

## Intellectual Disabilities/Developmental Disabilities (ID/DD)

**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

**How Developed:** Young Adults with intellectual disabilities or other developmental disabilities face many challenges as they strive to transition from childhood to adulthood. Along with striving for greater independence and to participate in the educational, vocational, and social activities typical for their age, they also have to move from the pediatric providers that have cared for them to new adult providers. This transition can be difficult for all involved due to some of the unique needs of these young adults. In order to help facilitate this transition and ensure good communication and care coordination, the primary care work group developed tools specific to the needs of young adults with intellectual disabilities or other developmental disabilities. The work group included input from primary care providers and young adults as well.

Tool Name	Description of Tool	How to Use Tool
<a href="#"><u>Transition Readiness Assessment for Youth with Intellectual Disabilities or Developmental Disabilities (Pediatric)</u></a>	<p>*Modified to a 4<sup>th</sup>-grade literacy level</p> <p>An assessment tool intended to be filled out by the intellectually disabled youth and utilized by the pediatric care team or other clinicians caring for youth to begin the conversation about the youth’s needed skills to manage his/her health and health care. This tool indicates the elements specifically related to the clinical condition that should be assessed and documented by the transferring pediatric practice.</p>	<p>This <a href="#"><u>form</u></a> is suggested to help assess the <a href="#"><u>teen/emerging young adult’s</u></a> knowledge of their health care needs and their skills in managing them. It is intended to be given to the adolescent patient as early as age 14 and intermittently thereafter up until the time the patient transfers to an adult provider. Useful as a guide for the provider, patient, and their family’s efforts to help the teen develop skills identified as areas of concern. A final assessment prior to transfer will provide important information for the pediatric team to convey to their adult counterparts.</p>

<p><u><a href="#">Transition Readiness Assessment for Parents and Caregivers of Youth with Intellectual Disabilities or Developmental Disabilities (Pediatric)</a></u></p>	<p>An assessment tool intended to be filled out by parents and/or caregivers and utilized by the pediatric care team or other clinicians caring for youth to begin the conversation about the youth’s needed skills to manage his/her health and health care. This tool indicates the elements specifically related to the clinical condition that should be assessed and documented by the transferring pediatric practice.</p>	<p>This <u><a href="#">form</a></u> is suggested to help assess the <u><a href="#">parent/caregiver’s</a></u> opinion of the teen/emerging young adult’s knowledge of their health care needs and their skills in managing them. The tool is intended to be given to the parent/caregiver starting when the patient is age 14 and intermittently thereafter up until the time the patient transfers to an adult provider. It can be used to guide the provider, patient, and their family’s efforts to help the teen develop skills identified as areas of concern. A final assessment prior to transfer will provide important information for the pediatric team to convey to their adult counterparts.</p>
<p><u><a href="#">Medical Summary for Young Adults with Intellectual Disabilities or Developmental Disabilities (Essential Clinical Information)</a></u></p>	<p>A medical record summary that indicates essential clinical information specifically related to the clinical condition that is to be included in the patient’s medical record upon transfer to the adult practice.</p>	<p>The clinical summary/transfer record <u><a href="#">form</a></u> should be completed, signed, and dated on last page by the referring provider and patient at the time of transfer. At this time the form should be given to the new adult providers prior to the first visit. The form can be completed before the time of transition and used as a tool to help the young adult to become familiar with their health care plan and needs as part of the process of developing the knowledge and skills they will need to assume responsibility for their own health.</p>

<p><u><a href="#">Self-Care Assessment for Young Adults with Intellectual Disabilities or Developmental Disabilities</a></u></p>	<p>*Modified to a 4<sup>th</sup>-grade literacy level</p> <p>An assessment tool to be filled out by the intellectually disabled youth and utilized by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed to ensure optimal management of the medical condition(s).</p>	<p>This <u>tool</u> should be given by the adult health care team to the young adult once they establish care. Its purpose is to help the adult provider and their practice and the young adults to better understand what areas the young adult will need assistance and support with to ensure that their care quality remains high and to help determine areas for continued education and skill development.</p>
<p><u><a href="#">Self-Care Assessment for Parents or Caregivers of Young Adults with Intellectual Disabilities or Developmental Disabilities</a></u></p>	<p>An assessment tool to be filled out by a parent and/or caregiver of an intellectually disabled youth and utilized by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues that need to be addressed to ensure optimal management of the medical condition(s).</p>	<p>This <u>tool</u> should be given by the adult health care team to the young adult once they establish care. Its purpose is to help the adult clinician and their practice and the young adults to better understand what areas the young adult will need assistance and support with to ensure that their care quality remains high and to help determine areas for continued education and skill development.</p>