SELF ADVOCACY AS A SURVIVAL TOOL

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Self-Advocacy as a Survival Tool

In any decent person, there is a natural tendency to want to protect those who are innocent and defenseless. While a crying child can drive anyone to distraction after several hours, it is only the truly sociopathic who can look at a young child and not feel an urge to protect and care for that small, young person. This instinct will likely be even stronger when the child is disabled or ill. However, as natural and as praiseworthy as it may be to shelter young children and particularly those with special needs, such an instinct may prove to be harmful in the end. This paper argues that teachers, while certainly trying to protect their students from physical and psychological harm, should not shelter them too much. As harmful as have been past school policies that forced some children with special needs to try to deny those needs are policies that infantilize students with special needs. As is true of all young people, students with special needs must be taught how to be advocates for themselves. Indeed, this is arguably even more true of children with special needs than it is of “typical” children.

This need for teaching students how to serve as their own advocates means that teachers must still strive to create a classroom environment that is physically and psychologically safe for all students. Such a safe atmosphere is an essential part of the process of teaching students to learn to trust themselves and those around them, which is itself a key element in the process of learning to self-advocate. But teachers – and this of course includes other adults in a child’s life – must also give children the tools to speak out about their own needs. This is the case because at some point those children will be on their own and will not have any adults to speak for them but also because (and again this is especially the case with children with special needs) often only those children are
fully aware of their own needs. This high school junior who has Obsessive-Compulsive Disorder praised a writing tutor she had in seventh and eighth grade.

I’ve been lucky because I’ve had a lot of great teachers. And except for maybe one or two of them took the time to talk to me about OCD and what it was like for me and some of them even went out and got books on OCD so that they could help me. And I don’t want to sound like I don’t appreciate the extra distance that they went for me.

But the most helpful teacher I ever had was my middle-school writing coach because she was very straightforward. “You’ve got a disability that will be with you for the rest of your life. So what our job is is to figure out a way for you to make that disability a part of your life plan. I can’t do that for you because I don’t know exactly what it’s like to be inside your life. Decide what you want to do with your life and then make a plan to get there, and part of that plan is how to deal with your disability and how to make other people see you as a person first and someone with a disability second. She didn’t let me hide behind OCD, and that’s easy to do. But I don’t want to hide. I want to be me. And the only way that that is going to happen is if I know who I am and what I want and that I deserve a chance as much as anyone else (S. Smith, personal communication, March 11, 2004).

This idea perfectly encapsulates the concept of self-advocacy for children with special needs, which requires teachers to give students the tools that they need to express their own needs. Anyone who has spent a lot of time around large groups of small
children – or teenagers – might think that getting them to express their desires might not be something that adults need to encourage. But while many students do express themselves and often quite vocally, this does not ensure that they are accurately articulating their own needs rather than simply going along with the crowd. This is an especial danger for children and teens with special needs who are often more interested in fitting in (or trying to fit in) than in addressing the specific barriers that they may face and that may be limiting their chances for success.

It is, of course, important that all individuals be encouraged to become self-advocates, be taught how to seek what they need for themselves without limiting the chances or choices of others. As Brinckerhoff (1994) argues, self-advocacy, although the term may be relatively new and still relatively unfamiliar, is a long-established philosophy within the educational establishment. Self advocacy is the state of knowing what one wants, what one is entitled to, and how one can effectively craft a path that will lead one to accomplish one’s own goals within the limitations of those entitlements.

Looking more specifically at the educational arena, the following description of older students must be modified when applied to younger students, who are not responsible or at least not wholly responsible for self-identification, but it can serve as a useful baseline to the concept of self-advocacy for the student with special needs:

Since students with disabilities are responsible for self-identification and self-advocacy at the postsecondary level, they must be effective self-advocates. This means that they must be able to understand and be comfortable describing their:

- Type of disability
• Academic strengths and weaknesses

• Learning styles

• Helpful accommodations (Brinckerhoff, 1994).

The literature that follows examines how the concept of self-advocacy has recently been developed within the context of special needs education. This literature review, while focusing on the developments within school systems, must also touch upon the growing emphasis on self-advocacy and self-determination that exists within the disability movement as a whole. The impetus that exists in some classrooms and some school districts to help children acquire the tools that they will need to be articulate and powerful advocates for themselves cannot be divorced from larger social and cultural ideas about the responsibility that society as a whole has to those who struggle with particular challenges or from larger cultural ideas about the potential that even those with significant personal challenges have to live a life that is rewarding and successful.

Asking teachers and school administrators to help students of all abilities but especially those with special needs to become advocates for themselves may seem as if it were another burden placed upon an educational system that is already burdened with far too many responsibilities. There is no doubt that such a request does at least initially require more work on the part of individual teachers and schools. However, teaching students to serve as their own self advocates is like teaching the person in the proverb how to fish. Giving a person fish ensures that she eats for only a day but teaching her how to fish ensures that she is self-sufficient for a lifetime.
Teaching students to be effective self-advocates gives them the tools that they need to help themselves, whether in the classroom or the wider world beyond. Not only should such self-sufficiency be the moral and philosophical goal of every teacher, but it should also quickly lighten the load of responsibilities that teachers carry as they find their students being more and more capable of caring for themselves.

Literature Review

It is one of the most fundamental tenets of our American democratic system that every child deserves an education, for that education will allow each American to grow up to have a rewarding and successful life. This ideal – the idea that every child who attends school should be given the psychological and educational tools to go as far in life as he or she wishes and desires to go – is one that often falls far short when we examine what actually happens in individual classrooms or school districts. This is especially true when one considers the experiences of children with special needs.

Both local and federal educational policies acknowledge this gap. George W. Bush’s *No Child Left Behind* program does emphasize the importance of inclusive education in terms of children with special needs:

The education of all children, regardless of background or disability, while chiefly a State and local responsibility, must always be a national priority. One of the most important goals of my Administration is to support States and local communities in creating and maintaining a system of public education where no child is left behind. Unfortunately, among those at greatest risk of being left behind are children with disabilities. The Individuals with Disabilities
Education Act (IDEA) is a landmark statute that asserts the rights of all children with disabilities to a free, appropriate public education. My Administration strongly supports the principles embodied in the IDEA and the goal of providing special education and related services to children with disabilities so that they can meet high academic standards and participate fully in American society. It is imperative that special education operate as an integral part of a system that expects high achievement of all children, rather than as a means of avoiding accountability for children who are more challenging to educate or who have fallen behind (Bush, G.W., 2001, para 2).

This idea that each individual should be empowered by the educational process to go as far as possible on her or her own merits is as American as spring training. And yet, too often classrooms are designed so that children with special needs are not only empowered but are in fact disempowered by programs that either place too many restrictions on children or attempt to push children, and their families, into programs or pathways that do not meet their specific needs (Wright & Wright, 2001).

Importance and Limitations of IEPs

To address this latter problem – the problem of special needs programs not meeting the actual needs of special needs students – many school districts establish individual learning programs that allow a student’s teacher(s) along with specialists in special education, the student’s family and school administrators to craft a program that is individually tailored to meet the needs of the student (Anderson, 1990). These programs are frequently reviewed and updated so that as a child’s needs and skills change the
program remains relevant. This is, at least, the ideal. However, such an individually focused program often fails to be developed or instigated for a number of reasons (Alper, Schlos, & Schloss, 1996).

The two primary reasons are the failure of teachers to understand the importance to a particular student of creating and supporting an individualized educational plan and the second is the growing pressure on teachers to provide such a wide range of sources to students with such varied needs that it is impossible for them to do so. (Anderson, 1990) This high school teacher outlines some of the problems that she faces in instituting “IEP’s”.

I want to say right off that I am fundamentally sympathetic to any parent who has a child with disabilities or special needs and is trying to address those needs through the public school system. My son – who is twenty now and pretty much independent – has autism, and it seems to me that I spent about half of my time and almost all of my energy when he was younger trying to find a program and a teacher that would work with him. So I know firsthand how difficult it is to be in such a position.

But I also know what it’s like to be a teacher. Four years ago my average class size was 28. This year it’s 36. I have nearly 200 students, all of whom are supposed to do better on standardized tests than did my students who took those tests last year, despite the fact that these students have an entirely different set of skills and challenges.
Of course, I’d love to be able to be an advocate for every child, but I’ve found that this simply isn’t possible. Students have to learn to be advocates for themselves. I know that sounds terrible, as if I’m not doing my job. But my job these days covers so much ground that I’m doing as much in each different as I can (K. Jones, personal communication, April 10, 2004).

This attitude, even if it is rarely expressed by most teachers, is relatively common. It is one reason that so many parents have come to believe that they must serve as advocates for their children with special needs (Taylor, Coughlin, Marasco, 1997).

Parents as Advocates

Although the focus of this paper is on helping students to become advocates for themselves, this process is inseparable from the process of parents’ becoming advocates for their children. Indeed, as Galloway, Armstrong, & Tomlinson (1994) argue, the issue of the role of parental involvement as advocates within the educational process is central to the issue of students becoming their own advocates.

(Galloway, Amstrong & Tomlinson, 1994) a decade after the publication of this study, argue that there has been a shift in American education from the family’s serving as the locus of responsibility to the school and the teacher serving a greater and greater enforcement role. The three do not focus on why this shift should have occurred or who may be to “blame” for it but in all likelihood it reflects several broader social shifts that arise from outside of the educational arena. Schools, and this has only become more true in the past three years with Bush’s No Child Left Behind policy, have become increasingly institutionalized and professionalized. This is certainly in many ways a good
thing, but it does have some unfortunate consequences, the most important of which may be that there is an increasing divide between students and their families and the educational professionals who can, all too often, make parents feel that they have less of a stake in their children’s future and education than the educators do, something that is almost never likely to be the case (Armstrong, Armstrong & Barton, 2000).

One follow-up of the increasingly professionalized and bureaucratized nature of many school districts is that parents, who have either intentionally or unintentionally been made to feel that they do not belong, have retreated, ceding their children’s education to teachers, who then feel overwhelmed by the degree of responsibility that is being thrust on them (Wright & Wright, 2002). Others have responded by becoming professionalized and even legalistic. The following advice to parents who are meeting with school district officials – from a parents’ advocacy group – suggests that there is often a relatively high degree of antagonism on the part of parents seeking to get schools to craft a program that is highly specialized vis-à-vis their children. Such a description argues that a legalistic attitude should not be seen as “adversarial;” it is not difficult, however, to imagine the adversarial conditions under many such IEP meetings are conducted.

Many parents routinely record their IEP meetings and school district staff has become accustomed to it. Tape recording an IEP meeting is NOT “adversarial,” rather it is a parent’s right, set forth in California’s education code. Often, both parents cannot attend an IEP meeting. Meetings that last a long time are very tiring, and it is very difficult to remember everything that was said. Too, because of the length of those meetings, district employees do not
always get everything written down properly. Tape recording the meeting allows you to listen to the meeting again to be sure that all that was said is reflected in writing on the document. This allows you to go back to the district and insist that they write into the IEP, what the tape-recording reflects (Wright, 2002, para 4).

The same group also advises parents to “prepare a list of your child’s strengths, as well as the concerns you have as a parent” and to have a clear sense of what path the parent wishes the child to follow, both in that particular classroom, in school as a whole, and in the larger world that the child will enter when he or she leaves school:

Decide beforehand what your goal is for your child in terms of graduating high school. If it is your goal to have your child graduate with a high school diploma, make it clear to the IEP team and ask that it be written into the IEP. In this manner, all IEP team members will be clear on your expectations for your child and can all work toward the same goal, with the appropriate supports, services and programs needed to achieve this goal (Wright, 2002, para 12).

The role that parents can play as advocates for their children is a vital and essential one, but as Armstrong (1995) argues, it is very much a double-edged sword. Both common sense and a range of research tells us that students with a wide range of special needs are best served when those needs are identified at the earliest possible age. The magnitude of the problem of students with learning disabilities, as well as, the magnitude of the problem of not being able to identify those problems as soon as possible are summarized below.
Since the 1976-1977 school year, when Congress first required public schools to document the number of children with LD, the share of school-age students identified as LD has risen from 1.8 percent to 5.2 percent. Learning disabilities now account for more than half of all students enrolled in special education programs, an increase of 22 percent over the past 25 years. In the past decade alone, the number of students ages 6 to 21 identified as LD under IDEA has increased to 38 percent. The largest increase, 44 percent, is among adolescents ages 12-17.

Unfortunately, this rise in the identification of students with LD does not lead to improvements in learning, particularly in older students (9 years of age and above) and particularly in reading skills. For example, Eric Hanushek and his colleagues found that placement in special education was associated with a gain of 0.04 standard deviations in reading and 0.11 standard deviations in mathematics. Unfortunately, these gains are so small that children are not closing the gap between their academic performance and the performance of their higher achieving classmates. This lack of improvement has the further negative effect of keeping students in special education for lengthy periods of time (Lyon, G.R., 2002, para 4).

Parents are unlikely to be aware of this particular set of statistics; however, they are aware of the fact that early intervention is one of the most important things that they can do in helping their child achieve success in school. This leads parents (Wright & Wright 2001), to become advocates for their children’s needs at a very young age. With certain disabilities, such as autism, this advocacy can begin at the point of diagnosis, at
one to two years. Financial and social support for such early intervention is supplied to
parents by a number of public agencies (Kozloff, 1983).

Parents that begin by learning to jump through the hoops of public bureaucracies
when their children are still in diapers are likely to have become expert at doing so by the
time that their children enter school (Garner & Sandow, 1995). This expertise, along with
their sincere desire to do what is right for their children, combined with the experience
that most of them will have had that they cannot count on public entities to provide the
highest level of service to those children unless the parents serve as active watchdogs all
tend to ensure that parents continue to serve as advocates for their children’s needs once
they enter kindergarten and as they proceed through the elementary school years (Coyne,
1995).

There is, of course, another important reason that parents can and often must
serve as advocates for their child’s or children’s in their first encounters with public
agencies. The child is too young to do so themselves. This fact, as Anderson (1990)
argues, lies at another one of the difficulties in moving to have students serve as their
own advocates. Depending upon the type of special need and the age at being assessed or
diagnosed, the child is likely not to be in the position to serve as an effective advocate for
himself or herself. Although, as Anderson also notes, parents and other adults in the
child’s life are likely to underestimate how effectively children can serve as their own
advocates even at a very young age. This is not to deny the importance of children
learning to become their own advocates or to argue that the disabled are not often capable
of providing thoughtful and ringing endorsements of their own needs. Rather, it is an
assessment of the difficulty that any individual, or any family, is likely to encounter when trying to wrest benefits from a bureaucracy (Taylor, Coughlin & Marasco, 1997).

Unity in the Face of a Common Enemy

All too often the school district, its administrators and teachers become a common enemy for families with a child who has special needs. Families and students may believe that school officials do not understand the specific limitations faced by the child or, even if they do understand them, may not be sufficiently sympathetic to those needs (Alper, Schloss & Schloss, 1996). This may in fact be true, but the picture is in fact not quite so simple and must be fleshed out to paint an accurate sense of how it is that students can become effective and informed advocates for themselves (Brinckerhoff, 1994).

This retired high school principal described some of the problems that he has seen when parents serve as overly zealous advocates for their children.

The problems that I have with a lot of parents are twofold. Or I guess threefold. The first is that they are simply not dealing with the reality of the situation. Now no one is saying that parents shouldn’t do everything that they can to help their kids. For me, just personally, I think that if you’re not willing to do that than you really shouldn’t even be a parent to begin with. I’m a parent too – I have three daughters – and I’d like to think that I go to bat for them all the time.

But I also know that a school has limited resources, and the parents that I have the most problems with just do not seem to understand that. Or rather, because they’re smart, I think that they do understand it perfectly well but that
they are in denial about it. I say to them, “Okay, if we get this extra tutor for your child, we cut reading help to four other kids who are likely to drop out. Does that seem fair to you?” And they invariably say, “Yes – we don’t care about other kids. Let them fight their own battles.” Okay, they don’t say it that directly, but that’s what they are saying. And it makes me a lot less sympathetic to them.

And one of the reasons that it makes me so much less sympathetic – and this is the third problem that I have with them – is that they’re sending a lousy message to their kids. Yes, I believe that kids need to be taught to stick up for themselves. No one – no matter what age they are or what their abilities are – should let themselves get shoved around. But no one should shove other people around either. And that’s what I see a lot of parents doing, and that’s what I see them teaching their kids to do: Get yours first and the hell with everyone else (T. Jones, personal communication, March 10, 2004).

This school official brings up one of the key issues that must be addressed. How does one serve as the most effective advocate for oneself without infringing the rights of others? This is one of the most difficult tasks that those working with children with special needs face, as Cloyne (2002) notes. School districts are designed, both in terms of culture as well as in terms of their ability to serve children with a range of abilities on a limited budget, this forces parents to become aggressive to secure rights for their children. Once they become so aggressive, they are unable to find their footing on the very narrow line between advocacy and belligerence.
This tendency of parents – motivated by a number of complex and often intersecting goals – to push for every possible advantage for their child, even when such moves may endanger the chances of other students to receive an education or even when such aggressiveness may well prove not to be in the child’s best interest, is often exacerbated by the differing expectations that parents and teachers have about a child’s potential (Coyne, 1995).

And a Child Shall Lead

It is difficult for the child with special needs to serve as an advocate for himself or herself. It is difficult for any child to do so, for those without power in a society, and children are literally disenfranchised and relatively powerless, to be forceful advocates for themselves (Garner & Sandow, 1995). Children with special needs are often further discouraged (or prevented) from serving as advocates for themselves by the very conditions that cause them to have those special needs to begin with. For example, as Paluszny (1989) describes, children with autism are significantly hindered from serving as their own advocates by their condition, which tends to limit an individual’s ability to communicate easily or comfortably with others. In addition to the fact that many children are ill-equipped to serve as their own advocates because of both their youth and their special needs, they are in all likelihood to have become deeply dependent upon their parents to serve as advocates during their elementary school years.

But these problems may pale before the often larger problem that children with special needs may have of not having a good working model of what self-advocacy looks like. It is in supplying such a model that teachers and school administrators can serve an
important role (Brinckerhoff, 1994). Of course, parents can and should serve an important role in helping their children to develop the ability to serve as self-advocates, but if they fail to do so then educators can step in to help provide their students with the ability to act in a more autonomous way that will, in the end, benefit both student and teacher (Anderson, 1990).

The following checklist provides an overview of the skills and attitudes that are important in helping students to achieve the ability to serve as advocates for themselves. Not all of these skills apply only in the classroom, but this does not mean that they cannot be learned in the classroom or that they will not be helpful in the classroom as well as in other arenas:

Self-advocacy is:

- Taking responsibility for your own life
- Knowing your responsibilities
- Knowing your rights
- Making choices
- Asking for help when needed
- With self-advocacy skills, students can make choices:
  - At home
  - In the classroom
  - On the job
  - In receiving medical attention
  - In using transportation and other public services
  - In leisure activities (Taylor, Coughlin & Marasco, 1997).
One of the most important and helpful ways in which students can learn to become forceful (but not bellicose) advocates for themselves is by being a part of the IEP process. This is surprisingly often not the case. The principal quoted above summarized his experiences.

You would think that as kids get older that they would be included more and more in the process. But we’ve found that unless we insist on it that children are often left entirely out of the loop. There’s the teacher and whatever other instructional aides or faculty may be involved and there’s the parent or parents but the student – and this is true even at the high school level – just isn’t there.

And to me that really inculcates in the students a very dangerous kind of passivity. It’s very much a question of “We know what’s good for you so just sit down and be quiet and follow orders.” And that is the last thing that someone who is disabled needs. Someone with disabilities far more than someone who is “normal” needs to be able to speak up for himself or herself. (T. Jones, personal communication, March 10, 2004).

The tendency of parents who desperately want to provide the best possible chance for their child blended with the problems inherent with any bureaucracy blended with the real tendency on the part of many teachers and administrators to see children with disabilities or special needs as lacking the possibility for meaningful academic success can lead to a situation in which students with special needs not only habitually fail to serve as advocates for themselves but are simply incapable of doing so in large measure because they have never learned how to assess their own needs. This may seem to be a
puzzling lack, but many healthy adults are also limited in their ability to assess their physical, emotional or psychological needs so it should hardly be surprising that young people, especially those with cognitive limitations, should have difficult in doing so (Galloway, Armstrong & Tomlinson, 1994).

In seeking to become more engaged in the process of designing the specifics of their own curriculum, students can become more skilled in general at serving as their own self-advocates (Armstrong, 2003). This summary of the important goals of self-advocacy underscores the link between students’ taking a more active role in the classroom and their taking a more active role in their lives (Garner & Sandow, 1995). This is an important message that educators, parents, and students all need to be as aware of as possible.

The goal of all students, including those with special needs, according to Garner & Sandow (1995), should include the following and all parties to a student’s education – including the student, the family, and teachers – should do everything possible to this end:

- Become aware of your strengths and weaknesses and what helps you learn or perform better
- Be an active member of your education planning team
- Communicate effectively
- Listen carefully
- Make decisions and be responsible
- Learn how to ask for help when it is needed
- Help others
- Learn about available resources
- Understand it's okay to make mistakes and learn from them
- Learn to solve problems effectively
- Finish your education
- Learn strategies to manage the challenges of your disability
- Set personal goals
- Develop a positive attitude, flexibility and a sense of humor (Garner & Sandow, 1995)

While few parents or educators would be likely to argue with these goals for the student with special needs who wants to serve as his or her own advocate, they may seem vague. Operationalizing, or making more concrete, these goals and the pathway needed to follow to get to these goals, is often the stumbling block for the teacher who is already overwhelmed by duties, for the parent who is so accustomed to fighting pitched battles with a bureaucracy, and to the student who is (after all) just a child (Garner & Sandow, 1995).
Operationalizing Self-Advocacy

The key to determining how well a student is serving as an advocate for himself or herself is first to understand the key dimensions that make up a person’s ability to speak up for himself or herself and then to determine how to measure progress along each one of these vectors. The plan that we have been discussing (Garner and Sandow, 1995) suggests that communication skills are the most important skills that a child can be taught in order to serve as his or her own self-advocate. The fact that communication skills are also a central part of the general educational process and have wide applicability in the work world make the importance of inculcating such skills in each student even more key.

Students are also generally better able to serve as their own advocates if they feel generally confident in themselves. For children with special needs, this can be extremely difficult as their disabilities and their differences from other students tend to lead them to undervalue their skills (Armstrong, 2003). Students with special needs may need more explicit reinforcement by teachers, as well as their parents. It may seem unnecessary to praise students for every bit of progress that they make – every equation solved properly, every sentence parsed correctly – but a little bit of praise upfront can go a long way (Foster, 1986). Once students begin to acquire a sense of competence and confidence, their ability to assess their own strengths and weaknesses and their ability to ask for what they need will build upon itself. Just as a lack of confidence tends to lead to a downward spiral, a sense of confidence tends to lead to an upward spiral (Galloway, Armstrong & Tomlinson, 1994).
Students who are learning to be an active part of the educational process and to serve as their own advocates should be able to demonstrate an increasing level of skill in the following areas. Again, although not all of these are specific to the classroom, they each at least have roots in what children learn in the classroom.

- Communicating with others
- Identifying needed accommodations and supports
- Expressing hopes and wants
- Relating with people in authority
- Relating to peers
- Solving problems
- Controlling anger
- Finding out about jobs and careers
- Finding a job
- Getting an education or training
- Taking care of oneself
- Getting around in the community (Goodley, Armstrong, Sutherland & Laurie, 2003)
As noted above, these concepts while in some ways specific to the arena of students with special needs and certainly deeply relevant to the ability of students to learn to be self advocates have not arisen in isolation to each other. Rather, they are part of a larger social movement that has encouraged those with disabilities to become forceful and articulate defenders of their rights as American citizens (Armstrong, 2003). This “mainstreaming” of the disabled community now seems so normal to us that it is easy to forget how recently those with physical or psychological disabilities were hidden from sight, or chose to hide themselves from sight. For those students with physical disabilities, or conditions such as autism or bipolar disorder, their ability to serve as their own advocates within the school system will not only serve them well there but will also serve them well as they become functional adults who are protected by legislation like the Americans with Disabilities Act – laws that are only effective if people take advantage of them (Kozloff, 1983).

Students who have what might be considered to be more minor disabilities may actually have a more difficult time, as this teacher, who praises the state’s emphasis on self-advocacy, says:

I know that this may sound terrible to say, but I think that in some ways those students who have the most serious disabilities are better off in the sense that they will have that disability recognized. Of course, no one is saying that it’s good for a child to be blind. Of course not. Not that blind individuals can’t live rich and rewarding lives and contribute substantially to society, but there is a great deal of beauty in the world that one misses out on when one is blind and
there are a number of practical difficulties – in getting around if one cannot drive, in getting a job – if one is blind.

But, on the other hand, no one is going to look at a blind person and say, “Oh, they’re just faking it. Blindness isn’t a real condition.” No teacher is going to deny that blind student should have materials in Braille. And because a condition like blindness is such an old and well-established disability, there is also a long history of advocacy for those without sight. I think that our students with hearing and visual problems are in fact taught early on to stand up for their rights. I see them do it all the time and I’m proud of them.

They know what they need and they ask for it, which means that they’re getting the education that they need and it also makes my life a lot easier because I’m not always having to worry, did I miss something? Am I not doing something that I should be for them? Because I know that if there were something that they need then they would tell me. (K Smith, personal communication, April 11, 2004).

It is true that the position of students with other forms of disabilities or special needs tend to be overlooked or downplayed by teachers, and there are two responses to this. As Goodley, Armstrong, Sutherland & Laurie (2003) suggest, choosing which pathway to take may be extremely difficult, although once this choice has been made the pathway is fairly clearly laid out. If a student, or a parent, feels that the child’s special needs are not being met then the parent and student can use the fairly considerable means at the disposal of students to seek a remedy within the system. If, for example, a student with some hearing loss is having problems in a classroom because no special
accommodations have been made because the degree of hearing loss does not meet a certain threshold, then the family and the student should be doggedly persistent in getting the teacher and the school to accommodate the student’s needs. Partial deafness should not be allowed to prevent a student from learning, and the student can work with the teacher to be a clear and forceful advocate for his or her needs, such as asking for windows to be closed so that ambient noise is not distracting.

In other cases, it may well be appropriate for the student and the parent to reassess their position. This is where difficulties may arise. Student with special needs, because of this designation, often receive far more funding per pupil than do children in general education programs. This level of expenditure is effectively mandated by the federal laws that require that all American children receive an education if they choose to attend public schools (Armstrong, Armstrong, Barton, 2000).

Twenty-seven years ago the nation made a commitment to provide all children with disabilities a "free, appropriate public education." In 1975, the Individuals with Disabilities Education Act (IDEA) brought over one million children previously kept at home or in institutions into the public school system. Subsequent amendments expanded the scope of the program to include infants and toddlers. Overall the program has grown from serving 3.7 million children in 1977 to 6.5 million in 1999, an increase from about 8 percent to over 11 percent of the school population.

Because the 1975 federal legislation resulted in additional costs to the public schools to provide special services, the legislation included the goal that the federal government would provide 40 percent of the extra costs. In reality,
the federal government has never come close to meeting that goal, and even with recent increases in the federal share, the 2002 federal budget provides only 18 percent of the cost. It has been left up to state and local governments to fund the balance of the special education services.

The price tag for states and districts has been substantial. In a March 2002 report, the Special Education Expenditure Project (SEEP) calculated that in the 1999-2000 school year, the per student cost for students eligible for special education services was $12,474, or 1.90 times the $6,556 per student cost in general education. Nationwide, the total expenditures for educating students with disabilities in that year made up almost 22 percent of the total expenditures for elementary and secondary educational services (National Association of State Boards of Education Study Group on Special Education, 2002, para 7).

No one is more aware of the costs of special-needs programming than are school officials. It is no doubt, the case that what parents see as reluctance in providing the appropriate education promised in IDEA is a reasonable reluctance on the part of school officials to starve other parts of their budgets. In cases in which they do not feel that the demands of the parents are reasonable. This is yet another reason why children with special needs need to become advocates for themselves as quickly and as efficiently as possible (Coyne, 1995).

Often parents’ egos become involved in the process of advocating for their children. They may honestly believe that their child deserves special programs, but they
may also at some level at least simply want to “win.” This teacher has experienced this problem with parents.

I’m not a psychologist, but I think that after 23 years in the classroom that I do know something about children. And I think that a lot of these parents are frustrated with their children’s progress because maybe there is some subtle learning disability or maybe because – it’s like Little League parents – they want their kids to be brilliant and they’re just normal kids and the parents want someone to blame and the teachers and the school are handy for that.

And you see parents in here ranting on about something like Operational Defiant Disorder and I feel that it’s time to say enough. Sometimes it’s just parents who have a kid that needs help learning to read and they’re just too busy to be bothered to do it themselves so they put up this big fuss (M. Green, personal communication, April 12, 2004).

ODD – Operational Defiant Disorder – is an excellent example of how the concept of “special needs” has tended to become more and more diffuse (Armstrong, Armstrong & Barton, 2000). Whether such a syndrome even exists is in question, although its symptoms – which much occur for at least six months in length. ODD is considered by at least some mental health and behavioral experts to exist if four of the following symptoms are present:

- The individual often loses his or her temper
- The child or teen often argues with adults
• The child or teen frequently defies or refuses to comply with adults' requests or rules regardless of the appropriateness or reasonableness of those rules

• The individual often deliberately annoys people regardless of their own behavior

• The child or teen often blames others for his or her mistakes or misbehavior

• The child or teen is often touchy or easily annoyed by others

• The child or teen is often angry and resentful

• The individual is often spiteful or vindictive (Armstrong, 2003).

To many educators such “symptoms” sound like nothing more than the ordinary process of growing up. When they are brandished by parents whom teachers or administrators see as looking for an edge for their child, they are dismissed – all too often with the needs of other children (Armstrong, 2003). However, such problems when articulated by children themselves are likely to be given a more receptive hearing (Armstrong, 1995).

Summary

As a general rule, the needs that children put forth themselves are valued more by adults when children speak out. I know that there are eight-year-old psychopaths, but I trust kids. When a third-grader comes to me and asks for help in paying attention, well then I do listen and jump through hoops because I think that that child does honestly know what’s going on inside his or her head. But when a parent comes in ranting about how their kid can’t get into Harvard unless I get the school to buy him a new computer,
well, I guess its just a lot harder for me to feel that that is something that I need to listen to and jump to get accomplished.
References


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