

# Healthcare Transition of Youth with Special Needs to the Adult Medical World

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# Take home points

1. Healthcare transition planning is important
2. Start transition planning early (12-14)
3. Tools can help  
(transition readiness tools, medical summary tool)
4. Importance of encouraging independence, knowledge and safety
5. The importance of a team approach

# Defining Healthcare Transition

**“Transition is defined as the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems.”**

**Transition- The preparation**

**Transfer- The Warm-Hand off to the adult oriented provider**

*Blum RW, et al. Transition from child-centered to adult health-care-systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health.1993;14:570–576*



# Why is Health Care Transition Planning Important ?

Youth have improved outcomes.

- Decreased medical complications
- Better continuity of care
- Lower costs
- Better adherence to medical therapies
- Better experience for the patient

## Indicators for successful transition

- Patient/family trusts adult provider
- Ongoing continuity of care
- Disease self-management skills  
(if patient is capable)
- Patient does not use the ER for primary care
- Patient/family satisfied with transfer of care
- Maintain/improve health outcomes

List adapted from Suris JC, Akre C 2015

# When should we start the preparation ?

## Guidelines from:

American Academy of Pediatrics AAP

American Academy of Family Physicians (AAFP)

American College of Physicians (ACP)

Start transition process (preparation) at

**12-14 year old**

# Why Start Transition Planning so Early ?

- Planning starts Early –Transfer at 18-21 years old
- Time consuming process
- Barriers for Families
- Barriers for Medical Providers

# Healthcare Transition steps

## Parent/Guardian/Professionals

1. Assessing level of independence  
(core knowledge and skills)
2. Encourage independent functioning to the best of a youth's ability
3. Working with a Team  
Medical, social work, coordinators, teachers, therapists
4. Working with medical clinician to:
  - a. Create a medical summary, emergency preparedness plan
  - b. Find an adult medical provider

## Core Knowledge and Skills Competency and Self Care

- Medical Knowledge of the Condition
- Knowledge of Medications
- Current Activities of Daily Living
- Current Skills
- Strengths and Weaknesses

# Transition readiness tool for Parents

This document should be completed by caregivers of youth with intellectual or developmental disabilities who are under the age of 18 years old in order to assess their youth's readiness to transition to an adult health care provider. If a youth's intellectual or developmental disabilities do not prevent him or her from independently filling out this document, the youth should fill out the youth version of this Transition Readiness assessment form instead.

Please fill out this form to help us see what your youth already knows about their health and using health care and areas that you think they/you need to learn more about. If you need help completing this form, please let us know.

Date:

Patient Name:

Date of Birth:

Caregiver Name:

Are you the main/full-time caregiver?  Yes  No

## Decision-making/Guardianship

- My youth can make my own health care choices.
- My youth needs some help with making health care choices (Name: \_\_\_\_\_ Consent: \_\_\_\_\_).
- My youth has a legal guardian (Name: \_\_\_\_\_).
- My youth/I need a referral to community services for legal help with health care decisions and guardianship.

## Personal Care

- My youth can care for all his/her needs.
- My youth can care for his/her own needs with help.
- My youth is unable to care for himself/herself, but can tell others his/her needs.
- My youth requires help for all his/her needs.

## Transition Importance and Confidence

*On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

How important is for your youth to prepare for and change to an adult doctor before age 22?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
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How confident do you feel about your youth's ability to prepare for and change to an adult doctor before 22?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)
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[idd.transitions.tools.pdf](http://idd.transitions.tools.pdf) ([acponline.org](http://acponline.org))

From the American College of Physicians and American Academy of Pediatrics

# Transition readiness tool for Parents

<b>Your Youth's Health</b>	<i>Please check the box that applies to you right now.</i>	<i>Yes, my youth knows this.</i>	<i>My youth needs to learn this.</i>	<i>I need to learn this.</i>
My youth knows his/her medical needs.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth can tell other people what his/her medical needs are.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows what to do if he/she has a medical emergency.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows the medicines he/she takes and what they are for.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth can take his/her medicine by himself/herself without a reminder.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows what medicines he/she should not take.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows what he/she is allergic to, including medicines.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth can name 2-3 people who can help him/her with his/her health goals		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My teen can explain to people how his/her beliefs affect his/her care choices.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Using Health Care</b>	<i>Please check the box that applies to you right now.</i>	<i>Yes, my youth knows this.</i>	<i>My youth needs to learn this.</i>	<i>I need to learn this.</i>
My youth knows or can find his/her doctor's phone number.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth makes his/her own doctor appointments.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Before a visit, my youth thinks about questions to ask.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth has a way to get to his/her doctor's office.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows he/she should show up 15 minutes before the visit to check in.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows where to get care when his/her doctor's office is closed.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth has a folder at home with his/her medical information, including his/her medical summary and emergency care plan.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth has a copy of his/her plan of care.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows how to fill out medical forms.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows how to ask for a form to be seen by other doctors or therapists.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows where his/her pharmacy is and what to do when he/she runs out of his/her medicines.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows where to get a blood test or x-rays if the doctor orders them.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth carries health information with him/her every day (e.g. insurance card, allergies, medications, and emergency phone numbers).		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth knows when he/she is 18 the rules about his/her health privacy change.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My youth has a plan so he/she can keep his/her health insurance after 18 or older.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Encouraging independence

- Activities of Daily Living (ADLs)
  - Dressing and bathing oneself
  - How to call for help in an emergency
- Knowing the name of medical condition
- Knowing the name of medications
  - (Photograph medication labels)

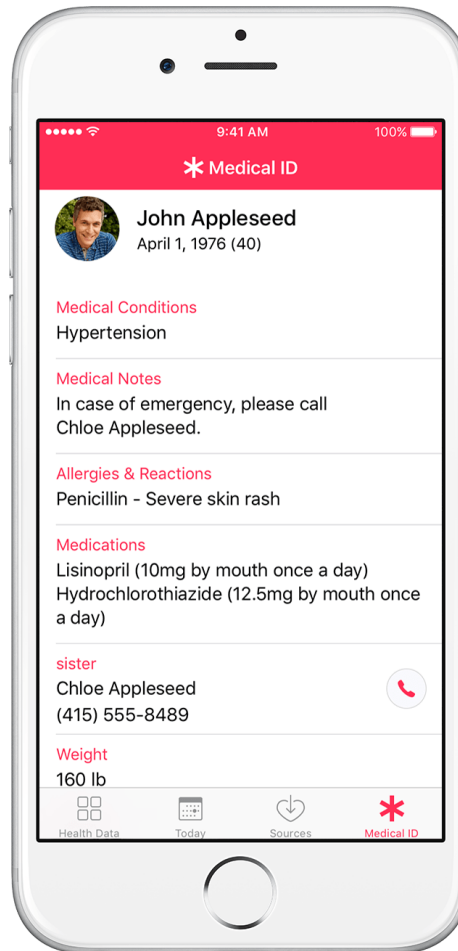
Elevator speech

Information on phone

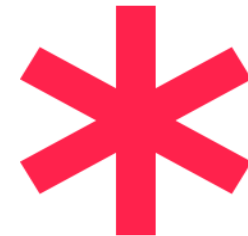
# Medical Summary on I-phone and android

Turn on:  
**Show When Locked**  
to make your Medical ID  
available from the Lock  
screen.

In an emergency, EMS can  
Access information from  
phone.



Tap on health icon  
Then go to medical ID



[Setting up the "Medical ID" Feature on Apple's Health App and on Android Phones \(gottransition.org\)](http://gottransition.org) available in Spanish

## GLADD model from FloridaHATs

How to teach youth with developmental disabilities how to communicate with the doctor

- **G**ive information
- **L**isten and **L**earn
- **A**sk Questions
- **D**ecide on a plan
- **D**o your part

[https://www.floridahats.org/wp-content/uploads/2017/03/HealthLiteracy\\_Rev1\\_2-20-17\\_full-size.pdf](https://www.floridahats.org/wp-content/uploads/2017/03/HealthLiteracy_Rev1_2-20-17_full-size.pdf)

## Ongoing Health Care

- Immunizations
- Nutrition
- Exercise
- Assessing for high risk behaviors
- Mental health
- Sexuality



## Safety and Sexuality

- Sexuality is a human right for all
- Consider sexual education to be added to the IEP
- Importance to prepare for pubertal changes
- Books to assist with education
- Specific resources for youth with autism

[The Healthy Bodies Toolkit \(vumc.org\)](http://vumc.org)

[Puberty, Sex, and Sexuality \(vumc.org\)](http://vumc.org)

[Navigating Puberty, Sex, & Sexuality \(vumc.org\)](http://vumc.org)

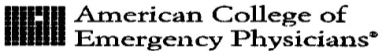
# Emergency Preparedness

1. Medical summary
2. How to get medication
3. Copies of important information
4. Legal documents

Emergency Preparedness Toolkit for Young Adults with Intellectual and Developmental Disabilities and their Primary Care Team

[Emergency Preparedness Toolkit for Young Adults with Intellectual and Developmental Disabilities and their Primary Care Team — The National Alliance to Advance Adolescent Health](#)

# Emergency Information Form for Children With Special Needs



Date form completed	Revised	Initials
By Whom	Revised	Initials

<b>Name:</b>		<b>Birth date:</b>	<b>Nickname:</b>
<b>Home Address:</b>		<b>Home/Work Phone:</b>	
<b>Parent/Guardian:</b>	<b>Emergency Contact Names &amp; Relationship:</b>		
<b>Signature/Consent*:</b>			
<b>Primary Language:</b>	<b>Phone Number(s):</b>		
<b>Physicians:</b>			
<b>Primary care physician:</b>	<b>Emergency Phone:</b>		
	<b>Fax:</b>		
<b>Current Specialty physician:</b>	<b>Emergency Phone:</b>		
<b>Specialty:</b>	<b>Fax:</b>		
<b>Current Specialty physician:</b>	<b>Emergency Phone:</b>		
<b>Specialty:</b>	<b>Fax:</b>		
<b>Anticipated Primary ED:</b>	<b>Pharmacy:</b>		
<b>Anticipated Tertiary Care Center:</b>			

<b>Diagnoses/Past Procedures/Physical Exam:</b>	
1. _____	<b>Baseline physical findings:</b>
2. _____	_____
3. _____	<b>Baseline vital signs:</b>
4. _____	_____
<b>Synopsis:</b>	<b>Baseline neurological status:</b>
_____	_____
_____	_____

\*Consent for release of this form to health care providers

## Education and Vocational Opportunities

- Transition part of IEP starting 14 years
- Team approach-family, school staff, and the Transition Linkage Coordinator
- Student “Ages Out” at 21 years old
- Need consider housing, vocation, college and training Programs, legal considerations

Thinkcollege.net

# How to assess levels of independence?

TEAM approach

Patient/Parents


Psychologist

Teachers

Therapists

Social workers

Care Manager

CHARTING the LifeCourse 

**Tool for Exploring Decision Making Supports**

This tool was designed to assist individuals and supporters with exploring decision making support needs for each life domain.

Name of Individual: \_\_\_\_\_

Name of person completing this form: \_\_\_\_\_

Relationship to Individual (circle one): Self Family Friend Guardian Other: \_\_\_\_\_

How long have you known the individual? \_\_\_\_\_

For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.





	 I can decide with no extra support	 I need support with my decision	 I need someone to decide for me
 <b>DAILY LIFE &amp; EMPLOYMENT</b>			
Can I decide if or where I want to work?			
Can I look for and find a job (read ads, apply, use personal contacts)?			
Do I plan what my day will look like?			
Do I decide if I want to learn something new and how to best go about that?			
Can I make big decisions about money? (open bank account, make big purchases)			
Do I make everyday purchases? (food, personal items, recreation)			
Do I pay my bills on time (rent, cell, electric, internet)			
Do I keep a budget so I know how much money I have to spend?			
Am I able to manage the eligibility benefits I receive?			
Do I make sure no one is taking my money or using it for themselves?			

Chart Life course

Community Based Skills Assessment (CSA)

<https://www.gottransition.org/resource/?hct-family-toolkit>

<https://www.lifecoursetools.com/>

<https://www.autismspeaks.org/sites/default/files/2018-08/>

[Community-based%20Skills%20Assessment.pdf](https://www.autismspeaks.org/sites/default/files/2018-08/Community-based%20Skills%20Assessment.pdf)

# Legal Considerations

## Supported Decision Making

“ practice by which people with intellectual and developmental disabilities (I/DD) are able to make their own decisions with the support of trusted persons in their lives and retain all their legal and civil rights. ”



[What is Supported Decision-Making? – SDMNY](#)

[Supported Decision-Making | National Resource Center \(supporteddecisionmaking.org\)](#)

## Legal Considerations

- Supported Decision Making
- Guardianship-all decisions made by the family
- Conservatorship-Divided decision making
- Health Surrogate- Legal or informal need to keep up to date on medical issues
- Health Guardianship- makes only limited decisions.
- HIPAA rules
- [www.guardianship.org](http://www.guardianship.org)
- [What is Supported Decision-Making? – SDMNY](#)



## Ready for Transfer

- Find an adult clinician
- Work with pediatrician to make a medical summary
- Patient parent to review medical summary
- Patient/parent to write a summary
  - include:
    - How youth communicates best
    - How to approach/examine youth
    - Special talents/strengths
- Legal considerations

# Coordination with the Medical Clinician.

## Medical Summary

### Medical Clinician to fill with patient/family input

Pediatric to Adult Care  
Transitions Tools

**Medical Summary & Emergency Care Plan for**  
*Young Adults with Intellectual/Developmental Disabilities*

<b>Adaptive Functioning Domains</b>		
Communication:		
Social:		
Self Direction:		
Community Activities:		
Work:		
Functional Academics:		
Functional Grade Level:	Date Tested:	
FSIQ:	Date Tested:	
Home Living:		
Leisure:		
Sleep Issues:		
Nutritional Issues:		
Quality of Life Issues:		
Safety Issues:		
<b>Emergency Care Plan</b>		
Emergency Contact:	Relationship:	Phone:
Preferred Emergency Care Location:		

[idd\\_transitions\\_tools.pdf \(acponline.org\)](http://idd_transitions_tools.pdf(acponline.org))



## Final Thoughts

1. Healthcare transition planning is important
2. Start transition planning early (12-14)
3. Tools can help  
(transition readiness tools, medical summary tool)
4. Importance of encouraging independence, knowledge and safety
5. The importance of a team approach

# QUESTIONS ?



# Resources

1. General resources [www.gottransition.org](http://www.gottransition.org) -Got Transition
  - a. Family Toolkit
    - <https://www.gottransition.org/resource/?hct-family-toolkit>
  - b. Phone medical summary
    - [Setting up the "Medical ID" Feature on Apple's Health App and on Android Phones \(gottransition.org\)](#) available in Spanish
2. Medical knowledge and skills
  - a. Transition readiness tool for youth with developmental disabilities  
[idd transitions tools.pdf \(acponline.org\)](#)
  - b. GLAD model how to communicate with your doctor
    - [https://www.floridahats.org/wp-content/uploads/2017/03/HealthLiteracy\\_Rev1\\_2-20-17\\_full-size.pdf](https://www.floridahats.org/wp-content/uploads/2017/03/HealthLiteracy_Rev1_2-20-17_full-size.pdf)

# Resources

## c. Emergency preparedness

- [Emergency Preparedness Toolkit for Young Adults with Intellectual and Developmental Disabilities and their Primary Care Team — The National Alliance to Advance Adolescent Health](#)
- [Emergency Information Form for Children with Special Needs \(smchealth.org\)](#)
- [Emergency Preparedness for Children with Special Health Care Needs aap.org](#)

## d. Safety and Sexuality

- [The Healthy Bodies Toolkit \(vumc.org\)](#)
- [Puberty, Sex, and Sexuality \(vumc.org\)](#)
- [Navigating Puberty, Sex, & Sexuality \(vumc.org\)](#)

# Resources

## 3. Assessing level of independence

- a. <https://www.gottransition.org/resource/?hct-family-toolkit>
- b. <https://www.lifecoursetools.com/>

## 4. College

- <https://thinkcollege.net/>

## 5. Legal Supports

- a. [What is Supported Decision-Making? – SDMNY](#)
- b. [Supported Decision-Making | National Resource Center \(supporteddecisionmaking.org\)](#)
- c. [www.guardianship.org](http://www.guardianship.org)