Providing & Assessing Health Care Transition in Youth with ASD & Developmental Disabilities

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Disclosures

I have no relevant financial relationships with the manufacturers(s) of any commercial products(s) and/or provider of commercial services discussed in this CME activity.

I do not intend to discuss an unapproved/investigative use of a commercial product/device in my presentation.

Funding

Department of Defense Autism Idea Development Award

Autism Speaks Autism Treatment Network and Health Resources and Services Administration
Objectives

• Identify the importance of the health care transition (HCT) service delivery and implementation.

• Examine young adult and caregivers perspectives on HCT services

• Review of guidelines and tools used to implement HCT services.

• Identify and apply tools in which to measure HCT readiness.

• Examine innovative training: ECHO Autism- Transition to Adulthood
Adolescents with Special Health Care Needs
Growing Demand for Adolescent and Adult Services

• 90% of children with special health care needs (SHCN) survive into the second decade of life

• 6 million adolescents with a SHCN in the U.S.
  • 24% of the population
  • Over 260,000 in Illinois

• Over 784,000 adolescents with Autism Spectrum Disorder in the U.S.
  • Nearly 83,000 in Illinois

(American Academy of Pediatrics et al., 2002; Goodman et al., 2011; Quinn et al., 2010; NS-SHCN, 2009/2010; Scal et al., 2008; Survey: 2016-2017 National Survey of Children's Health)
Changing race/ethnicity of America’s adolescents

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>2014</th>
<th>2050</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>54.1%</td>
<td>40.3%</td>
</tr>
<tr>
<td>Hispanic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td></td>
<td>31.2%</td>
</tr>
<tr>
<td>Asian</td>
<td></td>
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<tr>
<td>AIAN Alone</td>
<td>22.8%</td>
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<tr>
<td>HPI Alone</td>
<td>14.0%</td>
<td>13.1%</td>
</tr>
<tr>
<td>Multiracial</td>
<td>4.7%</td>
<td>7.0%</td>
</tr>
</tbody>
</table>

Adolescents living in poverty and low-income status

[Image of a pie chart showing 36% in low-income and 16% living in poverty]

Where adolescents live

- **19.6 million**
  - *Suburban*: Living in a metropolitan area outside of a principal city

- **10.9 million**
  - *Urban*: Living in a principal city of a metropolitan area

- **5.5 million**
  - *Rural*: Living in a non-metropolitan area

Poor Outcomes Among Transferred Adults

↑ Organ rejection (Annunziato et al., 2007; Watson 2005)

↑ hemoglobin A1C (Cadario et al., 2009)

↑ disease activity in R. and Juvenile arthritis (Hersh et al., 2011)

↑ 2° conditions, late effects & complications
  ◦ ↑ Alzheimer in DS < 50 yr (Dykens, 2007)

Lapse of medical care in Congenital Heart Disease (Yeung, 2008)
  ◦ 32% told no need for follow up care
  ◦ 3.1 more likely to require urgent cardiac care

Little to no data on adults with ASD or Developmental Disabilities
• 50,000 people with ASD age into adulthood each year
• 50-80% of children with ASD have a Co-Occurring Conditions
• *In some cases, the co-occurring conditions can cause a greater barrier to success than the core features of ASD*

*Autism Speaks*
Need for Health Care Transition Services
Health care transition – an important part of transitioning to adulthood
Characteristics of the Field

• Health care transition is a relatively new field of practice

• Has become an field of practice not only relevant but essential to promoting the provision of long-term services for adolescents and emerging adults with disabilities and/or special health care needs.
Your Transition Experience

• What was your transition to adult-oriented health care like?
  ◦ Continuous or Interrupted
  ◦ Active or Passive
About to graduate from art school

In the throes of new love

can only really communicate through comics

No idea how to make $

All depressed over the political state of the U.S.

Adulthood

Gaping chasm of uncertainty

Childhood
Health Care Transition Services

“A multifaceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from the child-focused to the adult-focused health care system”

-Society of Adolescent Medicine
Health Care Transition Services

- Addresses the biopsychosocial needs of
  - Early adolescents (11-15 years of age)
  - Late adolescents (16-18 years of age)
  - Emerging adults (18-25 years of age).

- Facilitate uninterrupted, continuous transfer of care to adult services

- Increase youth self-management, determinations and advocacy

- Person-centered needs assessment and planning

- Prepare for
  - Adult health care
  - Work/independence
  - Community life
Receipt of HCT Services

- Receive HCT: 40% Physical, 35% Mental, 22% Developmental
- Discussion transition to adult provider: 45% Physical, 41% Mental, 42% Developmental
- Discussion adult health care needs: 60% Physical, 55% Mental, 51% Developmental
- Discussion health insurance continuation: 35% Physical, 32% Mental, 34% Developmental
- Provider usually or always encouraged youth responsibility: 78% Physical, 74% Mental, 49% Developmental
Receipt of HCT Service for youth with ASD

- Received HCT: 21.1% (ASD), 42.5% (Other)
- Discussion transitioning to adult provider: 14.1% (ASD), 19.7% (Other)
- Discussed adult health care needs: 40.4% (ASD), 46.7% (Other)
- Discussed health insurance continuation: 22.4% (ASD), 21.4% (Other)
- Provider usually/always encouraged youth responsibility: 73.5% (Other)

*Youth with ASD
*Youth with other special health care needs
Caregiver Report of Number of HCT Discussions their Young adult with ASD Needs

- Needed all discussions: 44.7
- Needed 2 discussions: 17.5
- Needed 1 discussion: 27.2
- Needed no discussions: 10.5
Family and Youth Predictors of HCT Services

- Age
- Gender
- Family structure
- Ethnicity
- Education and income level
- Health insurance status
- Complexity of condition
  - Multiple health conditions
  - Developmental disability
- Medical home
- Satisfaction with health care services
- Family, youth/young adult have future orientation
- Family members/HCP foster independence

(Betz et al., 2015; Betz et al., 2013; Reiss, Gibson, & Walker, 2005)
Provider Predictors of HCT Services and Transfer Success

• Initial involvement of pediatric and adult providers
  • Pediatrician continues to be involved in adult care settings
  • Provider foster independence
• Senior leadership engagement
• Team-based approach

• EHR customization
  • Availability of care coordinator
  • Use of Transition Clinic
  • Continue to receive services within same care system
• HCT training
Result of Lack of HCT

• Continuous use of pediatric services into adulthood or discontinuity of care
• Increase in adults with chronic conditions seeking inpatient care in children’s hospitals
• Lack of primary care provider
  • 18.5% of young adults (18-24) with functioning limitations had no usual source of care compared to 6% of youth (12-17) with limitations

• For Young adults with ASD
  ▪ Medical service use is much lower after an individual with ASD exits the education system
  ▪ One year after high school
    ▪ 23.5% used medical service
    ▪ 35% used mental health services
    ▪ 9% used speech therapy
    ▪ 39% had no services in the last year
"It's a coming-of-age story."
Adolescents with ASD view of transition
Voices Not Heard: An Integrative Review of Adolescents’ and Emerging Adults’ Perspectives of Health Care Transition

• 33 studies focusing on Adolescents experiences of HCT

• Five themes identified
  • AEA-SHCN reflections of HCT experience
  • HCT service recommendations
  • HCT obstacles
  • Expectations of transfer to adult care
  • Self-management self reliance

(Betz, Lobo, Nehring, & Bui, 2013)
Adolescents with ASD Perspective: Transition Services

Major themes from qualitative analysis

◦ Confusion about medical provider’s role
◦ Anxiety about managing their medical lives independently
◦ Lack of confidence and motivation
◦ Desire to learn more
Adolescents with ASD Perspective:

“Well, personally I feel as though is my parents just keep taking care of the business. I still don’t know what to do yet, because I’m not told anything.”

“We kept asking them [doctors] constantly about guardianship because I’m afraid that I may not know what to do first when my dad kicks me out of the door. Like, I don’t know where I’m going to live and all that stuff...I don’t feel like I’m ready to become an adult yet.”

“I’m going to have to ask [my parents] what some of the papers that they usually turn in to some of the doctors [are]. I’m going to have to ask what some of the definitions mean, ‘cause I’m going to get some random words dizzied or who knows what.”
Adolescents with ASD Perspective:

“[the doctors] are going to ask me about medication. I don’t [know about] medications...So I want to stay away from it.”

“Because of my autism, they won’t never let me work; because most kids with autism can’t work...They [doctors] said I would never be able to take responsibility for most of the things that happen. So someone else will have to do it for me.”

“I feel they’re trying to push us into the future when -- and I don’t want to have that happen. I want to focus mainly on the present. I don’t want to find out what my colleges are, my opportunities are yet. I want to focus on the now. I don’t want to think about the then”
It’s a sad but necessary step in adulthood when you accept the fact that you will never be a famous actor, rock star, author or athlete.

Luckily, it hasn’t happened to me yet.
Photovoice Project

Research and empowerment project providing youth with ASD with cameras to document the challenges they perceive in transitioning

11 Young Adult with ASD Participated

- 9 focus group meetings
- 406 pages of transcribed data
- 11 individual interviews
- 437 pages of transcribed data
- 11 professionally developed “Photo Stories”
- Over 110 photographs
“I took that picture at my Dad’s. It used to be a – kind of a small pond – years ago....[Looking at] it kind of brings back the good times... You know when you’re a kid you don’t have to worry about all that much... You don’t really think ahead to the next year or anything. Like me, I got to worry about college, well I don’t have to worry about it but I always do, and a whole bunch of other things... I’d like to go back to a point where I wasn’t so full of anxiety...”

Good Times
Challenges

“That’s a broom. I took a picture of it because I cannot sweep with it. My mom has tried to get me to do that and she eventually gave up and said, ‘just use a vacuum.’ ... There are some things I can’t do and no matter how much you train me I won’t be able to do them.”
Success

“I made that all by myself...[I learned] from my mom...once you get it down it’s pretty easy, she encouraged me [to learn].”
Caregiver’s view of transition
Transition Needs of Parents of Youth With Special Needs and Disabilities

• 30 studies focusing on parents of youth with special health care needs views of HCT

• Major themes identified:
  • Changing expectations related to future planning
  • Parental role changes
  • Youth’s changing role
  • Parental HCT perspectives
  • Parental HCT stressors
  • Helpful HCT support/services
  • Parental perceptions of the child’s HCT experience

(Betz, Nehring, & Lobo, 2015)
Parent Perspective: Transition Services

Major themes from qualitative analysis

◦ Difficulties transitioning from pediatric to adult care
◦ Lack of education and sensitivity about ASD among providers
◦ Challenges related to guardianship
◦ Parents become gap filler and care coordinator
◦ Very concerned about mental health issues
  ◦ Youth
  ◦ Family
Parent Perspective: Transition Services

“[They had] a six year relationship. [The doctor] knew him and [asked] questions that she remembered from the last visit...That’s a doctor you want to hang on to... I think that’s hard for [our kids], not only for them but for us to trust somebody else.”

“Every time we do have to switch doctors, we have to re-educate the doctor [about] our child. He may understand the big picture of Autism, what’s on the handouts. But when you’re talking about Autism, we’re talking about complete individuality with our children...All children with ASD are not going to look the same.”

“...I guess the problem we have ...is being able to figure out what kind of help that they need and where to get it. And, how is it going to be financed?”

“...It’s once you hit 18 and she’s out of school that we have had the biggest issues because there are so many waiting lists that your child gets put on this waiting list and that’s where you sit...”
How to do HCT planning
American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians

2011 and 2018 Practice Recommendations

• Provide structure for training, CE and research;
• Advance practice-based recommendations
• Algorithm protocol (decision making tool)
• Start around 12 years of age
• Transition planning should be standard of care
6 Core Elements General Milestones

Age 12 - Review transition policy with youth and family
Age 14 – Start HCT planning process
Age 16 – Discuss youth and families expectations and preferences regarding adult health care
Age 18 – Transition to adult model of care
  ◦ Secure appropriate guardianship if needed
Age 18-22 – Transfer care to adult medical home and specialists
Strategies to Prepare for Transition: Clinic-level

• Develop policy that describes practice’s approach to transition
• Educate all staff about the policy, practice’s approach to transition, and their roles
• Develop electronic process to identify transitioning youth and track progress toward transfer
• Allow for care coordination or additional staff assistance to get the transition process in place
Strategies to Prepare for Transition: Provider-level

• Distribute and discuss transition policy with caregivers and youth
  • Start initial discussions at age 12

• Conduct transition readiness assessment annually
  • Review assessment results with youth and family
  • Utilize HCT Plan of Care documents to develop transition plan and current goals for all parties

• Develop a medical summary to improve information sharing with new provider
Strategies to Prepare for Transition: Provider-level

- Prepare youth and caregivers for adult approach to care
  - Practice self-advocacy and youth self-determination
  - Address legal changes in decision-making, privacy and consent

- Establish and communicate timing for transfer
  - Assist family in identifying adult provider
  - Release of medical information

- Introduce adult provider while still in pediatric care
  - Joint visit if possible (parallel care)
Turning 18: What it Means for Your Health

Turning 18 may not make you feel any different, but legally, this means you are an adult.

What does this mean?
- After you turn 18, your doctor talks to you, not your parents, about your health.
- Your health information and medical records are private (or confidential) and cannot be shared unless you give the OK.
- It is up to you to make decisions for your own health care, although you can always ask others for help.

Things to know
- The confidentiality between you and your doctor is legally known as the Health Insurance Portability and Accessibility Act, or HIPAA.
- This law gives privacy rights to minors (people who are under age 18) for reproductive and sexual health, mental health, and substance abuse services. Check your state’s minor consent laws for more information.
Strategies to Prepare for Transition: Youth with ASD

• Assist youth in practicing self-determination skills
  • Talk to youth during medical visit
  • Encourage question asking and participation during visit
  • Practice active listening techniques

• If appropriate meet alone with provider for a short time during each medical visit

• Encourage youth to take on health-related responsibilities
  • Sign up for patient portal that allows for secure email communication with provider if available

• Develop Personal Medical Passport
  • This is Me
Strategies to Prepare for Transition: Caregiver

• Encourage caregivers to promote youth’s self-determination
• Listen to and address caregivers transition and transfer concerns
• Assist with guardianship procedure if needed
• Provider caregivers with strategies for researching adult providers
• Continue to be available to caregivers after transfer if needed and slowly transition to new provider
Best Practices

• Introduce adult provider while still in pediatric care
  ◦ Joint visit if possible / Parallel care

• Care coordinator assist with:
  ◦ System navigation
  ◦ Self-management and self-advocacy skills
  ◦ Transfer of care

• Referrals
  • Employment, educational, rehabilitation, community living and disability community services

• Transition clinic
  ◦ Involves Med-Peds, social worker, and care coordinator
  ◦ Identifies adult provider, assist with insurance, improve self-care, address education and vocational needs and life planning needs
Resources: Got Transition

**Side-by-Side Version**

**Six Core Elements of Health Care Transition 2.0**

The *Six Core Elements of Health Care Transition 2.0* are intended for use by pediatric, family medicine, med-peds, and internal medicine practitioners to assist youth and young adults as they transition to adult-centered care. They are aligned with the AAP/AAPA/ACP Clinical Report on Transition.¹ Sample clinical tools and measurement resources are available for quality improvement purposes at [www.GotTransition.org](http://www.gottransition.org).

<table>
<thead>
<tr>
<th>Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)</th>
<th>Transitioning to an Adult Approach to Health Care Without Changing Providers (Family Medicine and Med-Peds Providers)</th>
<th>Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Transition Policy</strong></td>
<td>Develop a transition policy with input from youth and families that describes the practice’s approach to transition, including privacy and consent information. Educate all staff about the practice’s approach to transition, the policy’s statement, the Six Core Elements, and distinct roles of the youth, family, and provider with care team in the transition process, taking into account cultural preferences.</td>
<td>Develop a transition policy with input from youth and families that describes the practice’s approach to transitioning to an adult approach to care at 18, including privacy and consent information. Educate all staff about the practice’s approach to transition, the policy’s statement, the Six Core Elements, and distinct roles of the youth, family, and provider with care team in the transition process, taking into account cultural preferences.</td>
</tr>
<tr>
<td><strong>2. Transition Tracking and Monitoring</strong></td>
<td>Establish criteria and process for identifying transitioning youth and enter their data into a registry. Utilize individual flow sheet or registry to track youth’s transition progress with the Six Core Elements.</td>
<td>Establish criteria and process for identifying transitioning youth/youth adults and enter their data into a registry. Utilize individual flow sheet or registry to track youth’s transition progress with the Six Core Elements.</td>
</tr>
<tr>
<td><strong>3. Transition Readiness</strong></td>
<td>Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care. Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.</td>
<td>Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care. Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.</td>
</tr>
</tbody>
</table>

Resources: AASPIRE Healthcare Toolkit

• Improve the healthcare of adults with autism

• Patients, Supporters, and Healthcare provider supports:
  • Staying healthy
  • Rights in healthcare
  • Medical information
  • Checklists and worksheets
  • Caring for patients on the spectrum
  • Legal and ethical considerations
  • Associated conditions

https://autismandhealth.org/
Resources: Autism Speaks Transition Toolkit

Introduction
Self-Advocacy
Developing Independent Living Skills
Planning for Transition
Legal Matters to Consider
Community Living
Employment and Other Options
Postsecondary Educational Opportunities
Housing and Residential Supports
Health
Technology
Conclusion
Resources

https://www.autismspeaks.org/tool-kit/transition-tool-kit
Resources: Roadmap to Transition: A Handbook for Autistic Youth Transitioning to Adulthood

- Developed by Autism Self-Advocate Network
- More general covering
  - self-determination and self-advocacy
  - legal rights
  - how to make a transition plan
  - how to get supports, and
  - what supported decision-making is and how to use it

HCT readiness and self-advocacy
Use a Formal Assessment Process

• Use a tool to measure transition readiness.
  • Repeat measure through transition process

• Lack of evidence as to what constitutes “transition readiness”

• No studies have reported a planned approach to determining readiness across time

• Current measure focus exclusively on medical need

Betz et al., 2015; Betz, 2004; AAP, AAFP, ACP, ASIM, 2011; Chu et al., 2015; Ferris, Harward, Bickford, et al. 2013; Wood et al., 2014
Transition Readiness

Medical Condition as it relates to knowledge of:
- Underlying physiology
- Medications/treatments
- Past medical history
- Report current illnesses/functional status
- Decision-making skills related to health care

Demonstrates ability to adhere to:
- Treatment regimen at home, school and community settings
- Taking medications appropriately
- Keeping appointments with MD, therapists
- Engaging in preventive health behaviors
- Seeking care when problems arise
Transition Readiness Measures

- Current measures
  - STARx Questionnaire (Ferris et al., 2015)
  - The Transition Readiness Assessment Questionnaire (TRAQ) (Wood et al., 2015)
  - UNC TRxANSITION Scale (Ferris et al. 2012)
  - Measuring Transition Readiness: A Correlational Study of
  - Perceptions of Parent and Adolescents with Sickle Cell Disease (Speller-Brown, et al. 2015)
Health-Related Independence for Young Adults with ASD

Youth with ASD’s ability to manage health and self-care needs and independently manage needed health care services, within an adult model of care, to the extent possible.

<table>
<thead>
<tr>
<th>Health-related Independence (HRI)</th>
<th>Understand and manage health care needs</th>
<th>Boost self-care skills</th>
<th>Promote independence in healthcare setting</th>
<th>Encourage independence</th>
</tr>
</thead>
</table>


Development of Health-Related Independence (HRI) measure

Qualitative Interviewed Youth and Caregivers to identify HRI constructs

Measurement Dev. Question development with clinicians; Cognitive interview & Pretesting

Psychometric Testing Validated the HRI measure on 510 caregivers nationwide

Study supported by Department of Defense Autism Idea Development Award
HRI measure components

Medical and mental health condition knowledge
  - My young adult can describe his/her mental health conditions to someone.

Health care and medication management skills
  - My young adult can make an appointment with his/her doctor.

Health insurance knowledge
  - My young adult can provide health insurance information when asked.

Sexual health knowledge
  - My young adult can explain that pregnancy results from intercourse between a woman and a man.

Safety and sexual safety
  - My young adult can distinguish between a romantic relationship and a friendship.
HRI measure

Additional measures based on young adult/family interest

- Self-care
  - My young adult can complete personal grooming tasks such as dressing, brushing teeth, or combing or brushing hair.

- Life skills
  - My young adult can cooperate with law enforcement if needed.

- Personal finance and banking
  - My young adult can manage a personal bank account

- Goal planning
  - My young adult's goals are realistic.
Health-Related Independence success

• Young adults and caregivers
  • Identify strengths and challenges

• Providers and Health care systems
  • Meets medical home criteria
  • Improves quality of care

• Utilization of HRI as outcome measure
  • HCT and Independence intervention
  • Provider training

• Future
  • Youth/young adult version
ECHO Autism: Transition to Adulthood
ECHO Autism: Transition to Adulthood

Goals

- Establish the feasibility & effectiveness of a tele-mentoring model (ECHO) in training PCPs in evidence-based care for youth and young adults with ASD
- Increase in PCP self-efficacy across a variety of domains
- Facilitate practice change

#Goals
How ECHO Works
Extension for Community Healthcare Outcomes

LEARNING LOOP

Specialist Team

Local Care Teams

Individuals with Autism
The ECHO Autism Format

Weekly 1- hour ECHO Autism sessions over 3 months

- Introductions
- Case Presentation
- Clarifying Questions
  - Spokes
  - Hub Team
- Recommendations
- Brief, high-yield Didactic
Hub Team

Adult Neurologist – Gary Stobbe, MD (Lead)
Med Peds – Mavara Agrawal, MD
Psychologist – Rachel Loftin, PhD
Family Navigator – Katrina Davis, BS/Amy Hess, BS
Family Advocate/Sleep Specialist – Beth Malow, MD
Self-Advocate – Mark Tapia, MA
## Curriculum

<table>
<thead>
<tr>
<th>Topic</th>
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<tbody>
<tr>
<td>What is Autism</td>
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<tr>
<td>Psychiatric Co-Occurring Conditions</td>
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<tr>
<td>Medical Co-Occurring Conditions</td>
</tr>
<tr>
<td>Behavior Management in Primary Care</td>
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<tr>
<td>Supporting Families through Transition to Adulthood</td>
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<tr>
<td>Healthcare Transition Planning (Role of the PCP)</td>
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<tr>
<td>Life Skills Development</td>
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<tr>
<td>Supporting the Self Advocate</td>
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<tr>
<td>Guardianship</td>
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<tr>
<td>Special Education Transition to ADA</td>
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<tr>
<td>Housing and Community Supports for Adults with Autism</td>
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<tr>
<td>Relationships and Sexuality in Autism</td>
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</table>
Spokes

Primary Care Providers (n=16)
- Pediatricians (n=6)
- Family Medicine Physician (n=9)
- Internal Medicine Physician (n=1)
Satisfaction

![Satisfaction Ratings (n=12)](image)

- The technology for the ECHO Autism clinic functioned smoothly
- I have been satisfied with the technology associated with the ECHO Autism clinic
- Case-based learning increased my knowledge about youth/young adults with autism
- Discussions with other participants enhanced my knowledge about youth/young adults with autism
- The didactic presentations enhanced my knowledge about youth/young adults with autism
- I respected the professional advice received from ECHO Autism experts
- ECHO Autism specialists provided guidance in managing youth/young adults with autism
- I was able to connect with peers and colleagues through participation in ECHO Autism
- I learned best-practice care for youth/young adults with autism through participation in ECHO Autism
- Participation in ECHO Autism improved my ability to care for youth/young adults with autism in my practice

Yellow: Strongly Agree  | Blue: Agree  | Grey: Neutral or No Opinion  | Red: Disagree  | Black: Strongly Disagree
Excerpts of Qualitative Responses

I have started talking with patients and families about adding vocational and transition planning to their IEPs. I am working on developing a transfer of care form for families to take to their 'adult' doc. I am also gathering information to share with families about Guardianship laws.”

“I'm discussing transition at an earlier age, providing more resources and providing parents with more information regarding the transition process.”
Self-Efficacy
Practice Change

Participants Reporting Practice Change

<table>
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<tr>
<th>Category</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Changes in Practice</td>
<td>75%</td>
</tr>
<tr>
<td>Changes in Patient Relationships</td>
<td>67%</td>
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<tr>
<td>Interest in Future Patients w/ ASD</td>
<td>100%</td>
</tr>
<tr>
<td>Less Professional Isolation</td>
<td>67%</td>
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<tr>
<td>Positive Impact on Community</td>
<td>100%</td>
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Department of Defense funding focused on building capacity of providers of adults on the autism spectrum, with an emphasis on understanding motivators and barriers faced by these providers.

Future work will include chart reviews that document practice change, patient and family outcomes, self-advocacy outcomes, and measures of cost-effectiveness.
Conclusion

- 6 million young adults with a special health care needs in the U.S.
  - Nearly 800,000 young adults with ASD transition

- Less than half of young adults with a special health care needs and a quarter of young adults with ASD received HCT services

- Young adults with ASD report feeling anxiety and confusion about the transition process while caregivers report system level challenges, concerns about young adult mental health, and feel overwhelmed by gap-filler duties

- Well developed HCT process, resources, and readiness measure
  - Including new Health Related Independence measure for young adults with ASD

- Successful demonstration of ECHO Autism- Transition to Adulthood training shows provider interest and practice change potential.
Questions?
Resources


