

# **AGOSCI Inc. Submission to the inquiry into the prevalence of different types of speech, language and communication disorders and speech pathology services in Australia**

## **Summary**

- AGOSCI is a national volunteer group interested in enhancing the participation of all people with complex communication needs.
- Developing and supporting people with complex communication needs requires specialist multidisciplinary support.
- Specialist services vary across Australia but generally have long waiting times.
- Specialist communication technology is expensive and poorly funded; this may lead to individuals purchasing inappropriate equipment.
- There are concerns that NDIS may limit community education services and not acknowledge the resource intensive nature of establishing and supporting Augmentative and Alternative Communication (AAC) systems.
- Specialised literacy and AAC knowledge is scarce. Literacy is power for people with complex communication needs.
- Mentoring and social support services are lacking for people with complex communication needs.

## **About AGOSCI**

Established in 1981, AGOSCI is an inclusive group interested in enhancing the participation of all people with complex communication needs. AGOSCI also aims to build the capacity of society to achieve our vision.

Our vision is that people with complex communication needs participate fully in all aspects of life.

AGOSCI's membership includes individuals with complex communication needs, family and community members, teachers, speech pathologists and other professionals.

AGOSCI's current activities include:

- Education and Training
- Conference
- National Tour
- State based events

- Networking/Information
- AGOSCI In Focus magazine
- Listserv
- Website
- Participation in Social Media
- Advocacy

Topics associated with complex communication needs may include:

- Augmentative and Alternative Communication
- Speech Generating Devices
- Sign and Gesture systems including Key Word Sign
- Mealtime assistance/dysphagia
- Saliva control
- Personal experiences

### **Focus of this submission**

AGOSCI is one of the major organisations in Australia able to represent the needs of people with complex communication needs (CCN – see definition in Appendix 1). AGOSCI membership includes individuals experiencing complex communication needs, family and community members, teachers, speech pathologists and other professionals. AGOSCI is managed by a volunteer committee with representation in all states and territories of Australia.

Information for this submission has been garnered through discussions with the membership, members' knowledge of services, issues, etc from their experiences in their respective areas in Australia, and topics of discussion that have been posted over our Listserve during the past year. There are currently 693 people registered on the listserv.

This submission has the specific intent to represent people with CCN and their families within the context of this inquiry. The expertise drawn from our membership includes first-hand accounts of the challenges that face people with CCN and their families.

### **Who are people with CCN?**

In a demographic study by Perry et al., (2004), an estimated 0.2% of Victorians are living with a disability and complex communication needs.

Speech Pathology Australia estimates that 14% of Australians have some form of communication disability (*not necessarily defined as a complex communication need*).

The large discrepancy between these figures is an indication of the difficulty defining and identifying those who have CCN as a subset of the larger group with communication difficulty of some kind. It also suggests that there are a large group who may benefit from recognition of the barriers they face and the provision of additional supports. A complex communication need may mean that a person:

- is able to use speech as their main form of communication but is difficult to understand and requires interpretation by another person
- is able to use speech but their expressive language is limited due to cognitive or language delay or disorder
- is only able to use some speech and uses some form of augmentative and alternative communication (AAC) to support this
- is unable to use speech and uses AAC as their main form of communication
- has difficulty understanding spoken language and requires accommodations to support comprehension.

An AAC system refers to a multi modal system of AAC tools that a person may choose to use dependent on the situation, communication partner and requirements of the conversation. This may include gesture, body language, sign language, vocalisations, picture or word boards and speech generating devices. Many people with disabilities use alternate forms of access to select items on an AAC system (e.g. Scanning, head pointer, eye gaze, etc). This adds to the time required to generate a message and may require a support person.

### **Availability of services and supports**

Across Australia speech pathology services for people with CCN vary enormously. Generally, where specialist services are available through publically funded disability agencies, services are extremely limited and the model of service delivery provided has been predominantly aimed at assessment, prescription and sometimes ongoing use of a communication system by an individual. One member stated that waiting list times for speech pathology services in their local area could be up to six months. In another area of Australia, waiting list times for specialist AAC services were reported to be up to two years. Additionally, people may be required to travel large distances to seek specialist services.

Assessment, intervention and support for people with CCN generally requires multidisciplinary input, especially speech pathology and occupational therapy (OT) e.g. OT required for positioning/seating/equipment for clients with swallowing difficulties, and assessment for augmentative and alternative communication (AAC) require input on client's physical skills (reach and point) and vision abilities.

Intervention is lengthy and can be intense, especially when establishing a communication system.

One member brought up concern about the cessation of registration of speech pathologists in Queensland leading to concerns of lack of regulation of quality services. Speech Pathology Australia maintains a program of self-regulation whereby members are required to demonstrate continuous education as well as maintain the ethical values of the Association. Membership of Speech Pathology Australia is voluntary and, while eligibility for membership is often a requirement of many employers, there may not be the same requirement amongst private practices.

This is evidenced by another member who reported that a newly graduated speech pathologist was employed as the sole speech pathologist in a local private practice that was providing specialist services for people with disabilities without supervision.

### **Demands/Service gaps**

Increasingly, referrals are focussed on using iPads or similar technology for communication. While this technology can be great communication tools for some people with complex communication needs, the assessment and implementation of technology for augmentative and alternative communication (AAC) is a highly specialised area of practice.

There is a lack of specialist services to support people who use AAC to learn and implement communication technology. There can be long waiting periods to access services and, due to demand, services are generally limited to assessment only. This relies on speech pathologists in other services to provide support to customise, teach and implement highly technical speech generating device technology for individuals and all their communication partners. As well as a lack of specialist knowledge in this area, there is also a lack of adequate staffing levels in services to provide the ongoing support that a person using a speech generating device requires to maintain and develop their communication skills.

Because mainstream technology is readily accessed people often forego specialist assessment and purchase unsuitable technology. People may source their own technology but then need support to try to make the person fit the technology instead of choosing technology to fit the person.

For those who are unable to use mainstream communication technology and require highly specialised equipment (often due to physical and sensory disabilities) there is inadequate access to public funding for speech generating devices. Funding varies between states and territories and may depend on the age and disability of the person. For more information on assistive technology funding schemes which include funding for communication devices see the following report from Tasmania <http://www.ent.tas.gov.au/ctee/Joint/Reports/Final%20Report%2019%20Nov%202008.pdf>

## **National Disability Insurance Scheme (NDIS)**

The disparity between services which fund communication equipment won't be fully addressed by the NDIS. Currently, if equipment is to be funded via an NDIS plan, they first approach the existing equipment programs (mostly state funded) and then NDIS will provide gap funding. This may further complicate issues around equipment ownership and maintenance.

Another concern regarding NDIS is that the individualised funding does not allow for community capacity development projects, or to work with other people who are in the same environment as a person with an NDIS plan. For example, in a referral for communication strategies to address behaviour concerns of a person living in a group home setting, the intervention ideally addresses the needs of all residents of the house, rather than just the client referred. It may also not address supports and training for support staff and communication partners.

Setting up and maintaining communication systems takes considerable time and is often a hidden task which is not properly resourced. Most speech pathologists who work in the AAC field spend considerable personal time developing and programming resources for communication. This includes taking speech generating devices home to program and printing, cutting out, and putting together communication books in their own time. One speech pathologist reported spending over 100 hours of initial programming of a speech generating device for one client.

Even where organisations have therapy aides or volunteer help to put together resources there still needs to be input from experienced speech pathologists to design and customise resources. There is concern that this time will not be adequately covered under NDIS plans and that, being "hidden" time NDIS participants may not think to prioritise this when their plan is being developed.

## **Literacy**

AGOSCI has held biennial Literacy through AAC workshops which have been well attended, however places are extremely limited, up to 30 per intake. There is no other specialist program in Australia. This demonstrates a gap in the knowledge of specialist education services for literacy and AAC.

For people with CCN literacy is the only way that they may have access to a full vocabulary, without relying on someone else to anticipate their needs and program vocabulary into their communication system.

## **Mentoring and social support**

Through our listserv and conferences there are frequently requests for social groups and mentoring programs for people who use AAC. The benefit of meeting other people who may communicate in the same way and face similar challenges is recognised as important both for potential skill development, as well as social emotional support. This is particularly powerful for children and young adults. Some localised social groups have formed following meetings through conferences etc, but this is ad hoc and generally instigated by a motivated parent of a child with CCN. There is a role for a more sustainable and supported system for providing this support.

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21 February 2014

## APPENDIX 1

### Definitions of Complex Communication Needs (CCN) and Augmentative and Alternative Communication (AAC)

Complex communication needs is the internationally preferred term to describe having limited or no functional speech. 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. (Balandin, 2002).

People with CCN include those with Cerebral Palsy, Autism, Stroke, Intellectual Disability, sensory impairments and degenerative conditions such as Motor Neurone Disease.

People who have CCN and their communication partners may use augmentative or alternative communication (AAC) strategies and techniques to support their communication either temporarily or permanently. AAC may be used as an *alternative* to oral speech, or to *augment* oral speech and/or to support expressive and/or receptive language.

The individual may fit into one of the following categories:

1. Individuals who do not use oral speech and use AAC "predominantly" to support expressive and/or receptive language.
2. Individuals who use oral speech and *may* use AAC to support their receptive and/or expressive language.

## APPENDIX 2

### Reference List

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