



Integrating Young Adults with Autism Spectrum Disorder into Your Practice: Tips for Adult Health Care Clinicians

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INTRODUCTION

This resource is intended as a possible list of ideas and activities for clinicians who are accepting new young adult (YA) patients with Autism Spectrum Disorder (ASD) into their practice. It offers a broad set of suggestions that a practice can consider, depending on the practice's resources, to prepare its office and staff as well as tips to consider prior to, during, and after the initial visit. These suggestions are consistent with the 2018 Clinical Report from the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians.¹

PREPARE YOUR OFFICE AND STAFF

1. Consider an in-service training or “lunch and learn” session(s) for all staff about caring for individuals with ASD, including an understanding of sensory and communication barriers they experience, supported decision-making/guardianship options, “people first” language, and ASD not as a disease, but as a sometimes-challenging life experience which may often include co-existing health conditions or risks.
2. Consider identifying a staff person as the “office champion” for this population – maybe someone who has a family member with ASD – who can keep the office supplied with local and regional resource information, workshop availability, and related health news. This individual can also be asked to elicit and share regular feedback on the practice's approach in caring for this population.
3. Consider the health disparities and inequities that adults with ASD often experience and try to integrate sensitive and unbiased care into the office practice.

4. With a YA with ASD or a parent/caregiver, organize a “walk-through” or “ride through in a wheelchair” of the office for all staff – from the parking lot through an entire hypothetical office visit – to understand the challenges that patients may experience and to ascertain areas for improving access.
5. Make linkages to local, state, and national family support resources such as Family-to-Family Health Information Centers (see #5 in Additional Practice Resources) available to patients and staff, for information about public benefits important to the health and well-being of all adults with ASD, such as Medicaid and Medicare, Social Security benefits, Section 8 housing benefits, and long-term developmental supports and services (case management, individual direct care workers, etc.).
6. Consider inviting a few YAs with ASD and parents/caregivers to participate in a focus group or a transition improvement process in your practice. Include discussion with them on how to engage individuals with ASD in all steps of medical care, including check-in/out and communication with the medical team both in the office and in between office visits.
7. Review coding and reimbursement options for health care transition services so the practice can improve payment for caring for this special population.²
8. If the office is pursuing or maintaining National Committee for Quality Assurance (NCQA) medical home recognition, consider addressing health care transition.³

PRIOR TO THE FIRST VISIT

1. Ask for a medical summary from previous clinicians(s), including recent care plans along with an adaptive care plan, if available, that aids in communication with YAs with ASD and their parents/caregivers,⁴ active problem lists, medication lists, and health care transition readiness/self-care assessment status. Even if the adult clinician is on the same EMR system as the referring clinician, a medical summary that was created with the YA and parent/caregiver should be requested and made available to the adult clinician.
2. Review the tools available in the Six Core Elements of Health Care Transition™ (“Integrating Young Adults into Adult Health Care⁵”) found at GotTransition.org and consider adapting at least some of the core elements to this population’s needs. For example:
 - a. Develop a transition policy or statement,⁶ with input from YAs with ASD and their parents/caregivers, that describes your practice’s approach to welcoming YAs and, if needed, their parents/caregivers. This can be shared with all staff and discussed with YAs and their parents/caregivers at their first visit.
 - b. Create an office registry⁷ for new YAs with ASD in order to track individual progress related to health care transition, such as receipt of their current medical records, welcome and orientation to your practice, clarification of adult model of care and shared decision-making and, if not previously addressed, options for supported decision-making,⁸ self-care assessment with goals and prioritized actions in plan of care,⁹ and updated and shared medical summary and emergency care plan.¹⁰ The registry can also be used to track the status of the population’s health, preventive care status, and health risks.
 - c. Identify the clinicians in your practice who are interested in caring for YAs with ASD.
 - d. Develop a brief welcome letter¹¹ and frequently asked questions (FAQs) about your practice with input from YAs with ASD and parents/caregivers, and post the content on your website.

3. Ask the pediatric clinician to send you information about the YA's specific ASD-related needs, including sensory challenges, barriers to accessing medical care and methods of caring for them that have been successful in the past.
4. Ascertain shared decision-making status and implications (guardianship, powers of attorney, and consent to share personal health information).
5. Ascertain the YA's preferred communication method if other than verbal speech and identify use of any other assistive technology to assist in communication. Recognize that individuals with ASD who use verbal communication may do so in atypical ways or with unexpected meanings.
6. Arrange for staff to inquire prior to the first visit if there are any special accommodations that will be necessary during the visit (see Sidebar).
7. Schedule adequate time for a successful first visit taking into consideration assistive devices for mobility and/or communication, presence of parents/caregivers and others, and need to orient the new patient to your practice and to adult health care in general. Understand that some patients with ASD may require several visits to accomplish the goals that might usually be met in one visit for other patients.
8. Explain to parents/caregivers accompanying the YA the importance that they are familiar with the YA's current health issues if the YA has difficulty sharing or understanding health information.

DURING THE VISIT

1. Treat the patient as an adult regardless of communication ability or intellectual ability – greet the patient first, speak and direct questions to the patient even if a parent/caregiver provides responses. Encourage the highest level of involvement of the patient in their care. Assume competence.
2. Ascertain name, contact information, and role or relationship to the patient of any parent/caregiver(s), case manager(s), and other individual(s) present at the visit as well as any key members of the patient's support system who are not present.
3. Explain what will happen during the visit and invite the parent/caregiver to "translate" if necessary.
4. Provide an orientation to the practice or clinic to the patient and parent/caregiver, including methods for 24/7 access to care, access to any electronic patient portal, process for prescription renewals and for referrals.
5. Offer the same quality and process of care that you would provide to a patient without ASD (all vital signs recorded, complete history obtained, complete physical examination conducted, same treatment recommendations delivered, all recommended preventive care and screening measures provided). At times, the elements of a process of care may require several office visits.

POSSIBLE ACCOMMODATIONS FOR IMPROVED CARE

Some possible accommodations that may help individuals with ASD include:

- Bypassing the waiting room or utilizing a separate, less stimulating waiting area
- Dimming or turning off lights in exam rooms
- Waiting in their car until the doctor is ready to see them
- Bringing items that will comfort or distract them during the visit
- Delaying vital signs at intake until later in the visit if the patient does not tolerate them well
- Notifying patients prior to touching them
- Planning for a larger exam room (if available) or seating space for family members or other support personnel who may accompany the patient

6. Create or update the medical summary and emergency care plan and share with the YA and parent/caregiver.¹⁰
7. Continue a process of offering an annual self-care assessment and discuss education strategies with the parent/caregiver so the YA gains the highest possible level of self-care skills.¹²
8. Practice with “anticipatory care” – gradually exposing the patient to new or more challenging aspects of care, such as office-based procedures, genitourinary exams, and venipuncture with the understanding that even if not necessary now, many of these will become needed in the future. It can be helpful to ask the parent/caregiver what protocols have worked around procedures in the past if they have been challenging (e.g., venipuncture) and follow them.
9. Create or update a plan of care⁹ including the needed skill building for the YAs to manage their health and health care and identify the status of and responsibility for action items.
10. Determine the status of all specialty care with respect to the process of transition from pediatric to adult specialists. Some specialty care may need to remain in the pediatric domain until appropriate adult specialists are identified. Additionally, some conditions that are managed by pediatric specialists may be managed by the adult primary care clinician. When referring, identify that this YA has ASD, and send information that includes any adaptations, accommodations, and communications strategies that you found helpful for this YA. Discuss what you are comfortable managing and what care will require the involvement of specialists.

AFTER THE VISIT

1. Consider more frequent than annual visits even for someone without secondary chronic conditions to strengthen the relationship more quickly and to familiarize the patient with the office. The best care for any patient is relationship-based.
2. Review and record any accommodations needed and challenges experienced during the visit as well as ideas to overcome these challenges in future visits.
3. Consider a follow-up telephone call from a clinical office staff member to review plan of care, medications, and procedures for accessing the office.
4. Follow-up with the prior pediatric care clinician team to thank them for the referral, confirm that the patient has arrived in your care, clarify any questions arising from the visit, and ascertain availability of the pediatric care team for future “reverse consultations.”
5. Consider a process for eliciting feedback about the first visit and the YA’s and parent/caregiver’s experience of the transition process from pediatric to adult care.¹³

In Memoriam: Dr. Thomas Cheetham, co-author of the original version of this Tip Sheet, died on August 20, 2018. Dr. Cheetham was a family physician and former Deputy Commissioner for Health Services for the Tennessee Department of Intellectual and Developmental Disabilities. He was a major advocate for access and appropriate health care for adults with intellectual disabilities and an important contributor and advisor to the creation of the Vanderbilt University Toolkit cited above.

REFERENCES

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3. Incorporating Pediatric-To-Adult Transition into NCQA Patient-Centered Medical Home Recognition. gottransition.org/resourceGet.cfm?id=444.
4. Integrating Young Adults into Adult Health Care - Full Package. gottransition.org/resourceGet.cfm?id=212.
5. Liddle M, et al. A Collaborative Approach to Improving Health Care for Children With Developmental Disabilities. pediatrics.aappublications.org/content/142/6/e20181136.
6. Sample Young Adult Transition and Care Policy. gottransition.org/resourceGet.cfm?id=248.
7. Sample Transition Registry. gottransition.org/resourceGet.cfm?id=250.
8. Guardianship and Alternatives for Decision-Making Support. gottransition.org/resourceGet.cfm?id=17.
9. Sample Plan of Care. gottransition.org/resourceGet.cfm?id=252.
10. Sample Medical Summary and Emergency Care Plan. gottransition.org/resourceGet.cfm?id=253.
11. Sample Welcome and Orientation of Young Adults. gottransition.org/resourceGet.cfm?id=251.
12. Sample Self-Care Assessment for Young Adults. gottransition.org/resourceGet.cfm?id=255.
13. Sample Health Care Transition Feedback Survey - Young Adults. gottransition.org/resourceGet.cfm?id=256.

ADDITIONAL PRACTICE RESOURCES

1. American College of Physicians' Pediatric to Adult Care Transition Initiative. acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative/condition-specific-tools.
2. Healthcare for Adults with Intellectual and Developmental Disabilities: Toolkit for Primary Care Providers. ykc.mc.vanderbilt.edu/etoolkit/.
3. AASPIRE Healthcare Toolkit: Primary Care Resource for Adults on the Autism Spectrum and their Primary Care Providers. autismandhealth.org/.
4. National Resource Center for Supported Decision Making. supporteddecisionmaking.org/.
5. Family-to-Family Health Information Centers. familyvoices.org/wp-content/uploads/2018/06/F2FBrochure_1.20.16.pdf.



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