

Submission:

Senate Standing Committees on Community Affairs

February 2014

INQUIRY INTO THE PREVALENCE OF DIFFERENT TYPES OF SPEECH, LANGUAGE AND COMMUNICATION DISORDERS AND SPEECH PATHOLOGY SERVICES IN AUSTRALIA



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Introduction

Communication Rights Australia ("Communication Rights") is the only specialist advocacy and information service within Australia representing the interests of people who have communication difficulties and/or little or no speech.

Communication Rights strives for a world free of discrimination for the people we represent. We bear witness to human rights infringements; we take action with, or on behalf of the individual or group; and we bring necessary change to protect their future rights.

Communication Rights' services are designed to break down barriers to inclusion and remove discrimination through:

- Individual advocacy, advice and referral when the system has broken down;
- Information on human rights and the right to communicate;
- Community education – how to ensure the protection of a person's communication rights.

Communication Rights represents a range of people on a continuum, from severe speech and communication difficulties, such as Autism Spectrum Disorder, acquired brain injury, illness (for example Motor Neuron Disease, stroke, mental illness, physical and sensory impairment or intellectual disability), through to children whose capacity to communicate impacts on their ability to correctly and consistently send their message (Apraxia). The criterion for access to our services is if the person's ability to communicate his/her message is impacting on their ability to access their rights.

Communication Rights uses the UN Convention on the Rights of People with Disabilities, Victorian Charter of Human Rights and Responsibilities, disability discrimination legislation and government Policies to ensure people can enjoy their rights without fear of judgement or exclusion.

Disability Discrimination Legal Service is a community legal centre that specialises in disability discrimination legal matters. DDLS provides free legal advice in several areas including information, referral, advice, casework assistance, community legal education, and policy and law reform. The long term goals of the DDLS include the elimination of discrimination on the basis of disability, equal treatment before the law for people with a disability, and to generally promote equality for those with a disability

Executive Summary

The ability to communicate affects the most fundamental aspects of a person's life. Education, socialisation, decision-making, safety, employment and personal relationships are unattainable if one cannot communicate. The most basic human rights as set out in legislation such as the *Convention on the Rights of the Child*, *Convention on the Rights of Persons with Disabilities*, and *International Covenant on Civil and Political Rights* require the ability to communicate to obtain.

Therefore it is not a favour when children and adults with speech and language disorders/delays/impairments/difficulties ("disorders") receive appropriate speech pathology services to ensure they can communicate to their potential - it is a right. The role of speech pathologists, including to provide comprehensive assessments; develop, supervise, monitor and evaluate language programs; advise on language technology; train others to work competently with people with speech and language disorders, should be respected and recognised as a vital component in the attainment of a high quality of life for this group.

Communication Rights Australia and the Disability Discrimination Legal Service believe that children and adults with speech and language disorders will not experience full social inclusion without being given the language skills and equipment needed to be educated, to be employed, and to be able to convey their decisions and wishes to those around them. In light of this, we appreciate the opportunity to reinforce the availability and importance of high-quality speech pathology services for all Australians who require those services.

Recommendations

1. That recognising the links between speech and language disorders, illiteracy and juvenile justice, government schools are provided with the resources required to ensure best practice speech pathology services, whether obtained internally or externally, are provided to individual students who have speech and language disorders.
2. That the services described above are based on individual assessment and need, and are evidence based.
3. That the review of the *Disability Standards for Education 2005* is revisited, and the minimum requirements of speech pathology/language services needed to ensure that children and adults with speech and language disorders are able to achieve the aims and objectives of the *Disability Discrimination Act 1992* are set out with less ambiguity. This should be done in conjunction with Speech Pathology Australia.
4. That in the absence of a quick resolution of the recommendation directly above, in conjunction with Speech Pathologist Australia, the Commonwealth government develop procedures for government schools which ensure children and young people with speech and language disorders are provided with best practice speech pathology services throughout their education.
5. That the provision of professional language, social skills and literacy services occur in juvenile justice facilities for those who have speech and language disorders.
6. That state police services are required to include in their procedures a commitment to the provision of professional communication access for victims, offenders and witnesses, following the same establish guidelines in place for language interpreters. This should be done in conjunction with Speech Pathologist Australia.
7. That in relation to the above recommendations, the resourcing of people with complex communication needs and their requirement for expert advice and support in using Augmentative and Alternative Communication, be prioritised.

The prevalence of different types of speech, language and communication disorders and swallowing difficulties in Australia

In Australia 20% of the population have a disability, and according to Speech Pathology Australia, 1.1 million people live with a communication disability - 1.3% of the total population of Australia. Speech Pathology Australia believes this figure could be much higher.

Estimating the numbers of people with communication difficulties is problematic for the following reasons:

- Speech difficulties can be varied - people may have problems in their expressive language, speech, pragmatics, fluency or voice;
- No clear definition of the cohort.
- A communication difficulty may not be registered due to that difficulty being a secondary condition to another disability or health condition, such as stroke or acquired brain injury.

Speech Pathology Australia states that 20% of four year old children in Australia exhibit difficulties in making themselves understood to others, or understanding others. In addition there is a significant link between children with communication difficulties being more likely to have reading problems, when compared to children without speech problems (Speech Pathology Australia, Factsheet).

A child's participation in education and their social interaction will be affected by their communication difficulty.

A Monash University study by Snow and Powell revealed that 50 per cent of Australian children in juvenile detention have a communication or language disorder¹.

The problems range from acquired brain injury, to foetal alcohol syndrome, to Autism Spectrum Disorder. Snow reports that the more violent the offence, the more likely the children are to have speech difficulties¹.

In addition, English research has found that 'the numbers of prisoners with language and communication disorders is higher than that of the overall population (Bryan, Freer, & Furlong²). Snow found the relationship between communication disabilities, mental health problems, juvenile delinquency and special education has an impact on all areas of a young person's life, such as their opportunities for employment (1990; Speech Pathology Australia). This fact emphasises the importance of supporting people with speech problems in their communication.

¹ Snow, P; Powell, M (2013) Youth (in)justice: Oral language competence in early life and risk for engagement in antisocial behaviour in adolescence

² Bryan, K, Freer, J and Furlong, C (2007) Language and communication difficulties in juvenile offenders INTERNATIONAL JOURNAL OF LANGUAGE & COMMUNICATION DISORDERS, 42 (5). 505 - 520. I

The availability and adequacy of speech pathology services provided by the Commonwealth, state and local governments across health, aged care, education, disability and correctional services

Communication Rights' clients experience the daily impact of not being able to access adequate speech pathology services due to the:

- Difficulties accessing Speech Pathologists who have adequate training in working with people who use alternative forms of communication to speech;
- Rigidity of service providers/government in the provision of speech pathology services by imposing limitations and boundaries on those services which will create limitations on the delivery of holistic services (for example, a funded speech pathology service will be provided in one aspect of a person's life such as their day centre, but not provided in that person's home);
- Age criteria limits when accessing some services;
- Inadequate numbers of Speech Pathologists within rural and regional areas;
- Cost of accessing speech pathology services;
- Lack of experience or training in particular methods of communication;
- Services not being offered in areas of need - for example partner assisted communication;
- Failure of schools to support speech pathology assistance to students with disabilities;
- Limited access to Speech Pathologists who have expertise in augmentative and alternative communication methods.

Communication Rights is the only funded specialist advocacy service for people with communication difficulties within Australia. They are funded for one position across Victoria. Data extracted between 1/7/12 through to 30/6/13 within Victoria indicates that 16% (16) of cases were related directly to a person's failure to access speech therapy services being a barrier to accessing their human rights. In addition another 87 people reported difficulty in accessing service systems such as education, justice and so on based on those services' lack of understanding of their communication, method of communication or preparedness to make appropriate adjustments for the individual's communication within their service to enable inclusion.

The lack of access to speech pathology services impacts on every person who has communication or speech difficulties within Australia. To elaborate, a person who for example relies on full access to an effective non-verbal communication method cannot enjoy a rich and fulfilling life unless speech pathology and ancillary services support:

- access to the communication method (device, equipment or otherwise);
- training to use that method (consistently over time and taking into account communication methods may change);
- training for communication partners (including integration aides, family members, attendant carers, day centre staff, or work colleagues).

Without all of the above, full access to communication does not occur.

Evidence of the social and economic cost of failing to treat communication disorders

The failure to provide extensive well-resourced speech pathology services to people with communication difficulties imposes a range of disadvantages on those individuals, such disadvantages then having a flow on effect to many others in the community. These disadvantages include:

- the responsibilities placed on family members who are relied upon to communicate in a range of situations on behalf of a person who has no effective communication method;
- an inability of general service staff to provide services to a person with whom they cannot communicate;
- the risks associated with decision-making on behalf of someone who may have strong views about their needs and wishes, but cannot communicate them;
- the high levels of abuse experienced by people who are unable to independently communicate, at times leading to involvement as victims of crime in the justice system.

For individuals who are constantly battling to be understood, every aspect of their life is affected.

Reflecting the multidimensional nature of disadvantage, the costs of language disorders can be categorised in terms of the impact of disadvantage on material living standards (economic costs) and people's quality of life (social costs). Individuals who have speech and language disorders are entitled to have such disabilities ameliorated in order that they can access our quality of life enjoyed by those without those disabilities. Their rights to services are upheld in domestic and international human rights legislation. However for those who are disinterested in viewing these issues from a social/human rights perspective, economically, it is clear that we all are disadvantaged when people with speech and language disorders are not able to function as independent members of the community due to those disorders.

An example of the research into the cost to individuals, families and governments of speech and language disorders is "*The Cost to the Nation of Children's Poor Communication*" (I CAN UK) which while a United Kingdom paper, sets out universal principles which can apply universally.

Failure to access education, obtain employment, social exclusion, subsequent mental health issues - these consequences of not being able to communicate are self evident.

Speech/Language Pathology services for children

There are many good reasons to highlight the barriers to speech and language services to children and young people with disabilities, and prioritising the removal of those barriers.

The poor socioeconomic status of people with disabilities is widely accepted, supported by the Price Waterhouse Cooper report "*Disability Expectations Investing in a Better Life a stronger Australia*" 2011 which states that "around 45% of those with a disability in Australia are either living near or below the poverty line." [p3]

The benefits of an education are inarguable. For people with disabilities to be independent, gain tertiary qualifications, employment and be able to participate in the community as equally as others, education is paramount.

The *Disability Standards Education* 2005 set out a legal framework by which children and young people have the right to fully access and participate in their education, pursuant to the *Disability Discrimination Act* 1992.

The research in relation to the links between speech and language disorders, literacy and juvenile justice has been well known for over a decade, as mentioned earlier in this submission, yet support for children with speech and language disorders in schools is critically inadequate and has deteriorated in the last decade.

The Victorian Experience

In 2006, the Victorian Department of Education and Early Childhood Development ["DEECD"] lifted the criteria benchmark needed to qualify for individual funding through the Severe Language Disorder category of its Program for Students with Disabilities, from two standard deviations from the mean, to three standard deviations from the mean. This was done without the endorsement of any professional speech pathology body, and was at the recommendation of the Royal Children's Hospital Education Institute, an organisation fully funded by the DEECD. As a result of this change, out of approximately 2700 children receiving individual funding to assist their language disorder, approximately 2500 children immediately lost their funding overnight.

In its place, the 'Language Support Program' was introduced, which comprised resources for teachers in relation to oral language only, and which was entirely voluntary.

The current situation is that children with speech and language disorders who require individual funding must have a disorder three standard deviations from the mean³ or greater, and must demonstrate "critical educational need". This "need" has no definition. Severe pragmatic language disorders do not meet the category.

The 2012 report by the Victorian Equal Opportunity and Human Rights Commission "*Held Back-the Experience of Students in Victorian government schools*" sets out in Chapter 6 the difficulties students have in accessing therapy services through their school. However the serious ramifications for children with speech and language disorders are worth highlighting by setting out the consequences of insufficient funding in the public school system.

³ Program to Students with Disabilities Handbook 2014, DEECD p7

Responsibilities of schools

It is not possible to access or fully participate in education without being able to communicate. Students with speech and language disorders must be individually assessed, and collaboration between the school and home actively initiated in respect of a chosen communication method to ensure consistency across environments. Parents of children who cannot afford private speech pathology services will rely upon school Speech Pathologists to provide the necessary assistance their child needs to access their education. If a child's speech or language disorder is impeding their ability to access the curriculum, it is the responsibility of the school to address that barrier. Even those parents who can afford private speech pathology for their children cannot pay for those speech pathologists to work in the school environment, as this is against DEECD policy (despite a lack of clarity on this issue⁴). It will always be necessary for a Speech Pathologist to address barriers to accessing the classroom for students whose disorders impede that access.

Special schools

Special schools, having a concentration of children with complex disabilities often including complex communication difficulties, require significant speech pathology resources. Ironically it is the special school environment that often delivers the least in terms of quality in speech pathology services for children with language disorders, partly due to the fact that individual funding awarded to a child with a disability, on the basis of the severity of that disability, is pooled rather than set aside for that particular child.

It therefore matters not how severe one child's language disorder may be, they will often receive no greater service than a child with lesser language disorder.

Speech pathology sessions are often provided to a class as a group in this environment. Special schools often have an unwritten policy to use a particular communication method, for example PECS [Picture Exchange Communication System]. This communication method can be imposed on all children with communication difficulties in the school, whether or not that method has an evidence base following formal speech pathology assessment for each individual. Formal speech pathology programs based on comprehensive assessment, goals, strategies, measurable outcomes, monitoring and evaluation rarely occur.

The reason for the practices described above is that DEECD Speech Pathologists are not employed in sufficient numbers to provide quality services to the children they are employed to assist.

Communication Partners

Students with severe language disorders who are nonverbal and require communication devices need not only funding for the purchase of that device, but funds set aside for training, and funds to pay for the physical Communication Partner

⁴ Victorian Auditor General Office Report 2012 "Programs for Students with Special Learning Needs" p 24

whose responsibility it is to assist the student to use the device and progress their communication. It is inadequate to provide a device, put it on the desk of the student, and then leave the student with that device with minimal support. Speech Pathologists are required to oversee the training program for both the student and the Communication Partner. Current resourcing does not allow such assistance, particularly in special schools where class ratios can be commonly be 2 staff to 10 children.

Access for secondary school students

Evidence provided by DEECD in open court has confirmed that secondary students do not receive direct speech pathology services as a matter of policy. Whether this policy is followed strictly is unclear, but while the research on early intervention clearly guides us in prioritising the provision of services to younger children, when children's speech and language disorders continue to impact on their education throughout the school life, these issues must be addressed no matter their age.

Summary

Speech pathology documentation in schools indicate an inability to provide professional individual assistance to children with speech and language disorders.

Returning to the research on the links between language disorder literacy and juvenile justice, in 2013 the DEECD launched a pilot educational program, Parkville College, which was established within a secure youth justice centre. The educational centre was established recognising the low levels of literacy/education of the offenders, links between language disorders and juvenile detention, and the desire to constructively and proactively address.

The decision by the DEECD to put resources into reacting to the problem of illiteracy and the law, but continuing to withhold resources from younger students is at odds with best practice.

Children with speech and language disorders need to be provided with services proactively in order to give them the best opportunity of avoiding involvement in the juvenile justice system.

There continues to be significant unmet need for support services for students with disabilities in Victorian schools, including integration aides, occupational therapists, speech therapists, other specialist staff and assistive technology. If these are not provided when required, students with disabilities cannot participate effectively in education.⁵

⁵ "Held Back-the Experiences of students with disabilities in Victorian schools" 2012 Victorian Equal Opportunity and Human Rights Commission p83

Case Studies

1. Education – Lack of choice in speech pathology services

- Issue

A young boy who has autism and no speech attends a special development school. He requires partner assisted access to his electronic communication device and has stated that he wants to go to a mainstream school to learn like his other siblings.

- Barriers

The special school have informed his parents that mainstream schools do not take children who require this kind of communication support and he should stay at the special school. Despite the child being on the Program for Students with a Disability and having Level 5 funding, the school's position is that the aide who works with the child providing him with the necessary assistance to communicate, cannot be present with him as he transitions to the mainstream school.

The main stream school made contact with their relevant region's representative, who informed them that the Department of Education's speech pathologists did not have the expertise in this child's chosen communication method and did not know how they could support the child's communication needs.

The child could not access speech pathologists from larger organisations as they did not work with children in schools, nor did they have the expertise to suitably train the child's support team in his chosen communication method. There were few speech pathologists that specialised in this area and they required a fee for their service leaving the burden on parents to pay for the specialist service.

- Comment

If the aide / support team has no training in the child's communication, the child cannot receive adequate support to participate fully at school. Although funds can be relocated from the individual's package for this training it would result in the child having no individual support during the day and being required not to attend school on the days where there is no support, in breach of the *Education and Training Reform Act 2006*.

2. Access to rural speech pathology services

A 30 year old woman, Suzie, who has no speech and suffers from multiple differing types of severe seizures, is reliant on her support staff to read and interpret what she is communicating through her body language. Her parents have separated and she is now living with her father and occasionally has weekend access with her mother.

- Issue

There is a dispute between the separated parents as to what their daughter is actually communicating regarding access arrangements. Suzie's parents and support staff say her choice making is not clear. Suzie displays distressed behaviour

prior to access visits with her mother - she holds onto fixed structures around her and must be dragged away to meet her.

Support staff report that on Suzie's return she displays emotional distress, has an increase in her seizures, and exhibits signs of severe separation anxiety on her return home to her father.

- **Barriers**

Communication Rights Australia was contacted by Suzie's father and by another advocacy organisation to assist in ensuring her choices and her communication needs were acknowledged, respected and explored to enhance her independence.

Due to the conflict between the parents, the Office of the Public Advocate (OPA) was appointed as a limited guardian for Suzie's access with her mother. They have allowed ongoing visits to the mother to ensure there is still family contact with both parents. Suzie has faced significant blocks to speech pathology services due to limited access to the only speech pathologist in her rural area (who has previously provided limited reports but little practical therapy), and who has been unable to undertake the necessary assessments or execute any of her own recommendations due to lack of resources to pay for her services, and geographical boundaries.

Despite Suzie having an Individualised Support Package where her communication needs are frequently identified as a priority, the Department of Human Services will not intervene any further as they see the problem relating to the individual parents rather than the core issue being Suzie's inability to communicate effectively with all involved. Responsibility has been transferred to OPA to follow up.

- **Comment**

Communication Rights Australia has been liaising with OPA and the Department of Human Service (DHS) for Suzie to have a thorough communication assessment. We have requested that the speech pathologist develop a communication book to be used in all settings, in order that it is clear what choices she is making. We have also been negotiating with service providers (DHS and Speech Pathologist) to be responsive to the client's needs.

3. Communication / Justice

- **Issue**

A young lady, Jane, with a mild intellectual disability and no speech is living in the family home with her parents and younger siblings. She had been physically assaulted by her father. Jane raised the assault with the management at the day service she attends and wanted to make a statement to the police regarding the assault. Jane also complained about verbal abuse and threats to her that occurred frequently at home. A category one incident report had been completed and submitted to the Department of Human Services and the police had also been informed of the assault.

Jane was immediately withdrawn by her father from the day service, forced to remain at home alone, and was told that she wouldn't be going back to the day centre. Jane was told by her father that he would explore other services for her to attend.

- Barriers

After the local police station to the day centre were given an overview of the situation they informed the day centre that they could not do anything, and to contact the police station closest to Jane's home. Despite there being evidence of the abuse, the local police station would not go to the day centre, as Jane couldn't make an independent statement as to what had happened. The police station closest to Jane's home were prepared to visit and make a 'welfare check' on her at home only.

As Jane had no speech and the police had no specific training in working with people who have little or no speech, there was no communication support worker or access to a suitably experienced speech pathologist provided. As a result of not being able to communicate, the police reported no further action was to be taken. The police could only conduct a welfare check through observation. They stated they would listen to what Jane's father had to say and would not act if he said that everything was fine.

DHS did not respond to the category one incident report, despite subsequent phone calls and emails requesting an urgent response, and a request for DHS to become involved in providing speech pathology services.

Jane has funding through an Individual Support Package. DHS was provided with the contact details of a Speech Pathologist who had the necessary Augmentative and Alternative Communication training to enable Jane to give a statement to the police. Despite this urgent request for assistance to allow Jane to make her statement to the police, DHS placed her on a waiting list for a case manager to be appointed, then for an assessment to be undertaken by a DHS Speech Pathologist.

Jane has waited over 1 year before having access to a communication device, and now will need to learn how to operate the machine, prior to providing her statement to the police about the incident. During this time she was still living in the family home in fear.

- Comment

There is no crisis response for individuals who require speech pathology services urgently such as in Jane's case. The justice system did not have a framework to respond. Despite being a client of DHS, and participating in a day program funded through her package, Jane cannot get the system to respond to her need for an urgent speech pathology response. There is a one-year waiting list to gain access to a case manager who may then arrange access to speech pathology services for Jane. In that time Jane has been isolated and placed in a potentially dangerous situation.

If Jane had been able to independently communicate prior to this emergency, she would have been able to communicate effectively with the police at the time of the incident.

