

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

HVC Pediatric to Adult Care Transition

https://www.acponline.org/pediatric-adult-care-transitions/tools

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## **Internal Medicine**

<u>Transition Readiness</u> <u>Assessment for Parents and</u> <u>Caregivers of Youth with</u> <u>Intellectual Disabilities or</u> <u>Developmental Disabilities</u> (Pediatric)	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.	This <u>form</u> is suggested to help assess the <u>parent/careqiver's</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
<u>Medical Summary for Young</u> <u>Adults with Intellectual</u> <u>Disabilities or Developmental</u> <u>Disabilities</u> (Essential Clinical Information)	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.	their adult counterparts. The clinical summary/transfer record form 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.



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