



Australian senate inquiry: Prevalence of different types of speech, language and communication disorders and speech pathology services in Australia

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION AND COMPLEX COMMUNICATION NEEDS

**Submission prepared for the Community Affairs References Committee of the Australian Senate by
ISAAC Australia Inc. – The Australian Chapter of ISAAC.**

Submitted February 21st, 2014.

Contributing Authors (in alphabetical order):

Meredith Allan (Treasurer)

Kate Anderson (Australian Representative to the ISAAC Council)

Fiona Given (general member)

Gemma Holleran (Secretary)

Gayle Porter (President)

Barbara Solarsh (Ex-officio Member)

With anecdotal contributions from the ISAAC membership.

Table of Contents

Introduction	3
Section A/B: Prevalence and Incidence of CCN and PWUAAC in Australia.....	5
Sections C/D: Availability and adequacy of AAC-specific speech pathology services (public and private).....	6
Section E: Evidence of the social and economic cost of failing to provide AAC services.....	10
Section F: Projected demand for AAC services in Australia.....	12
Conclusion	13
References	15

Introduction

This submission, prepared by ISAAC Australia (www.isaacaustralia.com) relates specifically to the speech pathology field of Augmentative and Alternative Communication (AAC).

ISAAC Australia is the Australian branch of the International Society for Augmentative and Alternative Communication (ISAAC). This is a membership organisation that works to improve the lives of children and adults who use AAC. ISAAC's goal is to create worldwide awareness about how AAC can help individuals without speech. ISAAC's vision is that AAC will be recognized, valued and used throughout the world. ISAAC's mission is to promote the best possible communication for people with complex communication needs. Augmentative and alternative communication (AAC) helps millions worldwide who cannot rely on their natural speech to communicate. <https://www.isaac-online.org>

Definitions used in this submission:

*People with **complex communication needs (CCN)** have communication problems associated with a wide range of physical, sensory and environmental causes which restrict/limit an individual's ability to participate independently in society. These individuals and their communication partners may benefit from using Alternative or Augmentative Communication (AAC) methods either temporarily or permanently (Balandin, 2002).Speech Pathology Australia (2012, p.9)*

***Augmentative and Alternative Communication (AAC)** is an area of clinical and educational practice that provides communication strategies, techniques, and interventions for people with a range of communication limitations. The term 'augmentative' in this context means supplemental or additional to speech. Augmentative techniques (e.g. gestures, facial expressions, and items of reference) are commonly used when communicating and interacting with others. The use of the term 'alternative' acknowledges that there are some individuals whose speech is sufficiently impaired that they must rely completely on strategies, systems, and techniques which do not augment speech but are alternatives to speech (Vanderheiden & Yoder, 1996).*

Speech Pathology Australia (2012, p.6)

AAC incorporates the full range of communication modes other than speech, including written messages, communication boards or books, high-tech speech generating devices, signed languages, and gesture. AAC may be used to support understanding and/or expressive communication (Beukelman & Mirenda, 2005).

Speech pathologists support people who use AAC (PWUAAC) by assessing individuals for appropriate AAC systems, creating AAC resources and materials when necessary, and providing training around the use of these systems for communication. Children with CCN require long-term intervention to develop their communication and language skills using an alternative form. Children with CCN require considerable support during the school years to assist teachers and others in the school community to learn and problem-solve social and curriculum access, participation and learning using AAC. As communication needs change into adulthood, PWUAAC frequently require further intervention throughout their life to learn new skills, to accommodate for their changing communication needs. Not all adults who have CCN, had the opportunity to develop competent communication skills using AAC as a child. As technology changes the new possibilities need to be explored and new communication strategies learned. People who acquire CCN as adults will need to assessment and intervention to learn to use AAC later in life. Speech pathologists also work to build the capacity of the general community to interact with people who use AAC.

For adults with CCN, limited communication has a direct effect on community participation and inclusion central to current government policy (Johnson, Douglas, Bigby & Iacono, 2009). Further there are limited paid positions and a shortage of speech pathologists experienced in AAC to offer services to adults with CCN (Iacono, Johnson, Humphreys, & McAllister, 2007). As for children, AAC services need to be ongoing and considerable training of support staff and families is required for effective outcomes. In addition AAC expertise in AAC technology tends to be focused in metro regions, with some limited outreach services to regional areas. This leaves people with CCN in regional Australia vulnerable, unless there is a funded service with strong focus on capacity development with a regional distribution.

The Communication Access Network (CAN) started in 2004, has been the only additionally funded service aimed at increasing access for adults with CCN to AAC services. CAN aims to increase the skills and capacity of generic speech pathologists to offer services across Victoria (Johnson, 2004) as well as to develop capacity of disability staff to support people who use AAC.

Case in Point: The Right Equipment

MP is a young woman from regional Victoria who acquired a head injury in 2012, which resulted in the loss of her speech. On discharge from hospital in Melbourne, all she was provided with was a paper-based alphabet board for her to spell out her messages by pointing to the letters. This was extremely frustrating for her which resulted in depression and anger. She was eventually referred to the CAN speech pathologist in her region who arranged for her to receive Proloquo2go software for her iPad, as well as a switch2 scan through the Victorian Aids and Equipment Program. These resources opened her world and gave her a voice.

Within CAN a further AAC support has been provided through the establishment of the Non Electronic Communication Aid Scheme (NECAS). This scheme produces non-electronic communication aids requested by families or staff, where there has been the capacity to design the communication aid. There is a limited budget, and this scheme, like CAN is only available in Victoria and is exclusively an adult service.

Section A/B: Prevalence and Incidence of Complex Communication Needs and People Who Use AAC in Australia.

An estimated 1 in 500 people in Australia have severe communication disabilities or complex communication needs (Perry, Reilly, Bloomberg & Johnson, 2002).

People who could potentially benefit from AAC include children and adults associated with a range of physical, neurological, cognitive, emotional and/or sensory disorders including, but not limited to, autism, cerebral palsy, Rhett's syndrome, Angelman's syndrome, developmental delay, dyspraxia, motor neuron disease, Parkinson's disease, stroke, dementia, and traumatic brain injury.

Some populations have significantly higher rates of CCN. For example, up to 25% of people with Cerebral Palsy have little or no functional speech and will use AAC (Australian CP register, 2013; Access Economics, 2008; Goldsmith & Novak, 2010). It has been estimated that 17%-25% of children with Autism Spectrum Disorders fail to develop functional speech (National Research Council, 2001).

People with developmental disabilities and complex communication needs have lifelong conditions, and their communication needs will change as they develop, age and engage in different life experiences. Some people with acquired conditions will also develop complex communication needs secondary to the condition affecting speech, language and/or cognition. Their complex communication needs may continue through the remaining years of life or may increase over time if the condition is progressive. Some people may have only temporary complex communication needs arising from short term conditions or states associated with illness (e.g., Guillain Barre Disease), injury (e.g., requiring intubation), or surgical interventions impacting upon speech, language and/or cognition (Beukelman et al., 2007).

Speech Pathology Australia (2012, p.14)

The incidence of CCN is not likely to vary much between different ethnic or language groups. However, there are some challenges with identifying CCN and gaining access to AAC services for people from culturally and linguistically diverse backgrounds. It can be challenging to access assistance with the translation of AAC systems into PWU AAC's family language. Often this is often ad hoc using volunteers, who rarely have the knowledge of linguistics to plan and organise language developmentally.

Sections C/D: Availability and adequacy of AAC-specific speech pathology services provided by the Commonwealth, state and local governments, and private practitioners

AAC is a specialist area of speech pathology – it can be further difficult to find a service that provides this specialist knowledge. As knowledge of AAC possibilities is still fairly low in the community, families may not know what to ask for. Some PWUAAC and their families do not know that AAC exists or how it can affect their life. Many speech pathologists are unaware of the range of options.

Although speech pathologists currently graduate with knowledge and skill in the principles and practices of multimodal communication (Speech Pathology Australia, 2011), Costigan and Light (2010) noted that students are at risk of having limitations in their expertise owing to many university academics having “minimal expertise in AAC” and concluded that it was unclear whether pre-service programs equipped professionals for entry-level AAC practice. Indeed, there are many qualified clinicians who have had limited practice in and knowledge of the area and as a result might actively avoid introducing AAC (Sutherland, Gillon, & Yoder, 2005). Despite the relevance of AAC across a range of groups with communication disorders, and the ever increasing evidence base, research has indicated that few speech pathologists feel competent in advising on AAC interventions or developing AAC programs (Sutherland et al., 2005).

Speech Pathology Australia (2012, p.12)

Adult AAC services

Adults with AAC in Australia may face long waiting times for new devices, or device repairs. Like Darryl, one of our members, adults often have to be outspoken before services and resources can be accessed:

“I had to wait over three years to get assess to get a new device. It wasn’t until really I kick up and demand my right to the service and highlighted my participation was being greatly effected that the gov agency did something. We shouldn’t have to be so forceful to get our basic rights met. Communication is hard enough!”

Case in Point: Waiting Too Long

“Margaret was a colleague at work, she enjoyed work and kept working even though she could afford to retire. When she did retire, Margaret and her husband moved interstate to be close to their son. It was discovered Margaret had a brain tumour, which was removed, and the long process of rehabilitation began. Her husband, her primary care giver, died suddenly. Margaret managed fairly well for a while. She then had a brain haemorrhage and she was left without speech and severe mobility issues. Margaret entered a Nursing Home. I emailed Margaret my Christmas letter after obtaining her son’s email address. Her son emailed me back, Margaret wanted to know what speech generating devices (SGD) were available. I gave him details of four suppliers of AAC devices (websites) and gave him a few pros and cons of a few devices. Margaret died four months later without a SGD or any AAC intervention. Margaret had travelled through at least three hospitals/health agencies in her last 12 months, why were no specialised services in AAC/speech pathology supplied. Margaret had the finance yet there was no initiative taken.”

Described by ISAAC member who uses AAC

Paediatric AAC services

Childhood AAC services have been a recent focus of research attention. Australian speech pathologists have reported having inadequate time available within their paediatric caseloads to meet the needs of children using AAC, particularly for the development of new AAC systems and resources, to provide adequate training to PWUAAC and their communication partners, and to keep abreast of best-practice literature in the AAC field (Anderson, Balandin, & Stancliffe, 2013; Iacono & Cameron, 2009). These demands can lead clinicians to continue AAC-related work outside of paid hours, increasing the risk for professional burn-out (Anderson, Balandin, & Stancliffe, 2013; Iacono & Cameron, 2009). Parents of Australian children who use high-tech AAC (i.e. speech generating devices) have reported feeling under-supported by government funded AAC service providers (Anderson, Balandin, & Stancliffe, 2013). Having to shoulder the majority of AAC responsibilities without support can place great strain on families. As one Australian parent in Anderson and colleagues' study explained:

"It took a lot of effort and concentration and determination. And particularly when you know that there's not a lot of support, it's really up to me... and just to take it on board and take on all that hard work is sort of daunting."

Parents' service concerns have included long waiting lists for assessment, AAC device funding, and intervention; poorly co-ordinated care within and across service providers; and a lack of accessible training for families with a new AAC device. Families living in rural or remote areas may be particularly disadvantaged in terms of service access (Anderson, Balandin, & Stancliffe, 2013; Verdon et al, 2011; Wilson, Lincoln, & Onslow, 2002). Parents of PWUAAC frequently tell of their journeys locating services with specialist knowledge in AAC and their observations that not all families or PWUAAC are as fortunate as themselves.

Case in Point: Finding Speech Pathology

"It saddens me to see others that maybe somewhat physically similar to our daughter, but because they didn't stumble across a speech therapist, who was one of a small group of therapists (which included OT and physiotherapy), as we did, are denied the potential to be seen as a worthy individual beyond their disability. We didn't know what services were available, we didn't know where to start, we didn't know where to go, we didn't know who to talk to, but we stumbled across a group of therapists at an early intervention centre that became the turning point in our life's journey. Speech therapy doesn't just address the individual's needs but it supports the whole family in understanding the needs, and developing the person inside."

Parent of a young woman with cerebral palsy and CCN.

Professional Expertise

Children with CCN may not follow a typical path of development, due to significant sensory and physical challenges affecting their early communication behaviours as well as the development of spoken language (Beukelman & Mirenda, 2005). As a result, therapists and educators without specialist knowledge of disability may assume that they are delayed, and may not consider them to be "ready for language". The phenomenon of "waiting for speech" to happen, or looking for "pre-requisite" criteria for communication occurs frequently, and precludes many children from accessing timely AAC services (Ronski & Sevcik, 2005). Children and adults can become stuck in a "Catch 22" (circular dilemma) where they are denied access to AAC because they cannot demonstrate the pre-requisite skills that they could only learn and perform with the use of AAC. As so eloquently expressed by Gus Estrella, an adult who uses AAC:

"I think I should start out with the expectations that some speech pathologists have in my experience. The first and perhaps the most poisonous is that we have to master and demonstrate the mastery of certain language concepts before we're allowed to try communication aids with the kind of power that might help us really talk. Umm, how can I master a language if I can't talk with my own voice, and you won't give me a communication aid?"
Estrella, 1997, p. 4.

Lack of information and training for professionals results in children and adults with CCN being denied a chance to communicate, to participate in society, and be recognised for their strengths and individuality. Currently, limited professional development resources impedes generalist speech pathologists from developing skills in this area. As one of our professional members illustrated:

"As a speech pathologist working for a not for profit organisation, it is difficult to attend specialised AAC professional development such as the AGOSCI tour on literacy and AAC. This course costs \$1800 which is significantly above the \$500 professional development allowance in my organisation. This makes it very difficult to build on my knowledge and skills without self funding a large proportion of training."

Case in Point: AAC as an option

"As a parent of an autistic AAC user, I cannot stress enough, the importance of making ACC a more general option and readily available to someone who has difficulty speaking. We were extremely fortunate to come across it when our daughter was 4 years old; I know there are many who even yet (she is 24 now) still are thought to be intellectually impaired because there has never been the support or encouragement or even the availability of the knowledge of AAC. Thank goodness for iPads – this is opening up the way a lot, but even so, there needs to be conformity, knowledge, training etc across the board generally. I always liken AAC to a non-verbal person, to a guide dog for the blind. Without it, the individual can get no-where!"

Parent of a young woman with Autism and CCN.

Availability of AAC Resources

Another difficulty faced by speech pathologists is the cost of some of the specialist resources required for AAC assessment and intervention. In addition to specialist knowledge, specialist software and equipment is required to make communication boards and books. Clients also require access to a range of trial speech generating devices and software. While many of the suppliers of dedicated speech generating devices offer short-term loan periods for their devices, the waiting lists to access these devices are lengthy, and many clients require access to a device for longer periods of learning prior to making a decision on its applicability. Becoming familiar with the range of communication apps that can be used on mainstream technology is particularly challenging for speech pathologists as there are few free trials. As the more sophisticated communication apps are often in the range of \$150-300 it is usually not possible for a speech pathologist to privately pay for and review multiple apps with clients. This can lead to speech pathologists recommending apps based on the limited range they have to hand.

Similar issues are also faced by generalist government agencies, where funding for this equipment to be used by a smaller proportion of the whole client group is not made available. There are some AAC and assistive technology assessment services across Australia (notably the Independent Living Centres). However there are often long waiting lists and these services typically can not accommodate for the longer term learning required by some PWUAAC during the assessment process.

Challenges for Private AAC service provision

As a specialised field, parents of children who use high-tech AAC have reported difficulties in finding and accessing private speech pathologists who are experienced and knowledgeable in AAC (Anderson, Balandin, & Stancliffe, 2013). Australian clinicians have also expressed concerns regarding the AAC expertise of private therapists, and the expense for generalist therapists of maintaining adequate, up-to-date knowledge in AAC best-practice. As one of our professional members (a private SLP) described:

“Private practitioners don’t necessarily have the skills or experience to give good quality AAC therapy. I’ve heard a number of instances where therapists have told families to buy a so-and-so iPad app. The family does, and then the practitioner says: ‘ok, let’s see how this works!’...”

It can be extremely difficult for private practitioners to fund and access the necessary training and resources to develop adequate expertise in AAC, for a small proportion of their client load. Nonetheless, private SLPs are increasingly expected to provide AAC services to clients who feel under-supported by their existing disability service provider, those who are ineligible for public services, or those living outside of main catchment areas. The proportion of individuals receiving AAC interventions from private practitioners has also been greatly increased by the introduction of the FACSIA funded Helping Children with Autism and Better Start initiatives. Currently there are no guidelines around minimum clinical proficiencies or professional development requirements specifically for AAC practice. There are also no set curriculum guidelines for the teaching of AAC content at a pre-professional level. Most importantly, there are no formal qualifications or certifications that families can use to identify practitioners with specialist or advanced AAC knowledge.

Finally, given the complex nature of individuals who use AAC, particularly in regard to co-morbid movement, sensory and postural disorders, AAC services typically necessitate collaborative practice between multiple professionals, including educational specialists, physiotherapists, occupational therapists, vision and hearing specialists, etc. This need for collaboration has been recognised by the Federal Government in their establishment of the HCWA/Better Start initiatives. Within private practice contexts, this style of ‘multidisciplinary’ practice is not always possible or supported.

In summary, to achieve best practice in this field, speech pathologists require more frequent access to affordable training. This will likely necessitate greater time and expense allocation to speech pathologists working in this field. Furthermore, a review of AAC funding models is required to provide more ready access to AAC communication aids, including resources to support the making of communication boards and books, as well as client access to longer-term assessment and intervention.

Section E: Evidence of the social and economic cost of failing to provide AAC services

Having Complex Communication Needs affects all aspects of everyday life. Adequate AAC services enable participation in home and work life, facilitate education, and support relationships. As one of our members explains:

“Without them [AAC services] our communication would be a lot worse thus our social participation would considerably less. This could also affect our mental health due to the lack of social interactions. Also, our economical output would be a lot less. Our love lives could also be hampered too.”

As communication is so integral to participation in all life’s activities, the social and economic costs of failing to provide AAC services on the lives of people with CCN is also too big to encompass. The social and economic costs of people being left without any way of expressing themselves include

- Personal expression and relationships
- Personal safety and control
- Family relationships
- Increased family stress as other members of the family assume the role of the person’s voice
- Educational failure. At its core teaching is communication between the teacher and the learner.
- Employment

From a purely fiscal perspective, supporting the communication needs of Australians with CCN from an early age facilitates their participation as financially contributing members of society. This is evidenced by the engagement in volunteer and paid employment that is achieved by many adults who use AAC technology, leading to long-term financial independence (McNaughton, Light, & Arnold, 2002). PWUAAC have identified communication technology as an important factor in their successful, ongoing employment (McNaughton, Light, & Arnold, 2002).

Case in Point: Life and Work in the Verbal Culture

I live and work in the verbal culture. Sometimes I think it would be a whole lot easier to curl up in and live in the AAC culture, only letting family and a few friends enter my comfort zone. I like living in my world of gestures and saying a few words and expecting people to understand the unravelling book inside my head. However gestures don’t always work, I could end up with 3 kg of stirfry instead of 300 grams.

There are no shortcuts in the workplace. With a multicultural workforce I cannot say “arvo”, I have to say “afternoon”. In my work a two cent error, could mean hours of reverse work flow. I have to be clearly understood. My words must be clear, and concise in the information I provide to internal and external clients. It has taken years to build up the respect and credibility I now hold. I have built a safe environment where my “voice” can be heard.

It is important to communicate with colleagues both in a business sense and socially. It is becoming increasingly noticeable, with a mobile workforce, that work friends are now social networks as well.

It is imperative to enable People with CCN the opportunities to be motivated /learn how to break through the barriers to engage with verbal world.

Meredith (PWUAAC ISAAC member).

Provision of AAC systems, especially complex speech-generating devices, must be accompanied by intensive and sustained guidance from a professional AAC team to support optimal device uptake within the person’s communication environment. Failure to do so results in sub-optimal outcomes,

including complete abandonment – a costly outcome for tax-payers, given that many of these devices are publicly funded. As one parent from Anderson and colleagues’ research (2013) illustrated:

“I was beside myself, I was so angry that I’d been given this eleven-and-a-half thousand dollar machine, and nobody in [the state] could give me any kind of support.”

Finally, having access to and proficiency in using an appropriate and supported AAC system is a vital safety mechanism for people with little or no functional speech. Two primary examples of this lie in health outcomes, and personal safety. People with CCN are more likely to experience adverse events when in hospital (Bartlett et al., 2008), directly related to communication barriers including to a lack of communication opportunity, lack of access to an AAC system, or poor staff awareness around AAC. Each of these issues can be directly addressed by trained speech pathologists supporting the individual, but places additional time and resource demands on clinicians that cannot always be accommodated. As a result, communication barriers and adverse events in the health-care system can lead to poor health outcomes for people with CCN. Similar issues also affect the personal safety and legal rights of people with CCN, and research demonstrates that this population is at high risk of abuse and assault. For instance, the majority of adults with CCN who participated in Collier and colleagues’ study (2006) reported experienced a range of abuses including sexual abuse, and had no means to communicate about these instances with justice system representatives, or indeed members of their own support networks.

Australia’s legal obligation

Access to communication is a human right. This is expressed in Article 21 of the United Nations Convention of the Rights of People with Disabilities (UNCRPD), which was ratified by Australia in 2008. This article on freedom of expression, opinion and access to information explicitly states that State Parties are obliged to “(b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;”. Further Article 26, on rehabilitation and habilitation requires States Parties to “take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.” This includes access to speech pathology services.

The Communication Bill of Rights was developed by the American Speech and Hearing Association. It states that people have the right to be spoken to directly and to have access to alternative and augmentative communication. The Communication Bill of Rights provides a strong guideline for those wishing to shape communication-accessible policies in Australia.

Section F: Projected demand for AAC services in Australia

As a heterogeneous group, Australians using AAC have a diverse range of needs that current service providers struggle to address within current resource and funding limitations. These include:

- Assessment of an individual's AAC needs (new or replacement AAC systems) across all communication settings
- Generation of low-tech (paper-based) AAC resources
- Funding or fundraising for AAC technology
- Programming and setting-up new AAC systems
- AAC system training for clients with a new device, and their communication partners
- Environmental modifications, including supporting curriculum modifications for children and adults attending educational institutions
- Intensive, long-term language and literacy intervention for children who are acquiring language through an augmented or alternative means.
- Community education and AAC advocacy.

ISAAC members have identified improved support for AAC and communication in everyday settings as a critical priority. As one member who uses AAC stated:

"[We need] services that facilitate our social participation in our communities. Education for us to engage with our communities and education for communication partners. Access to the right AAC in various settings."

The recent explosion in mainstream technology for communication and special education needs (e.g. the Smartboard; the iPad and other tablet technology), has caused a sharp increase in demand for AAC consultation around these applications. In addition, AAC professionals are seeing increasing scientific evidence supporting high-tech AAC use for a wider range of populations that previously considered. For instance, there is a growing field of evidence supporting the use of speech generating devices for children with Autism (e.g. Trembath, Balandin, & Togher, 2009; Trembath, Roberts, & Sutherland, 2009). In addition, current best practice recommends early assessment, followed by regular and intensive communication intervention to optimise long-term outcomes for these children. As David Trembath, one of our member experts in Autism Spectrum Disorders (ASD) explains:

"Children with ASD are at major risk for poor social, education, and health outcomes if their communication needs are not met at an early age. Children with autism share common core social, communication, and behavioural impairments but present with a spectrum of individual needs. There is clear evidence that Early Intensive Behavioural Intervention targeting social-communication skills can alter the developmental trajectories of children with, and at risk for, Autism Spectrum Disorder. Speech Pathologists are usually the first port of call for parents who are worried about their children's development. A child learning to say his or her first words, for social purposes, within the appropriate developmental window, is our single best clue that their development is on track and that they are on their way to healthy, independent, adult lives."

With growth in this area set to continue, we anticipate that AAC service demands for children with Autism and similar developmental disabilities will place ever-increasing strain on already over-stretched speech pathology caseloads, increasing the risk of clinician burn-out, client dissatisfaction, and poorer outcomes overall for PWUAAC.

Conclusion

The ability for people with CCN to interact with others and to be heard is dependent on the tools and opportunities provided to them. For a person who is unable to use speech alone to communicate with the world, the ability to communicate using AAC is vital in every aspect of their life. A lack of information within the community can lead to assumptions about the capacity of people with CCN.

As Michael Williams advised fellow PWUAAC to prioritise learning to use AAC in his WORDS + outstanding consumer award speech at the ISAAC conference in Vancouver, 1996, we also need to prioritise supporting people to learn an AAC system as a basic human right.

“Have you got anything better to do? Listen to me: There is nothing more important for you to be doing right now than to learn how to express your thoughts and feelings to other people. I know how painful it is when people stare at you and think that you are somebody other than who you really are because of how you look on the outside. Believe me this won’t change unless you have some way to tell people who you are on the inside.”
Williams (1996).

Emergent research evidence, coupled with rapid changes in the development of assistive technology, make AAC a fast-paced specialist field in speech pathology. This raises a number of priority issues for speech pathologists adequately supporting PWUAAC. Primarily, current challenges call for:

- a) **A greater number of speech pathologists with sufficient knowledge in AAC**, across both government and private practices for all populations. This may be achieved through:
 - Increased funding for speech pathology personnel within government departments and NGOs, to relieve caseloads that currently preclude speech pathologists from spending adequate time providing services to people with CCN.
 - Improved financial support for AAC professional development for Australian speech pathologists working within private practice, public service and NGOs.
 - Improved access to specialist AAC assessment/consultation services for clients, families, and generalist speech pathologists.
 - Instillation of Speech Pathologists with skills to deliver a capacity development model of communication interventions such as the Communication Access Network described.
- b) **Increased community, health and disability services knowledge of how AAC can support individuals with CCN**. This would include having clearer referral pathways, to ensure timely access to required resources, and prevent PWUAAC and their families from missing out on AAC due to a lack of awareness of the possibilities.
- c) **Appropriate and timely access to necessary AAC equipment** (for learning and communication). This could be assisted through:
 - Ensuring at least one designated service in every state and territory that has access to latest AAC technologies for longer-term learning and trial. This will ensure more informed decision-making by AAC teams around appropriate AAC prescriptions.
 - All-ages funding schemes for non-electronic communication systems (such as communication boards and books) available in every state. This may be similar to the current Non-Electronic Communication Aids Scheme (NECAS) in Victoria (currently only available for adults).
 - Funding for communication devices that reflects an individual’s needs, as identified by the referring speech pathologist, rather than an externally identified price limit. Pre-determined limits lead to prescriptions based on price, rather than client need. Currently there is a lot of time spent by PWUAAC, their family, friends and speech pathologists trying to find funding for AAC systems (electronic and non-electronic). This significantly distracts from interventions to further develop communication competency.

- Funding consistency across states and territories and the ability to move from one place in Australia to another without losing your communication aid (your voice). Currently if a PWU AAC moves to a different state, their state funded AAC device has to be returned and re-prescribed / re-funded in the new state.

- d) Finally, there needs to be a recognition in speech pathology funding schemes that **the provision of a communication aid is only one element of the process towards using it to communicate**. There needs to be mandatory provision of support, training and intervention for individuals who are funded for a new communication device. This support should be maintained until the device is well established across the individual's communication environments (Anderson, Balandin & Stancliffe, 2013).

References

- Anderson, K., Balandin, S., & Stancliffe, R. (2013). Australian parents' experiences of speech generating device (SGD) service delivery. *Developmental Neurorehabilitation, Early Online*. doi:10.3109/17518423.2013.857735
- Bartlett, G., Blais, R., Tamblyn, R., Clermont, R.J., MacGibbon, B. (2008). Impact of patient communication problems on the risk of preventable adverse events in acute care settings. *Canadian Medical Association Journal, 178*(12), 1555-62.
- Beukelman, D. R., & Mirenda, P. (2005). *Augmentative and alternative communication: Supporting children and adults with complex communication needs (3rd ed.)*. Baltimore: Paul H. Brookes.
- Collier, B., McGhie-Richmond, D., Odette, F., & Pyne, J. (2006). Reducing the risk of sexual abuse for people who use augmentative and alternative communication. *Augmentative and Alternative Communication, 22*(1), 62-75.
- Estrella, G. (1997) 1st Annual Edwin and Esther Prentke Distinguished Lecture. <http://www.aacoinstitute.org/Resources/PrentkeLecture/1997/GusEstrella.html>
- Iacono, T., & Cameron, M. (2009). Australian speech-language pathologists' perceptions and experiences of augmentative and alternative communication in early childhood intervention. *Augmentative and Alternative Communication, 25*(4), 236-49.
- Iacono, T., Johnson, H., Humphreys, J., & McAllister, L. (2007) Recruitment of speech pathologists into positions considered less attractive. *Advances in Speech-Language Pathology, 9*, 204-212.
- Johnson, H. (2004). Developing services for people with complex communication needs. *ACQuiring Knowledge in Speech, Language and Hearing, 6*, 162-163.
- Johnson, H., Douglas, J., Bigby, C. & Iacono, T. (2009) Maximizing community inclusion through mainstream communication services for adults with severe disabilities. *International Journal of Speech-Language Pathology, 11*(3): 180-190
- Mcnaughton, D., Light, J., & Arnold, K. B. (2002). "Getting Your Wheel in the Door": Successful Full-Time Employment Experiences of Individuals with Cerebral Palsy Who Use Augmentative and Alternative Communication. *Augmentative and Alternative Communication, 18*, 59-76.
- Romski, M., & Sevcik, R. A. (2005). Augmentative Communication and Early Intervention Myths and Realities, *18*(3), 174-185.
- Speech Pathology Australia (2012). *Augmentative and Alternative Communication Clinical Guideline*. Melbourne: Speech Pathology Australia.
- Trembath, D., Balandin, S., & Togher, L. (2009). Peer mediated teaching and augmentative and alternative communication for preschool aged children with autism. *Journal of Intellectual & Developmental Disability, 34*(2), 173-186.
- Trembath, D., Roberts, J. M., Sutherland, R. (2009) *Speech Pathology Australia Autism Spectrum Disorder Evidence Based Position Paper*. Speech Pathology Australia.
- Verdon, S., Wilson, L., Smith-Tamaray, M., & McAllister, L. (2011). An investigation of equity of rural speech-language pathology services for children: A geographic perspective. *International Journal of Speech-Language Pathology, 13*(3), 239-50.
- Wilson, L., Lincoln, M., & Onslow, M. (2002). Availability, access, and quality of care: Inequities in rural speech pathology services for children and a model for redress. *International Journal of Speech-Language Pathology, 4*(1), 9-22.