

TechOWL



Technology for Our Whole Lives



Communication First in Collaboration with ACES: **Accessing Better Communication for Deciding Together (ABCD)**



Institute on Disabilities

ACES: Talking with Doctors Who Gets to Decide?

October 6, 2020



Institute on Disabilities

Housekeeping

- Have mic turned off when not speaking
- Questions and comments can be typed in the chat
- There will be time at the end for more questions

Thing to Keep in Mind

- Respect the privacy of other participants
- Things that are shared here, stay here
- This is a safe and collaborative space
- You do NOT need to share if you are not comfortable
- You do NOT need to have your video on
- All communication is valued here (devices, mouthwords, typing, etc.) → use what you are comfortable with!



Why do you go to doctors, hospitals, clinics, etc.?

- Checkups
- Preventive care
- You feel sick or not yourself
- Managing difficulties with eating, moving, completing daily tasks, and talking
- Diagnosing and treating current or new medical problems

It's your body

It's your right

It's your responsibility



Institute on Disabilities

Why I Access Healthcare

- Video: <https://www.youtube.com/watch?v=CPIkrW5zYm8&feature=youtu.be>



How Are Decisions Made About Your Health?

Who decides:

- You?
- Your parents/family?
- The doctor?
- Other?

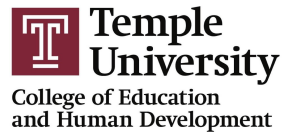


Who Makes Decisions About My Care

"The majority of my healthcare decisions are made by my parents — albeit, with my input. Most doctors do not look to me and fail to ask what I want in terms of medical care."

- AAC User

Poll: Who makes decisions about my care?



Institute on Disabilities

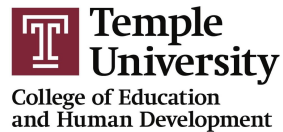
What is “Informed Consent?”

- When a patient and doctor talk about the risks, benefits, and options of a procedure or treatment using terms you understand
- You can ask the doctor questions to make sure you understand
- The patient makes a voluntary decision about what to do
- The conversation should include:
 - What the procedure or treatment is
 - Risks and benefits of it
 - Other options
 - Risks and benefits of other options
 - Review of your understanding

4 Tenets of Informed Consent



1. Do you understand what the doctor recommends and why?



Institute on Disabilities


2. Do you understand how the treatment could help and what could go wrong?



Institute on Disabilities

3. Do you understand what happens if you say **YES** to this care?

Do you understand what happens if you say **NO** to this care?



4. Do you get to ask questions and get answers in the way you understand best?

Can you get the information in plain language?

Why Informed Consent is Important

- Dr. Clarissa Kripke's video: https://www.youtube.com/watch?v=4YvJNK_rPig

Dr. Clarissa Kripke's Main Points: Barriers

- Communication can be hard
- Lack of information about disability
- Attitudes of health care providers
- Not enough time because of medical emergencies and doctors are busy

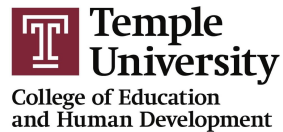
Dr. Clarissa Kripke's Main Points: Tips

- Educate yourself before you go
- Learn everything you can about yourself, your body, your health
- Tell doctors how you learn best - write it down
- Engage directly with your doctor - don't rely on your support person
- Make sure you get ALL information
- Ask for a second opinion if necessary (going to another doctor)
- Do your own research, ask family and friends, people who have gone through similar things
- Understand doctors are busy, prepare ahead of time
- Write questions down
- Bring someone with you to help listen and discuss later

Poll: What happens at your doctor's visit?



What Should Happen at a Doctor's Visit?



Institute on Disabilities

You Tell the Doctor...

- Why you are there
- What you want to learn
- Who you are
- How you communicate
- What is important to you about your health, life, and future

You and the Doctor

You have the chance to ask your doctor questions

You get to ask about your health and what steps you might take

Your doctor gives you information about your health and choices

You get to think about these choices and what they mean

You make decisions based on the information you have learned



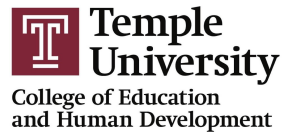
Takeaways

- You need to receive adequate information about the pros and cons of all treatment decisions
- What could happen if I choose treatment?
- What could happen if I do NOT choose treatment?

Why You Might NOT be Included in the Decision Making

- Perceptions of the person's ability to make their own decisions
- Misperceptions about communication abilities based on lack of knowledge of AAC
- Bias against someone with a complex body
 - Belief that disability = lack of ability to decide
- The doctor directs all communication towards the support person
- Emergency, life-threatening situation or if you are unconscious

What happens if you and the doctor disagree?



Institute on Disabilities

How I Navigate Doctors Visits

I am able to speak but it is often difficult for outsiders to understand me, you need to focus on what I am saying and not be distracted. When I have a lot to say it can become jumbled and you may only get bits of pieces and a lot can be lost in translation. I schedule most appointments, ask for prescription refills and message any questions or concerns I have to most of my doctors through My Penn Medicine portal. Most Penn doctors are great about communicating back and forth with me through the portal. In person at a doctor visit I bring my iPad and usually one of my parents is with me. I typically already have my questions/concerns typed out and usually printed since it is time consuming waiting for me to type. During the visit my parents sit back and allow me to answer but then will interpret what I have said to the doctor if he/she has difficulty understanding me.

- Caitlyn Connelly, 23

<https://www.youtube.com/watch?v=xqhpSWgH07w>



How I Navigate Doctors Visits: Example from Patient Portal

Dr. X

A few weeks ago, Dr. X's assistant changed the way my X is dosed. It's working well and seems to have an effect on my spasticity in the afternoons and evenings.

1. I think my pump dose needs to come down in the afternoons and at night. I usually stand in a special walker that I am buckled into to help make dinner and I've noticed that my legs are a little heavy, my neck and trunk are weak.
2. Also, having trouble independently, self catheterizing due to trunk weakness.
3. Transfers, if I wake up at night are difficult due to trunk instability.
4. My speech is more difficult to understand especially in the afternoons so, I use my device more often. This could be related to my baclofen dose but may also be due to not having my cochlear implants programmed in a while due to CV-19.
5. My right foot is turned in and this is making it difficult to use my AFO when standing. Is there anything that could be done?
6. Could X make the dose change to the pump or do I need to come in?

I've tried contacting your office to see if you need to see me in person but have received inconsistent responses. My last My Chart note to the scheduler wasn't responded to so, I kept our virtual appointment. I also called the office and was told someone would call me back but my call wasn't returned.

Taking Charge

- Your health, your rights, your responsibilities
- What are your rights?
- What accommodations could you request?
 - Communication assistant
 - Supported decision making
 - Other

Poll: What are your responsibilities?



Institute on Disabilities



Questions?

Comments?



Institute on Disabilities

How to Get Ready for Roundtable 1

- We will be having a conversation about our experiences with doctors
- To get ready
 - Think about your experiences
 - Prepare a story to share with the group (optional)

What Will We Do at Roundtable 1?

- Those who wish can share their stories
- Role playing some interactions with doctors
- Writing some introductions to use with doctors

For Roundtable 1

- Prepare a self-introduction - (optional)
- Have a story about an experience with a doctor (positive or negative) - optional
- Answer the following questions:
 - Should I have to demonstrate my competence to be involved in my care?
 - How do I get the doctor to listen and talk to me and not my communication partner?
 - What strategies have or haven't worked for me during my appointments?

Contact Information

Institute on Disabilities at Temple University
1755 N 13th Street
Student Center, Room 411S
Philadelphia, PA 19122

Tel: 215-204-1356 Fax: 215-204-6336

Email: IOD@temple.edu

Web: <https://www.temple.edu/instituteondisabilities/>



Institute on Disabilities

Thank You: Please Complete This Survey!

Presenters: TechOWL

Topic: ACES Talking with Doctors 1

[BIT.LY/PIAT_T1](https://bit.ly/piat_t1)

