

Talking Politics: Empowering Communication Aid Users

Rosemary Crossley

Deal Communication Centre

Recently I had a phone call which reminded me how important communication is, and how vulnerable it is for people who cannot use their own voices.

The caller was 'Laura', mother of 'Fred', an adult with multiple disabilities who had used a Canon Communicator at his day centre and at home for many years. Because of his disabilities it is essential that someone holds the communicator and supports Fred's arm while he types. Last year, Fred moved to another day centre, which apparently doesn't believe in using any communication aids, and his attendant carers changed. This left his elderly mother as his only communication partner, and she only got out Fred's Canon when she wanted to know something, not when he had something to say.

Laura was ringing to say that she has just discovered that Fred is blind in one eye, due to a detached retina caused by him hitting himself when he was frustrated. She feels very guilty about this, and feels that his reduced communication opportunities have contributed to his frustration. Laura has been trying to get Fred a Macaw which would be easier for him to use without facilitation, for some time, and while he was waiting for this, his communication seemed to have fallen into a black hole, with no new partners being trained.

While a number of factors contributed to this tragedy, it seems reasonable to suggest that if everyone in Fred's life had recognised that he had a right to communicate it may have been prevented. The day centre would have enabled him to use his Communicator. The attendants would have been trained. Backup would have been provided for Laura as she aged, or a more independent communication strategy found for Fred. The agency responsible for providing the new aid would have done so more quickly. And so on. As it was, communication was apparently seen as an optional extra for Fred, to be provided or not at the whim of others. Silencing Fred was easy, because without his Communicator he had no way of complaining.

Disempowerment

A journey of a thousand miles starts with one step. The first step in establishing a right to communicate for non-speech people is to examine the current situation. An over-riding theme in the accounts of communication aid users is the disempowerment which many people with communication impairments, regardless of diagnosis or age, have experienced -- often at the hands (or on the recommendations) of professionals, but also in their families and the community at large. Disempowerment is often associated with an absence of communication, either because a means of communication has not been provided, or because an individual's communication strategy is for some reason unacceptable.

An associated issue is the relative importance given to the convenience of non-disabled people and the convenience of communication-impaired persons. While this obviously affects people who use facilitated communication, it also affects everybody whose communication is partner-dependent. The issue of convenience arises often with communication boards, which are inconvenient for speakers because they have to look at the board for relatively long periods of time while the user is putting together his or her message. People who use them may have their attempts to communicate ignored or find that speakers, even family members, cannot be bothered to use the board and shut it away. Part of the appeal of electronic communication aids seems to be that they reduce the effort and time

required of non-disabled communication partners.

Jim Viggiano, an institutionalised non-speech American with cerebral palsy, wrote

Half of the time I go to communicate some of the staff say 'What the hell do you want?' or 'Get lost' or 'I haven't got the time for that damn spelling board.' Some people have asked me questions and walked away before I point to a word to answer.

Most communication aid users, even those with very severe physical impairments, still rate their communication difficulties as their most severe disability. Ruth Sienciwicz-Mercer wrote that:

I have found that the most difficult aspect of my disability has been my lack of speech. People in the community at large have a tendency to equate one's speaking abilities with one's intelligence... The misconceptions on the part of those around a non-speaking person can be both painful and dangerous to that person, as it usually means he or she will be treated in a sub-human manner.

The varying ways in which speakers underestimate or misdiagnose people with severe speech impairments are summarised by Bob Counsell, who has severe dysarthria. He describes the different responses provoked by his speech:

Whenever I meet someone new ... if I don't speak to them I offend them... If I do speak to them they react in one of four ways; they look at me in horror and think that I am mad, they shout at me thinking my impeded speech means I am also deaf, they hear my voice and begin to ask those around me questions which should be asked of me, or they speak to me as they would to a baby or a beloved family pet.

The perception of non-speakers as stupid is raised frequently. Writing in 1981 about community attitudes, Maree Ireland remarked that,

"especially with nonverbal people, there is still the assumption that we are people with less intelligence than themselves ... Like that saying "Innocent until proven guilty", we should adopt a saying "Intelligent till proved unintelligent" without the need to prove it."

In 1996 Maree, now a lawyer, had the opportunity to explore current assumptions when she and some other CAUS members attended the memorial service for nine residents of a state institution who had died in a fire. Being the most obviously disabled group present, the CAUS members were presumed to be residents of the institution and a number of strangers came up and welcomed them with gracious condescension. Two people patted Maree on the head.

Evelyn Mosely, a Victorian communication aid user, found that when she lost her speech after an attack of encephalitis more than her communication was disregarded:

Meeting new people ... was a frustrating experience.... Even when they became aware of the communication board they would direct the conversation to the person with me, not to me personally, and they avoided eye contact. This was when the impact of the communication barrier really hit me. I had become invisible.

Sometimes it is better to be ignored -- almost all non-speakers experience people talking about them in their presence. It is as if they are believed to be uncomprehending or unfeeling, if not deaf. At the age of 12, Anne McDonald heard a nurse say loudly that she would die from starvation in the next six months; at age 16, she was introduced to a middle-aged woman who said "If it was a puppy you'd knock it on the head, wouldn't you?"; at age, 20, after *Sixty Minutes* screened a story about her, a viewer wrote in to say she should be killed. The interesting thing about this last comment was that the producer had no hesitation

in putting it to air, an action which would be almost inconceivable if she had been a member of another devalued group -- black or Jewish, say.

Talking Politics

A significant social movement becomes possible when "there is a revision in the manner in which a substantial group of people, looking at some misfortune, sees it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable to society." The deaf community has produced many representatives who advocate for deaf people in general and complain of prejudice and discrimination - who perceive their problems as stemming from injustice rather than simply being the way things are for people with communication impairments. What about non-speakers?

Not only has action by non-speakers not been documented in the same way, its absence has been noticed. In *Stigma*, Erving Goffman suggested that the sociological study of stigmatized persons was "usually connected with the kind of corporate life, if any, that is sustained by those of a particular category." He cited "speech defectives" as a group "whose peculiarity apparently discourages any group formation whatsoever" (Goffman, 1968: 33-4). In the 1960's, before the introduction of Blissymbols and the development of electronic communication aids, this would have been a fair comment, as without advances in communication techniques and technology it was then impossible for non-speakers to undertake group action. Any groups of "speech defectives" would have consisted of individuals whose dysarthric speech was not understood by outsiders, and who were therefore not recognised as communicating.

By the 1980s enough non-speech people had obtained a means of verbal communication for it to be possible for them to form their own organisations.

When the Communication Aid Users Society (CAUS) started in Melbourne in 1981 it was reportedly the first organization set up by and for non-speakers anywhere in the world, a milestone in the development of group identity. Interestingly, CAUS has remained an organisation for those with severe communication impairments associated with severe physical impairments such as cerebral palsy and acquired brain damage. While there is nothing in the rules excluding people with diagnoses such as autism or Down Syndrome, the people most likely to use facilitated communication, this population has shown no interest in joining CAUS, possibly because information about CAUS has not reached them. The 1995 CAUS conference in Melbourne was also a landmark -- the first national conference in Australia and possibly the world to be held by communication aid users rather than about or for communication aid users.

Speech impairments associated with severe physical handicap, in particular cerebral palsy, place great barriers in the path of political organisation. Nonetheless, while the history of communication intervention with this group is very short (scarcely three decades) the first people with severe communication and physical impairments from birth are now educated adults with jobs and children. Having succeeded in the terms of the wider society, they have the skills necessary for effective lobbying, if they choose to use them.

Recent developments in mainstream communication technology, particularly in Internet access, have allowed non-speech people to connect to an extent which has not been possible previously. There is now an international community of articulate, active non-speakers who interact through ACOLUG, the Augmentative Communication On-Line Users Group. While every non-speech person certainly does not have access to the Internet, more AAC users are already connecting through ACOLUG than have ever been able to meet together, and they are sharing information and discussing advocacy issues around the world. This is a real opportunity for group formation, but one which as yet has not been taken up by FC users.

The first moves to establish a right to communicate started in the late eighties. In the United States AAC user Bob Williams tried to make the connections necessary to create a movement for non-speakers' rights through *Talking/Politics*, a newsletter for people

interested in thinking together about communication rights, set up in 1989 by Mayer Shevin. Williams said that

In the words and deeds of Anne McDonald and others with severe disabilities worldwide, we can hear the makings of a clarion call if we choose to listen. It is a clarion call to action similar to one issued nearly a decade ago. In 1979, the Centre for Human Policy helped stir many of us to action by calling for a universal community imperative. Ten years later, the typical life experiences of people labeled severely or profoundly disabled demand that we take another step closer to true community.

One way we can do this is by issuing a communication imperative which affirms and asserts that: **Every person regardless of the severity of their disabilities, has the right and the ability to communicate with others, express every day preferences and exercise at least some control over his or her daily life. Each individual, therefore, should be given the chance, training, technology, respect and encouragement to do so.**

Williams used words familiar from the American civil rights movement:

December 15, 1991, will mark the bicentennial of the ratification of the Bill of Rights, and its First Amendment guarantee of free speech. In the nearly two hundred years since the First Amendment's adoption, freedom of expression has gone on to be recognized not only as a fundamental right but a prerequisite to the full enjoyment of all other civil and human rights. However, for far too many Americans, freedom of expression remains an unrequited right at best: an American ideal which has yet to be fully realized.

He sought to build an organisational base for communication rights by mobilizing

"persons with severe speech disabilities to work in close alliance with our families, friends, and all other supporters of the First Amendment throughout the nation to realize free expression as a real right at long last"

Anne McDonald gave a presentation at the 1992 TASH disability conference in San Francisco entitled The Right to Communicate in which she proposed the establishment of "a right to communicate in formal situations such as courts, hospitals and schools" because "Without such legally enforceable rights, people without speech will be at the mercy of decision-makers who can arbitrarily refuse to disallow communication." Her words formed the basis of a resolution passed by TASH in 1993 and widely-promulgated in the U.S. (but virtually unknown in Australia). Bob Williams is now the U.S. Commissioner for Developmental Disability, the first non-speaking person in the world to head a government department.

New Voices

As successful lobbying and networking, especially for non-speakers, require academic skills if not formal qualifications, one would expect activism to follow on education. Sue Rubin, a Lightwriter user who started to type with facilitation, has just graduated from high school in Los Angeles and has taken Cesar Chavez, the organizer of farm workers, as her role model, maybe the wave of the future. She uses e-mail to communicate with other people with autism and writes that "Using Chavez as a model, I must organize autistic people who are able to communicate, to advocate for our human rights, and bring abusive situations to the public light..." She is realistic in her recognition "that people will not make changes in the condition of the disabled only because it is the right thing to do" but asserts that 'advocates can fight a world indifferent to our needs.' Rubin, who was once assessed as having an IQ of 24, recently won a major university scholarship in open competition and received a letter of congratulation from the President of the United States, Bill Clinton. Not only her words but also her achievements are agents for change.

Twenty-five years ago Bob Williams, Rick Creech and other successful AAC users and

advocates were the same age as Rubin is now. They blazed a trail which many other people with severe communication impairments have followed. Sue Rubin, Lucy Blackman, an FC user who has recently graduated university, and others like them may do the same for those who need facilitation in order to communicate. As Matthew,, "a voice of Autism, no longer silent" wrote "No disadvantaged group in man's history has improved their lot without being heard. Our situation is no different."

We live in an age of rapid technological change and communication, an age with the capacity to provide the mute with voices and spread the news around the world within a day. But those who are mute have a significant social role based on their disabilities -- they provide employment for large numbers of professionals, professionals trained to assess, teach or nurture people with severe disabilities. Consequently, their push for rights and autonomy is not only likely to meet resistance from those who don't know them - politicians, bureaucrats, the general public -- but from those who do -- their teachers, nurses, carers and parents -- those who believe they know what's best for them.

Unless we can establish an over-riding right to communicate, encompassing the right to accurate diagnosis and early intervention, the provision of communication aids as a matter of right (as is the case with hearing aids for deaf children), and access not just to therapy but to mainstream education, and ultimately to employment, we will find ourselves reaching a dead end. A lucky few will get the communication aids and education necessary to achieve their potential, a larger group will get limited vocabulary communication aids and limited education -- enough to complain but not enough to succeed -- and the majority will get so little in the way of communication and education that they will never be able to complain.