

PRODUCTIVITY COMMISSION

Inquiry into the *Disability Discrimination Act 1992*

Public Inquiry

Submission from ISAAC-AUSTRALIA (International Society for Augmentative and Alternative Communication – Australian Chapter)

Submitted by:

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3rd July 2003

About ISAAC-AUSTRALIA

ISAAC AUSTRALIA (Inc) is the Australian Chapter of the International Society of Augmentative and Alternative Communication (ISAAC). ISAAC is an organisation with over 3000 members across 52 countries devoted to advancing the field of Augmentative and Alternative communication (AAC). ISAAC-AUSTRALIA has approximately seventy members. Members of ISAAC-AUSTRALIA include People who use augmentative and alternative communication (AAC), Families of people who use AAC, Speech Pathologists, Rehabilitation Engineers, Occupational Therapists, Teachers, and many others who have a working interest in furthering successful communication for people who have complex communication needs.

About AAC

AAC is used by individuals who cannot use speech as a functional communication mode. Examples of AAC include symbol boards, letter boards, signing, and electronic voice output communication aids. The most famous person who uses AAC is Stephen Hawking.

About Complex Communication Needs

People who need AAC have a severe communication impairment or complex communication needs.

Some people have complex communication needs associated with a wide range of physical, sensory and environmental causes which restrict/limit their ability to participate independently in society. They and their communication partners may benefit from using Alternative or Augmentative Communication (AAC) methods either temporarily or permanently." (Balandin, 2002) p.2

[source: BALANDIN, S. (2002). Message from the President. The ISAAC Bulletin, 67, p. 2.]

Causes of Complex Communication Needs

There may be many causes for a person to have complex communication need, including:

Acquired Disability

Stroke

Parkinson's Disease

Guillain Barre Disease

Treatments for cancer (surgical, e.g., mouth, throat or larynx; radiotherapy, oral or neck region)

Brain Injury

Neurosurgery (as a result of excision of tumors)

Multiple Sclerosis

Motor Neuron Disease

Friedrich's Ataxia

Huntington Disease

Dementia

Developmental Disability

Intellectual disability

Cerebral palsy

Epilepsy

Autism

Autism Spectrum Disorder / Asperger's

Syndromes (e.g., Rett Syndrome; Down Syndrome)

Other

Speech impairment (dyspraxia; disordered co-ordination of speech)

Phonological delay or disorder

Language delay or disorder

Learning difficulties

Stuttering

Voice disorders

Considerations for the Inquiry into the Disability Discrimination Act, 1992:

1. People with 'complex communication needs' require access to an appropriate augmentative and alternative communication (AAC) system to communicate. These include both unaided AAC systems (signing or gesturing) and aided AAC systems (high technology voice output communication aids or low technology communication boards, books or passports). There should be no discrimination (e.g. on the basis of mode of communication, age, level of intelligence, location, gender, race, religion or socio-economic status) against provision of an AAC system to any individuals who requires one in order to communicate. Currently, in Australia there is no legislation protecting individuals' right to communicate. The ability to communicate is the essence of being human. People who are unable to communicate because they cannot speak and do not have an appropriate AAC system are the most disadvantaged in our community. They are open to abuse and discrimination and must be considered under the Disability Discrimination Act.
2. People should not be treated differently to others on the basis of their mode of communication. Mode of communication refers to primary means of expressing or understanding messages, and includes:
 - speech
 - symbol based systems (picture boards, communication books etc)
 - voice output communication aids (electronic devices)
 - gesture
 - writing
 - formal signing systems (such as Auslan or Australian Sign Language)
 - real-object communication arrays
(*this is not an exhaustive list*)
3. Some people need alternative options to access communication devices, computers, the internet, email, and telecommunications; all vital forms of communication in this information age. Such alternative options can include specific software, switch access interfaces, environmental controls, and adapted computer hardware. People with complex communication needs and physical disability may require specialised seating systems and access to computers and communication aids. They require integrated control systems that enable them the greatest level of independence in their environment. Systems need to be tailored to the individual and enable them to switch between control of the wheelchair, environmental controls, and communication systems as needed.
4. All children with disability and complex communication needs should have the same opportunity to participate in the classroom as children who do not have complex communication needs. This means that a classroom may have to be tailored to provide sufficient communication supports and access. Support and access include teacher knowledge and skill in augmentative and alternative forms of communication; access to aids to communication, and physical access to all parts of the school and classrooms. It also includes modification of the curriculum where necessary to ensure that the child who uses AAC can participate to the maximum of his/her ability in classroom activities, including assessment. Children who use AAC must be included in learning literacy and have access to literacy activities, including phonological processing activities which are a prerequisite to learning to read.

Literacy (reading and spelling) is a powerful communication tool and pathway to further learning. Lack of literacy skills disadvantages and disempowers a person throughout life.

5. Adults who have complex communication needs and who use augmentative and alternative forms of communication should not be discriminated against in relation to gaining access to information and education. They should be able to access the appropriate tertiary and vocational education options and should not be prevented from doing so because they do not have access to appropriate communication systems and support.
6. The time taken to communicate with augmentative and alternative forms of communication is typically much greater than the time taken to generate the same message using speech. Time taken to communicate should not be a discriminatory factor in enabling a person with complex communication needs to ask questions, find out information, respond to information, complain, request and so on. Demands to use only one form of communication (e.g., having to put a complaint into writing) discriminates against people who communicate in alternative ways (e.g., by use a symbol board or voice output communication device). Time limits in appointments in government departments (such as Centrelink, in Health Services,) discriminate against those who take a longer time to communicate. This could also be extended to taxis, i.e. the person with complex communication needs should not be charged the extra time needed to give directions to the taxi driver. When receiving direct support from a person (such as in "Home Care") a person with physical disability and complex communication needs may require an increase in the allocated time to communicate with the direct support worker.
7. Use of an AAC system should not compromise access to justice in any way. People who use AAC should be able to give legal report, to communicate in court, to be represented in court, and to address the court using their preferred mode of communication. This is also the case in other legal matters such as in questioning by police, in giving statements, or in providing witness reports.
8. Communicating with augmentative and alternative communication relies not only upon the skill of the person with complex communication needs, but also upon the active communication skills of the naturally speaking communication partner.

Communication partners, including those in government departments and in the community need to have awareness and experience in augmentative and alternative forms of communication to enable successful communication to take place. In the event that communication partners in legal, health or other settings are not knowledgeable or skilled in communicating with a person who uses AAC, the person who uses AAC should have access to an interpreter who is familiar with the person's mode of communication.

9. People with complex communication needs should have access to whatever form of AAC system that they need, whether it be High or Low Technology or a Combination of both. People should not be limited to use of low technology simply because it appears to be the cheapest option.

There will always be a need for low technology communication systems either 'back-up' high technology communication aids, for example if they are under repair or in situations where it is not possible to use a voice output communication aid (e.g. in theatre in hospital, or if a person is lying on their back in bed).

High technology communication aids are any aids that include microchips. They include aids that enable storage of audio recorded messages (digital recordings to the device) or retrieval of synthesised speech messages.

Due to market forces, high technology communication systems are expensive, varying in cost from a few hundred dollars to several thousand dollars. As with any equipment devices break or become outdated and need replacement on average about every 5-7 years. High technology communication aids have voice output and are therefore a powerful communication tool for a person who cannot speak. In addition, most have capacities similar to computers and are therefore useful for a wide range of activities across a variety of communicative contexts, including education, employment and participation in the general community.

Voice output communication aids are powerful. They can be used to communicate across a distance, gain attention, speak over the telephone, speak in a group, communicate independently, and are easily understood by someone who is not familiar with other forms of augmentative and alternative communication.

Voice output communication technology should be available as an option for any person who is unable to speak. Having access to voice output communication can increase independence, decrease reliance upon others to act as interpreters, increase safety, increase access to information, recreation, society, relationships, learning, and employment. At present there are approximately five people in full time open employment who use augmentative and alternative forms of communication in Australia. Most people who are unable to speak spend their days in community access services or at home as they are unable to find employment because they cannot speak.

10. Discrimination against a person on the basis of mode of communication in gaining employment and advancement at work is not acceptable.

It is unacceptable that functional augmentative and alternative communication is not viewed as favourably as fluent speech. A person's entry into a job or advancement at work should be reliant upon their skills and abilities in meeting the job performance criteria, and not upon their mode of communication nor the time it takes them to communicate a message utilising their augmentative and alternative communication system. People who use AAC report that they are discriminated against not because they use an aid to communicate, but rather that the message formulation can take a greater period of time and may be in a different mode (e.g., pictures, symbols, spelling, signing, gesturing). Many jobs specify 'sound oral communication skills' as a requirement, and this may discriminate against those who have 'sound communication skills' but who do not speak.

11. ISAAC-AUSTRALIA support the other submissions to the inquiry that refer to the Definition of Disability becoming tied to the “Social Model of Disability” and the definitions outlined in the International Classification of Function (WHO, 2002) rather than the medical model of disability.
12. ISAAC-AUSTRALIA also supports other submissions that call for a re-naming of the discrimination act to include reference to the ‘person’ with disability – i.e. People with disability discrimination act’. This reflects the perspective that the person is important and an individual and is not defined by any disability. Preference should be given to terms that promote the person’s humanity first “a person with aphasia” or “a person with cerebral palsy”.

Conclusion

In conclusion, ISAAC-AUSTRALIA urges the Commission to consider that to date people who have complex communication needs continue to experience discrimination because:

- They may not have access to most augmentative communication aid, often as a result of cost or lack of training
- Do not have equal opportunities in education or employment due to lack of a suitable communication aid, poor access, and lack of knowledge of educators and employers
- Do not have equal opportunity for community participation due to lack of appropriate communication systems, poor access, and lack of community awareness about communication in a mode other than speech.

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3rd July 2003