

Building the Capacity for Advocacy and Self-Advocacy

Allysa Ware, PhD, MSW

Executive Director, Family Voices

Lead Transition Faculty, Children's National Medical Center's LEND Program



Center for
Transition to Adult Health Care
for Youth with Disabilities

Agenda

Goal: The audience will understand the importance of advocacy and self-advocacy for adolescents and young adults with special health care needs in successful health care transition

Objectives: The audience will be able to describe:

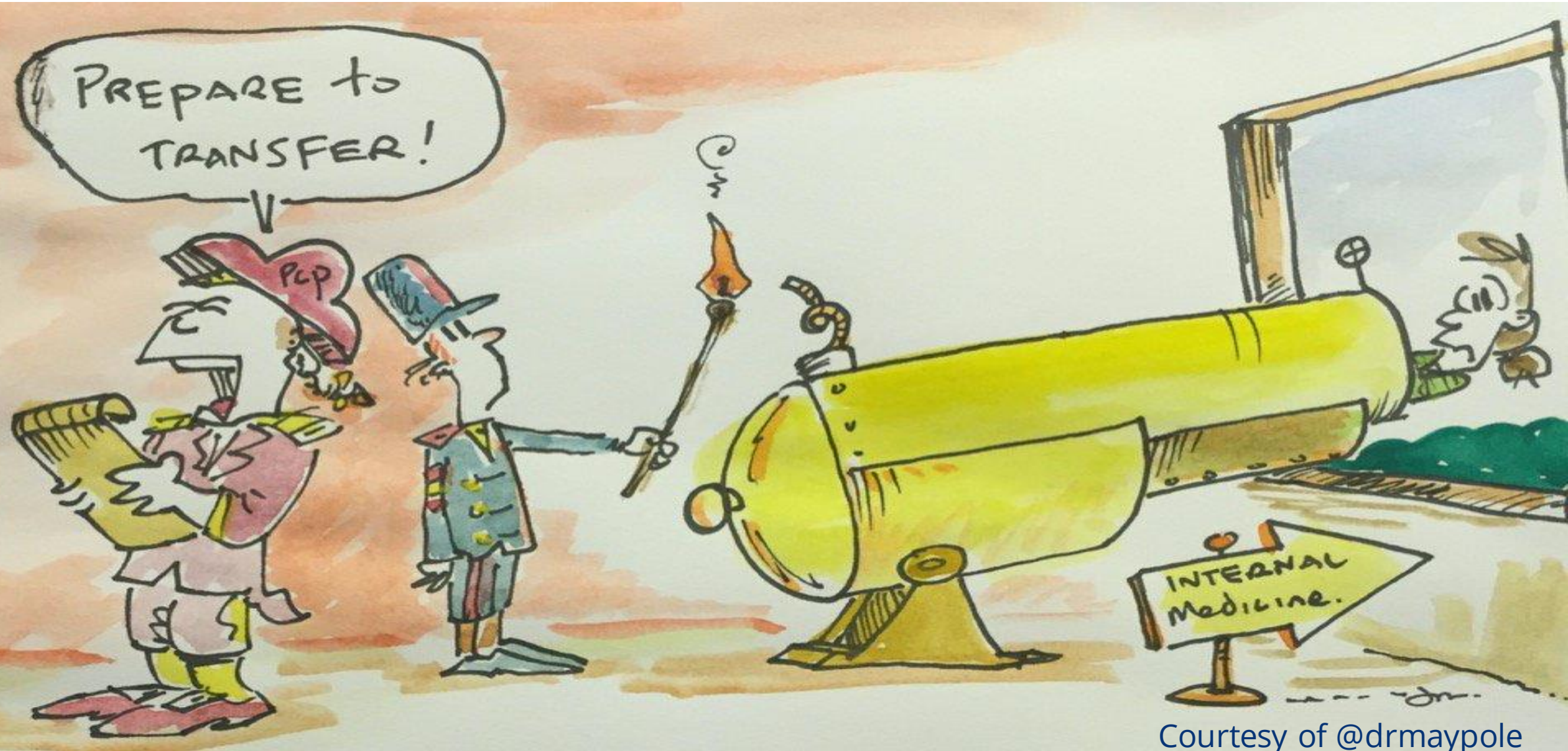
1. Self-advocacy and self-efficacy as learned behaviors
2. Improving knowledge of strategies to address bullying in adolescents and young adults with special health care needs

Health Care Transition



Health care transition is the process of moving from a child to an adult model of health care with or without a transfer to a new clinician.

Provider vs. Family Perspective on Transition



Transition Goals for Youth/Young Adults and Clinicians



- To improve the ability of youth and YAs to **manage their own health** and effectively use health services
- To have an **organized clinical process** in pediatric and adult practices to facilitate transition preparation, transfer of care, and integration into adult-centered care

Reaffirms that TRANSITION **≠** TRANSFER **or** PLANNING alone

TRANSITION = planning, transfer **and** integration into adult care

(Got Transition, 2014)

Advocacy is key to transition.

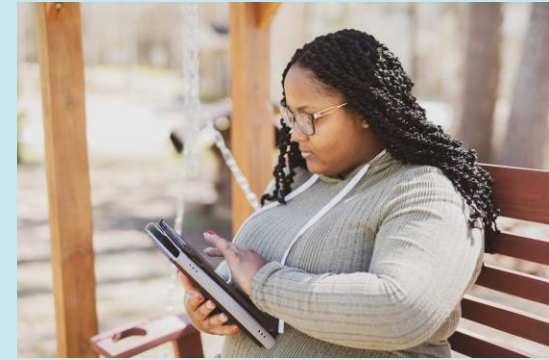


To advocate for their best life, youth must develop:

- self-advocacy **skills**
- an understanding of **disability awareness**
- an understanding of **disability rights**

ADVOCACY

Creating a vision for the future



Transition planning is all about figuring out:

- What **goals** the individual wants to accomplish in their life
- How to achieve those goals
- Based on the individual's:
 - Needs
 - Strengths
 - Preferences
 - Interests

Transition planning is also a way to learn more about the **options** they have after graduating, such as:

- Continuing education
- Learning professional skills
- Getting a job alongside people without disabilities
- Getting new support services
- Living independently
- Participating in the community

Critical skills for a successful transition



Self-Advocacy

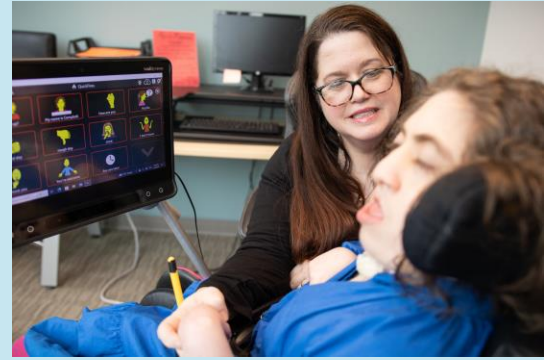
The ability to **communicate** your wants and needs effectively

Self-Efficacy

The **confidence** in your ability to be successful in specific situations and tasks



Why is self-advocacy important?



- Youth can make their own **choices**.
- Youth can set their own **goals**.
- Use their voice to get their **needs** met.
- What the youth **wants** may not happen if they don't speak up.
- **Change** requires a dedicated voice.

Strategies for self-advocacy



- You are the **expert** on you!
- Give **respect** to get respect.
- Go straight to the point
- **Ask** for help if you feel overwhelmed.
- Give yourself permission to make **mistakes**.

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**Teens and Young Adults with Disabilities:
Be Your Own Best Advocate**

As a teen or a young adult with a disability, you're probably used to adults in your life advocating for you. Your parents may have spoken out at Individualized Education Program (IEP) team meetings to help you get the services you needed at school. Your teachers might have made sure you got the support you needed to be successful in your classes. When you go out to eat with your family, someone usually talks to the server about your dietary restrictions, so you don't have to.

Becoming an adult and learning to be your own best advocate will make a big difference in your life. Speaking up for yourself will give you more control over making choices in your life and make it easier to stand up for your rights. Advocating for yourself will help people around you better understand what you think, what you want, and what you need.

Opportunities to advocate for yourself

You may need to advocate for yourself in many situations in your daily life. Practice helps! Here are some examples of times when it could be important to make your voice heard. For each situation, think about what you would do or say. You may want to role-play these situations with a family member or friend:

- A substitute teacher hands out a test. You have an accommodation to take your tests in a quiet room, but the substitute does not know this.
- Your bus arrives and someone you don't know offers to help you go up the steps. You would rather not have help, even if it takes you a few minutes longer to board the bus and take your seat.
- You have a reading tutor who works with you in the library every Thursday at 3:00 p.m. The tutor shows up late for the fourth week in a row.
- You rent an apartment with a good friend. He gets home from work earlier than you do every day. Lately, he's been opening your favorite magazines that come in the mail addressed to you before you get home, without asking you first.
- You're sick, so you ask your mom to take you to see your doctor. At the appointment, your doctor keeps asking your mom questions about your symptoms and how you're feeling instead of asking you.

Strategies to help you advocate for yourself

Advocating for yourself is a skill you will use throughout your whole life. Here are a few ideas you can use to help you build your advocacy skills.

1. **Remember YOU are the expert on YOU.** No one knows more about how your disability affects you. The one person who can use their voice to speak up for you better than anyone else is you. If someone assumes something about you that is incorrect, speak up and politely correct them.
2. **Give respect to get respect.** Show people the respect you expect them to show you. When you speak for yourself, talk to people the way you want them to talk to you.
3. **Go straight to the point.** Say only what you need to say. Information about your disability is private; you don't always have to tell people about your disability when you advocate for yourself. In many situations, you can just explain what you need, what you want, or what you think.

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Bullying and AYASHCN



- People with disabilities are **more likely** to be bullied.
- Bullying can take on three different forms:
 - **Verbal** bullying
 - **Social** bullying
 - **Physical** bullying

(SARTAC, n.d.)

Types of Bullying

(SARTAC, n.d., <https://selfadvocacyinfo.org/wp-content/uploads/2024/03/Bullying.pdf>)



Verbal bullying

- Making fun of someone
- Calling someone a mean name
- Saying unkind things about someone's body
- Saying they will hurt someone

Social bullying

- Not letting someone join in
- Telling others not to be friends with someone
- Spreading false stories or making someone feel embarrassed in front of others

Physical bullying

- Hitting, kicking, pinching, tripping, or pushing
- Taking or breaking someone's things
- Showing mean or unkind hand signs

Steps to address bullying

- Become an **advocate** or self-advocate.
- Develop a personal **action plan** against bullying.
- Involve an **adult** if you need support.



PACER's National Bullying Prevention Center.
Create a World Without Bullying | PACER.org/bullying

Student Action Plan Against Bullying

Designed for youth to complete with or without an adult

Bullying affects everyone and every student can play an important role in preventing bullying. That means YOU can take charge of what is happening around you! Use this plan to think through a difficult situation and take the person who bullies, this plan can help you think through potential responses and come up with next steps to help prevent the bullying.

What you can do.....

Become an advocate or self-advocate. An **advocate** helps others get what they need. A **self-advocate** communicates their own needs.

It's important to understand that being a self-advocate does not mean you need to take next steps on your own. Self-advocacy is about being a part of the process, expressing your opinion, and ensuring that you are comfortable with the action steps taken toward that solution.

How to use the Student Action Plan Against Bullying.....

1. Read through the examples on pages two and three of this document
2. Decide if you want to start this on your own or if you would like to involve an adult
Note: Even if you start this on your own, it's important to share with a trusted adult and provide them with information on the best way to support you. This is important because sometimes adults aren't aware that the bullying is happening, and many bullying situations won't get resolved until a caring adult is involved.
3. Complete the "My Personal Action Plan Against Bullying," on page four with your own experience as a target of bullying, a witness, or the person who is bullying
By completing this plan, you are taking action toward a solution.

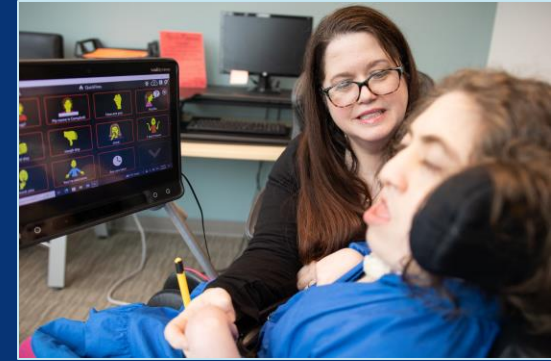
What's next?.....

- ✓ If you haven't shared your plan with an adult you trust, now is the time
- ✓ Let the adult know how important it is to have their help and support
- ✓ Talk through your ideas together
- ✓ Decide which steps to take and who will help
- ✓ Write down your notes in your action plan

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PACER.org/Bullying | PACERKidsAgainstBullying.org | PACERTeensAgainstBullying.org

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Additional resources for bullying



- SARTAC Bullying Resource - <https://selfadvocacyinfo.org/wp-content/uploads/2024/03/Bullying.pdf>
- PACER's Why your child needs you to become an advocate <https://www.pacer.org/parent/php/PHP-c226.pdf>



Strategies for Youth

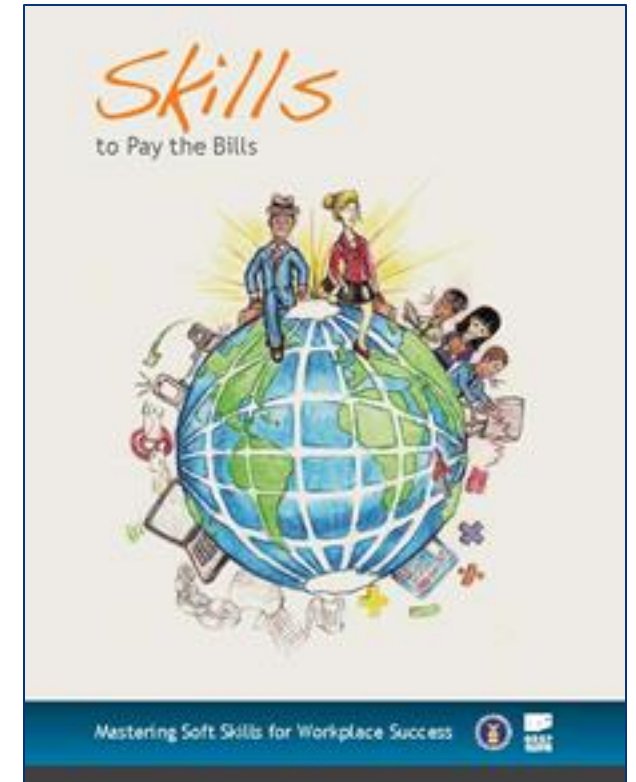
Help youth develop a self-advocacy plan by asking themselves questions such as:

- What are my interests and strengths?
- What do I want to learn or work on improving?
- What are my special concerns?
- What goals have I set for myself for the future?
- How do I explain my disability to others?
- What do supports do I need to reach my goals?
- Develop an IEP Owner's Manual
(<https://www.pacer.org/parent/php/PHP-a55.pdf>)

Strategies for Youth

Help youth develop the following “soft skills” for post-secondary success:

- Communication
- Enthusiasm and attitude
- Teamwork
- Networking
- Problem solving and critical thinking
- Professionalism



<https://www.dol.gov/agencies/odep/program-areas/individuals/youth/transition/soft-skills>

Questions and Discussion



Thank you!