHO™ (Extension of Community Health Outcomes)

- Goals
 - Spread knowledge
 - Expand capacity
 - Accelerate collective wisdom
- Guided-practice model
- Uses tele-mentoring
- Subject matter experts share expertise



NC Family Support ECHO (NC FSE)

- Healthy / Informed Families -> Healthy individual with disability
- Family support -> positive outcomes
- Family health education and support should be a core element of a comprehensive healthcare delivery system
- Need access to information, training, best practices, and colleagues



NC FSE Outcomes

Increases in....

- Knowledge of community resources
- Increased confidence
- Linking families to the best resources
- Connecting families
- Discussing educational system and EC process
- Collaboration



NC FSE Feedback

“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.”

“I didn’t expect it to be as powerful as it was. The expertise of the people participating was amazing. It exceeded expectations.”

“ECHO helped me to see you can always learn something new. Things are constantly changing.”

100% said they would participate in another Family Support ECHO

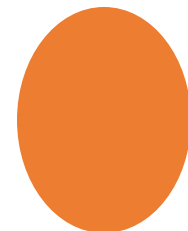
100% said they would participate in another ECHO program

ECHO™ is all teach, all learn

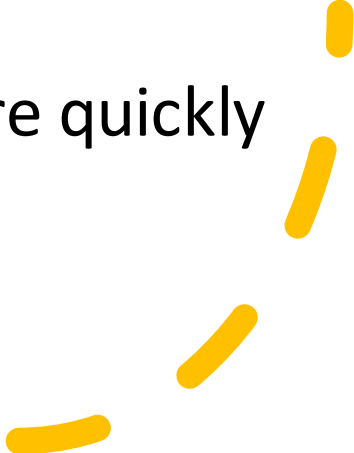
TEACCH Autism ECHO Programs

Improve ASD-specific knowledge and treatment self-efficacy of primary care and mental health providers in NC

Improve the quality of lifespan care received by individuals with ASD by increasing provider diagnostic screening and treatment of common medical and behavioral health comorbidities



TEACCH Autism ECHO Outcomes

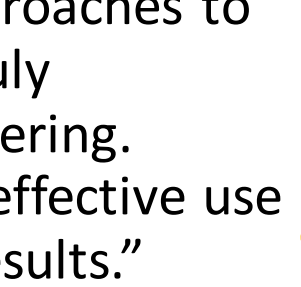
- High Satisfaction
 - Improvements in use of evidence-based interventions and practices
 - Improvements in ASD knowledge and self-efficacy
 - Increased number of MCHAT screenings
 - Referring children more quickly for evaluations
- 

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TEACCH
Autism
ECHO
feedback

“The most valuable aspect of this was learning about the resources available for me and my patients. I've also enjoyed how there is a team giving their unique feedback based on different roles caring for the patient. This has helped me broaden my vision of the care required for best outcomes.”

“I have gained a wealth of knowledge regarding interventions and approaches to interventions. This training is truly insightful, practical, and empowering. Hands down, this training is an effective use of time and is yielding fruitful results.”

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Down
Syndrome
Medical
Interest
Group
ECHO([dsmig-
usa.org](http://dsmig-usa.org))

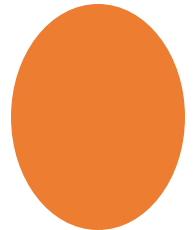
- Monthly virtual meeting for health care providers to learn and share information about the care of people with Down syndrome
 - An opportunity for healthcare providers to seek input from expert providers with significant experience in caring for people with Down syndrome
- 

Project ECHO Network in NC

- Support efficient and effective delivery of ECHO programs across NC
- Support ECHO programs that address health equity
- Ensure rural communities have access to ECHO programs
- Promote the fidelity of the Project ECHO model
- Identify state priorities that align with the ECHO model
- Enhance the evaluation of Project ECHO programs
- Work collaboratively with state and local governments, community-based organizations, academic institutions, health care and human service providers, funders, and other stakeholders to support ECHO programs that address educational needs of a diverse health and human services workforce
- Develop a sustainable business model to advance and sustain the PEN-NC and Project ECHO programs

Breaking Down Barriers

- Increase health professional and staff awareness and education about lived experience of individuals with disabilities and families
- Provide ongoing education for healthcare professionals
- Provide access to consultation expertise
- Promote an inclusive, patient-centered and family-centered care culture through hospital compliance with Section 504 and the ADA



Down Syndrome Resources

National Down Syndrome Society

<https://ndss.org/resources>

Health Care Guidelines; Aging and Down Syndrome

Down Syndrome Clinic to You

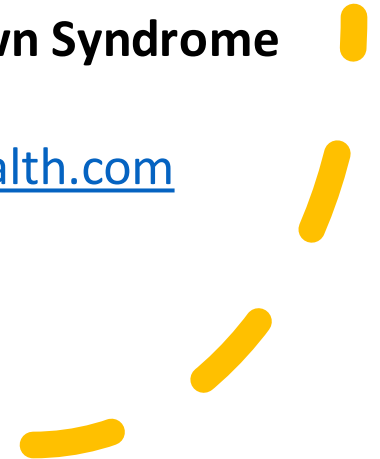
www.dsc2u.org/home

Global Down syndrome Foundation

<https://www.globaldownsyndrome.org/medical-care-guidelines-for-adults/>

Advocate Medical Care, Adult Down Syndrome Center

<https://adsresources.advocatehealth.com>



Some Resources

My Health Passport

[http://flfcic.fmhi.usf.edu/docs/FCIC Health Passport Form Typeable English.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf)

My Health Report

[http://flfcic.fmhi.usf.edu/docs/FCIC My Health Report Fillable.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_My_Health_Report_Fillable.pdf)

Health Care for Adults with Intellectual and Developmental Disabilities: Tool Kit for Primary Care Providers

<http://vkc.mc.vanderbilt.edu/etoolkit/>

Surrey Place Centre

www.surreyplace.ca/resources-publications

More Resources

American Academy of Developmental Medicine and Dentistry. Toolkits, Webinars, Dementia care, Advocacy, Medical provider education.

<https://aadmd.org/>

Philadelphia Coordinated Health Care. Education, Webinars, Health Promotion Activity Plans, Advocacy,

<https://www.pchc.org/>

Health Matters: health promotion and disease prevention program for people with developmental disabilities and their supports

<https://healthmattersprogram.org/>

Moving Forward



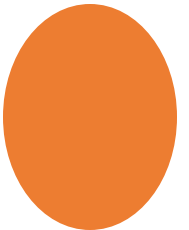
Vision: people with Down syndrome and their families achieve optimal health wherever they live

Goal: enhance the ability of primary care and other healthcare providers to address the health needs of individuals with Down syndrome across the life course

Goal: all individuals with Down syndrome have access to high quality medical services and research

Strategies:

- Education for healthcare providers, families and individuals
- Enhanced data collection on access to care and health outcomes
- Expanded partnerships
- Supportive policies and resource allocation



*Thank
You*

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[**www.iddmedicalhealthhomencinitiative.com**](http://www.iddmedicalhealthhomencinitiative.com)

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Keeping
the
Person at
the
Center of
Care

Bill's Story

Caregiver: "Something is Not Right."

Primary Care: "How Well Do You Know Them?"

- <https://www.youtube.com/watch?v=ChhzcpulsyY&feature=youtu.be>

