

Essential Self-Advocacy and Transition

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As young adults with autism leave the shelter of the family home and educational entitlements and transition into adulthood, self-advocacy is indispensable. There have been many definitions of self-advocacy, and although they may vary in nuance and scope, self-advocacy generally refers to the ability to effectively communicate one's wants and needs.¹ This is clearly vital for all individuals with disabilities, and although there are limited studies on the tangible outcomes of self-advocacy, we have already seen positive effects on self-concept, leadership ability, sense of belonging, and impact on community.^{2,3} Furthermore, self-advocacy is interdependent with self-determination, the ability to set and pursue one's goals.³ Wehmeyer and Palmer⁴ found that higher self-determination skills during the transition period lead to better outcomes in multiple facets of adult life, such as employment and financial independence.

In addition to improved outcomes, supporting people with autism in developing self-advocacy ability opens doors to learning more accurate information about their needs and aspirations. Moreover, as the ability to identify, communicate, and autonomously address everyday needs and long-term goals increases, deferring to others (who only can attempt to interpret them) diminishes. In this way, self-advocacy requires that young people with autism develop awareness of their needs, preferences, interests, and rights and build competence in implementing strategies to attain them. Learning self-advocacy skills increases the possibility that they will communicate effectively with others, and in turn, positively affect interpersonal relationships. People with autism also may need to disclose something about themselves (their diagnosis or a request for an accommodation), which may enable others to more deeply understand them, perhaps with increased empathy.²

Self-advocacy and transition planning programs are available for the general disability population, and there is a small body of literature regarding their effectiveness in positively impacting measures of self-determination,⁵ improved self-advocacy, and decision-making.⁶ However, a vital need for self-advocacy curricula remains, specifically for young people with autism in transition

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Dr. Paradiz provided oversight to the design of the data collection instrument, drafted, reviewed, and revised the manuscript; Mr. Nelson gathered data, drafted, reviewed, and revised the manuscript; Ms. Kelso designed the data collection instrument, drafted, reviewed, and revised the manuscript; Mr. Earl designed the data collection instrument, gathered data, and reviewed, and revised the manuscript; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

DOI: <https://doi.org/10.1542/peds.2016-4300P>

Accepted for publication Sep 26, 2017

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

FUNDING: No external funding.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

TABLE 1 Components of Self-Advocacy Curricula

Program	Autism Specific	Knowledge of Self: Diagnosis and Needs	Knowledge of Self: Interests and Skills	Knowledge of Rights	Identification of Supporting Individuals or Organization	Communication	Leadership Skills	Self-Advocacy for Reasonable Accommodations	Goal-Setting	IEP Participation	Transition Planning
The Integrated Self-Advocacy ISA Curriculum for Self-Advocates Autism and Learning Differences ME! Lessons for Teaching Self-Awareness & Self-Advocacy Whose Future is it Anyway? Student-Directed Transition Planning	Yes	Yes	Yes	Yes	Yes	Yes	—	Yes	Yes	Yes	Yes
	Yes	Yes	—	Yes	Yes	Yes	Yes	—	—	—	—
	Yes	Yes	—	—	Yes	Yes	—	Yes	Yes	Yes	Yes
	—	Yes	—	Yes	—	Yes	—	Yes	Yes	Yes	Yes

IEP: individualized education program; —, not applicable.

to adulthood. In addition, studies of such curricula to measure outcomes and to establish standards of practice in instruction are virtually nonexistent.

Curricula we know of are the *Integrated Self-Advocacy ISA Curriculum: A Program for Emerging Self-Advocates with Autism Spectrum Disorder and Other Conditions*,⁷ which targets transition-aged individuals and emphasizes self-awareness of their particular expression and experience of autism, as well as individual agency for current and future advocacy; *A Curriculum for Self-Advocates*,⁸ which specifically teaches civil rights and collective self-advocacy; and *Autism and Learning Differences: An Active Learning Teaching Toolkit*,⁹ intended to help professionals “impart essential life skills,” including self-advocacy.

In Table 1, we compare the components of these 3 curricula alongside 3 other curricula designed for all individuals with disabilities.^{10–12} Worth mentioning is that, as most of the curricula focus on future planning, we take special note of those that teach students to advocate in their current environment. For individuals with autism, this usually means advocating for sensory and social needs.

Strong self-advocacy programs for individuals with disabilities are built on several key components. An individual’s development of self-determination is paramount, with an emphasis on communicating, acting, and decision-making. Opportunities to share views, to be listened to, and to make choices should be ample, and participants should be given freedom to make mistakes.³ Self-awareness and self-knowledge¹ are critical skills needed in virtually every aspect of self-advocacy. Individuals must know themselves well enough to sense when agitation or discomfort is occurring, when life events arise that do not match their goals and desires, and how to make and implement

an advocacy plan based on this self-awareness. Additionally, it is crucial that individuals understand the laws and entitlements impacting their quality of life.^{7,13,14} For young adults in transition, this often means being able to understand the shift from programs affecting their educational entitlements to legislation impacting the lives of adults. Communication skills are also vital. A person is only a self-advocate insofar as he or she is able to effectively communicate his or her own needs and rights.¹ These skills should celebrate and be accessible for the diverse range of communication strategies that individuals on the autism spectrum use.¹⁵ Although leadership is not a vital component of self-advocacy,¹⁶ it is still important to understand system dynamics and how to organize like-minded people to redress shared issues.^{1,13}

For individuals with autism especially, learning skills to increase awareness of environmental triggers, cues, and situations that require self-advocacy decisions are essential.^{7,17} For example, individuals can work to understand how their own physiology and sensory experience interface with a given environment and then develop a strategy to improve their participation within that setting. Social awareness is another core component of self-advocacy development.^{7,17} For many individuals on the autism spectrum, addressing social challenges and differences, such as interpreting nonverbal cues, managing anxiety, and navigating workplace interactions, will be a high-frequency need that requires self-advocacy strategies. Instruction aimed at improving ability should also address self-regulation plans and strategies.¹⁷ Such plans should be developed out of the interplay between a person's self-awareness and social-environmental understanding.

Self-awareness and self-advocacy skills are vitally important in the

Name: _____ Date: _____ Scan Location: _____				
ISA SENSORY SCAN™ Text & Visuals-Auditory				
 <p>Pay attention to the sound in this environment. What do you hear? Is it ok or not ok (distracting or annoying)?</p>				
	 <p>Others talking when teacher is speaking</p>	<p>OK</p> 	<p>NOT OK</p> 	Notes:
	 <p>Too many people talking at the same time</p>	<p>OK</p> 	<p>NOT OK</p> 	Notes:

FIGURE 1
ISA sensory scan text and visuals–auditory.

pediatric–medical setting. Individuals with autism may struggle with pinpointing areas of physical discomfort or other symptoms of illness and may experience significant challenges with conveying and disclosing their health information to others. Curricula exist to help young people with autism learn more about their bodies and sensory systems and how to relay what they are experiencing to others.^{7,17} Efforts spent on helping youth with autism understand and share what they experience physiologically will have many intersecting benefits, including expressing medical needs in home and clinical settings and greater self-directed medical care as adults with autism. Self-advocacy programs and learning experiences are implemented with the individual or group learning new skills. Creating an environment in

which communication differences are embraced and supported is necessary.^{3,15} Communication methods may vary, and programming must be fluid enough to support them. In similar spirit, learning tools must be flexible enough to meet individual needs.^{3,7,18} For example, some learners may require visuals to support text-based materials, whereas others may need only visuals (see Figs 1 and 2). An often overlooked program element, participants also may use self-advocacy to design the learning setting by advocating for environmental setup, curricular items, meeting structure, ground rules, and other components. The program facilitator must take care to only assist, to give control to participants, and to fade or change their roles as they gain skills and independence.^{3,14}

Name:		Date:		Scan Location:	
ISA SENSORY SCAN™ Visuals-Visual					
					
				Notes:	

FIGURE 2
ISA sensory scan visuals–visual.

In Figs 1 and 2, we show two integrated self-advocacy (ISA) sensory scans,¹⁹ modified for those who require text and visuals or visuals only when conducting environmental scans.

When ready, learners find ample opportunities to help them move from self-advocacy practice to implementation. Transition meetings from secondary education to young adulthood,²⁰ for example, provide fertile ground. Practice can also occur in clubs or advocacy groups²¹ and in solo sessions with mentors or allies.¹⁴ Meetings or experiences relevant to employment, housing, medical care, and postsecondary education²¹ will likely require self-advocacy, including the building of community networks and connections.¹⁴ More specifically, the transition into young adulthood necessitates a shift in medical care from pediatric to adult care providers. The combination of focused, medically specific, self-advocacy skill building from an early age and proactive transition planning, with the coordinated transition help of pediatric and adult care providers

themselves,²² can support adults with autism in developing and maintaining agency in their medical services and accommodations.

The need for self-advocacy in transition and beyond is growing. In the next decade, 500 000 students with autism are expected to exit high school into young adult life.²² Greater efforts must be made to support communication and learning differences in their self-advocacy development to ensure their diversity of needs met.^{15,21} Also, effective communication methods, including visual-based strategies, prerecorded requests, and video or technology supports^{3,7,18,19,23–25} will help increase access to self-advocacy opportunities. Learning self-advocacy skills can start far before the time of transitioning,¹ but engaging in self-advocacy will be important throughout each student's life. Ensuring that students with autism not only understand their differences, but also have the liberty and power to act on their needs and rights, is one of the most essential lessons

we can impart to them before they transition to adulthood.

ABBREVIATION

ISA: integrated self-advocacy

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Pediatrics 2018;141;S373

DOI: 10.1542/peds.2016-4300P

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