

TO: Productivity Commission Disability Support Inquiry
FROM: Catriona Gunn

Sue Egan of PDA has asked me to make a submission with respect to the communication needs of people with disabilities, particularly those who have "complex communication needs" but also anyone unable to communicate independently. I made a similar submission to the previous inquiry held by the Productivity Commission. The situation has not changed since that time, except that there are now an increased number of both people who have complex communication needs and those who are not able to communicate independently.

The definition of being able to communicate independently is considered to be, "**The ability to make contact at any time with a stranger and ask for assistance without the assistance or interference of any other person.**" Anyone unable to do this is considered to have a communication impairment. By definition those with complex communication needs are also unable to communicate independently. This is an issue which raises questions of participation in family life, participation in society, access to services, privacy and, even more importantly, safety and protection from abuse. The failure to address the issue, indeed even to recognise that it exists, is cause for serious concern.

Communication issues affect at least 80% of all people with disabilities, possibly more. They can range from mild difficulties with making a verbal inquiry or handling written material to profound difficulties in communicating simple messages. Even mild difficulties can cause major problems with respect to access to services. Those with profound difficulties often find that they are not consulted about decisions taken with respect to their welfare.

The research I have undertaken very clearly shows the following:

- (1) People with disabilities do not have the same level of access to sources of information as people without disabilities. Overall literacy skills are significantly depressed, especially (but not exclusively) among people with intellectual disabilities.
- (2) People with disabilities have a significantly lower rate of access to the internet, to newspapers, to other written literature and to their personal choice of radio and television programmes. As a result they are significantly less well informed about a very wide range of issues. This affects their capacity to access services of all types, not just services concerned with disability.
- (3) It is clear that this lack of access is sometimes being used by others to deny people with disabilities the services to which they are entitled. *"If they don't know about something I am not going to tell them. It saves the government money and money is tight. I would rather use it to shut up those who do know."* (Comment by public servant.)
- (4) Although documents are said to be written in Plain English the reality is that many people with disabilities still do not understand written literature which is given or sent to them. This is often not recognised by those who have provided the material, especially when forms are returned after being filled out by a family member or carer.
- (5) If they require assistance to fill in forms the information on forms is sometimes inaccurate. *"He didn't know the answers so I just made some up."* (Carer.) It is common for those who require assistance to provide inaccurate information because they do not know the answers, do not wish to share private information with a carer outside the family, because they misunderstand the nature of the question being asked or believe that certain answers are required of them. (This is particularly where issues can have 'politically correct' connotations and people believe that to offer an honest opinion will label them as politically incorrect.)
- (6) There is still a serious and widespread problem for those who require assistance to vote. Many of those who have to rely on others continue to say that they dislike being dependent and will vote in accordance with their helpers (perceived) wishes rather than risk retribution. It is also clear that there are a number of people on the electoral roll who are not able to make an informed vote and that their carers effectively have a second vote.

- (7) There have been great advances in technology designed to give people with profound complex communication needs a 'voice' through the use of 'voice output communication aids' (VOCAs). These are still expensive and, especially where children are concerned, can frequently break down and require repair. The provision of these, their care and repair are still issues of great concern. It is also a matter of concern that alternative and extremely cheap communication aids are not made available because of a range of time constraints, lack of awareness and philosophical objections to means which are not seen as 'normal' modes of communication. It is of particular concern in relation to children who have been placed in mainstream schools and can adversely affect their ability to participate in school life for considerable periods of time.
- (8) While written material is sometimes provided in languages other than English there is still insufficient attention being given to the needs of people with disabilities who come from non-English speaking backgrounds and homes where English is not the primary language. The apparent severity of a disability can be greatly magnified by failure to address this issue.

Where people have complex communication needs and use an augmentative or alternative communication device research strongly suggests the following:

- (a) Access to communication improves the ability to access services and the standard of care given to the individual
- (b) Access to communication improves the independence able to be displayed by the individual
- (c) Access to communication reduces the time required to help care for the individual by between 20-30 minutes a day.
- (d) Access to communication increases the satisfaction with the care received.
- (e) Access to communication reduces the time required to resolve issues about care on a daily basis and with respect to longer term outcomes.
- (f) Access to communication increases contact with the community. There is a direct correlation between the number and type of interactions made by a person with CCNs and the provision of appropriate communication aids.
- (g) Overall there is a direct positive correlation between access to communication aids and the health, welfare and care of a person with CCNs.

There is an urgent need to set in place a national strategy to raise awareness of the needs of people with complex communication needs, an awareness of the value and use of diverse alternative means of communication and ongoing training for those who work with people who have CCNs.

There is a small but active chapter of the International Society of Augmentative and Alternative Communication in Australia. Time and financial constraints have lessened the potentially very positive impact of this group. It is still attempting to obtain Deductible Gift Recipient status and this is indicative of the lack of awareness on the part of others as to how communication impairments can impact on the life of individuals and those around them.

It is suggested that the biggest problem faced by people with communication impairments is that they are in fact unable to communicate the depth and breadth of their largely invisible difficulties and thus their needs go unnoticed by all, including those holding successive inquiries into all other aspects of disability. However, until the issue is addressed, there cannot be a significant improvement in service delivery for people with disabilities.

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