



Integrating Young Adults with Intellectual and Developmental Disabilities into Your Practice: Tips for Adult Health Care Providers

W. Carl Cooley, MD

*Consultant, Got Transition/The National Alliance to Advance Adolescent Health
Chief Medical Officer, Crotched Mountain Foundation
Clinical Professor of Pediatrics, Geisel School of Medicine at Dartmouth*

Thomas Cheetham, MD

*Deputy Commissioner, Office of Health Services
Tennessee Department of Intellectual and Developmental Disabilities
Adjoint Assistant Professor of Developmental Disabilities, Vanderbilt University*

In General to 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 intellectual and developmental disabilities (ID/DD), including an understanding of supported decision-making/guardianship options, “people first” language, and ID/DD not as a disease, but as a sometimes challenging life experience, which may often include co-existing or condition specific health problems or risks.
2. Consider identifying a staff person as the “office champion” for this population -- maybe someone who has a family member with ID or DD -- who may keep the office supplied with local and regional resource information, workshop availability, and related health news. This individual may also be asked to provide regular feedback on the practice’s performance in caring for this population.
3. Organize a “walkthrough” 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.
4. Consider inviting a few young adults with ID/DD and parents/caregivers to participate in a focus group or a transition improvement process in your practice.

Prior to the First Visit

1. Review the tools available in the Six Core Elements of Health Care Transition (“Integrating Young Adults into Adult Health Care”) found at www.gottransition.org and adapt the core elements to this population’s needs. For example:
 - a. Develop a transition policy or statement, with input from young adults with ID/DD, that describes your practice’s approach to welcoming young adults and, if needed, their

caregivers. This can be shared with all staff and discussed with young adults and their caregivers at their first visit. (See sample policy from Six Core Elements, which can be customized for your practice.)

- b. Create an office registry for this population in order to track individual progress related to receipt of their current medical records, welcome and orientation to your practice, clarification of shared decision-making status and implications (guardianship, powers of attorney, and consent to share personal health information), self-care assessment, and plan of care. The registry can also be used to track the status of the population's health, preventive care status, and health risks. (See sample registry from Six Core Elements.)
 - c. Identify the clinicians in your practice that are interested in caring for young adults with ID/DD.
 - d. Develop a brief welcome letter and frequently asked questions (FAQs) about your practice with input from young adults and caregivers, and post the content on your website. (See sample welcome letter and FAQs from Six Core Elements).
2. Obtain health records from previous provider(s) including recent care plans, active problem lists, medication lists, and health care transition readiness/self-care assessment status.
 3. Ask the pediatric provider to send you information about the youth's specific childhood-onset/congenital conditions (e.g. Down syndrome, Fragile X syndrome) associated with the patient's intellectual disability, including any existing preventive care guidelines for such conditions.
 4. Ascertain shared decision-making status and implications (guardianship, powers of attorney, and consent to share personal health information).
 5. Ascertain the young adult's ability to communicate and communication method if other than verbal speech, and identify use of any other assistive technology, including mobility devices. Recognize that individuals with ID/DD 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.
 7. Schedule adequate time for a successful the first visit taking into consideration assistive devices for mobility and/or communication, presence of 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 ID/DD may require several visits to accomplish the goals that might usually be met in one visit for other patients.

During the Visit

1. Treat the patient as an adult regardless of level of intellectual disability – greet the patient first, speak and direct questions to the patient even if a caregiver provides responses. Encourage the highest level of involvement of the patient in his or her care.
2. Ascertain name, contact information, and role or relationship to the patient of any caregivers and others present at the visit.
3. Explain what will happen during the visit and invite caregiver to “translate” if necessary.
4. Provide an orientation to the practice or clinic to patient and caregiver, including methods for 24/7 access to care, access to any electronic patient portal, process for prescription renewals and for referrals.
5. Demand of yourself and your staff the same quality and process of care that you would provide to a patient without intellectual disability (all vital signs recorded, complete history obtained,

complete physical examination conducted, same treatment recommendations delivered, all preventive care and screening measures provided). At times, the elements of a process of care may require several office visits.

6. Continue the use of a care plan identifying status of and responsibility for action items.
7. 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.
8. Continue a process of readiness/self-care assessment and education for the highest possible level of self-management. (See sample readiness/self-care assessment and plan of care forms in Six Core Elements.)

After the Visit

1. Consider more frequent than annual visits even in someone without secondary chronic conditions in order to strengthen the relationship more quickly and to familiarize the patient with the office. The best care for any patient is relationship-based.
2. Consider a follow-up telephone call from a clinical office staff member to review plan of care, medications, and procedures for accessing the office.
3. Follow-up with the prior pediatric care provider 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.”
4. Consider a process for eliciting feedback about the first visit and the patient’s and caregiver’s experience of the transition process from pediatric to adult care. (See sample transition feedback survey in Six Core Elements).



Got Transition™/Center for Health Care Transition Improvement is a program of the National Alliance to Advance Adolescent Health and is funded by cooperative agreement U39MC25729 HRSA/MCHB ("Transition Services in Adolescent Health - Healthy and Ready to Work"). The author of this practice resource is solely responsible for its contents. No statement in this practice resource should be construed as the official position of the Health Resources and Services Administration or the Maternal and Child Health Bureau. For more information about our work and available publications, contact our office at info@GotTransition.org. Also visit us on our website at www.GotTransition.org.

Copyright © 2015 by The National Alliance to Advance Adolescent Health

All Rights Reserved