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

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

Dr. Sanjeev Arora, MD, Founder

NC Family Support ECHO
www.iddmedicalhealthhomencinitiative.com/projects/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
  o Spread knowledge
  o Expand capacity
  o Accelerate collective wisdom

➢ Guided-practice model
➢ Uses tele-mentoring
➢ Subject matter experts share expertise
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
“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
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
“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.”
Down Syndrome Medical Interest Group ECHO (dsmitg-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
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://adscresources.advocatehealth.com
Some Resources

My Health Passport
http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf

My Health Report

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
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
Bill’s Story

Caregiver: “Something is Not Right.”

Primary Care: “How Well Do You Know Them?”

• https://www.youtube.com/watch?v=ChhzcpulsyY&feature=youtube