

Navigating Transitions from Pediatric to Adult Medical Care

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Learning Objectives

Participants will be able:

- Explain the process of transition from pediatric to adult medical care, and how ASD and other medical conditions make this process even more important
- Identify components of transition to address as your child ages
- List available resources to aid in transition planning
- Apply the information gained in today's session to create one transition goal for the coming year



National Survey of Children with Special Health Care Needs

- Youth with ASD are not receiving HCTS at the same rate as their peers
- 21% of youth with ASD have received services for HCT
- Youth with ASD are in particular need of continuous, comprehensive health care at a medical home



Statistics

- ~ 50,000 youth with ASD are turning 18 every year
- 50% have a co-occurring medical condition
- 60% of all 15-17 yr old Autistic youth have at least 2 medical conditions in addition to ASD
- Co-occurring conditions include intellectual disability, mental health conditions, ADHD, and epilepsy
- Better health care transition and more comprehensive health care in young adulthood has the potential to improve the health outcomes of people with ASD

The Medical Home and Health Care Transition for Youth With Autism, *Pediatrics* (2018) 141 (Supplement_4): S328–S334.



Transition is a process

“Health care transition, or HCT, 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. It involves **planning, transfer, and integration** into adult-centered health care.”

Transition takes time....


- “Healthcare transition is easy to put off to a later date (back burner)”
- “I’ll wait until our pediatrician cannot see my child any longer”
- “I have too many other priorities (IEPs, work, other children, family needs)”
- “Someone else will find us a new adult physician when we need one.”
- “They won’t make me change if I don’t agree to”



Transition takes time....



- All youth can participate, but adjustments may need to be made for age and developmental level

- Transition (process)  Transfer (event)
- Utilize the vast wealth of information on the internet and choose wisely
- Plan, plan and plan some more...
- Never too early or too late to begin
- Information is power, ask questions of providers, other patients and parents



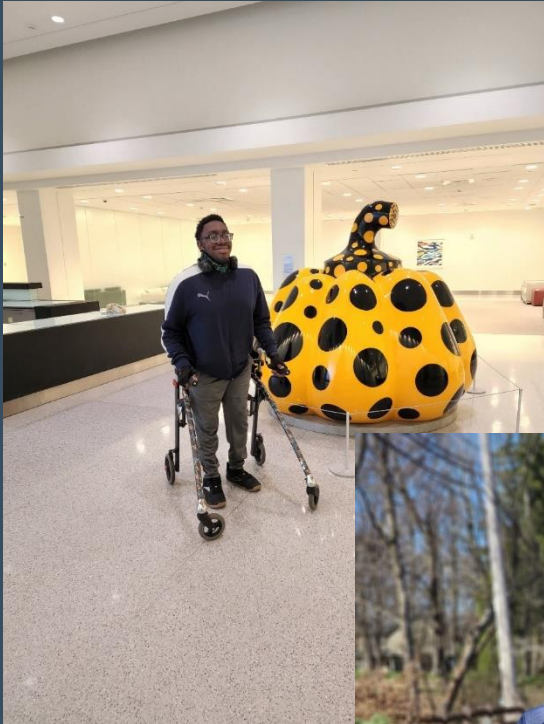
Small victories

- Celebrate the health, accomplishments, hopes and dreams realized by your young adult
- Transition for typical as well as medically complex patients (and their families) with or without ID/DD is daunting and very emotional
- Procrastination, lack of planning and avoidance will **not** prevent the need to transition
- Early and thoughtful planning, communication and knowledge will aid in a positive outcome

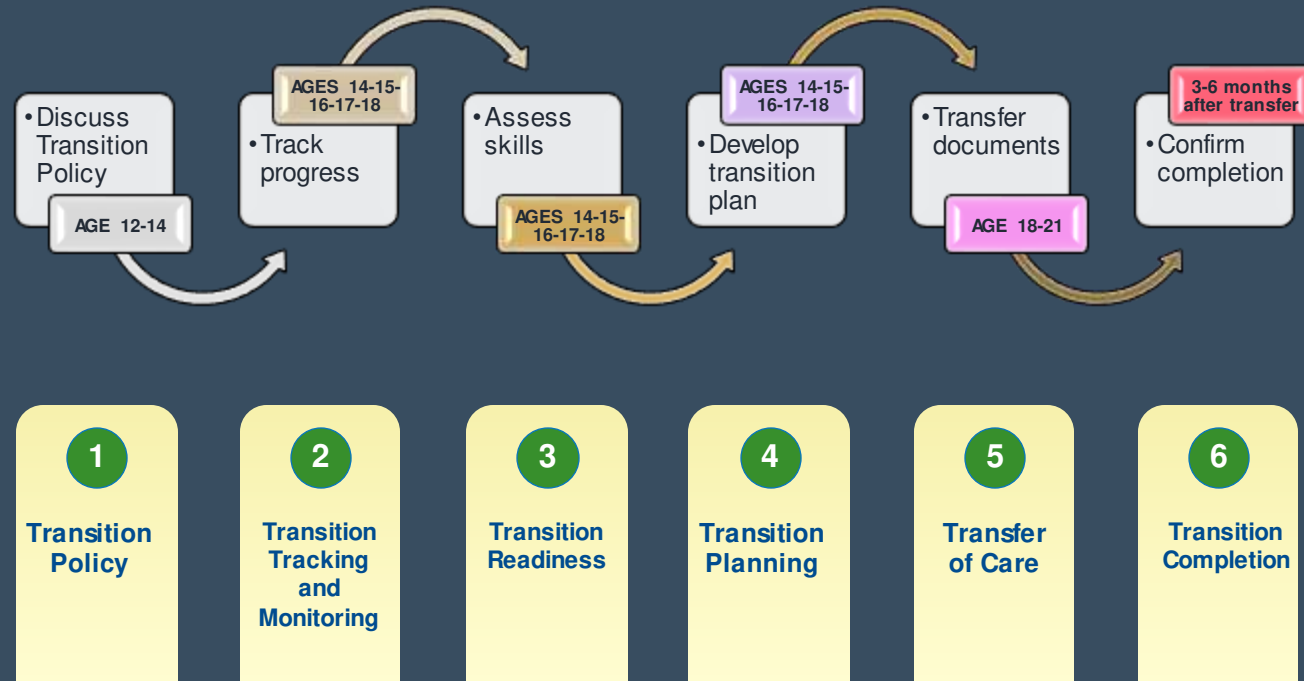
Got Transition®

Got Transition® (www.gottransition.org)

- Excellent resource for youth, parents, providers, educators
- Variety of tools for typical as well as complex pts, with or without ID/DD
- Tools are intended to be individualized and reproduced
- Many healthcare organizations are utilizing this as a framework for their transition programs



Got Transition® and the Six Core Elements of Transition



Got Transition®



Are you ready to transition?

<https://www.gottransition.org/youth-and-young-adults/hct-quiz.cfm>

Youth, young adults, and families: Do you want to learn about transitioning to adult health care?

These tools can help you learn about moving from pediatric to adult health care.

Are you ready to transition to adult health care?



What transition topics should you think about each year?



Is your health information on your smartphone?



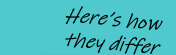
What questions should you ask your doctor about transition?



What changes for your health care when you turn 18?



What are the differences between pediatric and adult health care?



Do you know how to find an adult doctor?



Do you have an Individualized Education Plan (IEP)?



Are there assessments to check your readiness for transition?



For more information, visit [GotTransition.org](https://www.gottransition.org).

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Transition Readiness Assessment

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.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know how to ask questions when I do not understand what my doctor says.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know my allergies to medicines.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know my family medical history.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I talk to the doctor instead of my parent/caregiver talking for me.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I see the doctor on my own during an appointment.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know when and how to get emergency care.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know where to get medical care when the doctor's office is closed.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I carry important health information with me every day (e.g., insurance card, emergency contact information).				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know that when I turn 18, I have full privacy in my health care.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know at least one other person who will support me with my health needs.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know how to find my doctor's phone number.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know how to make and cancel my own doctor appointments.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I have a way to get to my doctor's office.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know how to get a summary of my medical information (e.g., online portal).				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know how to fill out medical forms.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know how to get a referral if I need it.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know what health insurance I have.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know what I need to do to keep my health insurance.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I talk with my parent/caregiver about the health care transition process.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
MY MEDICINES If you do not take any medicines, please skip this section.										
I know my own medicines.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know when I need to take my medicines without someone telling me.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
I know how to refill my medicines if and when I need to.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				
WHICH OF THE SKILLS LISTED ABOVE DO YOU MOST WANT TO WORK ON?										



HCT Timeline: 12-14 years

- Help your teen learn about their own health condition, medications, and allergies
- Encourage your teen to ask their doctor questions about their own health
- Endorse time alone for part of visit with provider and teen
- Explore Assistive Technology (AT) devices or services to help people with disabilities participate more independently
- Ask your teen's provider if and at what age they no longer care for young adults



HCT Goals: Ages 12-14 years

- I (youth) will communicate directly with my providers for a portion of my visit
- I will prepare for visits by writing down questions before my appointment
- If appropriate, request that health skills be included in IEP



HCT Timeline: 14-16 years

- Parent and youth can complete Got Transition's Transition Readiness Assessments and discuss responses with your provider
- Help your teen learn more about their own health and what to do in case of an emergency.
- Help your teen practice making a doctor's appointment and ordering prescription refills (either by phone, online, or through an app).
- Encourage your teen to see the provider alone for part of the visit to help gain independence in managing their own health and health care.



HCT Goals: Ages 14-16 years

- I can summarize my health history in 3 sentences or less to share with medical providers
- I know my own medications and can take my medicines without someone telling me
- I know allergies to medications
- I talk with my parent/guardian about the health care transition process
- I see my medical provider alone for part of my visit
- If appropriate, request that health skills be included in IEP



HCT Timeline: 16-17 years

- Carry contact information for medical providers and insurance card in wallet or on cell phone
- Create “My Health Passport” and keep a copy in wallet or on cell phone
- Patient Portal- enroll in, explore and use
- Explore need for shared decision making- work with agencies and a lawyer to determine level of oversight
- Establish limited or full guardianship at age 18
- Identify adult providers – primary and subspecialty providers as needed



HCT Goals: Ages 16-17 years

- I know how to ask questions when I do not understand what my doctor says
- I talk to the doctor instead of my parent/guardian talking for me
- I see the doctor on my own during an appointment
- I know how to find my doctor's phone number
- I know when/how to get emergency care or medical care when the doctor's office is close





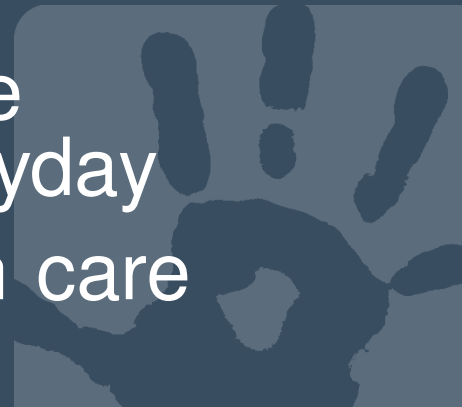
Turning 18: What it Means for Your Health

- Turning 18 may not make you feel any different, but legally, this means you are an adult.
- After you turn 18, your doctor talks to **you**, not your parents, about your health.
- Your health information and medical records are private (or confidential) and can't be shared unless you give the OK.
- It is up to you to make decisions for your own health care, although you can always ask others for help.



HCT Goals: 18+ years

- I know how to obtain a summary of my medical information from the health portal
- I know how to make and cancel my own doctor's appointments
- I have a way to get to my doctor's office
- I know how to get a referral if I need it
- I know how to refill my medicines if and when I need to
- I know what insurance I have and what I need to do to keep my health insurance
- I carry important health information (health insurance cards, emergency contact information) with me everyday
- I know when I turn 18 I have full privacy in my health care



Transition Plan

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Sample Plan of Care

This sample plan of care is created jointly with youth and their parent/caregiver to set goals and outline a plan of action that combines health and personal goals. Information from the transition readiness assessment can be used to develop goals. The plan of care should be updated often and sent to the new adult clinician as part of the transfer package.

<i>Preferred name</i>	<i>Legal name</i>	<i>Date of birth</i>
<i>Primary diagnosis</i>	<i>Secondary diagnosis</i>	

WHAT MATTERS MOST TO YOU AS YOU BECOME AN ADULT? HOW CAN LEARNING MORE ABOUT YOUR HEALTH NEEDS AND LEARNING HOW TO USE HEALTH CARE SUPPORT YOUR GOALS?

Youth's Prioritized Goals	Transition Issues or Concerns	Actions	Person Responsible	Target Date	Date Completed

<i>Clinician/Care staff name</i>	<i>Date plan created/Updated</i>
<i>Clinician/Care staff contact information</i>	<i>Clinician/Care staff signature</i>
<i>Youth signature</i>	<i>Parent/Caregiver signature</i>

Transfer Documents

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Sample Transfer of Care Checklist

Preferred name _____ Legal name _____ Date of birth _____

Primary diagnosis _____

Social/Medical complexity information _____

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 _____

THE SIX CORE ELEMENTS OF HEALTH CARE TRANSITION™ 3.0

Sample Transfer Letter

[Date]

Dear [Adult Clinician Name],

[Name] is a(n) [age] year-old patient of our pediatric practice who will be transferring to your care. Their primary chronic condition is [condition], and their secondary conditions are [conditions]. [Name's] related medications and specialists are outlined in the enclosed transfer package that includes their medical summary and emergency care plan, plan of care, and final transition readiness assessment. [Name] acts as their own guardian and is currently insured under [insurance plan].

The needed next steps in [Name's] plan of care are _____. [Name] would like you to know the following non-medical information about them: _____.

I have had [Name] as a patient since [age] and am very familiar with their health condition, medical history, and specialists. Our practice will provide care for them, such as refilling medications, until they come to the first visit in your practice. Please send us a note or call when [Name] has attended their first appointment in your practice. I would be happy to provide any consultation assistance to you during the initial phases of [Name's] transition to your practice. Please do not hesitate to contact me by phone or email if you have any questions.


Thank you very much for your willingness to care for [Name].

Sincerely,

Pediatric Clinician Name

Email

Phone

 Transitioning Youth to an Adult Health Care Clinician
Six Core Elements of Health Care Transition™ 3.0
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<https://www.gottransition.org/6ce/?leaving-transfer-checklist>
<https://www.gottransition.org/6ce/?leaving-transfer-letter>

Transition Resources

- Got Transition: [A Family Toolkit: Pediatric-to-Adult Health Care Transition \(gottransition.org\)](https://gottransition.org)
- National Resource Center for Supported Decision-Making [Supported Decision-Making News | Supported Decision Making](https://www.supporteddecisionmaking.org)
- Autism Research Institute <https://www.autism.org/?s=transition>
- Milestones Autism Planning (MAP) Tool <https://www.milestones.org/map>
- Autism Speaks Transition Toolkit <https://www.autismspeaks.org/tool-kit/transition-tool-kit>
- Child Neurology Foundation Transition of Care Toolkit <https://www.childneurologyfoundation.org/wp-content/uploads/2020/10/CNF-2020-Transition-of-Care-Toolkit.pdf>
- Family Voices <https://familyvoices.org/?s=transition>



Ohio Family to Family

Free one-on-one **support**
and **training** on:

- health-related and disability services,
- community resources,
- advocacy, and more!

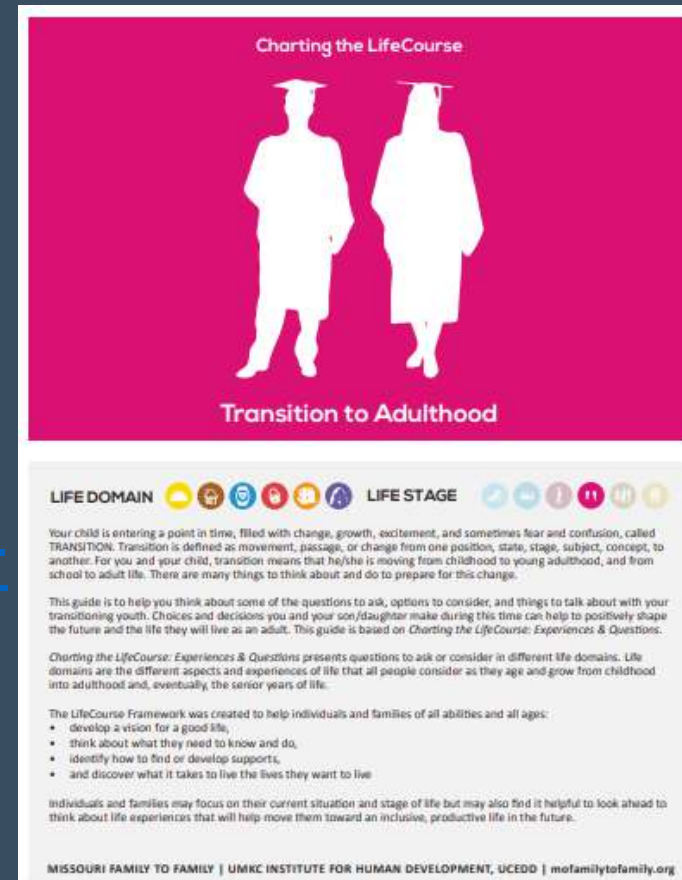
Contact: 513-814-0674 or
amy.Clawson@cchmc.org



Transition Resources, Cont'd

- Charting the Lifecourse Tools

[Charting-the-LifeCourse-Focus-on-Transition-4pager-june-2016.pdf](#)
[\(lifecoursetools.com\)](#)



Finding an Adult Provider

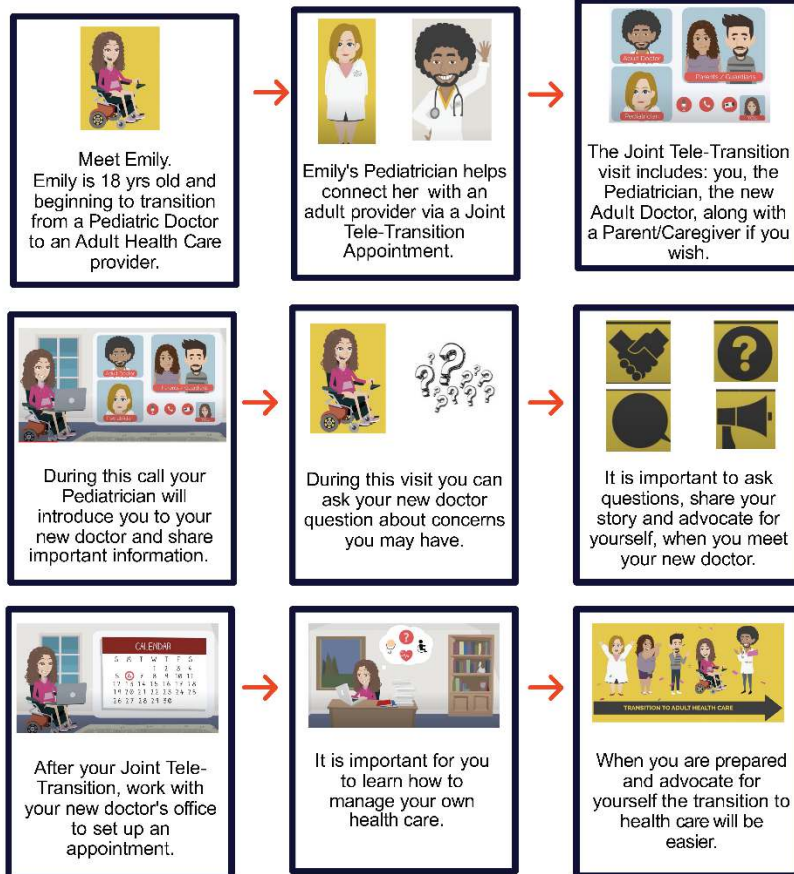
- Ask your primary care provider
- Seek out major hospitals who have transition clinics
- Ask your case manager or county board of developmental disabilities
- Network with family support groups and state work groups



A new video and social story!



Steps for a successful Joint Tele-Transition



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CARES Telehealth 2020 - Youth - Family Voices



Meet and Greet: “Improving Health Care Transition Through Tele-Transition Services”



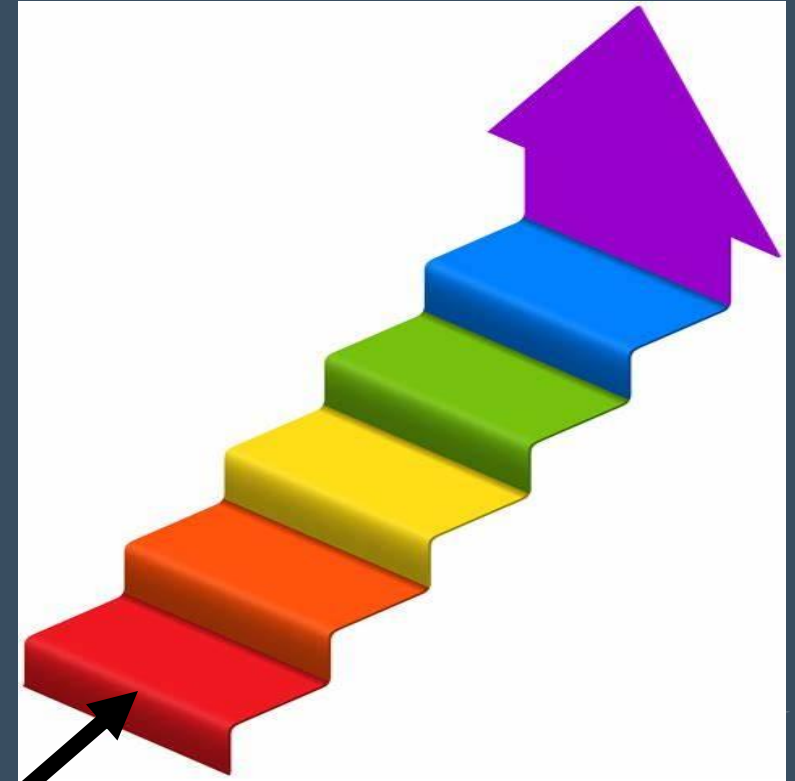
<https://youtu.be/onYfTnQ86Lo>
<https://familyvoices.org/telehealth/youth/>

Ref: Got Transition, Connecticut Kids as Self Advocates (CT KASA), and Family Voices



Create Your Goal

- How will you prepare your first visit with your healthcare provider?
- Remember to think about:
 - self-advocacy
 - Independence
 - start somewhere



“I remember that I once feared so greatly these days that I’m living in now. But it’s not nearly as frightening when you have people walking alongside you and a good medical home with all the doctors in one place – and they talk to each other. That’s tremendous.”

