

GET READY, GET SET, GET HEALTHY

HEALTH CARE TRANSITION FOR
YOUTH WITH DISABILITIES



WHO AM I?

Professor at the University at Albany School of Public Health

AND

Parent of two boys, one with disabilities

AND

Wife of rare cancer survivor



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WHAT ARE WE GOING TO TALK ABOUT?

- What is health literacy? Why is it important for transition?
- How can you/your child be more health literate?
- What are key skills to learn?
- What are some helpful resources?
- Personal experience....



WHAT IS HEALTH LITERACY?

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Personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others

HEALTH LITERACY HELPS WITH...

- Taking medications correctly
- Knowing when to go to the doctor and what type of doctor to see
- Using your health insurance
- Understanding health information

QUESTIONS YOU MIGHT HAVE

- “How do I gather more information on my health?”
- What choices do I have in my treatment and healthcare?
- What charges will my health insurance cover for my doctor visits?
- Exactly what does my insurance company cover in my plan?
- What are my healthcare needs today and how will they change this year?
- What decisions should I make to improve my health?”

WHAT IS HEALTH LITERACY?



Organizational health literacy is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others

ORGANIZATIONS SHOULD...

- Make forms and information easy to read and understand
- Use clear signs and instructions to know where to go
- Help providers know how to communicate well with patients
- Ensure services and information are accessible
 - Ensure language access
 - Provide ASL or address other communication needs



**HOW CAN YOU BE
MORE HEALTH
LITERATE?**

TIPS

- Prepare for medical visits
- Bring someone with you if needed
- Ask questions and take notes
- Seek out a patient advocate or patient navigator if one is available



OBTAIN

- Find health information and services by asking others and using sources you trust.
- Ask your current provider for detailed information on medical diagnosis, treatment, and medication.
- Understand how to use and pay for health care.



COMMUNICATE

- Advocate for yourself by asking questions.
- Keep trusted family members involved in health care and health decisions.
- Be sure to tell providers about your communication needs (ASL, etc).



PROCESS

- Think about where you are getting your information and whether it is a source you should trust.
- Think about the health information you get and ask your health provider questions when you need to.
- Know what to do **AFTER** your appointment.
- Do not be afraid to ask questions!



UNDERSTAND

- Request information to be provided in simple, easily understood terms.
- Repeat back what you were told by your provider to make sure you understand.
- Ask for interpreter if needed.
 - You have a right to language access at no cost to you.
- Ask if there are materials or websites that might be helpful.

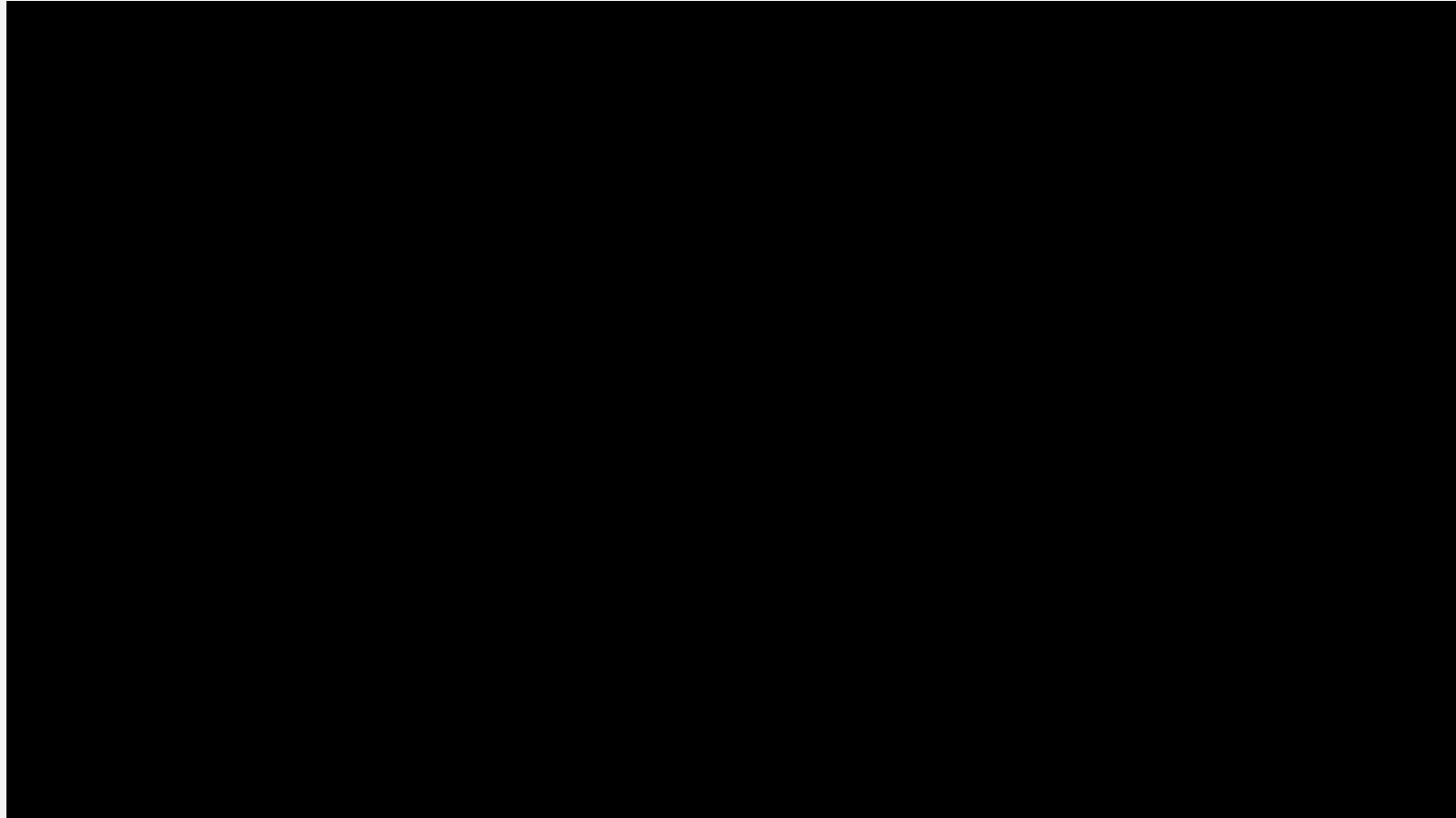


USE

- Take the information you learned to make informed decisions regarding your health and healthcare needs.



ASK ME 3



ASK ME 3

- You can ask questions when:
 - You are with a doctor, nurse, pharmacist, or other healthcare provider
 - You are getting ready for a procedure
 - You have been given a new prescription
 - Anytime!!!!
- Still not understanding?
 - No problem. Ask for clarification and don't worry about time or being ashamed as you are not alone. This is what providers are there for!



SOME QUESTIONS FOR PEOPLE WITH DISABILITIES

- What medical emergency(s) am I at risk of?
- What should I do and who should I call in case it happens?
- What other health care professionals should I be seeing?
- What resources and supports are available to me?
- When should I schedule my next visit?
- Who should I call if I have questions?





**HOW CAN YOU
GET YOUR CHILD
MORE INVOLVED?**

INCLUDE YOUR CHILD



- Prepare them for the visit:
 - Explain why you are going
 - Talk about what will be done
 - Show them videos
 - Bring toys or other things that can help distract them while waiting or provide comfort
- Make your child a part of the process:
 - Write down questions
 - Let them make choices (such as which arm to draw blood from)
 - Encourage them to speak directly to the provider



TRANSITION CHECKLISTS

HOW DO YOU KNOW WHEN YOUR CHILD IS READY?

HEALTH CARE TRANSITION QUIZ

Is your child ready to transition to adult health care?



Transitioning your child from a pediatrician to an adult doctor is a big step. Like going to college, getting a job, or going to live on their own, your child's transition to adult care takes independence, self-advocacy, and preparation.

CHECKLISTS

- These checklists can help you determine what skills you can work on with your child
- They can be useful in helping you know when your child is ready to be more independent
- You can also think about skills that may be specific to your own child and their healthcare needs
- Some have age recommendations
 - Consider your child's developmental age
 - What is appropriate for them?

Sample Transition Readiness Assessment for Parents/Caregivers

Please fill out this form to help us see what your child already knows about their health and the areas you think they want to learn more about. After you complete the form, you can ask your child to share their answers from their completed form, and you can compare them. Your answers may be different. Your child's doctor will help you work on steps to increase your child's health care skills.

Youth name

Parent/Caregiver name

Youth 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 your child 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 child's 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 CHILD'S HEALTH & HEALTH CARE *Please check the answer that best applies now.*

	NO	THEY WANT TO LEARN	YES
My child can explain their health needs to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to ask questions when they do not understand what their doctor says.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows their allergies to medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows our family medical history.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child talks to the doctor instead of me talking for them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child sees the doctor on their own during an appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows when and how to get emergency care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows where to get medical care when the doctor's office is closed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child carries important health information with them every day (e.g., insurance card, emergency contact information).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows that when they turn 18, they have full privacy in their health care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows at least one other person who will support them with their health needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to find their doctor's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to make and cancel their own doctor appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has a way to get to their doctor's office.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to get a summary of their medical information (e.g., online portal).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to fill out medical forms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to get a referral if they need it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows what health insurance they have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows what they need to do to keep their health insurance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child and I talk about the health care transition process.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MY CHILD'S MEDICINES *If your child does not take any medicines, please skip this section.*

My child knows their own medicines.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows when they need to take their medicines without someone telling them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child knows how to refill their medicines if and when they need to.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

WHICH OF THE SKILLS LISTED ABOVE DOES YOUR CHILD MOST WANT TO WORK ON?

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 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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'OWNING YOUR OWN HEALTH' CHECKLIST

- Add the names, phone #s and addresses of your care providers to your contacts in your cell phone. (Doctors, dentist, etc.)
- Get a copy of the insurance cards for all of my coverage- medical, dental, prescription (sometimes medical and prescription are on the same card).
 - Or take a picture of the cards and keep them in a folder in your cell phone's camera roll. (This item is for people old enough to go to medical appointments without a parent/guardian.)
- Add your emergency contacts and essential medical information to the Medical ID app in your cell phone.
- Schedule your own medical appointment to practice your skills.
- Check in at on your own at a medical appointment – talk to front desk and try answer all their questions without help from your parent/guardian.
- Fill out your own registration forms at a medical appointment.
- Memorize key events and dates in my personal and family medical history so that you can complete a health history form at a medical appointment (or add them to a notes page in your cell phone.)
- Describe my symptoms to a care provider with detail – when it started, how it feels, etc.
- Take note on paper or in my cell phone during a medical appointment so that I don't forget what was said after I leave.
- Ask my care provider for more details or to answer questions if they didn't give me enough information or the information wasn't clear



IEP GOALS

Sample Goals for the Health Care Transition Readiness Assessment for Students with an IEP

If a student has responded “No” or “I want to learn” to any of the items on the Health Care Transition Readiness Assessment (here), please use the following sample goals as a guide when creating goals in the IEP transition plan.

HCT READINESS ASSESSMENT ITEM	SAMPLE GOAL
MY HEALTH	
I can name my learning differences, disability, medical, or mental health diagnosis (e.g. diabetes, depression).	By the end of the IEP cycle, student will say aloud and/or spell out and/or enter into their cell phone the name(s) of their medical or mental health diagnosis(es), with ___% accuracy.
I can name 2-3 people who can help with my learning differences, disability, medical, or mental health needs in an emergency.	By the end of the IEP cycle, student will input their emergency contacts’ information on their phone and name and identify the contacts in their phone when asked, with ___% accuracy.
Before a doctor’s visit, I prepare questions to ask.	By the end of the IEP cycle, student will prepare and practice asking a few questions to their doctor before their next appointment, with ___% accuracy.
I know to ask the doctor’s office for accommodations, if needed.	By the end of the IEP cycle, student will identify which accommodations they need to request at a doctor’s office, with ___% accuracy.
I have a way to get to my doctor’s office.	By the end of the IEP cycle, student will plan transportation to their doctor’s office ahead of time, with ___% accuracy.
I know the name(s) of my doctor(s).	By the end of the IEP cycle, student will input their doctor’s contact information on their phone and name and identify their doctor in their phone when asked, with ___% accuracy.
I know or I can find my doctor’s phone number.	By the end of the IEP cycle, student will name and identify their doctor in their phone when asked, with ___% accuracy.
I know how to make my doctor’s appointments.	By the end of the IEP cycle, student will know how to call their doctor’s office or use an online portal to schedule a future appointment, with ___% accuracy.
I carry my health information with me every day (e.g. insurance card, emergency phone numbers).	By the end of the IEP cycle, student will keep their insurance card safely in their wallet/backpack or take a photo of it and store it on their phone and be able to retrieve the insurance card when asked, with ___% accuracy.
I know my food allergies.	By the end of the IEP cycle, student will be able to say aloud and/or spell out and/or enter into their cell phone the name(s) of the foods they are allergic to, with ___% accuracy.



Sample Goals for the Health Care Transition Readiness Assessment for Students with an IEP

<i>HCT READINESS ASSESSMENT ITEM</i>	<i>SAMPLE GOAL</i>
MY MEDICINES	
I know the name of the medicines I take.	By the end of the IEP cycle, student will say aloud and/or spell out and/or enter into their cell phone the name(s) of their medicines, with __% accuracy.
I know the amount of the medicines I take.	By the end of the IEP cycle, student will say aloud and/or spell out and/or enter into their cell phone the dosages of their medicines, with __% accuracy.
I know when I need to take my medicines.	By the end of the IEP cycle, student will identify at what time to take their medicines, with __ % accuracy.
I know how to read and follow the direction labels on my medicines.	By the end of the IEP cycle, student will identify, read, and follow the directions on their medicines, with __ % accuracy.
I know what to do when I run out of my medicines.	By the end of the IEP cycle, student will call their doctor's office or pharmacy to ask about medication refills, with __ % accuracy.
I know my medicine allergies.	By the end of the IEP cycle, student will say aloud and/or spell out and/or enter into their cell phone the name(s) of the medicines they are allergic to, with __% accuracy.



RESOURCES

RESOURCES

- Healthy Transitions NY
 - Checklist of skills for youth with developmental disabilities
 - Videos to learn skills
 - Lesson plans
 - <https://healthytransitionsny.org/category/scheduling-an-appointment/>
- National Parent Center on Transition and Employment
 - Several resources
 - <https://www.pacer.org/transition/learning-center/health/>
- Maryland: Care notebook
 - Provides an organized way of documenting health information
 - https://health.maryland.gov/phpa/genetics/docs/HCTL/Notebook_log_071017.pdf
- Columbus OH: CAP4Kids
 - Has some useful resources such as finding a doctor
 - <https://cap4kids.org/columbus/teen-resources/transition-to-adult-resources/>

AUTISM SPECIFIC RESOURCES

- AASPIRE healthcare toolkit
 - Checklists and worksheets
 - Autism Healthcare Accommodations Tool
 - <https://autismandhealth.org/?a=pt&p=main&theme=ltlc&size=small>
- Autistic Self Advocacy Network
 - Has useful tips and information
 - <https://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-healthcare-toolkit-final.pdf>

TECHNOLOGY

- Explore technologies to support your child
- Medminder
 - Electronic pill dispenser designed for seniors
- Apps
 - Medication reminders
 - Fitness/sleep, etc.
 - Health provider portals
 - Augmentative and Alternative Communication (AAC)
 - And more!





PERSONAL EXPERIENCE

CHECKING IN

- When my son was younger I started having him check himself in
- Go up to check in and given them his name

ASKING QUESTIONS

- At recent visits, we talked about what questions he might have
- I try to get him to come up with one question he will ask each time
- During his recent physical, the question he asked his pediatrician was “When do I have to switch to a different doctor”?
 - I had to remind him to ask 😊



COMING UP NEXT...

- Calling to make an appointment
- Learning about patient portals
- Showing him his medical records files
- Explaining how to get his medications
- Teaching him how to put the pills into his pill organizer



THANK YOU!