

Supporting Autistic Self-Advocacy in Middle & High School: Information for Caregivers



WHAT IS SELF-ADVOCACY?

Self-advocacy means knowing, understanding, and communicating one's own strengths, challenges, needs, and rights, and making decisions that help pursue one's own goals in life.

The self-advocacy movement began in the 1960s and is related to the broader civil rights movement. To learn more about the history of self-advocacy and disability rights, visit:

- ❑ [Parallels in Time: A History of Developmental Disabilities](#) by the Minnesota Department of Administration Council on Developmental Disabilities and information,
- ❑ the [Self Advocacy Resource and Technical Assistance Center](#), and
- ❑ [Autistic Self Advocacy Network](#) (ASAN)'s definition of self-advocacy and "Nothing About Us Without Us" movement.

WHY SUPPORT SELF-ADVOCACY?

Autistic and non-autistic people live together in a world where we manage complex relationships, show different amounts of social interest, and advocate for the things we need. Both autistic and non-autistic individuals can learn about other people's experiences and communicate about their own in order to live, work, play, and interact together in meaningful ways. Autistic people may benefit from specific teaching and support related to self-advocacy skills.

"For me, one of the most critical aspects of self-advocacy is to overcome misconceptions, misunderstandings, and to help educate those in the neuromajority (NM) who may otherwise misinterpret our struggles and gaps in understanding NM ways of thinking/communicating... To help establish effective two-way communication by sharing how we think/use language and encouraging others to be more direct/blunt with their own language (i.e., in a manner we can understand). Also, hopefully, to build some patience/understanding into the whole process, in both directions."

~Dave Caudel, TRIAD Advisory Committee Member

Self-advocacy skills allow people to live **self-determined lives**. This means they set their own goals and take steps toward those goals. Self-determination is a set of attitudes and abilities that allow a person to be guided by their own personal goals so they can live more fulfilling lives.^{1,2}

Self-advocacy and self-determination are related to outcomes including:³⁻⁷

SCHOOL OUTCOMES

- Higher grades
- Increased access to academic accommodations

LONG-TERM OUTCOMES

- Independent living
- More positive employment
- Community inclusion opportunities and experiences
- Quality of life
- Life satisfaction & happiness

The development of self-advocacy and self-determination skills can and should be addressed from a young age!

SELF-ADVOCACY SKILLS



Self-awareness and self-knowledge. Self-awareness is “the ability to accurately recognize one’s emotions, thoughts, and values and their influence on behavior.”⁸ This includes recognizing one’s own strengths, challenges, needs, preferences, and boundaries.



Self-regulation is the process of monitoring one’s own actions.¹ It involves self-observation and coping, as well as managing stress, impulses, and personal motivation.⁸



Decision making is the skill of choosing between all available options and evaluating the consequences of each option.¹ This includes **choice making**, or choosing between two available options. Decision making skills involve considering “ethical standards, safety concerns, social norms” and “the wellbeing of self and others.”⁸



Problem solving is a skill used when a solution is not readily known. Decision making and choice making are part of process.¹ Problem solving also includes identifying possible solutions, evaluating the outcomes of each solution, and knowing who, when, and how to ask for help. Skills for identifying and solving problems related to communication and relationships may be especially important to address for autistic individuals.



Goal setting and attainment is the skill of determining how you are going to accomplish what you want, including setting the goal, making a plan to achieve the goal, and measuring success.¹

STRATEGIES FOR SUPPORTING SELF-ADVOCACY IN MIDDLE & HIGH SCHOOL

- ❑ Help your teen identify what he or she does and does not like, thinking about activities, situations, and ways of interacting with the world. You can observe and comment on their behavior. You can also ask them questions about their preferences. For example, “You looked like you were really enjoying helping Mom with dinner. What’s your favorite part about cooking?” See the *Self-Awareness for Self-Advocacy* resource for strategies to teach and support self-awareness.
- ❑ Involve your teen in choice-making and decision-making within your home. For example, making decisions about weekend activities, whether to complete chores in the morning or afternoon, or what to buy during shopping trips.
- ❑ Teach your teen ways to communicate their preferences and needs, including teaching ways to ask for help, ask for a break, and say “no” to things they do not want. Help them communicate in ways that are more comfortable for them. This might mean teaching words or sentences, teaching gestures, or using visual supports, such as visual supports to ask for help or to say no.
- ❑ Model, or demonstrate, self-advocacy skills throughout your day. For example, you can talk about your likes and dislikes, ways that you ask for help, and ways you manage your emotions when needed (e.g., “It is really loud in this restaurant! I think I’d rather get our food to go tonight.” “I’m not sure what these directions mean. I’m going to call tech support for help.” “I feel so frustrated with this traffic. I need to take some deep breaths to help me calm down, then let’s put on some different music.”)
- ❑ Include your teen in Individualized Education Program (IEP) meetings. Over time, help them practice roles of observer, notetaker, question-asker (with planned questions), spontaneous speaker, choice-maker, or decision-maker.

For more information about self-advocacy, including additional resources for teaching and supporting self-advocacy skills, please visit: triad.vumc.org/autism-mental-health

The Tennessee Center for Decision-Making Supports is a website designed to help individuals with disabilities and their families find resources related to the decision-making process. For more information, please visit: www.tndecisionmaking.org

REFERENCES

- [1] Wehmeyer, M. L. (1996). *Self-determination in youth with severe cognitive disabilities: From theory to practice*. In L. Powers, G.H.S. Singer, & J. Sowers (Eds.), *On the road to autonomy: Promoting self-competence in children and youth with disabilities* (pp. 115-133). Baltimore: Paul H. Brookes Publishing Co.
- [2] Tennessee Department of Education. (2018). *Special Education Framework*. Retrieved 10 Oct 2022. tn.gov/content/dam/tn/education/special-education/framework/sped_framework.pdf
- [3] National Center for Learning Disabilities, Inc. (2018). *Agents of their own success: Self-advocacy skills and self-determination for students with disabilities in the era of personalized learning*. Retrieved 10 Oct 2022. ncl.org/wp-content/uploads/2018/03/Agents-of-Their-Own-Success_Final.pdf
- [4] Nota, L., Soresi, S., Ferrari, L., & Wehmeyer, M. L. (2011). A multivariate analysis of the self-determination of adolescents. *Journal of Happiness Studies*, 12(2), 245-266.
- [5] Wehman, P. (Ed.). (2013). *Life beyond the classroom: Transition strategies for young people with disabilities* (5th ed.). Baltimore: Brooks Publishing.
- [6] Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination. *Education and training in developmental disabilities*, 131-144.
- [7] McDonald, T. M., Taylor, J. L., Loring, W. A., Chen, I., & Malow, B. A. (2020). *Setting and Pursuing Self-Determined Goals* [Toolkit]. Vanderbilt Kennedy Center. 1-24.
- [8] Tennessee Department of Education (2017). *K-12 Social and Personal Competencies Resource Guide*. Retrieved 10 Oct 2022. tn.gov/content/dam/tn/education/safety/safe_sch/SPC_Resource_Guide.pdf