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Abstract

These two pages were handouts at the "Right to Communicate" conference in 1992. Anne McDonald, who fought a hard battle to gain her discharge from an institution in Victoria with the aid of facilitated communication (introduced to her by a worker named Rosemary Crossley), summarises the right to communicate. Professor Doug Biklen, Director of the Facilitated Communication Institute at Syracuse University, USA, summarises access to communication, the presumption of competence, legal issues and education with regard to the right to communicate. **Keyword: Self determination**

The right to communicate

**Conference papers and handout
McDonald – Borthwick – Bicklen – Mayer Shevin**

F/16/17

Anne McDonald has had athetoid cerebral palsy since birth and was once diagnosed as having profound intellectual impairment. She cannot talk, walk or feed herself, and she communicates by spelling with facilitation. She was placed in St. Nicholas Hospital, Melbourne, an institution for people with severe disability, at the age of three, and lived there for twelve years before Rosemary Crossley established communication with her in 1977. Once she was able to make her wishes known she sought her discharge from St. Nicholas. Her parents and the hospital authorities denied her request on the grounds that the reality of her communication had not been established. Eventually she took a habeas corpus action against the Health Commission in the Supreme Court of Victoria. The court accepted that her communication was her own. She won the case.

More Supreme Court proceedings were required to win Anne the right to manage her own financial affairs. Since those court cases she has passed school and university exams and is now in the final year of a Humanities degree.

For people without speech, talking is often dependent on the generosity of others, either in providing interpretation or facilitation or in giving up time to listen. While this is inevitable, there needs to be an irreducible right to make one's opinions known on issues concerning your future well being. At the moment social conversation and medical consent are equal in the sight of the law, both depending on the accidental availability of communication partners with the necessary skills and commitment. There is no right to be heard. There is no right to an interpreter. There is no obligation to listen.

While social interactions are always dependent on the politeness and tolerance of individuals, it should be possible to legislate for a right to communicate in formal situations such as courts, hospitals and schools. Without such legally enforceable rights, people without speech will be at the mercy of decision-makers that can arbitrarily decide to disallow communication.

Communication falls into the same category as food, drink and shelter - it is essential for life, and without it life becomes worthless.

**Anne McDonald
17 November 1992**

The right to communicate is a both a basic human right and the means by which all other rights are realised. All people communicate. In the name of fully realising the guarantee of individual rights, we must ensure

- that all people have a means of communication which allows their fullest participation in the wider world;
- that people can communicate using their chosen method, and
- that their communication is heeded by others.

Where people lack an adequate communication system they deserve to have others try with them to discover and secure an appropriate system. No person should have this right denied because they have been diagnosed as having a particular disability. Access to effective means of communication is a free speech issue.

Access to Communication

All persons born with disabilities should be given therapy and training directed towards permitting them to communicate freely. All people with communication handicaps should be given the full opportunity to use augmentative and alternative communication. 'Access' includes access to assessment to judge the suitability

of the method, access to training in the method, and access to any equipment needed both in the short term during training and in the longer term for continued use on a daily basis if training is successful.

Education

Education in communication techniques is an essential element of the education of people with communication disabilities. People using augmentative or alternative communication must be given any assistance necessary to use that system in the educational system. Any equipment, training or staffing necessary to enable communication to take place must be supplied, both to that person and to those with whom he or she wishes to interact on a regular basis.

Freedom to Communicate

No person should be able to veto the use of another person's augmentative or alternative communication, and in any instances where such use is forbidden there should be a recourse to the legal and protective systems. People with communication disabilities must be allowed to use the communication system of their own choice in all communication interactions in any setting.

Legal Issues

People using augmentative communication must be permitted to use the system of their choice in court. Any person using a communication strategy requiring the involvement of another person to receive and relay their communication e.g. manual sign, communication boards, facilitated communication, must be permitted to use the partner of their choice in court.

Presumption of Competence in Decision-Making and Advocacy

People are presumed to have an active interest in decisions affecting their lives on a short-term and long-term basis. In planning or decision-making on a person's behalf, that person's participation must be ensured regardless of the formal communication modalities used. This may include the involvement of allies, advocates and communication partners before and after meetings, and may also include the involvement of a "communication ally" during the course of the meeting.

Doug Biklen, Chris Borthwick, Mayer Shevin, 1992