



Complex Child E-Magazine

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The Right to Communicate by Susan Agrawal

Amendment 1 to the Constitution of the United States of America [Ratified 1791]

Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof; or abridging the freedom of speech, or of the press; or the right of the people peaceably to assemble, and to petition the Government for a redress of grievances.

Universal Declaration of Human Rights, Article 19 [United Nations, 1948]

Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

When I read important documents like our Constitution or the UN's famous declaration on human rights, it seems obvious that the concepts of free speech and thought are created on the foundation of the more basic right to communicate. I am not the first to note this connection. Multiple organizations, including UNESCO, have been debating whether or not the right to communicate should be listed as a basic human right. Others have argued that the right to communicate underlies all other rights, and no expression of speech, religion, assembly, or press can exist without the right to communicate.

These ideas, while remaining primarily in the political sphere for most individuals and organizations, have profound implications for people with disabilities. If anyone has lacked a voice—both physically and figuratively—over the years, it is people with disabilities.

TASH, an international organization that advocates for the rights, independence, and education of people with disabilities, developed a resolution on this very issue.¹ It states in part:

The right to communicate is the means by which all other rights are realized and is, in itself, a basic human right. All people communicate and have the ability to make and express choices, although it may take a patient and skilled person to elicit and interpret such expression. In the name of fully realizing the guarantee of individual rights, we must ensure:

- that all individuals have a means of communication which allows their fullest participation;
- that people are given access to assessment in a range of various communication methods;
- that people can communicate using their chosen method in all of the settings in which they spend time; and that their communication is understood and heeded by others.

Why is it that so many people with disabilities still lack a voice?

As the parent of a child who cannot speak or even vocalize much, I have struggled for years to give her a voice through augmentative communication. Accessing her right to communication has not been easy for my daughter. She does, of course, have severe motor and visual impairments that significantly limit her ability to access any sort of device. But she was also limited by the fact that only one center—one very, very distant center with a long waiting list—was approved to evaluate children for communication devices through the early intervention program. Then she was limited by the fact that there were no trained augmentative communication experts in our area who took Medicaid or private insurance. We have thus far been lucky with getting funding for my daughter's device, but if her "voice" happens to break, she will be left voiceless unless we pay out-of-pocket for another device.

Historically, financial considerations have had a large impact on whether a child has access to augmentative communication. Even wealthy families have difficulty paying for dynamic communication devices, whose price tags range from \$3000 to more than \$7000. Need an eye gaze system? That's another \$7000. Therapy is as much as \$150 a week.

In particular, many insurance carriers do not feel that communication is inherently "medical," and thereby deny both communication devices and the ongoing therapy necessary to use these devices. Our already under-funded schools, suffering for years with a federal government that refuses to make good on promises to fund special education, lack both the money to purchase devices and, in many cases, the expertise to train children how to communicate using alternative means. Our health care system is so broken that many therapists have chosen to only accept cash payments since everything having to do with augmentative communication is always an insurance reimbursement battle. Manufacturers get little support from the government or corporate America and are forced to charge exorbitant fees for their devices just to cover research, production, and marketing.

The financial reasons are many. But ultimately it is our children who suffer. We, as a collective nation, are denying our children the right to communicate *because it costs too much*.

I see the right to communicate denied again and again every time I enter my daughter's classroom at school, not only due to funding, but also a lack of experience. Despite the fact that my daughter is probably the most physically disabled child in her class, she is the ONLY child in her room who uses a dynamic computerized communication device. The teachers are the first to tell you that they lack expertise in this area, but repeated attempts for external grants to increase augmentative communication in her school have been denied. It also does not help that the general belief of the district-wide assistive technology consultants is that preschool-age children are too young to scan, effectively eliminating the right to communicate for any child unable to point and press a button unless the parents provide the device.

Almost every child in my daughter's class could use a communicator to some degree. Why don't they have them? The major reason is that most of the parents do not even know the technology exists. Shockingly, many therapists, including speech pathologists, know little about augmentative communication beyond PECS. If parents knew about the devices or therapists routinely introduced them to youngsters, perhaps demand would lead to much greater access.

The saddest situation of all is the teacher, therapist, or even parent who has made up her mind that a given child does not have the physical skills or the cognitive skills to use a communicator. Had I not pushed so hard to get a device for my daughter, my guess is she may have fallen into this category. She is extremely physically limited, visually impaired, and only has two consistent volitional movements, severely limiting her methods of access. But she CAN do it, perhaps not proficiently, but enough to get her message across and have a little fun telling jokes.

I believe that there are children across this country who would be able to communicate to some degree if just given the proper equipment, ongoing training, and, most importantly, a chance to try. It is time for all of us as parents and compassionate citizens to demand our children be given a voice, even if that means a \$7000 communicator and daily sessions with a specially trained augmentative communication expert.

I cried the first time my daughter said "I love you" with her communicator. Every child has the right to communicate her love for her mother, and every mother has the right to hear those magically touching words.

¹ <http://www.tash.org/IRR/resolutions/res02communication.htm>