

ANNE Mc DONALD
A lesson in the assessment of people
who have severe disabilities and little or no speech



B.Hum, Deakin University 1994

Anne McDonald had severe cerebral palsy, and couldn't walk, talk or feed herself. In 1979 she was living in St.Nicholas Hospital. She was 18 years old but weighed only 15 kilos after 14 years in state care. She had been labelled severely retarded.

When Anne used facilitated spelling to ask to leave the hospital, the Health Commission said her files only contained negative assessments of her cognitive and communicative status, and they wouldn't let her go.

The Health Commission achieved the desired degree of negativity by

1. Concealing and/or denigrating all positive reports about Anne's communication and academic skills, including test results.
2. Accepting reports by people with little or no expertise in non-speech communication as valid evidence.
3. Citing reports by professionals who conducted 'assessments' without allowing Anne to communicate because no-one told them how Anne communicated. (Remember, a quadriplegic without speech has no way of telling people she needs her communication aids, and can't just go and get them.)

4. Using functional assessments that could not be passed by anyone who could not speak or use their hands.
5. Obtaining a report by a group of 'independent experts' whose views were well known, and who relied on the negative reports from 2, 3 and 4 above.
6. Inflating the number of negative reports by citing the group assessment in 5 above as separate individual assessments.

Despite the Health Commission's dishonesty Anne won her action for Habeas Corpus in the Supreme Court, left St Nicholas, co-authored Annie's Coming Out, graduated from university and became an internationally-known advocate for people without speech. She was presented with the National Disability Award for Personal Achievement in 2008.

Anne died suddenly on October 22nd 2010.

Sadly recent emails show that nothing has changed in the past thirty years. People who cannot speak are just as vulnerable to mis-statements and mis-assessments now as they were when Anne was incarcerated in St. Nicholas.

Back in 1992 Anne gave a presentation at the TASH Conference in San Francisco in which she said:

For people without speech, communication is always difficult. It is slow, and often restricted by constraints of body and mind. For successful communication to take place, it is necessary for both parties to be patient and persevering.

The person with severe communication impairments is always vulnerable to the manipulation of people who can speak. The most common manipulation is the refusal of the speaker to acknowledge that the non-speaker has opinions and the right to make these opinions known. Can we really say everyone has free speech when many people with severe communication impairments have no means of communication and many of those who do have communication skills are not allowed to use these skills?

We must 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 who 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's words remain true today.