



Anne M^cDonald Centre

A new deal for people with little or no speech

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**Submission to the
Parliament of Australia
Senate Community Affairs Reference Committee
*Prevalence of different types of speech, language and
communication disorders and speech pathology services
in Australia*
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People with Little or No Speech

This submission from the Anne McDonald Centre is on behalf of hearing children and adults with very severe and intractable speech problems, most of whom are unlikely ever to speak more than a few words. Typically they receive scant benefit from standard speech therapy. Instead they need access to communication aids, and to skilled professionals to teach them how to use them. It is hard to find reliable figures on the incidence of such severe expressive impairments as they are typically associated with other diagnoses, such as CP, ASD, DS, ID, MND, PD, CVA¹ etc, but a commonly used minimum figure is 1 in 500 Australians, or some 46,000 people.

The Anne McDonald Centre

When the Anne McDonald Centre opened in 1986 under the name DEAL Communication Centre, it was the first service in Australia solely dedicated to providing therapy to people with little or no speech. In the years since we have seen 3,000 people who need communication aids, and have been active in lobbying for increased rights for all people who cannot speak.

In addition we have researched and reported on the needs of specific groups of people who need communication assistance, including nursing home residents, children with Down syndrome, girls with Rett syndrome, and people with acquired brain injury diagnosed as being in persistent vegetative state (in conjunction with Melbourne University and St Vincent's Hospital). Most recently we have been investigating the use of iPads as communication aids by children with autism, in a project funded by the Paul Newman Foundation.

We are a small charitable organization. We provide free services to people without third party funding.

¹ CP – cerebral palsy, ASD – autism spectrum disorder, DS – Down syndrome, ID – intellectual disability, MND – motor neurone disease, PD – Parkinson's disease, CVA – cerebro-vascular accident (stroke)

AAC² can be life-changing

While improving speech and articulation is important, finding a substitute for dysfunctional speech can literally be life-changing. Without a means of communication non-speakers are condemned to life on the margins, with no ability to participate in school, to work, manage their affairs or vote. And of course their social interactions are extremely limited. Imagine never being able to say “I love you.”

Assessment: AAC & IQ

Children without functional speech need alternative means of communication as early as possible, ideally by the age of 2, for obvious social and emotional reasons. Research shows that using an augmentative communication strategy will not impede speech, but will scaffold speech in those children who have the potential to speak. And of course it will allow those who cannot speak to communicate.

An additional reason for ensuring that all children are able to communicate fluently before age 5 is that many education departments insist on using IQ tests such as the WISC, which are normed on children who can speak, with children who can't speak.

Without AAC, children without speech cannot hope to show their potential. They typically receive IQ scores of less than 50 and are excluded from academic education. Their families often believe the test results, compounding their problems.

Lack of speech does not equate with lack of intelligence. There are lawyers, accountants and academics without speech who use communication aids in mainstream employment.

Sadly however, most people without speech do not receive either the communication intervention or the education that would enable them to make it into the workforce, or to vote, or to take charge of their lives.

Victims of a shortage of Speech Pathologists?

While there is an overall shortage of Speech Pathologists, people with little or no speech are just as likely to be victims of Speech Pathologists who are ill-trained or untrained in AAC. Most speech pathology courses barely give a token nod to AAC³ however Speech Pathology Australia still claims it as an area of expertise for their members. In the nature of things many of the skills taught to speech pathologists are not useful to people who cannot talk.

AAC is a complex multi-disciplinary field, involving elements of occupational, speech and physio therapy, and education. Any professionals working in AAC will have acquired their AAC skills after completing their basic qualification, probably through an internship and personal study. Often the parents of long-term AAC users are more expert than the professionals who are meant to be helping their children.

² Augmentative and Alternative Communication, the technical term which includes all the communication strategies used by people who cannot talk.

³ To put this in context, we delivered AAC courses for Certificate 3 and 4 students at Victoria University in 2010 which were twice as long and far more practically based than those being provided in most undergraduate Speech Pathology courses at the time.

As said above, AAC expertise extends across several disciplines, and is typically acquired on an individual basis rather than through formal training courses. Nonetheless it is convenient for bureaucracies to assume all AAC expertise rests with Speech Pathologists, and that all Speech Pathologists are AAC experts.

This has several undesirable consequences –

It contributes to the admitted shortfall of Speech Pathologists by putting pressure on them to step out of their area of expertise, and to complete the forms and write the reports required to obtain communication aids (which they may or may not know how to use).

It disadvantages non-speaking children and adults who may be assessed and treated by Speech Pathologists who mistakenly think they have the requisite expertise to decide whether an individual needs a communication aid and what aid is appropriate.

It leads to under-use of people with strong AAC backgrounds who are not Speech Pathologists.

Case study:

Two days ago 'Joe', an 18-year-old with autism, was brought to the Anne McDonald Centre for the first time. His speech was echolalic and dysfunctional. He had attended a school for students with IQs less than 50 and had no history of successful AAC use, despite having been seen by Speech Pathologist's during his 13 years at school. He had never even been given a strategy for answering Yes/No questions (he couldn't nod and shake). We gave Joe a 25 cm laminated strip with NO at the left end and YES at the right, and showed him how he could point to it to answer questions. He was able to point clearly and independently, which it made it easy to assess him.

Are you a guy? YES
Are your brothers girls? NO (with a grin)
Is Mum a guy? NO

After a few more such questions we moved on to a Wiig-Semel receptive language assessment, which only requires Yes/No responses. He scored 10 out of 10 on the first set of questions, a score appropriate for a 10 year-old. The test is geared to primary school children, so he could not be rated higher, but he had already broken the IQ 50 barrier, and flabbergasted his mother who had not realized he could understand even simple questions like "Are lemons sweeter than lollies?"

Joe went on to demonstrate and learn many more skills during the next hour. While his mother had warned us that Joe had a very short attention span and paced around all the time, he sat and concentrated for the full hour and at the end used the communication aid we had been showing him to say GOODBYE THANK YOU.

While it was exciting to see what Joe could do, it was also very sad. He has finished school and started attending an adult centre for people with ID, which

does not offer any educational programs. Enabling him to catch up on what he has missed is a huge task, and it may well not happen.

All that was needed to get Joe started and to establish that he had potential was a strip of laminated paper and the expectation that he might be able to use it. Not rocket science. He and his family have been failed by his school's speech pathologists and teachers, and the system that labeled him on the basis of an inappropriate IQ test.

Services for adults as well as children

It is often assumed that communication therapy is only necessary for young children (and a few adults with acquired disabilities). This is a serious error. While responsiveness to traditional speech therapy tapers off with age, children who have not responded to speech therapy will continue to need AAC support. And adults who have been long-term AAC users will need their systems reviewed and upgraded every few years.

"Janet" is an adult with cerebral palsy attending a day program run by one of the largest service providers in Victoria. When meeting Janet socially recently it was harder to converse with her than it had been when she was a teenager, because her communication board had been dumbed down by a new speech therapist, and the alphabet she needed in order to spell had been removed. Obviously this had happened some time ago as the names of staff on the board were completely out of date. Not surprisingly, Janet seemed very depressed. For the past 5 years that agency has not provided communication therapy to any of the adults attending its centres because of funding shortfalls.

Education Department responsibilities

In Victoria special school principals have a great deal of autonomy, and there appear to be no guidelines or expectations as to how the needs of their students should be met. While students with long-recognised and well-understood disabilities such as visual or hearing impairments usually receive appropriate support, there appears to be no notion as to what constitutes appropriate support for children who can hear but not speak, and who are likely to have been labeled as intellectually impaired.

The proportion of a school budget devoted to communication therapy appears to be completely arbitrary, and quite unrelated to the number of students needing help. Some schools refuse to allow any non-speaking students to use electronic communication aids, restricting them to a few picture cards. Some schools cease all attempts at communication intervention when students turn 12, and just 'try to make them comfortable' after that (personal communication from speech pathologist at a special school for children with physical disabilities, January 2014). Special Education courses in Victoria contain very little on AAC, so few teachers are equipped to assist students who need to use communication aids.

While this is a state issue, it is clear that any improvements in the availability of Speech Pathologists and in their training are going to have scant effect without major policy and perceptual changes in Education Departments and providers of residential

services and day programs for adults, and appropriate training for those staff who will actually be interacting with communication aid users on a daily basis.

Programs targeting specific ages or diagnoses.

Some years ago Commonwealth funding was made available to the parents of young children with autism, with the aim of enabling them to purchase services, especially speech therapy. This was disastrous, for the following reasons:

1. No-one had checked that there were unemployed or under-employed Speech Pathologists available to work with children with autism. There weren't, but the funding was generous, and this led many Speech Pathologists to advertise their willingness to work with children with autism, dropping their previous clients.
2. No-one checked if the therapists offering services had any expertise in autism, so a lot of money was wasted paying therapists who achieved nothing.
3. Parents of children with other disabilities either could not obtain speech therapy at all or had to pay more, out of their own pockets, to match the autism rates.
4. It became almost impossible to find speech therapists to work with older children or adults.
5. The demand for therapy became so great and waiting lists so long that some parents of young children entitled to funding were highly distressed to find that they could not receive services before their child turned 6 and aged out. (The fact that the government had provided funding sent a strong message that this intervention was vital and that if you didn't spend your funding you were failing as parents.). Support groups were established and finally the federal government extended the age range.
6. Parents of children with other diagnoses such as CP and Down syndrome were understandably ignored that their children were not seen as worthy of funding, and the scheme was extended, again on the basis of diagnosis, not need. This of course extended waiting lists and made it even harder for schools and adult services to obtain Speech Pathologists, especially experienced Speech Pathologists who might have some knowledge of AAC.

Providing more positions in Speech Pathologist courses, and encouraging and funding Speech Pathologist graduates to undertake specialist training in areas of need, training that could be specified in job advertisements, would have improved both the availability and quality of services.

How therapy services should be made available to children whose parents cannot afford to pay private rates is another issue. Better funding of early intervention programs is one option for younger children. For school age children, a pro rata allocation of therapy services based on the individual needs of a school's students could be appropriate, providing everyone wasn't just classified as requiring a half-hour group speech session once a fortnight, which is the most common therapy allocation reported to us. Basically useless, all it does is to allow schools to say they are providing speech therapy.

The Right to Communicate

Disregard of the needs and rights of people who cannot talk is extraordinarily pervasive. Late last year we had a phone call from an official from the Office of the Public Advocate in regard to one of our adult clients, for whom we were trying to obtain access to communication. She said that it was too much to expect the staff in the client's Department of Human Services residential unit to use a Yes/No card to ask her questions, such as "Would you like a drink?"

You will be aware of the UN's statement about the right to communicate.

We supplement it with a statement written by Anne McDonald (1961-2010) in 1992:

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.

Please do everything you can to empower people with little or no speech, and ensure that they do receive the skilled assistance they so desperately need.

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APPENDIX 1

Anne McDonald

National Disability Award Acceptance Speech

Parliament House, Canberra, December 3rd, 2008

I spent my childhood and adolescence in a state institution for severely disabled children. I was starved and neglected. A hundred and sixty of my friends died there. I am a survivor.

That isn't a heroic achievement. Anyone who was put into a large institution in the times when large institutions were sugarcoated concentration camps was as much a hero as I was. They stayed alive when they could and they died when they couldn't. Such heroism is easy to achieve in giant barracks where the prisoners stay alive through being cheery enough to attract a staff member to give them that vital extra spoonful of food.

I wasn't exceptional in anything other than my good luck. I was selected for an experiment.

Rosemary Crossley wanted a subject for her Bachelor of Education literacy project. She chose me. The aim of the experiment was to see if I could make gains in my tight-armed pointing to blocks with different colours on them. Rosemary found I could point to colours, then to words, and then to letters. She taught me to spell and to make my wishes known.

I made known my wish to leave the institution, and then all hell broke loose. I went to the Supreme Court and won the right to manage my own affairs.

Unfortunately, that didn't mean that the institution offered the other residents the right to manage their own affairs. I was an exception. Through no desire of my own, I was out front in the struggle to get rights for people without speech.

I tried to show the world that when people without speech were given the opportunity to participate in education we could succeed. I went to Deakin University and got myself a degree. That, too, was seen as an exception.

I gave papers and wrote articles on the right to communicate. I set up a website to show that there was hope for people without speech.

People thanked me for being an inspiration; however, they didn't understand why there weren't more like me. They continued to act as if speech was the same thing as intelligence, and to pretend that you can tell a person's capacity by whether or not they can speak.

Please listen to me now.

The worst thing about being an inspiration is that you have to be perfect. I am a normal person with only normal courage. Some people who should know better have tried to give me a halo. Anybody could have done what I have done if they too had been taken out of hell as I was.

If you let other people without speech be helped as I was helped they will say more than I can say.