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AUSTRALIAN GOVERNMENT

**Department of Families, Housing, Community Services
and Indigenous Affairs**

DEVELOPING A NATIONAL DISABILITY STRATEGY

FOR AUSTRALIA

Discussion Paper October 2008

Prepared by:

SPEECH PATHOLOGY AUSTRALIA

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The following document outlines the Speech Pathology Australia submission to the
National Disability Strategy





DEVELOPING A NATIONAL DISABILITY STRATEGY FOR AUSTRALIA

SPEECH PATHOLOGY AUSTRALIA SUBMISSION

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Speech Pathology Australia welcomes the opportunity to contribute to the Discussion Paper released by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) on a National Disability Strategy for Australia. Speech Pathology Australia is the national peak body for speech pathologists in Australia, representing approximately 4,200 members. Speech pathologists are university qualified specialists who provide a variety of services to people with communication and swallowing difficulties that may present across the life span. As such, the profession believes it is ideally placed to provide meaningful input into the development and implementation of the National Disability Strategy for Australia.

Speech Pathology Australia (the Association) commends FaHCSIA on its commitment to pursuing this agenda. The Association supports the introduction of a national strategy for improving community inclusion and participation of people with disabilities; however the Association cautions that the scope of the Discussion Paper is extensive, and as such there is potential for recommendations arising from the consultation process to be general in nature rather than address the needs of groups of people with specific disabilities. For example, specifically in relation to the field of speech pathology, if “people with disability” (p. 4) is understood to be any person with an impairment that significantly impacts their quality of life, this will include persons who have disabilities related to communication and swallowing. Impairment and disabilities associated with communication and swallowing can, like physical and intellectual impairment, result in significant disability, reduced social inclusion and limited community participation. As such, it is important for the National Strategy to recognise this and to accommodate a diversity of specialised needs.

Severe communication impairment may affect as many as 8-12 per 1000 population¹. At a minimum, difficulties communicating may affect 1.3% of the total Australian population², whilst difficulty swallowing (known as dysphagia) may affect up to 16% of Australians³. Considering disabilities in communication alone, one in seven users of government disability services (over 5 years of age) have little or no effective communication and over 40% of users require assistance with communication⁴.

¹ Beukelman, D.R., & Ansel, B. (1995). Research priorities in augmentative and alternative communication. *Augmentative and Alternative Communication*, 11, 131-134

² Australian Institute of Health and Welfare. (2004). *Disability and its relationship to health conditions and other factors*. (AIHW CAT No. Dis 37)

³ Eslick, G.D., & Talley, N.J. (2008). Dysphagia: Epidemiology, risk factors and impact on quality of life – a population-based study. *Alimentary Pharmacology and Therapeutics*, 27, 971-979.

⁴ Australian Institute of Health and Welfare. (2005). *Disability support services 2003-04: national data on services provided under the Commonwealth State/Territory disability agreement* (AIHW cat. No. DIS 40). Canberra, ACT: AIHW





Difficulties with speech and language are reported by⁴:

- 6% of people with Hearing Disorders
- 13% of people with Attention Deficit Hyperactivity Disorder (ADHD)
- 18% of survivors of Stroke
- 27% of people with Multiple Sclerosis
- 30% of people with Dementia
- 32% of people with Parkinsons Disease
- 55% of people with Cerebral Palsy
- 69% of people with Down's Syndrome
- 75% of people with Autism

Research indicates that in Australian communities, a conservative figure of 10% of children are developmentally vulnerable in their language and cognitive development, including basic literacy skills, and/or in their communication skills (including participation with other children and ability to understand others), by the time they start school [5]. This may be as high as 33% in some Australian communities⁵. Around 20% of children may be slow to develop spoken language⁶, and for 50% of these children, language problems persist into the early school years⁷.

Across the primary and secondary years, communication disorders (including any or all of difficulties with: understanding language, using language, social communication, speech, voice and fluency) affect as many as 12-13% of Australian children⁷. Indeed, in a recent study looking at the prevalence of communication disorders compared with other learning needs in primary and secondary school students, the prevalence of communication disorders was second only to specific learning difficulties.

Speech and language disorders have the potential to result in long term disabilities, not only in acquiring literacy and maximising academic achievement, but also in relation to psychosocial development and community participation and integration. Australian research demonstrates that severe speech and language disorders are associated with reduced employment options, social, emotional and behavioural problems across the life span, mental health problems, and criminal behaviour leading to juvenile offending and imprisonment^{8,9}.

⁵ Centre for Community Child Health (2007). *Australian Early Development Index (AEDI). Australian Results 2004-2006*. Melbourne: CCCH

⁶ Reilly, S., Wake, M., Bavin, E.L., Prior, M., Williams, J., Bretherton, I., et al. (2007). Predicting language at age 2 years: A prospective community study. *Pediatrics*, 120 (6), 1441-1449

⁷ McLeod, S., & McKinnon, D.H. (2007). The prevalence of communication disorders compared with other learning needs in 14500 primary and secondary school students. *International Journal of Language and Communication Disorders*, 42 (S1), 37-59

⁸ Snow, P., & Powell, M. (2007). Developmental language disorders and adolescent risk: A public health advocacy role for speech pathologists? *Advances in Speech-Language Pathology* 6 (4), 221-229

⁹ Smart, D. et al. (2004). *Patterns of antisocial behaviour from early to late adolescence. Trends and issues in crime and criminal justice*. No. 290





People with disabilities that include communication impairment are a unique group within the disability sector. Compared to people with disabilities but no communication impairment, people with disabilities that include communication impairment:

- have poorer employment outcomes and more employment restrictions. They are less likely to be employed, more likely to be restricted in the type of job, and more likely to need a disability support person or someone at work to assist them;
- have poorer social opportunities – are less likely to receive or make visits to family and friends, far less likely to communicate with family and friends over the telephone, and less likely to leave home for activities/visits;
- are more likely to be attending special schools, rather than attending normal school with a special class¹⁰.

In relation to difficulties with swallowing (dysphagia), as much as 5% of the population are affected by severe swallowing problems that require non oral forms of nutrition². Children and adults with disabilities resulting in dysphagia are at risk of malnutrition and dehydration, of choking, and of food and drink entering their lungs, resulting in infection.

Difficulties with swallowing/dysphagia have been found to be present in:

- 40-60% of survivors of Stroke¹¹
- 45% of people who have undergone chemoradiation for head and neck cancer¹²
- 69% of people with Parkinsons Disease¹³
- 84% of people with Alzheimers Disease¹⁴
- 25% of people with Multiple Sclerosis, increasing to 65% with severe disease¹⁵
- 35% of children with Cerebral Palsy¹⁶
- 70% of children who suffer a severe brain injury¹⁷

Dysphagia can result in significant disability, impacting on quality of life and having psychological consequences, including social isolation and depression¹⁸.

¹⁰ Australian Institute of Health and Welfare. (2003). *Communication restrictions – the experience of people with a disability in the community (Disability Data Briefing No. 23)*. Canberra, ACT: AIHW

¹¹ Mann, G., Hankey, G.L., & Cameron, D. (2000). Swallowing disorders following acute stroke: prevalence and diagnostic accuracy. *Cerebrovascular Diseases*, 10 (5), 380-386

¹² Nguyen, N.P., Moltz, C.C., Frank, C., Vos, P., et al. (2006). Dysphagia following chemoradiation for locally advanced head and neck cancer. *Annals of Oncology*, 15 (3), 363-364

¹³ Agency for Health care Policy and Research. (1999). HRQ Evidence report # 8. *Diagnosis and treatment of swallowing disorders (dysphagia) in acute-care stroke patients.*: Agency for Health care Policy and Research

¹⁴ Horner, J., Alberts, M.J., Dawson, D.V., & Cook, G.M. (1994). Swallowing in Alzheimers disease. *Alzheimers Disease and Associated Disorders*, 8 (3), 177-189

¹⁵ De Pauw, A., Dejaeger, E., D'hooghe, B., & Caton, H. (2002). Dysphagia in multiple sclerosis. *Clinical Neurology and Neurosurgery*, 104 (4), 345-351

¹⁶ Reilly, S., Skuse, D., & Poblete, X. (1996). Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: A community survey. *Journal of Pediatrics*, 129 (6), 877-882.

¹⁷ Morgan, A., Ward, E., Murdoch, B., Kennedy, B., & Murison, R. (2003). Incidence, characteristics, and predictive factors for dysphagia after pediatric traumatic brain injury. *Journal of Head Trauma rehabilitation*, 18 (3), 239-251

¹⁸ Nguyen, N. P., Frank, C., Moltz, C.C., Vos, P., Smith, H.J., Karlsson, U., ET AL. (2005). Impact of dysphagia on quality of life after treatment for head-and-neck-cancer. *International Journal of Radiation Oncology Biology and Physics*, 61 (3), 772-778





The inability to communicate effectively or to meet one's nutritional needs in the most appropriate manner may result in major disabilities for many people, whether present in isolation or as part of another disability. These issues relate to basic human rights. Speech Pathology Australia contends that through the proposed National Disability Framework, recognition be afforded to the complex and variable nature of disability, and its potential to impact social inclusion and participation at many levels and in many diverse ways.

CONSULTATION QUESTIONS

The following provides comment and recommendations from Speech Pathology Australia with regard to the Consultation Questions within the Discussion Paper.

What do you think should be included in the National Disability Strategy?

It is imperative that the National Disability Strategy include clear statements regarding the importance of access to services and facilities within the community for all people with a disability, together with their family and carers. It is essential these statements be underpinned by the development of and a commitment to policies that promote *meaningful* inclusion of people with disabilities. This should include the development of legislation that acknowledges the rights of persons with disabilities and provides avenues and opportunities for their voices to be heard and their opinions counted. Such legislation should also extend to the workplace where there are currently minimal opportunities for people with disabilities to participate or influence basic workplace rights such as safety and pay negotiation.

There is a wide and extremely variable group of individuals in Australia who have communication disabilities or complex communication needs. These people may be unable to communicate through speech, have limited speech or speech that is extremely difficult to understand. Speech pathologists assess and advise on the most appropriate means by which these individuals can communicate – this may include the use of Augmentative and Alternative Communication (AAC) devices. Such devices may range from communication boards and pictures to electronic voice synthesisers. Unfortunately, these devices are expensive and funding is currently inadequate to meet the needs of users. Often people with a communication disability are required to 'make do' with suboptimal forms of communication, thereby not only limiting their potential to communicate but also their ability to participate and develop their full potential in all aspects of their lives.

Funding for AAC devices is further restricted for those people who require an AAC device due to a communication disability but have no other disability or are deemed not eligible due to their socioeconomic situation. For example, speech pathologists report clients being denied funding for AAC devices because they reside in nursing homes; other clients have been denied access because they have a 'significant other', i.e. a spouse, who is expected to communicate for them. It is imperative that the right of all individuals to an effective form of communication be acknowledged,





regardless of their social or physical environment. This must be demonstrated by government commitment to appropriate levels of funding and appropriate eligibility criteria.

In relation to meeting the needs of people with disabilities that affect eating and swallowing, the National Strategy must consider models of service delivery that meet the complex and variable needs of this group of people. There is little understanding within the community regarding the very real difficulties faced by people with swallowing problems (dysphagia), and the many forms in which these difficulties may present. Current service delivery generally sees emphasis upon consultative services that fail to address the fluctuating nature of dysphagia and the impact of concurrent disabilities that may relate to psychological status, cognition and language. Goal setting and treatment planning often reflect limitations in access to services, including limited access to multidisciplinary services.

Dysphagia management for people with disabilities is best managed by a coordinated, multidisciplinary team approach that sees speech pathologists, medical professionals, dietitians and other professionals working closely with families and carers. Whilst some multidisciplinary services do exist, access is variable and the degree of support provided by key professionals is limited by funding and restrictions in service delivery. Limited access to professional services such as speech pathology has the potential to significantly the quality of life and functional outcomes of people with dysphagia.

The National Strategy should acknowledge the importance of providing access to therapy and other services *across the life span* for people with disabilities, including those with complex communication needs and swallowing difficulties. Increased funding is required to ensure adequate numbers of health professionals, including speech pathologists, occupational therapists and appropriately trained teachers, and support staff (such as teacher's assistants, social trainers, allied health assistants) so that services are available across all settings, whether it be at school, at work or in the home.

A commitment to raising public awareness about disability should be included in the National Strategy. Specifically in relation to communication and swallowing disorders, education should highlight types of communication and swallowing disabilities, the impact of communication and swallowing disabilities and advice on how to communicate with someone who has a communication problem. The Association applauds the current education campaign conducted by SCOPE in Victoria which encourages us to "See the person, not the disability". This campaign features a person with severe disabilities, including impaired speech, effectively using public transport and participating in daily activities. Such education campaigns are essential to breaking down attitudinal barriers within the community and to creating an environment where people with disabilities are afforded the greatest opportunity to live meaningful and fulfilling lives.





What are the greatest barriers that people with a disability face to participating fully within the community and what specific local and national actions could be taken to overcome these barriers?

Speech Pathology Australia believes barriers to participation for people with a disability include:

- limited access to timely and appropriate assessment and intervention;
- limited availability of support services within educational, work and social settings to facilitate inclusion;
- limited awareness of available services and how to access them;
- poor coordination of services and fragmented case management;
- conflict between State and Federal funding for disability services, resulting in confusion for families as to where to access services;
- limited understanding within the general public about the impact of a disability; this is certainly the case in relation to disabilities associated with communication and swallowing disorders;
- inadequate respite services for families and carers;
- inadequate support services for carers/families, resulting in a reduced income capacity and limited financial reserves;
- limited knowledge of health professionals in relation to the needs of people with disabilities, and lack of appropriate skills and training to address these needs;
- limited appropriate communication and transport services for people with disabilities.

Actions to address these issues include:

- provision of funding to ensure services and the number of professionals are sufficient to meet the needs of people with disabilities. Specifically, adequate funding to ensure appropriate numbers of speech pathologists are available to provide services to those with communication and swallowing disabilities.
- incorporation of disability education and training into tertiary courses relevant to the field of disability, including medicine and nursing, the health sciences, teaching, and support workers;
- interdisciplinary training of health care professionals as a means to counteract the silo mentality that currently exists in relation to service provision;
- communication and collaboration between government authorities and key professional organisations, Associations and support groups regarding the needs of people with disabilities;
- development of service delivery models that meet the individual needs of those with disabilities. For example, access to services in schools, hospitals, rehabilitation and community settings and the home;





- the establishment of specialist Augmentative and Alternative Communication services in all states and territories;
- adequate funding for the provision of aids and services, with the establishment of transparent guidelines in relation to eligibility and access;
- provision of adequate funding to ensure all those who require an Augmentative and Alternative Communication device are able to do so across the life span;
- widespread community awareness programs;
- an increase in the number of respite services, available to family and carers.

As a separate point, the Association wishes to draw attention to the multiple education barriers faced by children with complex communication needs. For example, there are very few teachers with any formal training in how to teach a child to read who is unable to speak. These children miss out on the quality education they are rightly entitled to. This is a huge concern as increasing numbers of children with disabilities are included in mainstream classrooms.

Actions to address these issues include:

- training of teachers in inclusive education methodologies that actively foster inclusion of children with disabilities. This training should provide teachers with the means to adapt the curriculum as required so as to meet the specific needs of students with disabilities, and in particular, where the sequelae includes speech, language and learning disabilities;
- the establishment of specialist teacher services to consult with mainstream teachers regarding children with disabilities;
- timely and equitable access to speech pathology services for all preschool and school age children with speech and language disabilities;
- specialist literacy programs for children with disabilities to assist their acquisition of literacy skills; programs to facilitate the acquisition of literacy skills should also be made available to adults with disabilities;

What areas of research do you think should be a priority to better inform the National Disability Strategy?

Priority areas of research include:

- the prevalence, scope and range of disabilities within the community;
- the impact of specific disabilities upon level of participation;
- evaluation of the effectiveness and relevance of current models of service delivery for people with disabilities;
- quality of life, participation and loneliness of people with disabilities;
- rights of people with disabilities, including rights in the workplace and in the legal system;
- anthropology studies looking at communities, cultures and attitudes to people with disabilities;





- evaluation of the international literature regarding disability;
- consideration of policy and strategies utilised internationally in the area of disability;
- best practice in teaching and in therapy services for people with disabilities;
- current waiting lists for services, and factors impacting access to services.

Discipline-specific research required in the field of speech pathology includes information regarding:

- the number of individuals with disabilities affecting communication and swallowing, including those with complex communication needs;
- a breakdown of the types of communication and swallowing disabilities associated with specific disorders;
- the extent of the use of Augmentative and Alternative Communication devices, including both met and unmet needs;
- the needs of people with disabilities affecting swallowing;
- literacy levels of people with disabilities;
- current levels of servicing and unmet demand for speech pathology services to people with disabilities;
- outcome data for speech pathology practice in the area of disability.

Please tell us about any time that you, or someone you care for or support, experienced barriers to participating in a community, social or work event?

Speech pathologists report multiple occasions when a person with a complex communication need has been refused service due to their inability to be understood. People who have speech that is difficult to understand report being accused of being intoxicated, of being ignored when making a request and being treated in a manner that suggests they are intellectually impaired. For those people who use an augmentative and alternative communication device, there are regular occasions when their attempts to communicate are ignored and potential communication partners actively refuse to incorporate the communication device into the conversation. Parents with children who have autism and associated communication problems report bypassing shopping centres because members of the public have commented in a derogatory manner about their parenting skills. For those persons with swallowing disorders, there is reluctance of behalf of restaurants and food outlets not only to accommodate special dietary requirements but also to provide an eating environment and location that meets the needs of a person who may require a degree of privacy and support during mealtimes.

What local action has made a positive difference to the life of someone you care for or support?

Organisations such as the Australian Association for Special Education (AASE), the Australian Group on Severe Communication Impairment (AGOSCI) and SCOPE in Victoria are just 3 of many state and nationally based organisations that make a real difference in the area of complex disability.





Through their advocacy work, as well as the provision of education and training, such organisations provide opportunities for professionals and members of the public to improve their knowledge and skills in the area of disability. These organisations work directly with people with severe disability, providing specialised services that aim to optimise the potential of people with disabilities and improve their ability to participate fully and meaningfully.

Professional associations such as Speech Pathology Australia, together with organisations and support groups such as the Australian Stroke Foundation, Multiple Sclerosis Society, and Autism Australia play a key role in supporting persons with disabilities. They offer advice on the needs of specific client groups and play an essential role in raising public awareness of the impact of disabilities across a broad spectrum of disorders. It is essential that such groups be actively engaged by government to inform policy development and advocate for the rights of people with disabilities.

What local action has made a positive difference to the life of someone you care for or support?

The following case scenario illustrates the impact of one local action upon the quality of life of a young child with complex communication needs.

Recently in Western Australia, a 5 year old boy who had been unable to speak since birth received a high technology voice output communication device. This device cost approximately \$13,000 and was fully funded through a local Western Australian disability funding scheme. Having this device has been a life changing experience for this young boy and his family. The communication device provides a means by which he can communicate, learn new skills, fully access school curricula, access a computer and socialise with his peers.

There are a number of reasons why the device was successfully funded. A key factor was that the boy's parents had been accurately informed regarding the importance for early intervention; thus they had been advocating strongly on his behalf for his right to communicate and be heard from an early age. Both parents were physically and emotionally well, had access to funded respite, and were motivated to work with their son and the device. At school, he was provided with a full time education assistant who could support him in the use of the device and facilitate its use into the classroom environment. The child's teacher was afforded time away from the classroom to attend training in how to use and implement the communication device in the classroom.

The speech pathologist involved in the boy's care had accurate knowledge of the local funding scheme and together with the child's parents, was able to advocate for funding. The speech pathologist knew how to access local "expert" support regarding communication devices and AAC in particular; thereby making the case that training would be provided so as to ensure successful use of the device. The speech pathologist also remained constant throughout the entire process,





from assessment and prescription, through to funding and implementation of the device. This is unusual given the shortage of speech pathologists in Western Australia and throughout Australia generally.

All of these factors have been important in helping this young boy achieve his communication potential. It is imperative that the many complex and interrelated factors impacting the potential of people with disabilities, as illustrated through this case scenario, are carefully considered when determining the key objectives and identified outcomes of a National Disability Strategy.

CONCLUSION

Speech Pathology Australia applauds FaHCSIA for its commitment to developing a National Disability Strategy for Australia that aims to address the very complex issues that impact upon the ability of people with disabilities to participate in the social, economic and cultural life of Australia. This submission provides the Association with the opportunity to advocate on behalf of the many individuals with complex communication and swallowing needs, their families, carers, support workers, teachers and therapists. Individuals with complex needs, particularly where their communication is impaired, are unable to advocate for themselves. Many people with disabilities in Australia have the potential to communicate and improve their quality of life, yet currently are not given a voice due to lack of access to services, poor public awareness fragmented service provision. Speech Pathology Australia looks forward to further consultation with FaHCSIA as the National Disability Strategy is progressed.

For further consultation, please contact:

A handwritten signature in black ink, appearing to read 'Gail Mulcair'.

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