

# The Secrets of Self-advocacy

## *How to Make Sure You Take Care of You* **BY STEPHEN M. SHORE**



YOUR 13-YEAR-OLD SON, "SAM," WHO HAS AUTISM AND IS IN AN INCLUSIVE CLASSROOM, HAS BEEN COMING HOME FROM SCHOOL CRYING FOR THE PAST WEEK. THROUGH DISCUSSIONS WITH SAM AND CLASSROOM OBSERVATION, YOU FIND OUT THAT SOME STUDENTS ARE TAKING GREAT FUN IN WATCHING SAM SQUIRM AS THEY LIGHTLY TOUCH HIM IN THE APPARENT HOPE THAT HE EVENTUALLY WILL STRIKE OUT, AND GET BLAMED FOR STARTING A FIGHT. YOU HAVE A GOOD ONGOING RELATIONSHIP WITH SAM'S EDUCATIONAL TEAM AND ARE GRATEFUL THAT THEY HAVE SAM'S BEST INTERESTS AT HEART.

As you pick up the phone to talk with his teacher—who of course will agree to relocate Sam's desk away from the bullies—you suddenly are struck with an idea. It's time to involve Sam in his *own* self-advocacy and the disclosure that goes along with the process. But how do you begin?

This article will examine some necessary preconditions for developing skills in self-advocacy and disclosure for people on the autism spectrum, teaching skills in self-advocacy using a developmental stage-level approach and preparing children with autism to appropriately advocate and disclose for themselves in a way others can understand and assist when the request is made. In short, we will look at how to empower Sam to make his own self-advocacy

and disclosure decisions as he prepares for transition toward adulthood.

## A Definition of Self-advocacy

*Self-advocacy involves knowing when and how to approach others to negotiate desired goals, and to build better mutual understanding and trust, fulfillment and productivity* (Shore, 2004). In a practical sense, suppose “Dot,” a 16-year-old intern with Asperger syndrome is shown to her new office which is lit with fluorescent lights, and she happens to be sensitive to this type of illumination. In fact, like many people on the autism spectrum, Dot perceives fluorescent lights the way most people see a strobe light—fun on Halloween, but hardly conducive for workplace productivity.

To advocate for herself, Dot will need to ask her supervisor if a change of lighting, perhaps to incandescent lamps, could be made. She also could suggest bringing in her own lighting, moving her workplace to a window for more natural lighting or even disconnecting the fluorescent light above her desk. However, with her self-advocacy effort, Dot also will have to disclose her disability.

*Successful self-advocacy often involves an amount of disclosure about oneself that carries some degree of risk to reach that subsequent goal of better mutual understanding* (Shore, 2004). In other words, Dot will have to explain why she needs this accommodation. In some situations, making a “hard” disclosure that she has Asperger syndrome may be appropriate. However, in this case, especially since the supervisor does not know about Dot’s placement on the autism spectrum, a “soft” or partial disclosure may be more appropriate. Perhaps Dot can merely mention that the fluorescent lights hurt her sensitive eyes.

The question remains, how can Sam, Dot and others on the autism spectrum learn the necessary skills for self-advocacy and disclosure? Ideally, it starts by setting the preconditions when the child is young.

## Setting the Preconditions for Success

An important precondition for successful self-advocacy and disclosure is self-awareness. Both Sam and Dot need to understand how autism affects their interactions with others and the environment. They must be familiar with their characteristics, both strengths and challenges. A parent or caretaker can do this with a child from a very early age. In fact, the earlier a child has an explanation about his differences, the better off he will be.

## Catch the Child Doing Something Well

Starting at age four, I would take apart watches using a sharp steak knife. Out would come the motor, the hands, faceplate, etc. I then would reassemble the timepiece, still working and with no pieces left over. My parents always let me know that I had a useful, unusual skill. Soon there were other objects to take apart, such as clock radios and other devices. Later on, I transferred this mechanical ability to learning bicycle assembly and repair. I was successful in paying for part of my undergraduate tuition by running a bicycle shop.

Fortunately, my verbal ability was strong enough that I understood my parent’s praise of this talent. For children more challenged in verbal communication, parents should let their child know of their strengths in any way they can, such as with graphics or sign language. In addition to developing greater self-understanding, these talents can be fostered for eventual courses of study and successful employment (Grandin & Duffy, 2004).

## Four Steps to Disclosure

I was lucky with disclosure. My parents used the word “autism” around the house for as long as I can remember. While we did not know much about what it was, it did explain a lot of my differences. For example, I had a reason for why I had difficulty making friends in school and learning certain school subjects, and for my strong science and mechanical skills.

However, sometimes through shame of the diagnosis or being mis- or undiagnosed, many people don’t find out about being on the autism spectrum until later in life. As a result, they often go through difficult times as they attempt to reconcile challenges in their lives without knowing the cause.

I have developed a four-step process for telling people that they are on the autism spectrum (Shore & Rastelli, 2006). The process can take as short as 10 minutes and as long as several months, depending on the person and how much denial may have built up over time.

For example, a child to whom I have been teaching music since age five has Asperger syndrome. Let’s call him “Nate.” His parents never used the word “autism” around the house, hoping that with enough intensive activity, the Asperger syndrome could be “early interventionized” right out of him. By age 13, well... he still had Asperger syndrome. His parents asked me to talk with him about autism—which would be the first time he had ever heard the word—so I followed the four-step process.

### The steps are as follows:

1. **Identify characteristics.** *Discuss with the person his or her strengths and challenges. I prefer to use the word “challenge” rather than “weakness” because the latter is a rather static word, whereas the former has the sense that the challenge can be worked through and met.*

We began the lesson with a discussion of Nate’s strengths in music, graphic design and mathematics. We then looked at his challenges in making friends at school, penmanship and physical education.

2. **“Rack up” the characteristics.** *Work with the person to start delineating the strengths and challenges. Ideally, you will help him realize that his strengths can be used to help accommodate his difficulties.*

After sorting out these characteristics, Nate and I talked about how he can use his strength in computers to help overcome the frustrations he experiences from the physical act of writing papers and other assignments by hand. He can type them much faster and more neatly than write them.

3. **Nonjudgmental comparison.** *Compare the characteristics with those of others to demonstrate that different people have different strengths and challenges. Examining a potential successful role model, such as those featured in Asperger Syndrome and Self-Esteem (Ledgin, 2004), with a similar set of characteristics can be helpful.*

We examined Nate’s younger sister’s set of characteristics and found that she had characteristics that both overlapped and were different than his. Unlike Nate, she has great penmanship and makes friends easily. However, they both share an affinity and talent for music. In fact, Nate is now teaching his sister to play the piano.

4. **Presenting the Label.** *Preface a discussion of the autism label by noting that there are scientists, teachers, doctors and others who study the wide diversity of characteristics found in people. You could say, “It just so happens that your characteristics line up with those of people with autism.”*

After the preface, I told Nate that his characteristics line up with what is known as Asperger syndrome, followed by a disclosure that I also have Asperger syndrome, and perhaps that is why we have gotten along so well over the past eight years. His next statement was, “Can we get to the lesson?” Nate had heard enough.

All told, this process took about 15 minutes. In fact, I told him nothing he didn’t know before, save for the label. People with autism, even young children, intuitively know that they have a difference. Nate knew he had the strengths and challenges we discussed, but also realized that accommodations were being made for him as needed. Revealing the label allowed him to make a cohesive whole

out of a sea of characteristics and accommodations. He now also knows that his differences are not because he is stupid or somehow lacking, but rather are a function of a neurological difference. (Shore, 2004).

Three weeks later, I met Nate’s father at work and asked him how Nate took the disclosure. His dad beamed, saying, “My son *loves* having Asperger syndrome. He’s on the computer learning that he is not alone, how to accommodate for his challenges and to celebrate his strengths.”

Armed with sufficient self-understanding, Nate now is ready to advocate for his needs in a way that others can understand and assist with his requests.

## Teaching Self-advocacy Skills

My experience with others on the autism spectrum suggests a lack of ability to successfully engage in self-advocacy and disclosure so others can assist in a meaningful way. Just as teaching social skills and reading nonverbal communication is necessary for those on the autism spectrum, self-advocacy and disclosure requires direct instruction to develop skills.

A great technique involves using a child with autism’s individual education program (IEP) as a tool to teach her about self-advocacy and disclosure. The Individuals with Disabilities Education Act (IDEA) mandates that public schools identify all children with disabilities, assess their challenges, and provide them with special education and services so they have as equal a chance for success in education as their peers in the least restrictive environment. It also calls for the development of an IEP for each child. IDEA actually encourages children of all ages to be involved in the development of their educational plan and mandates this involvement by age 16 for the period known as “transition” from school to adulthood. Some states even mandate this involvement by age 14.

Educational advocacy currently takes place through the IEP team, consisting of special and regular education teachers, aides, professionals who work with the child, a school representative and the parents or guardian. Unfortunately, at least until the above-mentioned transition period, the child is included only as an afterthought. However, there are ways to engage the child as a team player for the IEP process, no matter where he is on the autism spectrum.

## Involvement in the IEP for Children Across the Autism Spectrum

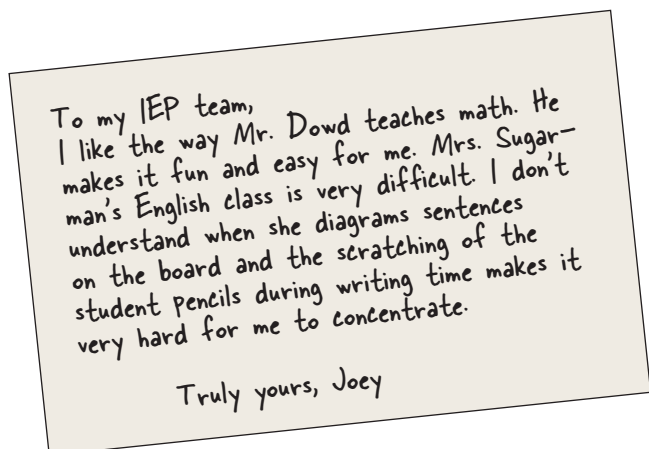
Some parents may say, “Involvement in the IEP and teaching self-advocacy is great for verbal children who are self-aware. But what about my five-year-old nonverbal, hyperactive child



who cannot sit still for more than two minutes?" Fortunately, children can be involved in their education program no matter where they are on the autism spectrum. The key is involving the child to the extent of her ability.

Below are some ideas for involving children who are more severely affected with autism:

- **Young, nonverbal and hyperactive.** Escort the child in at the beginning of the meeting, allow her to interact with a few team members she already knows, and then escort her out. Total time in the meeting: about one minute. There are two benefits to this: 1) the IEP members, who may work with dozens of children, are given a chance to connect the IEP to the face of the child and 2) the child gets the idea that there is a team of people gathered to help develop her educational plan.
- **Some communication ability.** Using the Picture Exchange System, sign language, verbal communication or another form of communication, the child can indicate which class or school activity he likes and which ones he doesn't. If possible, have him say or indicate specifics about these classes or activities that he prefers or dislikes.
- **Write a letter.** Some children can write a letter, such as this one:



From Shore, S. (2004) "Using the IEP to Build Skills in Self-Advocacy and Disclosure." Ask and tell: Self-advocacy and disclosure for people on the autism spectrum. Shawnee Mission, KS: Autism Asperger Publishing Company. pg. 80.

This type of letter gives the IEP team a lot of sensory and other information to work with.

- **Lead parts of the IEP meeting.** Some children can determine which accommodations are effective and can discuss possible appropriate services – under the watchful eye of the IEP team leader. Although not all children will reach this level during their grade school career, every step made toward successful self-advocacy and disclosure empowers them to do so at home, work, continuing education and in the community.

It is important to note that using the IEP requires familiarity with the document. Unlike college students, parents and educators, children with autism and other special needs will not sit for long explanations of the inner workings and parts of the IEP. However, they can be introduced to the document with the questions such as:

## MY INDIVIDUAL EDUCATION PLAN

Name: \_\_\_\_\_ Date: \_\_\_\_\_

QUESTION ANSWER

What are my measurable annual goals? \_\_\_\_\_

When is the date of my next review? \_\_\_\_\_

What does the "present level of educational performance" tell me? \_\_\_\_\_

What steps am I taking to prepare for life after graduation? \_\_\_\_\_

What right(s) will be transferred to me upon reaching the age of majority? \_\_\_\_\_

Adapted from Shore, S. (2004) "Using the IEP to Build Skills in Self-Advocacy and Disclosure." Ask and tell: Self-advocacy and disclosure for people on the autism spectrum. Shawnee Mission, KS: Autism Asperger Publishing Company. pg. 88.

## Getting Back to Sam

The best way to begin the process of teaching Sam skills in self-advocacy and disclosure is to involve him in the process. As mentioned above, your previous advocacy for Sam would have been to tell his classroom teacher directly about the problem and quickly resolve it. Now, we need to bring Sam into the decision-making process.

Initially, Sam's experience should be validated as one that is real and important to him. He should also know that through collaboration, something can be done about the situation. By teaching Sam self-advocacy according to his skill level, he can begin to learn how to ask for changes in the environment or assistance on his own, and to combine the appropriate self-disclosure.

## Six Developmental Stages of Self-advocacy

The six stages of self-advocacy as developed by Kassiane Sibley (2004) are:

- 1. Planning and modeling:** After planning his self-advocacy with the facilitator, the self-advocate should observe the facilitator advocate on his behalf. *Sam and the facilitator plan what the facilitator will say to the teacher, as Sam observes and learns.*
- 2. Facilitation and confidence building:** The facilitator serves as a guide for the self-advocacy process and remains ready to step in as needed. *In addition to collaborative planning, Sam conducts part of the advocacy conversation with the teacher, possibly with the help of the facilitator to introduce the subject of the conversation and stepping in when needed.*
- 3. Partnering:** This includes equal sharing of advocacy responsibilities. *Sharing the load 50-50, Sam will do about half the talking or interacting with the teacher, with the facilitator acting as a guide.*
- 4. Moral support:** Facilitator continues to assist with the preparation. *Sam will do most of the talking or interacting with the teacher, with the facilitator's encouragement.*
- 5. Taking the lead:** The self-advocate leads the entire process with the facilitator, but only under the self-advocate's direction. *Sam does all of the planning and advocating on his own behalf, with the facilitator assisting only upon Sam's request.*
- 6. Independent self-advocacy:** The self-advocate undertakes all the preparation, presentation and evaluation in a completely independent manner. *Sam does it all and the facilitator remains available, for example, by cell phone.*

## Matching the Developmental Stage to Sam

Given that Sam has not yet advocated for himself, he would be placed at stage one. After validating Sam's difficult experience, the advocacy facilitator can help brainstorm possible solutions and determine their suitability for taking action. Perhaps the idea of punching the offending students in the nose would be discussed. Of course the likelihood of getting suspended for violent behavior would make this a poor choice.

Eventually, the talk can be steered toward talking with the teacher and asking to be seated away from the bullies. Since this is stage one, after they both agree on what to tell the teacher, the

facilitator models the advocacy effort for Sam, as he watches the facilitator discuss the problem with the teacher and advocate on his behalf. Depending on Sam's ability, he may be given a chance to take part in the discussion with the teacher.

## Self-advocacy and Disclosure: Skills for a Lifetime

Self-advocacy and disclosure are vital skills for leading a fulfilling and productive life. Disclosing to people with autism that they have this condition as early as possible will make it easier for them to reconcile their differences with others as characteristics rather than as deficits. Using the IEP as a tool to familiarize students with the development of their own educational plan will empower them to become conversant in the appropriate ways to talk about their needs and suggest accommodations for doing so.

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