



# Integrating Young Adults with Intellectual and Developmental Disabilities 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 intellectual and developmental disabilities (ID/DD) 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.<sup>1</sup>

## 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 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 health conditions or risks.
2. Consider identifying a staff person as the “office champion” – maybe someone who has a family member with ID/DD – who can keep the office supplied with local and regional resource information, workshop availability, and related 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 ID/DD often experience and try to integrate sensitive and unbiased care into the office practice.

4. With a YA with ID/DD 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 #4 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 ID/DD, such as Medicaid and Medicare, Social Security benefits, Section 8 housing benefits, and long-term developmental supports and services (e.g. case management, direct care workers, etc.).
6. Consider inviting a few YAs with ID/DD and parents/caregivers to participate in a focus group or a transition improvement process in your practice.
7. Review coding and reimbursement options for health care transition services so the practice can improve payment for caring for this special population.<sup>2</sup>
8. If the office is pursuing or maintaining National Committee for Quality Assurance (NCQA) medical home recognition, consider addressing health care transition.<sup>3</sup>

## PRIOR TO THE FIRST VISIT

1. Ask for a medical summary from previous clinician(s), including recent care plans along with an adaptive care plan, if available, that aids in communication with YAs with ID/DD and their parents/caregivers,<sup>4</sup> 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. Ask the previous pediatric clinician to send information about any specific childhood-onset/congenital conditions (e.g., Down syndrome, Fragile X syndrome) associated with the patient’s ID/DD, including any existing preventive care guidelines for such conditions.
3. Review the tools available in the Six Core Elements of Health Care Transition™ (“Integrating Young Adults into Adult Health Care<sup>5</sup>”) found at [GotTransition.org](http://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,<sup>6</sup> with input from YAs with ID/DD 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 registry<sup>7</sup> for new YAs with ID/DD 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,<sup>8</sup> self-care assessment with goals and prioritized actions for a plan of care,<sup>9</sup> and updated and shared medical summary and emergency care plan.<sup>10</sup> 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 ID/DD.
  - d. Develop a brief welcome letter<sup>11</sup> and frequently asked questions (FAQs) about your practice with input from YAs with ID/DD and parents/caregivers and post the content on your website.

4. Ask YAs and parents about their approach to health care shared decision-making, such as guardianship, powers of attorney, and consent to share personal health information.
5. Ascertain the YA's ability to communicate and preferred 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 and that communication skills or intelligibility may not correlate completely with intellectual ability.
6. 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.
7. Arrange for staff to inquire prior to the first visit if there are any special accommodations that will be necessary during the visit.
8. 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 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 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 ID/DD (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.
6. Create or update the medical summary and emergency care plan and share with the YA and parent/caregiver.<sup>10</sup>

### BROAD GUIDELINES FOR IMPROVED CARE

Broad guidelines for better care of individuals with ID/DD include:

- Address the patient directly and assume competence
- Seek the highest level of self-care and self-determination for your patient
- Be mindful of person-first language
- Understand who provides what types of support to the patient
- Be clear about shared decision-making arrangements
- Understand underlying conditions and their unique preventive care requirements
- Go as slowly as needed including use of multiple visits
- Use an asset, not deficit-based approach in verbal and written communication

7. Create or update a plan of care,<sup>9</sup> 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.
8. 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.<sup>12</sup>
9. Ask the parent/caregiver what protocols have worked around procedures in the past if they have been challenging (e.g., venipuncture) and follow them.
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. When referring, identify that this YA has ID/DD, and send information that includes any adaptations, accommodations, and communications strategies that you found helpful for this YA.

#### AFTER THE VISIT

1. Consider more frequent than annual visits even for someone without secondary chronic conditions in order to strengthen the relationship more quickly and to familiarize the patient with the office and you and your staff with the patient. 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 clinician/care 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 clinician/care team for future “reverse consultations.”
4. 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.<sup>13</sup>

*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.*

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7. Sample Transition Registry. [gottransition.org/resourceGet.cfm?id=250](http://gottransition.org/resourceGet.cfm?id=250).
8. Guardianship and Alternatives for Decision-Making Support. [gottransition.org/resourceGet.cfm?id=17](http://gottransition.org/resourceGet.cfm?id=17).
9. Sample Plan of Care. [gottransition.org/resourceGet.cfm?id=252](http://gottransition.org/resourceGet.cfm?id=252).
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11. Sample Welcome and Orientation of Young Adults. [gottransition.org/resourceGet.cfm?id=251](http://gottransition.org/resourceGet.cfm?id=251).
12. Sample Self-Care Assessment for Young Adults with Intellectual Disabilities or Developmental Disabilities. [acponline.org/sites/default/files/documents/clinical\\_information/high\\_value\\_care/clinician\\_resources/pediatric\\_adult\\_care\\_transitions/gim\\_dd/idd\\_transitions\\_tools.pdf](http://acponline.org/sites/default/files/documents/clinical_information/high_value_care/clinician_resources/pediatric_adult_care_transitions/gim_dd/idd_transitions_tools.pdf).
13. Sample Health Care Transition Feedback Survey - Young Adults. [gottransition.org/resourceGet.cfm?id=256](http://gottransition.org/resourceGet.cfm?id=256).

## ADDITIONAL PRACTICE RESOURCES

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