EMPOWERING FAMILIES & INDIVIDUALS WITH DISABILITIES: PROMOTING SELF-ADVOCACY

ANNIE BAGHDAYAN, PH.D, BCBA-D, LBA-OK
UNIVERSITY OF OKLAHOMA
THE NATIONAL CENTER FOR DISABILITY EDUCATION & TRAINING
WHAT IS ADVOCACY?

• Advocacy: the act or process of supporting a cause or proposal; the act or process of advocating something… (Merriam Webster Dictionary)

• **Disability Advocacy** ensures the human and legal rights of people with disabilities are promoted and protected so that people with disabilities can fully participate in the community.

• An advocate in the disability sector works to ensure the rights of people with disabilities are upheld and supports people with disabilities to make decisions affecting their lives.
TYPES OF ADVOCACY

• **Individual advocacy**
  - Individual advocacy is when a person with a disability is assisted by an advocate who takes action on their behalf and in their best interests. This can be:
    • Providing information and advice so that the person with a disability can advocate for themselves.
    • Supporting the person with a disability to take action on any matter related to discrimination.
    • This type of advocacy can be undertaken by a relative, friend or professional advocacy service.

• **Self Advocacy**
  - A self-advocate is someone with a disability who is able to speak up and represent themselves.
  - There are a number of community based groups providing support and training to enable and empower people with disabilities to speak up for themselves.
PARENT ADVOCACY

• A parent of a child with disability is responsible to assure the child is receiving the appropriate services.

1. It is important to educate yourself about disabilities and in particular the child’s disability.

2. Collaborate with the child’s teachers and school forming a good working partnership.

3. Understand the parent’s rights under the law, which will be a key to the success.
PARENTS CAN & SHOULD

• Ask for regular evaluation of growth in retrospect to the year’s goal
• Lobby for adequate resources and staff qualifications
• Support sympathetic staff
• Be a team leader
• Notice what’s being done right
• Be firm but optimistic
• Recognize professional knowledge
• Maintain a provincial/territorial presence

• Resist quick fixes
• Do not overburden your child
• Expect change, but not miracles
• Demand a few focused goals rather than a dispersed “overhaul”
• Don’t wait, but don’t panic
• Ensure everyone’s role is clear, and that someone acts as case manager/team leader
• Be realistic and reasonable in your quest for growth.
FROM PARENT ADVOCATE TO SELF-ADVOCATE

- For most of the child’s life, parents have probably been advocating for—making decisions for him or her.
- As individuals with disabilities age, they will need to advocate for themselves to the best of their ability. Helping youths with disabilities to develop a sense of self will aid in the transition process and will develop a skill that will benefit them throughout their lives.
FIRST STEP: DISCLOSURE

- It is important to note that part of self-advocacy may involve disclosure.
- It is important that an individual with disability be told that he or she has a disability (e.g. autism).
- Share his/her strengths such as a very good memory, tremendous knowledge about a specific topic, or strong skills in a particular subject at school.
- Let the individual know the challenges they face because of the disability, and
- List some of the things that may be difficult for the individual.
There are many laws to protect the rights of people with disabilities. Three of the most important for youths are:

- **The Individuals with Disabilities Education Improvement Act (IDEA)** says that each student who receives special education must have an IEP.

- **Section 504 of the Rehabilitation Act** says that it is against the law to discriminate against people with disabilities in programs that receive federal funding.

- **The Americans with Disabilities Act (ADA)** says that it is against the law to discriminate against people with disabilities in jobs, transportation, public places, communications, and government activities.
DEVELOPING SELF ADVOCACY SKILLS

• “Self-advocacy is a life-long endeavor, and the teen years offer a particularly fruitful moment for cultivating self-awareness, self-monitoring, and deeper exploration of what it means to be an individual with a disability.

• Too often, we raise our kids, treat our patients, and educate our students without ever speaking to them directly about their disability. Perhaps we’ve made assumptions or even harbor fears that they aren’t capable of self-reflection. Yet if we deny kids this very important aspect of identity, we limit their ability to become the successful adults we want them to be.

• As with any academic subject, teaching self-advocacy takes training as well as knowledge of and respect for the disability movement. Parents can model self-advocacy at home, teachers can offer curricula in school, and most importantly, peers can offer strategies for good living and share mutual experiences.” Valerie Paradiz
SELF-ADVOCACY

• It is never too early to learn to self advocate.
• Teaching students advocacy skills starting in middle school will make it easier as they grow older and become more independent.
• It is important for the students to understand their disabilities and the strategies that can help them at school (books on tape, typing notes, quiet room, etc.)
WHAT IS SELF-ADVOCACY?

- Understanding your strengths and needs,
- Identifying your personal goals,
- Speaking up for yourself,
- Asking for what you need,
- Negotiating for yourself (working with others to reach an agreement that will meet your needs),
- Knowing your rights and responsibilities,
- Using the resources that are available to you,
- Being able to explain your disability either by the use of written words, pictures or gestures.
WHEN TO TEACH SELF-ADVOCACY?

- Middle school is an ideal time to start self-advocacy techniques.
- By starting in middle school the student will have an easier transition to high school when the workload gets more intense.
HOW CAN WE TEACH THIS AT SCHOOL?

• Kohler, 1996 published the Taxonomy for Transition Programming.

• The Taxonomy includes five essential areas:
  a) student-focused planning,
  b) student development,
  c) family involvement,
  d) program structure, and
  e) interagency collaboration.
HOW TO TEACH SELF-ADVOCACY SKILLS?

• There are many opportunities for teaching self-advocacy skills throughout the day.
• It starts with making choices – choices for meals, choices for leisure activities, even choices for which chores to do around the house.
• You may want to consider the ways listed in the following slide to further promote an individual’s preferences as well as his or her ability to be more independent.
HOW TO TEACH SELF-ADVOCACY SKILLS?

- **Timing of events** – choosing when to get up, when to go to bed at night, when to get a haircut or when to eat dinner.
- **Personal choices** – choosing what clothes to wear, what shampoo to buy or which cereal to eat.
- **Methods of training** – choosing where learning will occur or who will provide the support. ex: do you want to work at home or at the library?
- **Staff evaluations** – through interviews with individuals who are supported by staff or through observations of staff relationships with individuals.
- **Hiring of staff** – asking individuals to serve on hiring committees.
When teaching your adolescent about self-advocacy you may want to consider the following five decision making steps:

1. What is the decision you need to make?
2. What decisions could you make?
3. Evaluate each choice. What are the pluses and minuses of each choice?
4. Pick the best choice. Describe which choice you think is best for you.
5. Evaluate. Did you make the best choice for you?

As adapted from The Wisconsin Department of Public Instructions handbook, Opening Doors, (www.dpi.state.wi.us/sped/transition.html)
WHAT DOES ADVOCACY LOOK LIKE?

• David is a 16 year old young man with significant cognitive deficiencies. He receives special education services through his local school district. David participates in all of his annual review meetings. He assists in determining his course selection, and tells the committee what kinds of supports he feels he needs or can benefit from. He is included in the discussion of IEP goals and is held accountable for his role in trying to meet those goals.

• Matt is a 14 year old with cerebral palsy. He uses a wheelchair. His English teacher unwittingly uses demeaning language that Matt finds offensive, like “handicapped” or “non-verbal.” Matt writes his teacher a polite letter explaining his feelings and includes a “people first language” brochure.
BOOK RESOURCES

• Larry Silver’s book The Misunderstood Child,
• From Emotions to Advocacy and All About IEP’s and by Wrights Law
• Guiding Your Teenager with Special Needs Through the Transition from School to Adult Life: Tools for Parents by Mary Korpi
• Rick Lavoie’s Fat city DVD
WEB RESOURCES

- **www.youthhood.org** – Youthhood is a not-to-be-missed Web site for youths. This fun and engaging site will remind students that they are not alone as they explore community and build a future. It’s chockfull of great resources and information.

- **www.fvkasa.org** – Kids As Self-Advocates (KASA) is a national, grassroots network of youths with special needs and their friends. This group works to spread helpful, positive information among their peers about living with special health care needs, health care transition issues, education, jobs, and other topics. (Available in Spanish)
WEB RESOURCES

- The National Consortium on Leadership and Disability for Youth (NCLD-Youth) is a youth-led resource, information, and training center for youth and emerging leaders with developmental disabilities. NCLD is housed at the Institute for Educational Leadership. It is funded by the Administration on Developmental Disabilities.
WEB RESOURCES

  - This government-sponsored site encourages visitors to start exploring career options and offers information about employment trends and ‘hot’ jobs.

• [www.self-advocate.org/](http://www.self-advocate.org/)
  - Advocating Change Together (ACT) is a grassroots disability rights organization run by and for people with developmental and other disabilities.
IN SUMMARY

• Self-determination/self-advocacy refers to “the ability to make choices, solve problems, set goals, evaluate options, take initiative to reach one’s goals, and accept consequences of one’s actions” (Rowe et al., 2013, p. 8).

• Related to these essential components, teachers must be prepared to teach self-advocacy skills, goal-setting skills, choice-making skills, and problem-solving skills.
“We believe that people with disabilities should be treated as equals. That means that people should be given the same decisions, choices, rights, responsibilities and chances to speak up to empower themselves as well as to make new friendships and renew old friendships just like everyone else. They should also be able to learn from their mistakes like everyone else.” Self Advocates Being Empowered
REFERENCES


Thank you!
CONTACT US

Annie Baghdyan, PhD, BCBA-D, LBA
abaghda1@ou.edu
The National Center for Disability Education & Training
http://ncdet.ou.edu/
University of Oklahoma
3200 Marshall Ave.
Norman, OK 73072