



Transition to Adulthood: The "Cliff" for Neurodiverse Youth

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Disclosures

- Nothing to disclose



Objectives

- Summarize the timeline for transition planning
- Compare and contrast legal options for autonomy
- Formulate a formal "Transition Readiness" plan





Transition North Star

- Transition to adulthood is not a singular event
- It builds gradually
- Goal – maximize autonomy and independence
- Success for everyone is different
 - What does it look like for your patient?
 - What are their goals?



Transition



HEALTHCARE



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Healthcare Transition (HCT)

Got Transition® is the national resource center on health care transition (HCT). Its aim is to improve transition from pediatric to adult health care through the use of evidence-driven strategies for health care professionals, youth, young adults, and their families.



- *Healthcare Transition is the process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician*

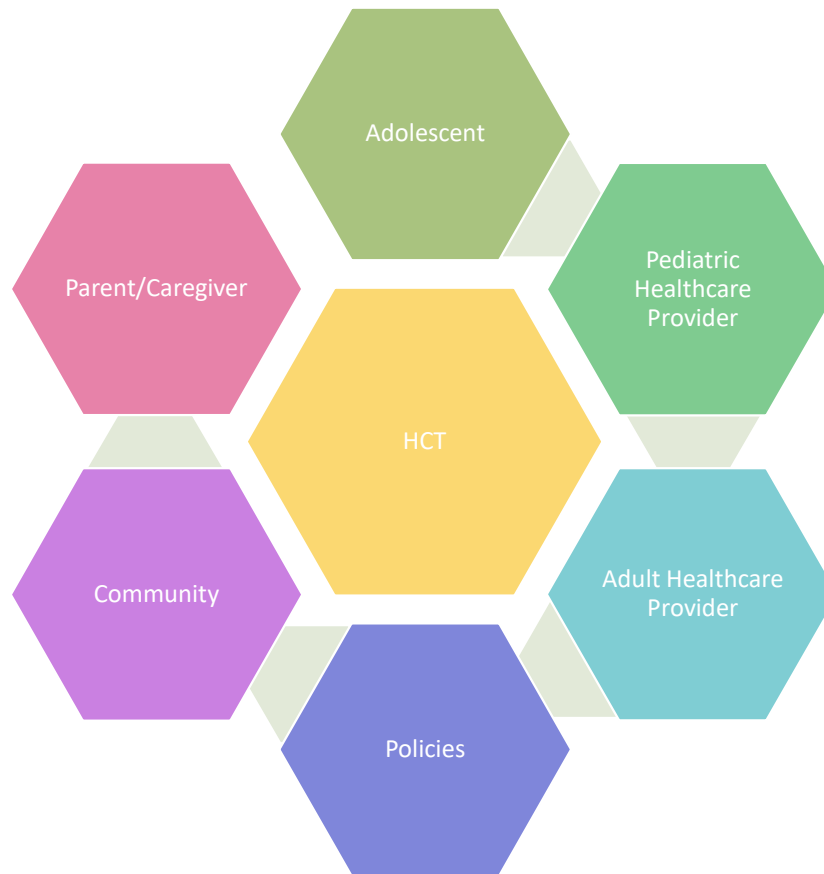
– Got Transition

- Goals of HCT

- Improve the ability of youth and young adults with special healthcare needs to manage their healthcare needs and utilize healthcare services
- To establish an organized process between pediatric and adult providers to ensure a smooth transition of care

<https://www.gottransition.org/>

Healthcare transition



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Charting the LifeCourse is designed to be used for your own life, for your family members, or in the work you do. The framework and tools will help you organize your ideas, vision, and goals, as well as problem-solve, navigate, and advocate for supports.



Center for
Transition to Adult Health Care
for Youth with Disabilities

Barriers to Transition



- Communication challenges
 - Concerns about whether information will be shared (or how)
 - Will adult provider understand the child's needs



- Continuity of Care
 - Worries about maintaining comprehensive care
 - Concerns about integrated systems with specialists etc



- Rebuilding Trust
 - Hard to re-establish especially with complex medical histories



Systemic Barriers

What happens at age 18

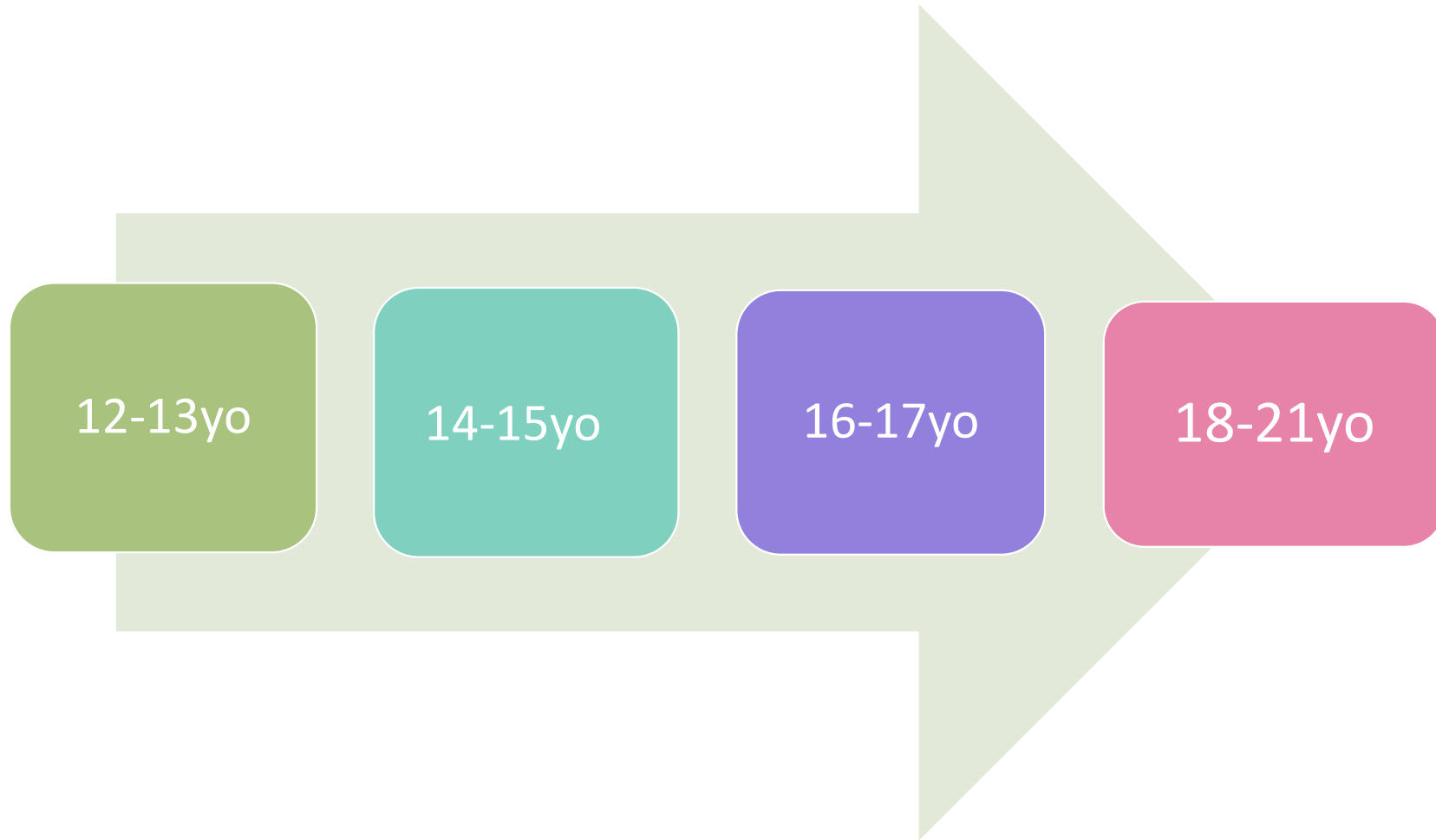
Legal adult

Parents no longer have medical decision-making rights

Privacy laws apply



Transition timeline



SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE



12-13 years of age

- Policy Making
 - Create policy with input from adolescents and families
 - Share with staff and providers so they are families
 - Accessible for view in clinical spaces

Pediatric Care (Where you are now)		Adult Approach to Care (Where you will be)
Your parent/caregiver is with you for most or all of your visit.		You see the doctor alone unless you agree for others to be present.
Your parent/caregiver helps answer questions and explain your medical conditions, any medicines, and medical history.		You answer questions and explain your medical conditions, medicines, and medical history.
Your parent/caregiver is involved in making choices about your care.		You make your own choices about your care, asking your parents/caregivers as needed.
Your parent/caregiver helps make appointments and get your medicines.		You make your own appointments and get your medicines.
Your parent/caregiver helps with your care and reminds you to take your medicines.		You take control of your care and take medicines on your own.
Your parent/caregiver can see your health information, including test results.		Health information is private unless you agree to let others see it.
Your parent/caregiver knows your health insurance and pays any charges at the visit.		You keep your health insurance card with you and pay any charges at the visit.
Your parent/caregiver keeps a record of your medical history and vaccines.		You keep a record of your medical history and vaccines.
Many pediatric specialists provide both specialty and some primary care.		Adult specialists often do not provide primary care, so you need to have a primary care doctor along with a specialist.

Got Transition

Education

- Educate families on what transition is
- Provide families with transition policy at check in to appointments
- Speak directly to adolescent
 - What can they learn about their healthcare?



14-15 years of age

- Transition readiness and planning
 - Complete the Transition Readiness Assessment
 - Got Transition
 - Transition readiness assessment for youth with IDD
 - Speak with the teen about their health
 - What to do in an emergency
 - Carry insurance card



Pediatric to Adult Care Transitions Tools

Transition Readiness Assessment for Parents/Caregivers of Youth with Intellectual/Developmental Disabilities

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 it 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)

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)

Your Youth's Health

Please check the box that applies to you right now.

Yes, my
youth
knows this.

My youth
needs to
learn
this.

I need to learn this.

- My youth knows his/her medical needs.
- My youth can tell other people what his/her medical needs are.
- My youth knows what to do if he/she has a medical emergency.
- My youth knows the medicines he/she takes and what they are for.
- My youth can take his/her medicine by himself/herself without a reminder.
- My youth knows what medicines he/she should not take.
- My youth knows what he/she is allergic to, including medicines.
- My youth can name 2-3 people who can help him/her with his/her health goals

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Pediatric to Adult Care Transitions Tools

Transition Readiness Assessment for Parents/Caregivers of Youth with Intellectual/Developmental Disabilities

My teen can explain to people how his/her beliefs affect his/her care choices.

☐ ☐ ☐

Using Health Care

Please check the box that applies to you right now.

Yes, my
youth
knows this.

My youth
needs to
learn this.

I need to learn this.

My youth knows or can find his/her doctor's phone number.

☐ ☐ ☐

My youth makes his/her own doctor appointments.

☐ ☐ ☐

Before a visit, my youth thinks about questions to ask.

☐ ☐ ☐

My youth has a way to get to his/her doctor's office.

☐ ☐ ☐

My youth knows he/she should show up 15 minutes before the visit to check in.

☐ ☐ ☐

My youth knows where to get care when his/her doctor's office is closed.

☐ ☐ ☐

My youth has a folder at home with his/her medical information, including his/her medical summary and emergency care plan.

☐ ☐ ☐

My youth has a copy of his/her plan of care.

☐ ☐ ☐

My youth knows how to fill out medical forms.

☐ ☐ ☐

My youth knows how to ask for a form to be seen by other doctors or therapists.

☐ ☐ ☐

My youth knows where his/her pharmacy is and what to do when he/she runs out of his/her medicines.

☐ ☐ ☐

My youth knows where to get a blood test or x-rays if the doctor orders them.

☐ ☐ ☐

My youth carries health information with him/her every day (e.g. insurance card, allergies, medications, and emergency phone numbers).

☐ ☐ ☐

My youth knows when he/she is 18 the rules about his/her health privacy change.

☐ ☐ ☐

My youth has a plan so he/she can keep his/her health insurance after 18 or older.

☐ ☐ ☐

Sample Transition Readiness Assessment for Youth

Please fill out this form to help us see what you already know about your health, how to use health care, and the areas you want to learn more about. If you need help with this form, please ask your parent/caregiver or doctor.

Preferred name _____ Legal name _____ Date of birth _____ Today's date _____

TRANSITION IMPORTANCE & CONFIDENCE Please circle the number that best describes how you feel now.

The transfer to adult health care usually takes place between the ages of 18 and 22.

How important is it to you to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not very

How confident do you feel about your ability to move to a doctor who cares for adults before age 22?

0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10
not very

MY HEALTH & HEALTH CARE Please check the answer that best applies now.

	NO	I WANT TO LEARN	YES
I can explain my health needs to others.	☐	☐	☐
I know how to ask questions when I do not understand what my doctor says.	☐	☐	☐
I know my allergies to medicines.	☐	☐	☐
I know my family medical history.	☐	☐	☐
I talk to the doctor instead of my parent/caregiver talking for me.	☐	☐	☐
I see the doctor on my own during an appointment.	☐	☐	☐
I know when and how to get emergency care.	☐	☐	☐
I know where to get medical care when the doctor's office is closed.	☐	☐	☐
I carry important health information with me every day (e.g., insurance card, emergency contact information).	☐	☐	☐
I know that when I turn 18, I have full privacy in my health care.	☐	☐	☐
I know at least one other person who will support me with my health needs.	☐	☐	☐
I know how to find my doctor's phone number.	☐	☐	☐
I know how to make and cancel my own doctor appointments.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know how to get a summary of my medical information (e.g., online portal).	☐	☐	☐
I know how to fill out medical forms.	☐	☐	☐
I know how to get a referral if I need it.	☐	☐	☐
I know what health insurance I have.	☐	☐	☐
I know what I need to do to keep my health insurance.	☐	☐	☐
I talk with my parent/caregiver about the health care transition process.	☐	☐	☐

MY MEDICINES If you do not take any medicines, please skip this section.

I know my own medicines.	☐	☐	☐
I know when I need to take my medicines without someone telling me.	☐	☐	☐
I know how to refill my medicines if and when I need to.	☐	☐	☐

WHICH OF THE SKILLS LISTED ABOVE DO YOU MOST WANT TO WORK ON?

Tracking and Monitoring

- Start Transition tracking/monitoring
- Identify when core elements of transition have been completed
- Can be integrated into health records
 - Identify who will be tracking this
 - Care Navigator
 - Provider
 - MA

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Sample Individual Transition Flow Sheet

Preferred name	Legal name	Date of birth
Primary diagnosis	Social/Medical complexity information	
TRANSITION AND CARE POLICY/GUIDE		
Transition and care policy/guide shared/discussed with youth and parent/caregiver		Date
TRANSITION READINESS ASSESSMENT		
Conducted transition readiness assessment	Date	Date
PLAN OF CARE/MEDICAL SUMMARY AND EMERGENCY CARE PLAN		
Updated and shared the medical summary and emergency care plan	Date	Date
Included transition goals and prioritized actions in youth's plan of care	Date	Date
Updated and shared the plan of care, if needed	Date	Date
Discussed needed transition readiness skills	Date	Date
ADULT MODEL OF CARE		
Discussed changes in decision-making, consent, and privacy (e.g., medical records) in an adult model of care	Date	
Discussed legal options for supported decision-making, if needed	Date	
Selected adult clinician:		
Name	Phone, fax, or email	
Practice	Date first appointment scheduled	
TRANSFER OF CARE		
Prepared transfer package including:		Date
☐ Transfer letter, including date of transfer of care ☐ Final transition readiness assessment ☐ Plan of care, including transition goals and prioritized actions ☐ Medical summary and emergency care plan ☐ Guardianship or health proxy documents, if needed ☐ Condition fact sheet, if needed ☐ Additional clinician records, if needed		
Sent transfer package		Date
Communicated with adult clinician about transfer		Date
Elicited anonymous feedback from youth/young adult and parent/caregiver about the HCT supports received in the pediatric practice while transitioning to adult care		Date

 **Transitioning Youth to an Adult Health Care Clinician**
Six Core Elements of Health Care Transition® 3.0

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16-17 years of age

- Planning and Decision Making
 - What healthcare goals are important
 - What actions will be taking
 - Who will be responsible?
- Medical Paperwork
 - Portable medical summary
 - Healthcare support needs
- Discuss legal documentation



Portable Medical Summary

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Sample Medical Summary and Emergency Care Plan

This document should be shared with the youth and parent/caregiver. Attach the immunization record to this form.

CONTACT INFORMATION

Preferred name

Legal name

Date of birth

Preferred language

Address

Cell phone/Home phone

Best time to reach

Email

Best way to reach (text, phone, email)

Health insurance and/or plan

Group and ID numbers

Parent/Caregiver name

Relationship

Phone

PLEASE SHARE SOME SPECIAL INFORMATION THAT THE YOUTH OR PARENT/CAREGIVER WANTS THEIR NEW HEALTH CARE CLINICIAN TO KNOW (e.g., they enjoy baseball, they play the piano)

EMERGENCY CARE PLAN

☐ Limited decision-making legal documents available, if needed

☐ Disaster preparedness plan complete

Emergency contact

Relationship

Phone

Preferred emergency care location

Common Emergent Presenting Problems

Suggested Tests

Treatment Considerations

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Sample Medical Summary and Emergency Care Plan

(Continued)

ALLERGIES AND PROCEDURES TO BE AVOIDED

Allergies

Reactions

To Be Avoided

Why?

☐ Medical procedures

☐ Medications

DIAGNOSES AND CURRENT PROBLEMS

Problem

Details and Recommendations

☐ Primary Diagnosis

☐ Secondary Diagnosis

☐ Behavioral

☐ Communication

☐ Feeding & Swallowing

☐ Hearing/Vision

☐ Learning

☐ Orthopedic/Musculoskeletal

☐ Physical Anomalies

☐ Respiratory

☐ Sensory

☐ Stamina/Fatigue

☐ Other

MEDICATIONS

Medications

Dose

Frequency

Medications

Dose

Frequency

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Sample Medical Summary and Emergency Care Plan

(Continued)

HEALTH CARE CLINICIANS

Clinician's name

Primary/(Sub)specialty

Clinic or Hospital

Phone

Fax

Clinician's name

Primary/(Sub)specialty

Clinic or Hospital

Phone

Fax

PRIOR SURGERIES, PROCEDURES, AND HOSPITALIZATIONS

Date

Surgery/Procedure/Hospitalization

Date

Surgery/Procedure/Hospitalization

BASELINE

Vital Signs:

Height

Weight

RR

HR

BP

Neurological status

MOST RECENT LABS AND RADIOLOGY

Test

Result

Date

Test

Result

Date

Test

Result

Date

EQUIPMENT, APPLIANCES, AND ASSISTIVE TECHNOLOGY

☐ Gastrostomy

☐ Wheelchair

Monitors:

☐ Tracheostomy

☐ Orthotics

☐ Apnea

☐ Suctions

☐ Crutches

☐ O₂

☐ Nebulizer

☐ Walker

☐ Cardiac

☐ Communication Device

☐ Other(s):

☐ Glucose

☐ Adaptive Seating

Transitioning Youth to an Adult Health Care Clinician

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Credit: Got Transition

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Medical Support Needs


Healthy Living | My Health Care Support Needs

My Name: _____ Date: _____

Supporter's Name (if needed): _____

MY HEALTH CARE SUPPORT NEEDS	
Understand Medical Information	
☐ I do not need help with understanding medical information.	
I would like help to:	
☐ Understand what my health care workers tell me or what they recommend.	☐ Understand the pros and cons of each option to help so I can make an informed decision.
☐ Learn about all my options or choices	☐ Other: _____
	☐ Other: _____
How health care workers can best support me:	
☐ Use photos or pictures to explain procedures or directions.	☐ Provide extra time.
☐ Use simple language.	☐ Other: _____
	☐ Other: _____
Communicate with Health Care Workers	
☐ I do not need help communicating with health care workers.	
I would like help to:	
☐ Share my current situation.	☐ Respond to the health care worker's questions.
☐ Communicate my decisions or choices.	☐ Other: _____
☐ Ask the health care worker questions.	☐ Other: _____
How health care workers can best support me:	
☐ Repeat my answers back to me.	☐ Ask me questions.
☐ Ask me to "teach back" instructions.	☐ Other: _____
	☐ Other: _____
Follow Through with Next Steps	
☐ I do not need help following through with next steps.	
I would like help to:	
☐ Follow through with my medical decisions or choices.	☐ Share a summary of my visit with: _____.
☐ Set up my medications.	
How health care workers can best support me:	
☐ Write down instructions for next steps.	☐ Give reminders of upcoming appointments.
☐ Update and organize my information such as my medication list or health care visit summary.	☐ Check-in with me to see how it is going.
	☐ Other: _____
	☐ Other: _____

18-21 years of age

- Transfer of care
 - Age timing can vary depending on provider
 - Identify adult provider
 - Internal medicine
 - Family medicine
 - Med/Peds physician
 - Specialists
 - Timing – start before last pediatric visit
 - Transfer records
 - Confirm insurance coverage
 - “Warm Handoff”
 - Family should bring portable medical summary
 - Meet and greet for first visit
 - Time of learning





SYSTEM DIFFERENCES BETWEEN PEDIATRIC AND ADULT HEALTH CARE

System Characteristics	Pediatric	Adult
 Orientation to Care	Growth and development	Maintenance of well-being with aging
 Practice Approach	Family-centered; shared decision-making with parents	Patient-centered; shared decision-making with young adult
 Primary Care Practice Patient Population	Majority of patients do not have chronic conditions	Majority of patients have chronic conditions
 Specialty Clinic Affiliation/ Location	Most pediatric specialty clinics located in children's hospitals	Most adult specialty practices located in private office-based settings
 Multidisciplinary Staffing	Most pediatric specialty clinics are co-located with other specialists and can offer ancillary therapies	Few adult specialty clinics are not co-located with other specialists and need to refer to other specialists and ancillary therapists
 Availability of Care Coordination	Most pediatric subspecialty clinics and many pediatric primary care practices have care coordination services. Several public care coordination programs (e.g., State Title V program) are available for youth with specific chronic conditions.	Few adult specialty clinics and even fewer adult primary care practices have the availability of care coordination services. Few public care coordination programs are available for adults with chronic conditions.
 Length of Appointment	Longer time	Shorter time

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System Characteristics	Pediatric	Adult
 Time Alone	Sometimes for part of the visit	Legally required for confidentiality over age 18, unless young adult gives permission for others to be present
 Patient Role as Self Advocate	Less, given parental support/presence during visit	Essential
 Patient Role in Making Appointments and Medication Refills	Parent handles	Patient handles
 Adherence to Care	Offer more reminders and work arounds (e.g., using shots or intravenous medications); provider has the legal option of contacting protective services if needed	The expectation of adherence; up to the patient to follow treatment/ medication recommendations; the provider has no legal options
 Medication Dosage	Depends on weight	Commonly one adult dose, but occasionally related to weight
 Use of Pain Medications	More liberal availability	More restrictive availability
 Years in Care System	Usually about 20-25 years	Average 50+ years

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Definitions



- Individuals with Disabilities in Education Act (IDEA)
 - Free and appropriate education (FAPE) to children with disabilities
 - Least Restrictive Environment
 - Birth through age 2 → Part C
 - Ages 3 through 21 → Part B
 - Individualized Education Program
- Section 504 of the Rehabilitation Act of 1973
 - Federal law designed to protect the rights of individuals with disabilities

Transition through IDEA

- Individuals with Disabilities in Education Improvement Act
 - Passed in 2004
 - Requirements for transition service to be in effect when the child is 16 (H.R. 1350 108th Congress)
 - Appropriate measurable postsecondary goals based upon age appropriate assessments
 - Contains transition services the child needs to reach their goals



School transition is a *coordinated* set of activities designed to move a student from school to post-school activities and may include components such as instruction, course of study, related services, and community experiences.

Transition in IEPs

- 92% of adolescents with autism had a transition plan
- 41% had living arrangement goals
 - Higher in adolescents with co-occurring intellectual disability
 - Those without ID may still benefit from living arrangement planning
- Those with intellectual disability had less secondary education goals
- Low utilization of mental health services
 - Significant racial disparities

IEPs should include

- Options for higher education, vocational training, or continuing education programs
 - Schools can refer to vocational rehab services
- Opportunities to build skills for competitive employment, supported employment, or other work based on the individual's abilities
- Work on building independent skills to focus on independence in housing, daily living skills, transportation, and community integration
- Teach youth to participate in their own care and educational decisions

Vocational Rehabilitation



Arizona Department of Economic Security
Your Partner for a Stronger Arizona

- Rehabilitation act of 1973
- Provide services to individuals with disabilities
 - With the ultimate goal to prepare for employment
- Arizona Department of Economic Security Criteria for eligibility
 - Have a physical or mental impairment
 - Physical or mental impairment constitutes or results in a substantial impediment to employment
 - Require VR services in order to prepare for, secure, retain, or regain employment
 - Benefit from the provision of VR services in terms of achieving an employment outcome.

What about graduation?



Graduation

- “Forced graduation”
 - Being told their child has aged out
 - Met criteria for graduation
 - FAPE eligibility ends at that time
- Requirements for graduation
 - 22 credits (with certain requirements in various subjects)
 - MUST align with Arizona’s academic standards
 - Completed coursework may NOT align with those standards
 - Parents can dispute if completed coursework does not align with standards

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Definitions

Term	Definition
Capacity	An individual's ability to perform a specific task (signing a contract, making an informed decision). Based on: • Appreciation of the nature of the situation • Understanding relevant information provided • Reasoning about risks and benefits • Expression of a choice
Competence	Legal determination made by a judge about the mental condition a person must be responsible for their decision or actions
Autonomy	Individual's right to make decision and put those into effect based on their own reasoning. Respect for autonomy should be a valued principle
Support decision-making	Enables individuals to make their own decisions whenever possible through support.
Guardianship	A person or entity appointment by court to manage an individual's financial, medical, personal matters. Some states use the term conservator.

Table adapted from: Turchi et.al., (2024) Considerations for Alternative Decision-Making When Transitioning to Adulthood for Youth With Intellectual and Developmental Disabilities: Policy Statement

Considerations for Alternative Decision-Making When Transitioning to Adulthood for Youth With Intellectual and Developmental Disabilities: Policy Statement

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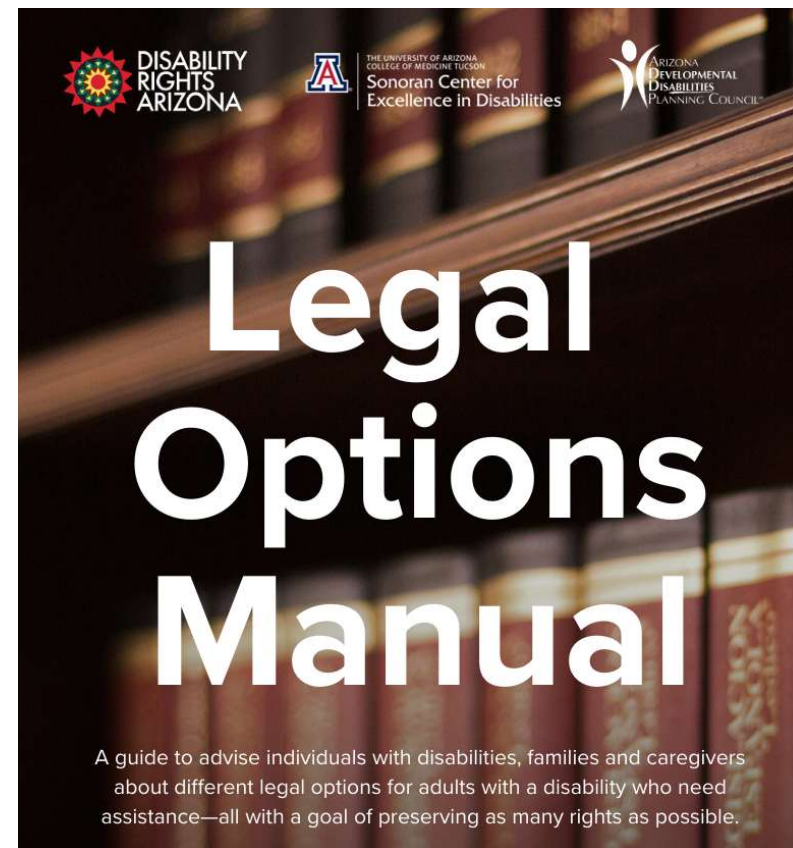
Decision making

Disclaimer – this is not legal advice

Disability Rights Arizona has great information

Families can apply reach out for support

Fantastic library of resources



Decision Making Options



Guardianship (most restrictive)

Court process

If an individual cannot communicate their needs or keep themselves safe

Limited – given specific duties based on the person's needs. Person can still make other decisions and keep some independence

Full – make all major life decisions for the person

Laws allow for voting and driving

Ends with petition to court



Power of Attorney (POA):

Appoint a person to make medical/financial decisions if they are unable to communicate it themselves

Retain their rights

Limited oversight

Must be witnessed and notarized

Can be revoked at any time



Supported Decision Making (SDM)

Arizona law passed in 2023

The individual signs an agreement identifying supporters to help them understand choices.

No court required (must be signed in front of two witnesses or notary)

Can be discontinued at any time



Legal Documentation

- Every decision is individual to each family
- Seek out support and guidance from lawyer trained in disability rights



Financial accounts

- Special Needs Trusts
 - Money/assets can be contributed to the trust
 - No penalty for government benefits/programs
 - Can enhance quality of life in addition to government support
 - Seek out support from lawyer when building trust
- AZ ABLE accounts
 - Tax free savings accounts
 - Save money without losing government benefits
 - Disability with functional limitations
 - Up to \$19,000 per year



Transition mistakes to avoid

- Waiting until 17.5 years of age
- Not teaching basic health skills
- Assuming guardianship is the only option
- Not involving the child in planning



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Transition Resources

- [Got Transition](#)



- [Center for Parent Information and Resources](#)



- [Encircle Families](#)



- [Disability Rights Arizona](#)



- [PACER center](#)



Additional Resources

- [The Arc of Arizona](#)



- [National Resource Center for Supported Decision Making](#)



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- [Assistive Technology Access Program](#)



- [Raise Center](#)



Key Takeaways

- Start Small
- Start Early
- Know local resources!



Autism Educational Summit

Provider Day

Friday, September 25, 2026

Learn More:



<https://AutismSummit.eventbrite.com>



Phoenix Children's



Thank you!



References

- Got Transition <https://www.gottransition.org/>
- Center for Transition to Adult Healthcare for Youth with Disabilities <https://movingtoadulthealthcare.org/>
- Life Course Nexus <https://www.lifecoursetools.com/>
- Disability Rights Arizona <https://disabilityrightsaz.org/>
- Peters VJT, Bok LA, de Beer L, van Rooij JJM, Meijboom BR, Bunt JEH. Destination unknown: Parents and healthcare professionals' perspectives on transition from paediatric to adult care in Down syndrome. *J Appl Res Intellect Disabil*. 2022 Sep;35(5):1208-1216. doi: 10.1111/jar.13015. Epub 2022 Jun 5. PMID: 35665576; PMCID: PMC9546452.
- Tsou AY, Bulova P, Capone G, et al. Medical Care of Adults With Down Syndrome: A Clinical Guideline. *JAMA*. 2020;324(15):1543–1556. doi:10.1001/jama.2020.17024
- Turchi RM, Kuo DZ, Rusher JW, Seltzer RR, Lehmann CU, Grout RW; COUNCIL ON CHILDREN WITH DISABILITIES; COMMITTEE ON MEDICAL LIABILITY AND RISK MANAGEMENT. Considerations for Alternative Decision-Making When Transitioning to Adulthood for Youth With Intellectual and Developmental Disabilities: Policy Statement. *Pediatrics*. 2024 Jun 1;153(6):e2024066841. doi: 10.1542/peds.2024-066841. PMID: 38804066.
- Findley JA, Ruble LA, McGrew JH. Individualized Education Program Quality for Transition Age Students with Autism. *Res Autism Spectr Disord*. 2022 Mar;91:101900. doi: 10.1016/j.rasd.2021.101900. Epub 2021 Dec 23. PMID: 35096138; PMCID: PMC8794292.
- White P, Schmidt A, Ilango S, Shorr J, Beck D, McManus M. Six Core Elements of Health Care Transition™ 3.0: An Implementation Guide. Washington, DC: Got Transition, The National Alliance to Advance Adolescent Health, July 2020.
- Hughes MM, Pas ET, Durkin MS, DaWalt LS, Bilder DA, Bakian AV, Amoakohene E, Shaw KA, Patrick ME, Salinas A, DiRienzo M, Lopez M, Williams S, McArthur D, Hudson A, Ladd-Acosta CM, Schwenk YD, Baroud TM, Robinson Williams A, Washington A, Maenner MJ. Health Conditions, Education Services, and Transition Planning for Adolescents With Autism. *Pediatrics*. 2024 Apr 1;153(4):e2023063672. doi: 10.1542/peds.2023-063672. PMID: 38501189; PMCID: PMC11098059.
- Hughes MM, Kirby AV, Davis J, Bilder DA, Patrick M, Lopez M, DaWalt LS, Pas ET, Bakian AV, Shaw KA, DiRienzo M, Hudson A, Schwenk YD, Baroud TM, Washington A, Maenner MJ. Individualized Education Programs and Transition Planning for Adolescents With Autism. *Pediatrics*. 2023 Jul 1;152(1):e2022060199. doi: 10.1542/peds.2022-060199. PMID: 37345494; PMCID: PMC10911052.