



AHA/AS/PDD

*Advocates for Individuals with  
High Functioning Autism  
Asperger's Syndrome and  
other Pervasive Developmental Disorders*

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[www.aha-as-pdd.org](http://www.aha-as-pdd.org)

## HELPING YOUR CHILD TO HELP HIM/HER SELF:

### Beginning Self - Advocacy

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Self-advocacy is realizing what one needs in order to maximize functioning in life and knowing how to arrange the environment or obtain accommodations to do so. Or put another way, it is being literate about one's own needs.

The road to self-advocacy includes discussions of disclosure, special interests, learning styles, learning accommodations, and even relationships. One place to teach these skills is through involving students in the development of their own Individualized Education Plan (IEP) the moment it is known that a person is on the autism spectrum.

#### Advocacy in Education as Training for Advocacy in Life

Given that the public schools are charged with enabling the nation's youth to lead fulfilling and productive lives, it only makes sense to include self-advocacy as part of that education for all students with disabilities. Including the student in the development of the IEP is a great way to accomplish this goal.

As much as possible, students should be involved in developing and leading their own IEP process as soon as possible. As mentioned in *Student-Led IEPs* (McGahee, Mason, Wallace, & Jones, 2001), given the great variance of student ability, there is a wide range of options. Some students may just be able to state or read part of their plan for the future to the IEP team, others may go on to explain their disability, describe the need for accommodations, share their strengths and challenges (present levels of performance), and talk about plans for the future.

The eventual goal is a student-led IEP meeting (under the watchful eyes of the IEP team). Dealing with the paradigm shift from being advocated for through the IEP to having to advocate for oneself after high school requires much long-term work. Starting the process of teaching self-advocacy ideally could begin before age 14 when transition planning for life after high school is mandated into the Individual Education Plan (IEP).

Providing students with a well-developed sense of self-advocacy through the process should be an integral part of education. Doing so is vital for gaining a greater understanding of how to obtain the required accommodations upon entering the community, in higher education, employment, and relationships during the late adolescence and adulthood years.

#### Ramifications of not Learning Self-Advocacy Skills

The ramifications from failing to acquire sufficient self-advocacy skills can be very debilitating. For example, at the higher education level, young adults in this unfortunate position may feel that special education is "all done" and want to "be just like everyone else." They enter college unaware of their needs and/or refuse to meet with the student support office. However, since variances in learning styles remain with the person, soon difficulties in coursework mount, and then the student may be at a loss on how to obtain the needed assistance. After high school, the onus of obtaining needed accommodations lies with the person themselves. For example, in higher education the student must initiate the process of acquiring accommodations by finding the appropriate office, making the disclosure, preparing the documentation, working with instructors, etc.

#### Conclusion

Many young adults on the spectrum are forced to learn the realities of self-advocacy after high schools and entering the community, workforce, or higher education. Proper preparation through the use of active involvement in the IEP process can help smooth the way for those on the autism spectrum to lead fulfilling and productive lives to greater potential.

Student resources for learning about their own IEPs

- *A Student's Guide to the IEP* (McGahee-Kovac, 2002), and the accompanying
- Technical Assistance Guide *Helping Students Develop Their Own IEP* (NICHCY, 2002).

Both are available at [www.nichcy.org/pubs/stuguide/st1.htm](http://www.nichcy.org/pubs/stuguide/st1.htm)

Teacher resources on developing self-initiated IEPs

- *Student-Led IEPs* (McGahee, Mason, Wallace, & Jones, 2001)

Available at <http://www.cec.sped.org/bk/catalog2/iep.html>

Teacher resources on developing self-initiated IEPs

- Teacher resource for transition planning self - assessment

Available at <http://www.vesid.nysed.gov/specialed/transition/t4trans.htm>