Autism Spectrum Disorder (ASD) Part VI: Transition to Adult Care

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Today's Agenda

By the conclusion of this presentation, participants will be able to:

- Define health care transition and understand its significance
- Identify health care transition goals for adolescents with ASD
- Explore health care transition strategies that can implemented throughout adolescents and discuss the importance of early planning for transition
- Describe legal matters to consider for families and individuals with ASD

DSM- 5 Diagnostic Criteria-Autism Spectrum Disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history

1. *Deficits in social-emotional reciprocity*, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. *Deficits in nonverbal communicative behaviors used for social interaction*, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. *Deficits in developing, maintaining, and understanding relationships*, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

DSM- 5 Diagnostic Criteria-Autism Spectrum Disorder

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:

1. *Stereotyped or repetitive motor movements, use of objects, or speech* (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. *Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior* (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
3. *Highly restricted, fixated interests that are abnormal in intensity or focus* (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
4. *Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment* (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

DSM- 5 Diagnostic Criteria-Autism Spectrum Disorder

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

Severity Levels for ASD

- Severity 1- Requiring support
  - Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions.
  - Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.
- Severity 2- Requiring substantial support
  - Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others.
  - Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
- Severity 3- Requiring ***very*** substantial support
  - Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others.
  - Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.

Autism Spectrum Disorder

- 1 of 59
- Comorbid Medical & Psychiatric Disorders
  - Anxiety
  - Depression
  - GI problems
  - Sleep disturbance
  - Obesity
  - Seizures

Today's patients

- A.J. is a non verbal 22 year old male with ASD (severity 3), intellectual disability, seizure disorder, MS and worsening SIB. He has been your patient since early childhood. He is scheduled for dental work under anesthesia and presents for a medical clearance.
- G.T. is a 13 year old girl with ASD (severity 2) presents for her first visit with you. Parents report she is healthy. They are concerned with her disruptive sleep pattern and "repetitive screen use". Karen is excited to talk to you about her collection of kittens.
- Z.M. is a 16 year old boy with ASD (severity 1), ADHD, Tic Disorder, and GAD. Parents report he is doing well academically and has made progress socially in his new high school. They are concerned with worsening blinking. Psychiatrist recently made adjustments to his medications.

Health Care Transition

- During which of these visits should health care transition services occur?
- Are there specific HCT tasks that should occur at any of these visits?
- Are there unique issues considered or tasks that must occur in the HCT process for patients with ASD?
- What is the role of the physician, patient, and parents/guardians in the HCT process?

What is Health Care Transition?

Background

- All Adolescents need to transition to adult-centered care
  - There are an estimated 60 million adolescents/young adults, ages 12-25
  - 18 million adolescents are ages 18-21, about ¼ of whom have chronic conditions
- Without transition support, data show health is diminished, quality of care is compromised, and health care costs are increased*
  - Patients age 18-26 have the 2nd highest ED utilization rate (after >75 year olds)
- Majority of youth and families are ill-prepared for this change.
- Surveys of health care providers consistently show they lack a systematic way to support youth, families, and young adults in transition from pediatric to adult health care

*Prior et. al. *Pediatrics* 134:1213 2014

Background

- Youth with ASD received health care transition services half as often as youth with other special health care needs.
- Youth with ASD had 70% lower odds of being encouraged to take on appropriate responsibility for his/her health care needs.
- Comorbid conditions were a strong predictor to HCT.

* Cheak-Zamora et. al. *Pediatrics.* 2013 Mar;131(3):447-54.

- Survey of adult health care providers show that despite recognizing autism characteristics, they have insufficient skills and tools for providing healthcare to patients with ASD, and need additional training.

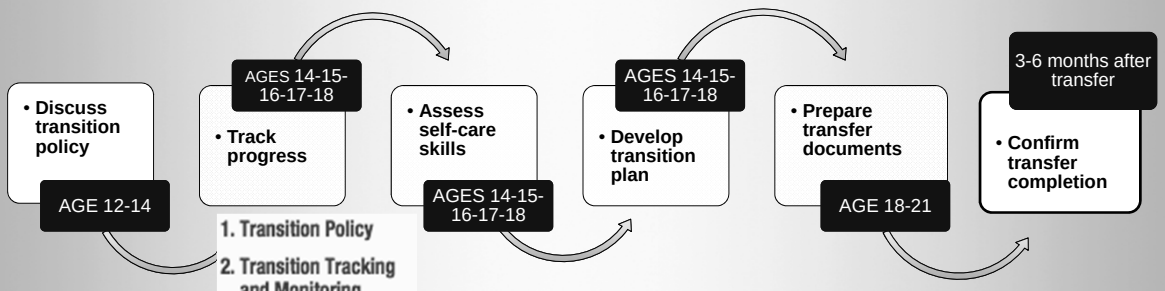
Background: AAP/ACP/AAFP Clinical Report on Health Care Transition*

- In 2011, Clinical Report on Transition published as joint policy by AAP/AAFP/ACP
- Targets all youth, beginning at age 12
- Algorithmic structure with:
  - Branching for youth with special health care needs
  - Application to primary and specialty practices
- Extends through transfer of care to adult medical home and adult specialists

Age 12	Youth and family aware of transition policy
Age 14	Health care transition planning initiated
Age 16	Preparation of youth and parents for adult approach to care and discussion of preferences and timing for transfer to adult health care
Age 18	Transition to adult approach to care
Age 18-22	Transfer of care to adult medical home and specialists with transfer package

*Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home" (*Pediatrics*, July 2011)

Six Core Elements to Health Care Transition



SUMMARY OF SIX CORE ELEMENTS APPROACH FOR PEDIATRIC AND ADULT PRACTICES

Practice/ Provider	#1 Transition/ Care Policy	#2 Tracking and Monitoring	#3 Transition Readiness/ Orientation to Adult Practice	#4 Transition Planning/ Integration into Adult Approach to Care/Practice	#5 Transfer of Care/Initial Visit	#6 Transition Completion/On-going Care
Pediatric*	Create and discuss with youth/family	Track progress of youth/family transition preparation and transfer	Conduct transition readiness assessments (RA)	Develop transition plan, including needed RA skills, prepare youth for adult approach to care/ Communicate with new clinician	Transfer of care with information and communication Assist with YA coming to first AP visit	Obtain feedback on the transition process and confirm YA seen by the new clinician
Adult*	Create and discuss with young adult (YA) and guardian, if needed	Track progress of YA's integration into adult care	Share/discuss Welcome and FAQs with pediatric practices, YA and guardian, if needed, on first visit	Communicate with prior clinician, ensure receipt of transfer package	Collab with PP to ensure YA 1st visit, Review transfer package, address YA's needs & concerns at initial visit, update self-care assessment & medical summary	Confirm transfer completion with prior clinician, provide ongoing care with self-care skill building and link to needed specialists

* Providers that care for youth/young adults throughout the life span could utilize both sets of core elements without the transfer process components

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Health Care Transition Policy Element #1

- **Health Care Transition Policy (12- 18 years)**
  - The policy should include the practice's approach to partnering with youth to develop independence and self-care skills.
  - It should also explain the legal changes that take place in privacy and consent at age 18.
  - The policy should be shared with youth and families beginning at ages 12 to 14 and publicly posted.
- **Young Adult Transition Policy**
  - The policy should include the practice's approach to accepting and partnering with young adults.
  - It should also explain the legal changes that take place in privacy and consent at age 18. The policy should be shared with young adults at their first visit and be publicly posted.

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Transition Tracking and Monitoring Element #2

- An individual flow sheet within the chart or EHR can be used to track individual patient progress with the Six Core Elements.
- Information from an individual flow sheet can be used to populate a registry and help to monitor the transition progress within a larger population.

Transition Readiness Element #3

- Use of a standardized transition/self-care assessment tool is helpful in engaging youth and families in:
  - setting health priorities;
  - addressing self-care needs to prepare them for an adult approach to care at age 18; and,
  - navigating the adult health care system.
- Results can be used to develop a plan of care with youth and families.
- Begin at age 14 and continue through adolescence and young adulthood, as needed.

Transition Readiness and Orientation for the Young Adult

- An orientation to the adult practice is important.
- The practice should provide young adult-friendly welcome materials that describe confidentiality, services offered, and the logistics of obtaining care.
- Offering get-acquainted appointments, if feasible can be a useful option for some prospective young adult patients.

Transition Planning Element #4

- Develop and regularly update a plan of care:
  - medical summary and emergency care plan;
  - goals and prioritized actions; and,
  - legal documents.
- Prepare youth and parent/caregiver for adult approach to care at age 18:
  - legal changes in decision-making and privacy and consent;
  - self-advocacy; and,
  - access to information.
- Determine of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources.

Transition Planning

- Plan with youth and parent/caregiver for optimal timing of transfer from pediatric to adult specialty care.
- Obtain consent from youth/guardian for release of medical information.
- Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports.

Transition Planning for the Young Adult

- Communicate with young adult's pediatric provider(s) and arrange for consultation.
- Prior to first visit, ensure receipt of transfer package (final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records).
- Pre-visit appointment reminder call welcoming new young adult and identifying any special needs and preferences.
- Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports.

Transfer of Care Element #5

- Clarify adult approach to care including:
  - shared decision-making;
  - privacy and consent;
  - access to information;
  - adherence to care; and,
  - preferred methods of communication, including attending to health literacy needs.
- Conduct self-care assessment and discuss needed self-care skills.
- Review young adult's health priorities as part of ongoing plan of care.
- Continue to update/share portable medical summary and emergency care plan.

Transfer of Care of the Young Adult

- Prepare for initial visit by reviewing transfer package with appropriate team members.
- Address any concerns that young adult has about transferring to adult approach to care. Clarify approach to adult care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs.
- Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss the young adult's needs and goals in self-care.
- Review young adult's health priorities as part of their plan of care.
- Update and share portable medical summary and emergency care plan.

Transfer Completion Element #6

- Assist young adult to connect with adult specialists and other support services, as needed.
- Continue with ongoing care management tailored to each young adult.
- Elicit feedback from young adult to assess experience with adult health care.
- Build ongoing and collaborative partnerships with specialty care providers.

Transfer Completion/Ongoing Care

- Communicate with pediatric practice confirming transfer into adult practice and consult with pediatric provider(s), as needed.
- Assist young adult to connect with adult specialists and other support services, as needed.
- Continue with ongoing care management tailored to each young adult.
- Elicit feedback from young adult to assess experience with adult health care.
- Build ongoing and collaborative partnerships with pediatric primary and specialty care providers.

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Readiness Assessment
Intellectual Disabilities/Developmental Disabilities (ID/DD)*

- Pediatric
  - Transition Readiness Assessment for Parents and Caregivers of Youth with Intellectual Disabilities or Developmental Disabilities
- Adult
  - Self-Care Assessment for Young Adults with Intellectual Disabilities or Developmental Disabilities
  - Self-Care Assessment for Parents or Caregivers of Young Adults with Intellectual Disabilities or Developmental Disabilities

*Developed by: American Academy of Family Physicians American Academy of Pediatrics American College of Physicians American Osteopathic Association Got Transition/Center for Health Care Transition Health Care Transitions Research Network Medicine-Pediatrics Program Directors Association Society for Adolescent Health and Medicine Society of General Internal Medicine

Transition Planning

- Care Plan
  - Medical Summary
  - Emergency plan
  - Action plan
    - Personal goals
    - Health goals
      - Timing of transition
- Insurance
- Legal changes for decision making
  - Guardianship
  - Patient advocate/health care proxy
  - Consent to share personal/health information

Planning/Transfer for the Young Adult

- Pre-visit appointment reminder text/email/patient portal communication
- Provide linkages to insurance resources, self-care management information, and community supports
- Provider (primary care and specialist) ASD training & education
  - Effective communication strategies
  - Atypical sensory response (e.g. noise, touch, light)
  - High rates of comorbid diagnosis

Planning/Transfer for the Young Adult

- Consider accommodations
  - Serene waiting room with few people waiting
  - Page/text system for virtual waiting room
  - Exam rooms with low light
  - Extra-large screen monitors that both doctor and patient look at together
  - Longer clinic visits

Summary

- Health care transition is a ***continuous*** process that should start in early adolescent and extending through early adulthood.
- 6 Core Element of HCT is doable and can be adapted to a variety of settings and patient populations.
- All youth with ASD, especially those youth with comorbid medical and/or mental health conditions, benefit from HCT services to optimize their health knowledge and health skills.
- Comprehensive health care transition for youth with ASD will require providers to engage in education/training specific to ASD to care for this population.

Resources and References

- Got Transition resources www.gottransition.org/resources/index.cfm
- SGIM book for adult clinicians. "Care of Adults with Chronic Childhood Conditions"
- Autism Now resources www.autismnow.org
- The Arc resources for guardianship www.thearc.org
- White P. et al. *Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home.* Pediatrics, Nov. 2018;142 (5)
- Cheak-Zamora et al. *Disparities in Transition Planning for Youth With Autism Spectrum Disorder*. Pediatrics, Mar. 2013; 131(3)
- *Croen, et al. Psychiatric and Medical Conditions Among Adults with ASD*. Delivered at the International Meeting for Autism Research, May 15, 2014
- Zerbo et al. *A study of physician knowledge and experience with autism in adults in a large integrated healthcare system*. Journal of Autism and Developmental Disorders, 2015. 45 (12)