



# **Easing the Transition to Adulthood for Children with Development Disabilities**

## **A Toolkit for Physicians**





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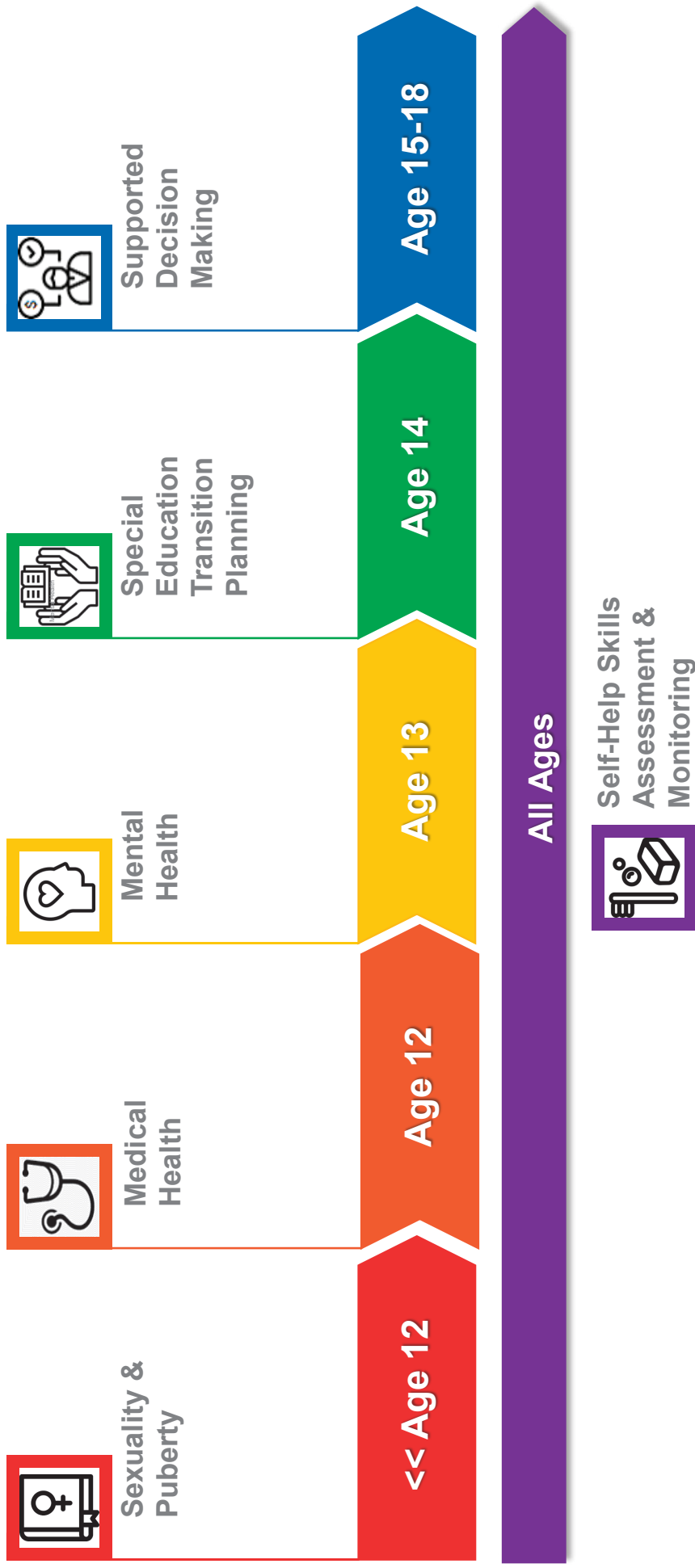
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# Adult Transition Planning Timeline





## Puberty and Sexuality A guide for physicians

### When do I talk to families and patients about puberty and sexuality?

Puberty and sexuality discussions should be a regular part of well child visits for all children, particularly those with special needs. As a pediatric provider, you are an integral part of initiating these discussions with family and patients especially early on **BEFORE** a child experienced body changes.

Girls may start puberty by 8 years old and boys may start puberty by 9 years old.

**NOTE:** Children with neurodevelopmental disabilities are at **GREATER RISK** of precocious puberty than other children, most commonly central precocious puberty.

### Why do I talk to families and patients about puberty and sexuality?

The goal is to normalize conversations about one's body and help prepare children and their families for upcoming changes. This will also allow more open conversations amongst families and clear conversations in the future if situations occur (sexual abuse, etc.).

### What kind of assessments are out there to help me?

**HEADDSS.** This is a commonly used mnemonic for adolescent social history taking. Adjustment needed based upon child's ability level and interests. This assessment uses open-ended questions with as little assumption as possible.

**THRxEADS.** T for Transition, H for Home, Rx for Medication and Treatment, E for Education and Eating, A for Activities and Affect, D for Drugs and S for Sexuality – new mnemonic for individuals with a chronic health condition or disability.

## Puberty and Sexuality

### A guide for physicians

#### How do I talk about birth control?

Every patient regardless of their disability should be provided information and options regarding birth control. Prepare caregivers by discussing birth control methods for female patients (IUD, Nexplanon, Depovera) not only as birth control, but also for menstrual symptoms. Place referral for adolescent medicine or ob/gyn so options can be discussed further and implemented.

#### What kind of advice can I give caregivers regarding puberty and sexuality?

Encourage parents to **take advantage of teaching moments**, such as “Why does mommy have breasts?” “Why is daddy’s penis bigger than mine?” “Why do grown-ups have so much hair?”

Encourage parents to **teach children the correct names** of all body parts.

Encourage parents to promote independent hygiene care. This can be taught by modeling and repetition. Visual aids like picture schedules can also be used. The caregiver handout has some examples and resources.

#### What kind of advice can I give patients regarding puberty and sexuality?

Encourage patients learn they are the “boss” of their bodies. This allows patients to know that they are in control of **who** touches their bodies and **how** they are touched.

Help patients understand that others are the bosses of their bodies too! The rules go both ways! They must ask before touching, listen to what others have to say, and think about what others are feeling.



## Puberty and Sexuality A guide for physicians

### Articles:

- Sieving RE, McRee A-L, Mehus C, et al. Sexual and reproductive health discussions during preventive visits. *Pediatrics*. 2021;148(2):e2020049411.
- Breuner CC, Mattson G; Committee on Adolescence; Committee on Psychosocial Aspects of Child and Family Health. Sexuality education for children and adolescents. *Pediatrics*. 2016;138(2):e20161348.
- Hagan JF, Shaw JS, Duncan PM, eds. *Bright Futures: Guidelines for Health Supervision Of Infants, Children, and Adolescents*. 4th ed. Elk Grove Village, IL: American Academy of Pediatrics; 2007.
- Cummins, C., Pellicano, E. & Crane, L. Supporting Minimally Verbal Autistic Girls with Intellectual Disabilities Through Puberty: Perspectives of Parents and Educators. *J Autism Dev Disord* 50, 2439–2448 (2020).  
<https://doi.org/10.1007/s10803-018-3782-8>
- Veazey, S. E., Valentino, A. L., Low, A. I., McElroy, A. R., & LeBlanc, L. A. (2016). Teaching feminine hygiene skills to young females with autism spectrum disorder and intellectual disability. *Behavior Analysis in Practice*, 9(2), 184–189.  
<https://doi.org/10.1007/s40617-015-0065-0>
- Zacharin, M. R. (2009). Puberty, contraception, and hormonal management for young people with disabilities. *Clinical Pediatrics*, 48(2), 149–155.  
<https://doi.org/10.1177/0009922808324492>

## Puberty and Sexuality

### A guide for physicians

#### Websites:

- Autism Speaks
  - [www.autismspeaks.org/audience/transition-age](http://www.autismspeaks.org/audience/transition-age)
- Autism Handbook
  - [www.autismhandbook.org](http://www.autismhandbook.org)
- Vanderbilt Kennedy Center – The Healthy Bodies Toolkit
  - <https://vkc.vumc.org/healthybodies/>
- Committee for Children activity blog
  - <https://www.cfchildren.org/blog/2017/08/activity-teaching-touching-safetyrules-safe-and-unsafe-touching/>

## Healthcare Transition

### A guide for physicians

### Introduction

Healthcare transition discussions should be integrated into routine well-child visits for all children, with special attention given to those with special needs. These conversations should commence when the child reaches 12 years of age and should gradually increase in depth and frequency as each year passes.

Adapted from [gottransitions.com/AAP](https://gottransitions.com/AAP) article: Supporting health care transition from adolescence to adulthood in the medical home. Pediatrics. 2011

### How can I facilitate successful healthcare transition for my patients?

#### Prepare Office Policy

- Establish a registry of patients with special healthcare needs for easy identification and integrate with EMR if possible.
- Establish an office policy by identifying a general approach for transition in your clinic. Examples of factors that need to be identified include:
  - Establish the age at which you will begin the transition process
  - Identify a specific age to transfer a patient to adult care

#### Assess Transition Readiness

- Assess with the adolescent and family the adolescent's knowledge of their medical health care needs and ability to care for themselves medically. Develop clear definitive goals together, such as "By the next visit, Joey should be able to list what medications he takes without assistance."
- Document progress towards goals within the plan of care and add additional goals over time.

## Healthcare Transition A guide for physicians

### Plan For Healthcare Transition with Your Patients

- Regularly update the plan of care with the family including:
  - Current and future medical oriented goals
  - An updated medical summary
  - An updated Emergency care plan
  - Any necessary legal documents
- Discuss openly with the family changes that occur after 18 regarding:
  - Decision making
  - Privacy
  - Self-advocacy
  - Consent
  - Access to information
- Help families identify an adult medical provider. Communicate necessary information with that provider.
- Discuss with the family optimal timing for transfer – *ideally when patient is most stable*. (If the child has multiple specialists you may need to coordinate together.)

### Transfer Care To Adult Providers

- Make a transfer package with caregivers including:
  - Plan of care including transition goals and actions that should be prioritized
  - Updated medical summary
  - Emergency care plan
  - Legal documents
- Confirm date of first adult provider appointment and communicate with adult provider about upcoming transfer of care.

## Healthcare Transition

### A guide for physicians

#### Completion of Transfer

- Contact patient and caregiver 3 to 6 months after last appointment to verify that they have met the adult provider.
- Be open to answering questions or getting feedback about the transition process from the patient and caregiver.
- Communicate with adult provider confirming transfer completion and answer any questions as needed.

#### Articles:

1. Transition Care for Children With Special Health Care Needs. Davis AM, Brown RF, Lounds Taylor J, Epstein RA, McPheeters, ML. *Pediatrics*. 2014; 134: 900-908.
2. American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group. Clinical Report—Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*. 2011;128: 182-200.
3. Transition of Adolescents to Young Adulthood for Vulnerable Populations. Shaw T, DeLaet DE. *Pediatrics in Review*. 2010;31: 498-505.
4. Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. Malik-Soni N, Shaker A, Luck H, Mullin AE, Wiley RE, Lewis MES, Fuentes J, Frazier TW. *Pediatr Res*. 2022 Apr;91(5):1028-1035.

#### Websites:

- Got Transition
  - [www.gottransition.org](http://www.gottransition.org)
- Adolescent Health Transition Project (University of Washington)
  - <http://depts.washington.edu/healthtr/hcp/transition.html>



## Mental Health Assessment

### A guide for physicians

### What are effective screening tools for mental health in children with DD?

The American Academy of Pediatrics (AAP) recommends screening for behavioral health concerns at the Well Child Check (WCC). Standard administration may need to be modified for youth with DD.

These **modifications** may include:

- having a caregiver or primary care provider ***read questionnaires***,
- ***asking additional follow-up questions to obtain qualitative data***,
- and obtaining ***collateral information*** from parents and teachers.

The following questionnaires are recommended:

- **Anxiety:** Generalized Anxiety Disorder-7 (GADS-7); Screen for Child Anxiety Related Disorders (SCARED)
- **Attention-Deficit/Hyperactivity Disorder:** Vanderbilt Rating Scale
- **Depression:** Patient Health Questionnaire Adolescent Version (PHQ-A); Ask Suicide Screening Question (ASQ),
- Columbia-Suicide Severity Rating Scale (C-SSRS),
- **Social Determinants of Health:** Center for Youth Wellness ACE Questionnaire (CYW ACE-Q), Pediatric ACEs, and
- Related Life-events Screener (PEARLS)

### How do I talk with families about mental health concerns?

Common mental health problems in children with DD include anxiety disorders and depressive disorders. Additionally, youth with DD are at a higher risk than the general population to experience various forms of victimization including bullying. They do attempt and commit suicide.

## Mental Health Assessment

### A guide for physicians

It is not always easy to know if a child with DD is struggling with mental health, as it may be particularly challenging for youth with DD to talk about their feelings.

It is still important to talk to the child about how they may be feeling in a way they understand.

It is also important to keep an eye on behavior changes that may be concerning such as isolation, increased aggression or moodiness, and self-harm.

#### Tips

**For normalizing mental health screening can include the following explanations:**

- This is part of standard practice.
- Parent and teacher perspectives are helpful in trying to understand how biological, psychological, and social factors interact and affect day-to-day functioning.
- You are a part of the child's team and it is your job to have a comprehensive understanding of their experience and to be a part of the plan to promote happiness and good mental and physical health.

**For discussing elevated scores:**

- Explain the purpose of the measure and identify items which were endorsed as being experienced frequently.
- Discuss that the child can feel better and identify empirically supported options.
- Use motivational interviewing strategies to engage the child in change talk and behavior.
- Arrange for a warm handoff with a mental health clinician.
- Provide an overview of the type of intervention recommended to help set expectations.



## Mental Health Assessment

### A guide for physicians

#### How do I explain empirically supported therapies?

A common empirically supported intervention for the treatment of **internalizing disorders** is **behavioral/cognitive-behavioral therapy**.

This type of intervention involves examining the relationship between thoughts, feelings, and behaviors. More specifically, patients learn:

- emotion and behavior regulation strategies,
- how to challenge errors in thinking,
- how to use graduated exposures to habituate to feared or avoided situations,
- and how to improve social skills and other adaptive behavioral skills.

For the treatment of **externalizing disorders**, **behavioral therapy** and **parent training in behavior management** are often recommended.

Behavioral therapy typically involves teaching strategies to minimize the impact of executive functioning deficits on day-to-day functioning including academic performance and social interactions.

Parent training in behavior management is designed to assist parents in developing a behavioral plan that identifies behaviors to reward, ignore, and which should receive consequences. This type of intervention typically involves a reinforcement system or token economy to reward targeted, adaptive behaviors.



## How is my Child Doing? (Older Children)

Please assess your child's behavior currently compared to previously and note how long the change has been present. Bring this to your child's doctor or health professional at their next appointment.

Behavior	Less	Same	More	Unknown or Not Applicable	How Long Has the Change Been Present? (Days/Weeks/Months)
Lost interest in activities previously enjoyed					
Low energy					
Spending more time alone/avoiding friends and family					
Dieting or exercising excessively					
Fear/concern about gaining weight					
Sleeping too much/ sleeping during day					
Sleeping too little					
Self-harm behaviors (cutting, burning, pulling/plucking hair)					
Smoking/vaping/ chewing tobacco					
Drinking alcohol					
Using illicit drugs (marijuana, cocaine, meth, heroin, etc.)					
Struggling at school/ declining grades					
Drinking multiple energy drinks per day					
Engaging in risky/ destructive behavior with or without friends)					
Thoughts of suicide					

Adapted from the National Institute of Mental Health "Children and Mental Health: Is This Just a Stage?" 2021. <https://www.nimh.nih.gov/sites/default/files/documents/health/publications/children-and-mental-health/children-and-mental-health-is-this-just-a-stage.pdf>



## How is my Child Doing? (Younger Children)

Please assess your child's behavior currently compared to previously and note how long the change has been present. Bring this to your child's doctor or health professional at their next appointment.

Behavior	Less	Same	More	Unknown or Not Applicable	How Long Has the Change Been Present? (Days/Weeks/Months)
Tantrums					
Irritability					
Talk about fears/worries					
Always moving/cannot sit quietly (except when watching a screen or playing video game)					
Sleeping too much/during day					
Sleeping too little					
Frequent nightmares					
Not interested in other children/difficulty making friends					
Struggling at school/declining grades					
Repeated actions or checking repeatedly out of fear					

Adapted from the National Institute of Mental Health "Children and Mental Health: Is This Just a Stage?" 2021. <https://www.nimh.nih.gov/sites/default/files/documents/health/publications/children-and-mental-health/children-and-mental-health-is-this-just-a-stage.pdf>



## Special Education IEP Transition Planning A guide for physicians

### What is a special education transition plan?

Many children with special needs who attend public school have an Individualized Education Program (IEP). If your patient has an IEP, the school is mandated to start the post-secondary transition planning process at age 14.

### When do I need to talk to families about school transition planning?

Age 14 is a good age to ask your families if their IEP team has talked to them transition plan.

### What is some information that I can give parents about the IEP transition planning process?

The educational team must complete an evidence-based assessment of some kind to determine postsecondary needs and goals. The transition plan should involve the student as much as possible in creating goals so that they are applicable to their needs and align with their interests.

### What is some advice that I can give parents when creating IEP transition plan goals?

Many times, goals are too broad or not applicable to the children's level of functioning or interests. It is important to inform parents that they should advocate for **SMART** (Specific, Measurable, Achievable, Realistic, Timely) goals.

## Special Education IEP Transition Planning A guide for physicians

### What resources are there to support parents in the IEP transition planning process?

- The Ohio Coalition for the Education of Children with Disabilities
  - [www.ocecd](http://www.ocecd)
- The Legal Aid Society of Cleveland
  - <https://lasclv.org/>
- Ohio Center for Autism and Low Incidence (OCALI)
  - [www.ocali.org](http://www.ocali.org)

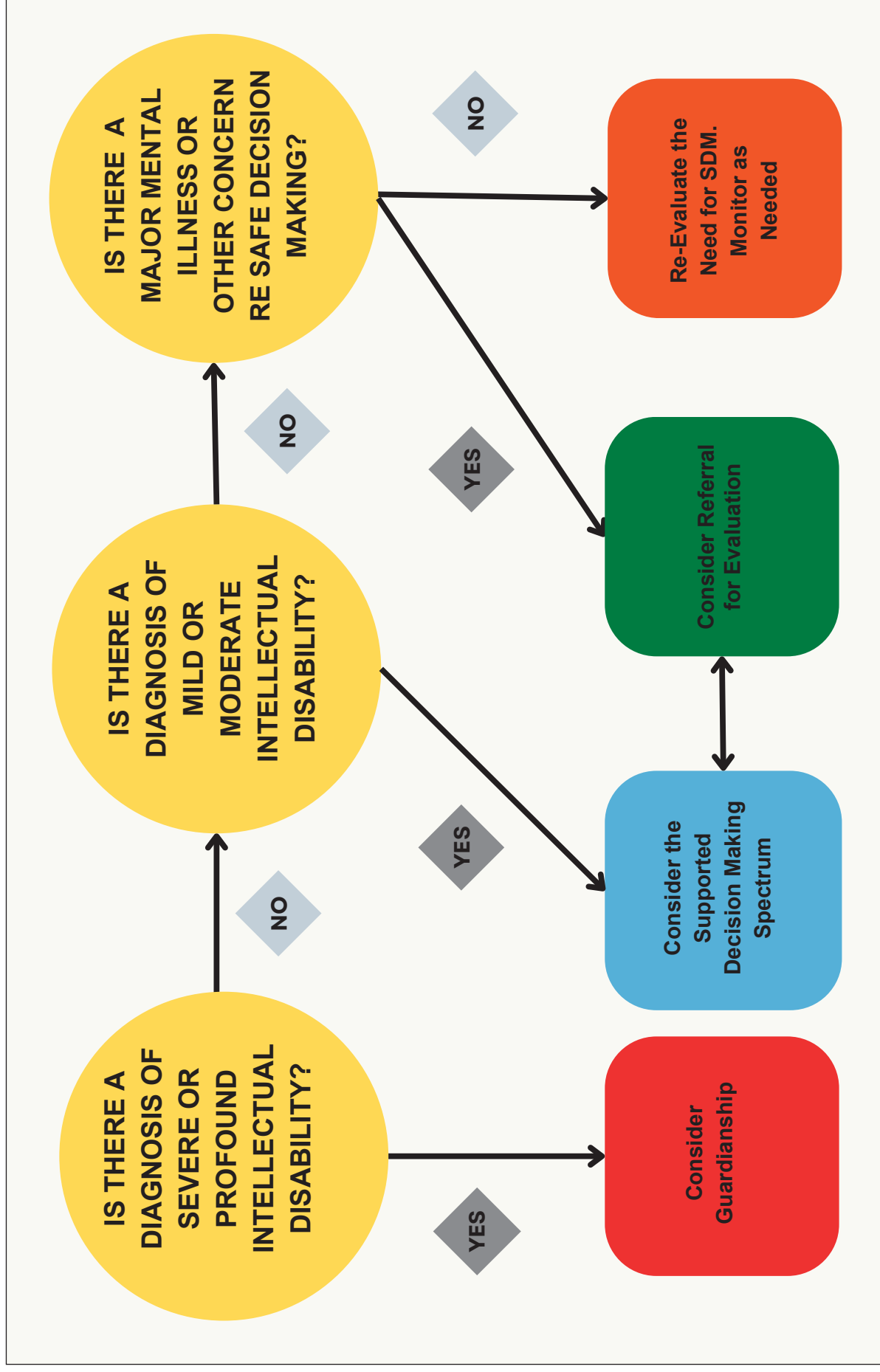
### What if my patient's school is not well equipped for providing transition experiences? What if they attend a private school or do not have an IEP?

This is a suitable time to ask parents what kinds of resources they have available to help their child plan for post-secondary experiences. You can ask your patient what kinds of work or training they are interested in and how they may get there. You can encourage them to volunteer or engage in work experiences.



# Supported Decision-Making

## Flowchart for Clinicians





## Adult Decision Making A guide for physicians

### When do I start talking to families about adult decision making?

It is important for physicians to discuss with families about their plans on how they will support their children's decision making a few years prior to legal adulthood (age 18). This is preferably by age 16 or before.

### How do I talk to caregivers about creating plans around legal decision making and/or guardianship?

Say something like this:

*At age 18, all children, regardless of ability or disability, are able to make their own decisions in the eyes of the law.*

*In other words, at age 18 the law will place all responsibility of decision making onto them and you will no longer have any legal say.*

*If you believe your child is **capable of independent decision making** when it comes to **personal, medical, and financial issues**, then no other steps are needed.*

*If you believe your child will have limitations in their decision making as an adult, it is time to decide what kinds of decisions they will need help making, and who should be making such decisions for them.*

*It is common for caregivers of children with disabilities to feel a bit overwhelmed when planning for this. Luckily, there are many options, some more comprehensive than others.*

***Legal guardianship** is a good option for individuals who are unable to make decisions and care for themselves. There are other less restrictive options as well for individuals who are more independent but may need help in some areas, like with health care decision making. This is called **power of attorney**.*

## Adult Decision Making A guide for physicians

*You should reach out to local resources for guidance on how to best support your child's legal rights as an adult. **This may mean contacting a lawyer in some cases.***

*Be sure to involve your child as much as possible in the conversations about decision making and encourage open communication so that everyone is on the same page.*

### What resources can I provide my patient families regarding decision making options such as guardianship?

- The Legal Aid Society of Cleveland
  - <https://lasclv.org/>
- Ohio Department of Disabilities
  - <https://dodd.ohio.gov/>
- Disability Rights Ohio
  - <https://www.disabilityrightsohio.org/guardianship>
- Health Care Power of Attorney document
  - <https://my.clevelandclinic.org/-/scassets/files/org/medicine-institute/healthcare-power-of-attorney-form.pdf?la=en>

## Self Help Skill Assessment and Monitoring

### A guide for physicians

#### At what age should I assess self-help skills?

Self-help skills should be measured and monitored across the lifespan. For the purposes of guiding adult transition, you should begin to assess self-help skills needed for independence **starting at age 12**. Use the transition checklist provided with your families to help establish some goals.

#### How do I assess my patient's self-help skills?

Assessment can be done in several ways. You can start by simply asking the parent and patient how well they are completing everyday tasks such as toileting, hygiene, and completing chores. Make sure you ask how well they are doing these tasks **WITHOUT PROMPTING OR REMINDERS**. You can also have the parents complete a simple checklist such as the one provided in this toolkit. Also, there are evidencebased measures of independent living skills which include the Vineland-3, and ABAS-3. Whatever way you choose to assess, you should choose at least a few skills as goals to work on before the next visit.

#### How do I talk about self-help skills with caregivers?

Say something like this:

*Self-care skills are skills like **basic hygiene, toileting, completing chores, and using safe behaviors in the community**, for example, looking both ways before crossing the street. It is what children need to care for themselves in order to gain independence.*

*Some children with developmental disabilities **will learn to be independent** while performing many self-care tasks, and **some will have trouble** with some or all of them throughout their adulthood despite lots of practice.*

## Self Help Skill Assessment and Monitoring

### A guide for physicians

*The only way to know how far your child can get is to **practice and reinforce skills every day**. The more routine and structure, the better. Set small goals and track progress.*

*You will work with your child on these skills on your own, but **you may also need support and guidance from professionals** such as behavior therapists or occupational therapists. These professionals may be available in your child's school, or through their local county board of DD.*

*Remember that **positive reinforcement** has been shown to be more effective than punishment or criticizing. Positive reinforcement builds confidence and **encourages your child to keep trying**.*

*Self-help skills may require a lot of support, repetition, and reinforcement initially, but the goal is to get your child to be as independent as possible. This is because the more independent your child is with self-care skills, the less they will need to rely on others as they get older. **Let's pick a few goals to work on before our next visit.***

### How do I talk about self-help skills and goal setting with my patient?

Say something like this:

*You are growing up fast! It is time for me to talk to you about self-help skills. Do you know what self-help skills are? These are **the skills you need to take care of yourself**. These include things like brushing your teeth, going to the bathroom on your own, making a meal, and cleaning your room. Can you think of any other examples of self-help skills with me?*

*Everyone has things that they are good at, and things they are not so good at when it comes to self-help skills. **Can you think of any self-help skills you are good at?** This would be something you can do all by yourself without help.*

*What are some skills you still need more practice with before you can do them on your own? **Let's pick a few to work on before our next visit.***

## Self-Help Skills Checklist

Child's Name: \_\_\_\_\_

Date Completed: \_\_\_\_\_

Completed by: \_\_\_\_\_

### Instructions

Please indicate the ability level for your child with each of the activities in the following tables.

**I** = Totally Independent

**0** = Needs coaching/reminders

**X** = Needs total assistance to complete task

### Example

- If your child can use a public restroom without any assistance, mark "I" for "Totally Independent."
- If your child can brush their teeth independently, but needs reminders to do it, choose "0" for "Needs coaching/reminders."





Dress		Eating / Food Preparation		Grooming / Hygiene		Cleaning / Laundry	
Ability Level		Ability Level		Ability Level		Ability Level	
Picks out "weather-appropriate" clothing		Can use utensils properly (including knives)		Brushes teeth on own		Puts dirty clothes in hamper	
Picks out clean / wrinkle free clothing		Pours liquids from a container into own cup without spilling		Takes a shower of bath on regular basis		Puts clean clothes away in proper place (folds, put in drawer, hangs clothes up)	
Picks out clothing appropriate for the situation (casual vs. work)		Can make simple "no-cook" meals (e.g., sandwich)		Blows / wipes nose with tissue or handkerchief		Can use a washing machine and dryer	
Puts on undergarments correctly		Can use a microwave safely		Cleans hands regularly (e.g., after using restroom)		Returns things to their proper place after using them (e.g., dishes after meals)	
Puts on pants and shirts correctly		Can use small appliances safely (e.g., can opener, toaster)		Uses toilet and wipes self		Picks up and throws away trash at home	
Zips zippers without help		Can use a stove top / oven safely		Uses public restroom		Wipes up spills at home	
Button buttons without help		Takes proper precautions handling food (e.g., cleaning hands)		Cleans or brushes self off if muddy or dirty		Washes dishes by hand or with dishwasher	
Puts on shoes (no tying)		Can tell when foods are expired / spoiled		Combs hair regularly		Cleans room or living quarters regularly (e.g., dusts, vacuums)	
Ties shoes		Follows a recipe		Uses deodorant		Takes out trash when trash is full	

Please indicate the ability level for your child with each of the activities in the following tables.

- I** = Totally Independent
- 0** = Needs coaching/reminders
- X** = Needs total assistance to complete task

Community		Ability Level	Safety / Health		Ability Level	Transportation		Ability Level	Social / Leisure		Ability Level
Looks both ways before crossing the street			Uses electrical outlets safely and carefully			Follows another person's directions to find a nearby location		Play with toys or games with others			
Knows own address and phone number by memory			Uses proper precautions around hot or dangerous items			Uses digital or printed map to find desired locations		Invites others to play			
Carries personalized identification when traveling in the community			Carries breakable objects safely			Can travel in the community (e.g., bike, bus, walking)		Engages in a variety of activities instead of only one or two			
Orders own meals when eating out			Calls for help if someone or self is hurt at home			Obeys traffic laws when traveling on foot or on a bicycle		Follows the rules in games and activities			
Locates correct area in store to get needs met (e.g., frozen food aisle in grocery store)			Cares for own minor injuries			Buckles seatbelt on own		Waits his or her turn in games / activities			
Can make their own purchases			Obeys requests from others only if they know and trust them			Uses helmet as needed		Is polite when interacting with others (e.g., says please, thank you)			
Thinks about their need for an item and cost of an item before making a purchase			Avoids people who will take advantage of them			Knows how to ask for directions if lost		Respects persons of authority			
Uses ATM			Knows how to contact 911 or emergency services			Can use a bus route		Shows good judgment when selecting friends			

Please indicate the ability level for your child with each of the activities in the following tables.

- I** = Totally Independent
- 0** = Needs coaching/reminders
- X** = Needs total assistance to complete task

## Provider ACTION PLAN

1. At what age(s) do I want to begin discussing transition topics with patients and their families? How can I make this part of my regular practice?

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2. Do I need to make connections or create collaborations with anyone in my community to help facilitate transition (e.g., family medicine, internal medicine, psychiatry, Board of Developmental Disabilities, financial planners, attorneys)? Are there current relationships that I can leverage?

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3. Are there changes I want to make within my practice related to supporting my patients through transition? If so, by what date? Examples of changes could be inclusion of specific handouts or more standardized assessment of adaptive behavioral functioning.

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4. Are there any topics that I want to become increasingly more comfortable discussing with patients and their families (e.g., puberty/sexuality, parenting, and legal/financial matters)? What resources do I need to further review or access to accomplish this goal?

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5. What subspecialties are your patients of transition age with developmental disabilities mostly commonly accessing? Are there any subspecialties you are now considering to incorporate more frequently?

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