

Q&A Summary
Autism Spectrum Disorder (ASD) Part VI:
Transition to Adult Care

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Available On-Demand:

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1. I would like to further my education and career in ASD. What are some opportunities to work with education and/or services for these children, adults and families?
There certainly are opportunities in the various interventional services (occupational therapy, speech therapy, applied behavior analysis [ABA] therapy), education (teachers, aides, special education) and social work services, among others. I certainly encourage you to explore opportunities in your local area.
2. Education and training for health care professionals (HCPs):
 - a. What training can be provided to HCPs to update their info and skills in taking care of adults with ASD? Are there any organizations taking this on?
 - b. Where can HCPs find more education?
 - c. What is being done nationally to train HCPs in the treatment of transitioning people with ASD?
There is national work to raise the awareness about the need for health care transition (HCT) for all youth, including those with special health care needs (SHCN). I would refer you to the Got Transition website (www.gottransition.org) for more information specifically for providers about the 6 core elements of HCT.
3. Adults with characteristics of ASD without formal diagnosis:
 - a. Who is the best resource for someone in their early 20s with ASD, who was never formally diagnosed, to help them with vocational selections and adulthood?
I would start with a formal diagnosis by a psychiatrist or psychologist.
 - b. A 30-year-old (level 1) with no previous ASD care is now struggling as an adult. Where to start?
Reaching out to local or national autism community organizations (e.g., Autism Speaks) would be an ideal starting point.
4. Guardianship and estate planning:
 - a. How do you find out what resources are available by state regarding guardianship?
Each state will have their own menu of guardianship options as well as laws to govern them. I generally refer patients to their local probate court to initiate this process.
 - b. As part of a health care plan, do you discuss or refer the parents/guardians to a resource for special needs estate planning?
While I do have local resources that I provide to families for estate planning, I have not included it in my care plan.

5. Puberty and sexuality:

- a. Is there any research about female patients and gynecologic care usage?
Personally, I have had many individuals' families refuse this care for preventative reasons due to the trauma the patient may endure.
I am not aware of research on female patients with ASD and gynecologic care usage.
- b. Please give an example of teach back for puberty? [See below.](#)
- c. What are good ways to help individuals with ASD adapt to the changes to their bodies as they progress through adolescence? What might be a good way to help an adolescent girl prepare for gynecologic exams?
Puberty and sexuality should be routinely addressed with all patients, including those patients with developmental disabilities. This topic should be addressed in the setting of each routine health visit and integrated as a part of the provider's routine health history, physical examination and anticipatory guidance as well as in response to patient and/or parent concerns. Questions regarding sexuality can start very early in any child's life as the HCP promotes the acquisition of self-help skills such as toilet training, bathing, or dressing. It is important for providers and families not to overlook a child's impending puberty and sexuality as they prioritize complex medical or developmental issues.

The following should be used to help youth with ASD understand puberty and their changing bodies:

- Use appropriate vocabulary when labeling genitals
- Ensure the privacy of each child and adolescent
- Assist parents in understanding how cognitive abilities of their children affect behavior and socialization
- Recognize that children and youth with special health care needs (CYSHCN) are at increased risk of sexual abuse and monitor for early indications of abuse
 - Provide appropriate routine sexually transmitted infection (STI) screening
- Encourage CYSHCN and their parents to optimize independence, particularly as it relates to self-care and social skills

Please review the resources below that are helpful to explain puberty and sexuality to CYSHCN.

Social Stories

[Boys, Girls and Body Science](#) by Meg Hickling

[What's Happening To Me?](#) by Peter Mayle

[Special Boys' Business](#) by Heather Anderson, Fay Angelo and Rose Stewart

[Puberty and Special Girls](#) by Heather Anderson, Fay Angelo and Rose Stewart

Books for Girls

[The Body Book: It's A God Thing!](#) by Nancy N. Rue

[Ready, Set, Grow!: A What's Happening to My Body? Book for Younger Girls](#) by Lynda Madaras and Linda Davick

[The Care & Keeping of You: The Body Book for Girls \(American Girl Library\)](#) by Valorie Schaefer and Norm Bendell

Books for Boys

[On Your Mark, Get Set, Grow!: A "What's Happening to My Body?" Book for Younger Boys](#) by Lynda Madaras

[What's Happening to My Body? Book for Boys: The New Growing-Up Guide for Parents and Sons](#) by Lynda Madaras

[The Guy Book: An Owner's Manual](#) by Mavis Jukes

6. Transition questions:

- a. Is the health care transition (HCT) process a standard of practice for primary care and pediatric providers? Is it reimbursable?

In my talk, I spoke about a specific HCT process called the 6 Core Elements (CE) to HCT. This is a structured process with customizable tools for a variety of practices to integrate into their clinical practices. Please do visit their website, www.gottransition.org for detailed information about the 6 CE and information on coding and billing for HCT activities.

- b. How does HCT planning for individuals with ASD differ, if any, from other individuals who may be in a facility?

The structure of HCT is the same for all youth regardless of diagnosis. Certainly, the intensity of some of the core elements depends on certain factors: chronic illness (physical or mental health), developmental/intellectual disability, as well as the social determinants of health should be considered.

- c. Often during transition a young adult may switch between different insurances. Any suggestions on making this transition smooth as new HCPs may need to be integrated into the care team?

The best approach is to start early with the process of considering insurance options for when the youth turns 18.

- d. How successful are individuals with ASD in the transition to adulthood? Do these individuals usually have guardians?

Overall, the quality of care is diminished (increased gaps in care, more emergency department visits, decreased adherence to medication management) as youth move from a pediatric to an adult approach to health care. Youth with SHCN, including those with ASD, fare worse in their quality of health care than those without a SHCN as they transition to an adult approach to health care. The need for some a form of a guardian is not specific to having an ASD diagnosis but is dependent on an individual's decision-making capacity.

- e. How is the transferring adult HCP selected? What is the process?

We engaged adult providers at the start of our HCT quality improvement work. This resulted in having 2 internal medicine practices that have worked to integrate the 6 CE into their clinical practice. Prior to patients leaving their pediatric practices, the patients partner with their pediatricians to identify their new adult provider.

- f. Is the school system part of planning or clued in on health care since transition programs go beyond 18 in schools?

In my experience, the school systems do not focus on or work to integrate HCT into their education transition plan.

- g. Do you have social workers in your clinic who provide support with the transition process?
No. My specific HCT quality improvement team includes pediatric and adult physicians, the nurses in their prospective practices, patient partners and administrators.
- h. How much input does the caregiver/parent/guardian have with HCPs if they don't appear to be "up to date" with the current recommendations? If the individuals are over 18, and especially if the young adult is high functioning? Do you have recommendations for bridging that gap?
Parents and guardians can have significant influence on the HCT process even if the provider does not seem to be "up to date." I would not assume that just because a provider is not currently implementing a structured HCT process, they would not implement one. More than likely, if a parent initiated the conversation along with providing resources to help in this process, I would suggest most providers would be grateful and would agree to partner with the patient/parents on some level of HCT implementation. Parents can find information on the Got Transition website under the youth and families tab.
7. Can you describe decision-making for a youth with ASD in regard to driving a vehicle?
I would recommend youth undergo evaluation and participation in a specialized driving readiness program prior to driving. In my state, I refer youth to the Drivers Rehabilitation Center of Michigan/A&A Driving School.
8. As part of a health care plan, do you talk about housing options as the person ages?
Although this is really an important issue, I have never included housing in my care plans. I do, however, provide my patients with information on a local community organization that does help youth with ASD with housing.
9. Do you ever use Skype to allow a child to meet with their adult HCP prior to their first visit?
Currently, we have a Meet & Greet appointment where youth meet with the nurse in the patient's new internal medicine practice. This is an appointment solely to provide a comprehensive orientation where basic information about the practice is provided and the youth's health history is reviewed. During this appointment, the youth does get to meet their new internist. We are planning to pilot a virtual Meet & Greet appointment in the upcoming year.

If you have questions regarding this document or the content herein, please contact:
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