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Speech Pathology Australia

SUBMISSION TO:

THE PRODUCTIVITY COMMISSION DISABILITY CARE AND SUPPORT

This document outlines the Speech Pathology Australia response to the Productivity Commission's Draft Report into Disability Care and Support

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PRODUCTIVITY COMMISSION DRAFT REPORT INTO DISABILITY CARE AND SUPPORT

SPEECH PATHOLOGY AUSTRALIA SUBMISSION
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Introduction

Speech Pathology Australia congratulates the current Government on the development of a draft National Disability Strategy and we support the vision – "for an inclusive Australian society that enables people with a disability to fulfil their potential as equal citizens" (National Disability Strategy, 2010-2020, page 8). We further commend the Government for ratifying the UN Convention on the Rights of Persons with a Disability in 2008.

Speech Pathology Australia applauds the Productivity Commission for producing such a strong, balanced, considered and cogent report on the needs of people with disability within Australia. We support the Commission's view that the disability system is "inequitable, underfunded, fragmented and inefficient and gives people with a disability little choice." We also support the Commission's view of the need for major reform and for a National Disability Insurance Scheme (NDIS).

Speech Pathology Australia supports the government's commitment to ensuring that people with disabilities have the same opportunities as other Australians – a quality education, appropriate health care, a job where possible and access to buildings, transport and social activities.

The National Disability Care and Support Scheme and ultimately the final National Disability Strategy must explicitly include people with communication and swallowing disabilities.

Speech Pathology Australia also supports the premise of a social insurance model that provides universal (not rationed) funding for access to the care and supports that enable individuals with disability to achieve these opportunities.

Preamble

In 2009, the Australian Government asked that the Productivity Commission undertake a public enquiry into a long term disability care and support scheme. The Inquiry aimed to explore alternative approaches to the funding and delivery of disability services with a focus on early intervention and long term care. The scheme was intended for people with significant need of support. People with a complex communication and/or swallowing impairment often have need of significant support across their life.

The rationale for the Inquiry was the opportunity to re-evaluate how people with a disability are supported (or not) in the community and how could they engage with their communities, participate in work and be socially included to ensure a contribution to the best possible and meaningful life.

The impetus for this Inquiry was the number of recently published reports that found the current system supporting people with a disability (and their family and carers) deeply flawed and increasingly unable to meet people's needs.

By recognising that many people with a disability and their carers need specialist supports and care, the commissioning of an inquiry into a National Disability Care and Support Scheme informs

approaches to funding and service provision that importantly focus on early intervention and long term care. The Scheme must adequately provide for a range of coordinated support options including appropriate accommodation, aids and appliances (including often expensive alternative and augmentative communication (AAC) devices), transport, respite, day programs and community participation. The Scheme must also assist persons with a disability to engage in supported decision making with the assistance of skilled and trained facilitators. It is also incumbent on the scheme to provide opportunities for people with a disability to participate in education, training and employment where it is achievable.

The Productivity Commission was asked by the Government to examine the feasibility, costs and benefits of replacing the current system of disability services with a new arrangement that provides essential care and support of ALL Australians in the event of a significant disability. The fundamental draft conclusion of the Productivity Commission report (28 February 2011) is that the current arrangements are systematically flawed. The report states that the country must better meet the needs of those people with a disability who currently do not receive any or inadequate support, and that their improved support packages would be portable across state and territory boundaries. The Commission recommends the introduction of a fully funded NDIS with individualised funding to ensure people with a disability and their families are able to exercise greater choice and control about the support they need. The Commission believes that new national insurance arrangements are feasible and achievable.

The Productivity Commission Draft Report takes into detailed consideration the many and complex elements that make up the requirements for a properly functioning and constituted scheme and gives these elements considerable thought and attention. For example, the matters of governance; financial management; thoughtful assessment processes; clear entry criteria to the scheme; empowering people with disability to make decisions and change arrangements; efforts to provide better conditions and satisfaction for the disability workforce and the development of better support mechanisms to better support service providers and ultimately, a commitment to a client centred system are all covered in this draft report.

Currently the disability support scheme is seriously underfunded and managed by two jurisdictions (The Federal Government as funders and the State Governments as providers); it is unfair, fragmented and inefficient. People with disability have little or no choice and are not encouraged to participate in supported decision making. Supports can be inadequate, inappropriate, insufficient, untimely or unavailable.

The current arrangements are unsustainable as the system relies heavily on informal unpaid volunteer carers for support and care. These carers are struggling to cope in an already severely rationed system. This adds urgency to the inquiry and the outcomes to be produced in terms of the carer workforce. The increasing burden of the ageing population (including those people with a disability), the ageing workforce and the rapidly increasing fall of workforce participation rates affect and will continue to affect the capacity to deliver a range of targeted services to people with disability including speech pathology services.

Increasingly, as demand for services continues to grow exponentially, there is the significant issue of a declining workforce and substantial problems around the recruitment and retention of speech pathologists (as well as other health professional groups) to be able to undertake the delivery of services. This is much more pronounced in rural, regional and remote parts of the country.

The proposition of the Productivity Commission that a new system is designed (the National Disability Insurance Scheme) that would be a universal scheme like Medicare in that Australians would know that they as a person with a disability and/or their families would have access to long term care and support if they were born with or acquired a significant disability.

The report also contains many individual and organisational stories relating to people's experience with disability and how they have found the system. These vignettes provide powerful feedback as to the inequities, injustices and poor decisions made by service funders that have adversely affected people's experiences of a range of issues, such as waiting 3 years for an appropriate wheelchair. Pleasingly, there has been extensive positive commentary from the media and social commentators about the value of the draft report and the recommendations contained therein.

Speech Pathology Australia

Speech Pathology Australia is the national peak body for speech pathologists in Australia representing approximately 4,500 members. Speech pathologists are university qualified health professionals who are specialists in the assessment and management of disorders of communication and swallowing that may present across a person's life Speech Pathology Australian. Speech pathologists contribute significantly to the assessment, care, management and quality of life of individuals through the provision of services that maximise communication (speech, language, voice, fluency, social skills and behaviours, literacy and numeracy, problem solving and general learning) and swallowing (eating, drinking, managing saliva) needs, through direct intervention, education, consultancy, advocacy or a combination of these approaches.

Speech pathologists work with large numbers of children with disabilities prior to and during their formal education, in public and private sectors, in education, health and disability programs. Speech pathologists also work extensively with the adult population who have acquired a communication impairment/disability or who have had a disability present from birth. Many of these people have communication impairments of unknown origin and are in need of significant supports that are currently not funded.

These people may be unable to communicate using speech, have limited speech or their speech is extremely difficult to understand. Often, people with communication disability are required to "make do" with suboptimal forms of communication, not only limiting their potential to communicate but also their ability to participate and develop to their full potential in all aspects of their lives. The profession of speech pathology believes that it is ideally placed to provide meaningful input into the draft report on Disability Care and Support, particularly in relation to the needs of people with communication and/or swallowing impairment.

In this submission, Speech Pathology Australia makes two key points:

- The Definition of Disability must include communication and swallowing disability of unknown origin, in addition to those arising as part of a specific disorder or complex syndrome,
- People with complex disabilities and associated communication and/or swallowing difficulties need funding for access to speech pathology services, and where required, augmentative and alternative communications (AAC) systems.

Speech Pathology Australia is keen to ensure that communication and / or swallowing impairment encompasses a range of communication and swallowing difficulties and/or disabilities affecting:

- Speech and Language (understanding and/or use)
- Social skills and behaviour
- Aspects of literacy, numeracy, problem solving and general learning
- Alternative forms of communication: for example, the use of communication devices by children and adults who cannot communicate using speech
- Eating, drinking and ability to meet nutritional needs.

Context

Communication Impairment is included in the definitions of disability under various United Nations (UN) Conventions and the World Health Organisation (WHO). UN Conventions and WHO state that communication is a basic human right and is essential for participation in society (World Health Organisation, 2007). Yet communication impairments are often the **"invisible"** disability in our society.

Hundreds of thousands of Australians suffer from communication disabilities. A communication disability is not dependent on age, socio-economic status, education or location. Access to speech pathology services is variable and inconsistent across Australia and in particular those people in remote and rural areas are seriously disadvantaged. For our Indigenous population the disadvantage is even greater.

Speech pathologists understand first hand that people with a disability, and, in particular, a communication disability are impacted on daily in all the aspects of living, learning, working and socialising. This prevents them from participating fully in their community. Participation in society must be supported by appropriate access to communication. The ability to communicate effectively – talk with and listen to others easily, learn, share ideas, express our needs and wants and be part of a social or work conversation – is a basic human right.

The speech pathology profession aims to partner with individuals with a communication disability to assist them to participate as fully as possible in our society. This means that the profession takes up a range of different roles from therapist, advocate, lobbyist, partner, researcher, educator and academic to counsellor as well as support person in order to work with key agencies and groups to develop and promote key initiatives that will optimise social inclusion for those people with a communication disability.

Legislation

Communication impairment is a prevalent childhood disability. The way countries formally recognise communication impairment impacts on the provision of services and long term outcomes for these children. Currently, Australia does not identify children with communication impairment in legislation and policy.

Australian legislation and policy does not adequately address the needs of children (and adults) with communication impairment, particularly those with communication impairment of unknown origin. Health professionals, educators and disability service providers are left to interpret ambiguous policies to make a case for service delivery.

Two Commonwealth Acts provide legislation for disability and health: Disability Services Act (DSA) 1986 and Disability Discrimination Act (DDA) 1992. In 2005, the Federal Government formulated the Disability Standards for Education, 2005 (The Standards) to clarify the obligations of education and training service providers under the Disability Discrimination Act 1992 as well as articulate the educational rights of people with disabilities (Commonwealth of Australia Disability Standards for Education 2006). Although communication disorders are not specifically identified as a "disability" in the DDA or the Standards, such disorders could be covered by the reference to "a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction." (Commonwealth of Australia, Disability Standards for Education, 2005 Guidance Notes.)

Access to speech pathology services is inconsistent across Australia's states and territories due to different interpretations and applications of the relevant federal and state legislation. Children with

communication impairment of unknown origin are rarely accounted for in Commonwealth or state legislation or policies.

Prevalence and Impact of Communication Disabilities/Impairment

Severe communication impairment may affect as many as 8-10 people per 1000 population (Beukelman & Ansel,1995). At a minimum, difficulties communicating may affect 1.3% of the total population (Australian Institute of Health and Welfare, 2004) whilst difficulty swallowing (dysphagia) may affect up to 16% of Australians (Eslick & Talley, 2008).

Considering disabilities in communication alone, one in seven users of government disability services (over 5 years of age) has little or no effective communication and over 40% of users require assistance with communication (Australian Institute of Health and Welfare, 2005).

Augmentative or alternative communication devices are used by 13,000 Australians (Speech Pathology Australia2008).

Data from the Australian Institute of health and Welfare: Disability Support Services 2008-2009; (January 2011) indicates that service users who reported their method of communication: 15% had little or no effective communication and therefore will face considerable barriers to social participation. Service users with the primary disability of Intellectual (27%), Autism (23%) and/or Deafblind (16%) were the most likely to report having little or no effective communication.

Cost Implications

The social and economic cost of communication and swallowing impairment is significant for the person and society as a whole and places a huge financial burden on government supports and services. The deleterious consequences of communication and swallowing disability affect Australians across their life.

A report by ICAN, a UK charity highlighted the triple cost of communication difficulties: costs to individuals, to families and to the country. There are costs to individuals such as lower educational attainment and social/emotional difficulties. Costs to families may include not only the direct costs of therapy but other costs such as travel. The costs to the country are related to the increased educational needs, higher unemployment rate and fewer employment opportunities of people with communication difficulties (ICAN, 2006).

As cited in McLeod 2010, a UK study found that the cost of education provision and welfare benefits was significantly higher for a child with developmental language disorders than for their siblings.

The Royal College of Speech Language Therapists commissioned a study in in 2010 to determine the economic value generated by speech – language therapy for 4 cohorts; adults with dysphagia post stroke; adults with aphasia post stroke; children with speech and language impairment and children with autism. The results of the analysis indicated that speech - language therapy for all four cohorts represented an efficient use of public resources; the net benefits of the interventions are positive and the benefit-cost rations are higher than 1. The annual net benefit across 3 conditions (aphasia; speech language impairment and autism) is £765 million. Matrix Evidence (2010.)

Speech Pathology Australia's response to the Draft recommendations posed by the Productivity Commission

Chapter 3 Who is the NDIS for?

Speech Pathology Australia supports the view that the NDIS is for all Australians. At Tier 1, it will provide insurance against the cost of support in the event of a person acquiring a disability. At Tier 2, people with, or affected by, a disability would be able to approach the NDIS for information and referral services. At Tier 3, people with a disability would be able to access funding support from the NDIS, i.e. people from 0 to pension age with sufficient needs for early intervention and disability support. (This level would require support from federal monies already allocated to disability plus taxpayer support).

At Tier 3, individuals must meet one of the following conditions:

i) a significant difficulty with core activity limitations i.e. communication, mobility or self-care

ii) have an intellectual disability and

iii) be in need of (as opposed to already in) an early intervention group. (Many children presenting with complex language impairment do not have a definitive diagnosis and must be acknowledged as having a significant disability.)

Speech Pathology Australia agrees that the NDIS would not cover people who needs are best met by other jurisdictions e.g. workplace accident or acquired catastrophic injury (to be covered by a National Injury Insurance Scheme) or people with terminal or life limiting illness (to be covered by palliative care services) or people with psychiatric conditions would best be served by the mental health system. Speech Pathology Australia cautions that the communication, referral mechanisms and relationships will need to be carefully managed so that people do not slip through the system.

A significant area of work will be to determine the scope of people who meet the criteria for the third level of the scheme. Eligibility must be based on a national standard set of definitions of disabilities and/or conditions such as communication disorders of unknown origin. These standard definitions should be informed by internationally accepted classifications of disability such as the International Classification of Functioning, Disability and Health (ICF). Peak professional bodies, such as Speech Pathology Australia, should be consulted as to the application of such definitions and/or conditions to the NDIS.

The determination of "significant" or rating of severity should be based on international and national standards requiring profession based specific input. Assessment of severity would require formal assessment and the use of accepted standards in regard to severity. One example in relation to language impairment is the use of specified test scores and accepted standards to determine severity.

Speech Pathology Australia contends that people with disabilities in communication (which also have significant long term impacts) must be included to ensure appropriate funds are available to access specialist services. This, in turn, will help mitigate the high impact on educational and social participation opportunities. People with equally complex communication needs occurring in the absence of an identified syndrome or multiple impairments, as in the case of a complex language disorder, childhood apraxia or acquired aphasia, and those of unknown origin must also be eligible due to the significant impact that communication impairment has on learning, socialisation and full participation in educational, work and community activities.

There are people who are currently eligible for specialist disability services (people with complex communication needs as part of a specific identified disorder or syndrome such as cerebral palsy, Down syndrome, autism and sensory impairments) who will require more support than currently exists and would receive more support under the NDIS.

Speech Pathology Australia provides two example which illustrate the impact of a pervasive communication impairment - these families are operating under severe duress due to the needs of caring for complex communicatively impaired individuals e.g. parents with children who have severe/profound disabilities (often more than one child) and are providing 24 hour care in order to prevent harm or injury to the child or to others. These parents live in a constant state of anxiety worrying about the long term outcomes including care and accommodation for their children and are often physically and emotionally unwell themselves due to the care burden. E.g. people who require expensive augmentative and alternative communication (AAC) devices are not consistently or adequately funded to purchase them. Such devices may range from communication boards and pictures to more sophisticated and costly electronic voice synthesisers. One example of such a piece of equipment is a high technology voice output communication device at a cost of $15,000.

The NDIS must fund all people who meet the criteria for individually tailored supports not only those who acquire a disability after the introduction of the scheme.

Chapter 4 What individualised supports will the NDIS fund?

Speech Pathology Australia contends that the NDIS should fund the full range of disability supports and specialist therapy services that are reasonable and necessary for an individual to participate in a full and productive life in society. Aids and appliances must include alternative and augmentative communication (AAC) devices and Speech Pathology Australia recommends the establishment of specialist AAC services in all states and territories.

Access to and the availability of specialist therapies such as speech pathology and other allied health disciplines are a necessary requirement for assisting a person with a severe and complex disability. Specialist packages of comprehensive multidisciplinary services (including speech pathology) must be available for those people with complex communication and/or swallowing impairment.

Speech Pathology Australia argues strongly for encouraging people with a disability to be able to undertake supported decision making around their care, treatment, accommodation, employment and social participation. This means that people working with the person with a disability (that involves communication or cognitive impairment) must be skilled facilitators of communication and should be an independent and unbiased communication partner. Speech pathologists also have a role as advocates and in providing advocacy services for people with communication disabilities who need assistance to “speak out” about their choices and decisions and wishes.

Chapter 5 Accessing Care and Support Needs

Speech Pathology Australia supports the use of the International Classification of Functioning, Disability and Health (ICF) as a framework for the assessment process. Speech Pathology Australia believes that the assessment process should include multiple sources of information including information provided by the person with the disability.

Speech Pathology Australia recommends the development of appropriate assessment tools (including a dedicated communication and/or swallowing component) based on functionality. Generally, the assessment tools should be able to identify the needs of each person, considering severity, function and complexity, as well as potential for improvement and future gains in communication. The tools should be objective and reliable so that they can be used throughout the country with a high degree of inter-rater reliability. Additionally the tools need to have a broad degree of acceptance and be relatively easy to administer so that core and common components can be administered by one health worker. The tools should be able to account for multiple aspects of assessment so that people are not subjected to repeated and multiple testing.

Speech Pathology Australia also notes that the development, administration and interpretation of assessment tools that relate to core functions such as communication and swallowing must be informed by relevant specialists and peak professional bodies.

More detail about the assessment tools is required, such as who can undertake them, the skill level and background of the assessor and that the tools are appropriate for people with complex communication needs. Recent experiences in terms of changes to disability services and the introduction of screening assessments in Tasmania suggest that there are large areas of unidentified needs and inappropriate referrals without follow up due to the lack of skill of assessors.

Speech Pathology Australia agrees that the assessment should be person centred and the assessment needs to be able to describe what an individual can do as opposed to what they cannot do.

Chapter 6 Who has the decision making power?

Speech Pathology Australia supports the premise that the NDIS be based on a “consumer choice” model. The individual with the disability should have much more power and choice over what and how services are provided and delivered. People with a disability could choose the support organisation and service providers that would provide the supports detailed in the person’s support package based on comprehensive valid and reliable assessment. When the individual has a complex communication impairment, the person should be assisted to use a model of supported decision making. Appropriately trained and credentialed individuals are required to assist an individual in supported decision making. Speech Pathology Australia could contribute expertise as to credentialing and appropriately recognised individuals who could undertake these activities.

Speech Pathology Australia agrees that the person with the disability (and/or their support network or chosen support disability organisation) and who wants to engage in self-directed funding is best placed to develop a personal plan as well as a funding proposal that outlines the person’s goals and the type of support required, necessary and reasonable to achieve these goals within the agreed budget. Self-directed funding should reside with the person who can exercise choice about the services that best meet their needs and promote social inclusion.

Chapter 7 Governance of the NDIS

Speech Pathology Australia supports the establishment of a new independent Commonwealth Statutory Authority, the National Disability Insurance Agency (NDIA) to administer the National Disability Insurance Scheme.

Oversighting governance arrangements must be put in place. Good governance will be required to ensure that the supports available are high quality and based on evidence or at least good practice and that the scheme is generally sustainable.

Speech Pathology Australia agrees with the establishment of an advisory council to provide the board of NDIA with ongoing advice on its activities and its effectiveness in meeting its objectives from various perspectives. The inclusion of peak professional bodies involved in service provision would add a valuable perspective to this council.

From a consumer perspective, the individual with the disability would have regular and direct contact with a local case manager and not interact with the NDIA itself.

Chapter 8 Delivering Disability Services

Speech Pathology Australia agrees that the NDIA should provide consumers with information and advice about the service providers, resources, products, services, costs, availability and information about performance and quality. Service providers need to be able to demonstrate that services are constructed on evidence based practice and efficacy of treatment.

There is a need to encourage and support inter-professional training, education and practice for all health professionals (doctors, nurses, allied health professionals, support workers) as a means to counteract the silo approach that currently prevails in relation to service delivery within and across jurisdictions.

In conjunction with delivering services, there is a significant need for increased training to a range of workers e.g. training of staff in residential houses, aged care facilities and other residential facilities where individuals have dysphagia or use alternative communication systems; training, consultative support and education by speech pathologists to teachers and teachers' aides particularly in relation to inclusive education methodologies that promote inclusion of children with disabilities; an increased trained staff presence at mealtimes so they can assist and supervise at mealtimes in residential facilities; mandatory training of carers and educators in ways to maximise language development or to ensure a functional communication system for the person.

The disability sector needs to address issues that will minimise barriers to participation in all facets of life including education, employment, access to community and recreational activities and facilities, socialisation and the opportunity to express views about culture, diversity, religion. One barrier is a complex and pervasive communication disorder.

The development of a shared electronic record is a key priority for a number of jurisdictions and is supported by Speech Pathology Australia.

Chapter 9 Disability within the Indigenous Community

Speech Pathology Australia supports the recommendation from the Productivity Commission that government considers overcoming the barriers to service delivery in the NDIS for Indigenous people with a disability by actively engaging and consulting with communities as to their needs and service requirements; by increasing the uptake of Indigenous people in relevant training places so that they

can become part of a disability workforce and developing cultural competencies of non-Indigenous staff.

Chapter 10 Collecting and using data under the NDIS

Speech Pathology Australia agrees with the draft recommendation of creating an extensive and robust data system that will provide information about services and interventions based on best practice; enabling performance monitoring and outcome evaluation and financial management.

Speech Pathology Australia also advocates for a national enquiry in to the social and economic impact of communication and swallowing disorders. There is an urgent need for further information and data about communication disorders in Australia, the services available, the gaps in service provision and future demand projections. Communication disorders contribute to lifelong disability, the need for increased supports and specialist services to maximise educational learning, reduced employment opportunities, increased dependence on government assistance, and increased behavioural problems and mental health issues as well as the increased need for government funded accommodation.

Chapter 11 Early intervention

It is the position of Speech Pathology Australia that access to timely and appropriately structured speech pathology services in early intervention settings is integral to the achievement of optimal education, communication and social outcomes for children. The first issue is to screen the “at risk” population/those diagnosed with a disability/those with a developmental or acquired disability (for communication and/or swallowing impairment) for the need for services and access to accurate and timely information. For those identified, there will be the need to provide further referral for assessment and intervention. For those assessed with a communication/swallowing impairment, specialist services are required to provide early intervention that is tailored to meet individual need.

Chapter 12 Where should the money come from? Financing the NDIS

Speech Pathology Australia argues that the system should be an entitlement based system (as it is in health care) and that the system cannot continue to run on rationing of funds and services. The system is currently in crisis and the growth in demand for disability services is estimated to be about 8% per annum (the same as in health care). The financing should be funded by government into a national fund and consolidated with existing expenditure currently allocated to the state and Territory governments.

Chapter 13 Workforce Issues

Current workforce arrangements are unsustainable as the system relies heavily on informal unpaid volunteer carers for support and care. These carers are struggling to cope in an already severely rationed system. This adds urgency to the inquiry and the outcomes to be produced in terms of the carer workforce. The increasing burden of the ageing population (including those people with a disability), the ageing workforce and the rapidly increasing fall of workforce participation rates affect

and will continue to affect the capacity to deliver a range of targeted services to people with disability including speech pathology services.

Increasingly, as demand for services continues to grow exponentially, there is the significant issue of a declining workforce and substantial problems around the recruitment and retention of speech pathologists (as well as other health professional groups) to be able to undertake the delivery of services. This is much more pronounced in rural, regional and remote parts of the country.

The core formal services that include personal care services, respite and accommodation services, community access and community support will need to be supported by the development of new worker roles such as the community support worker and other competencies arising from changes to the Health Training Package.

Disability education and training must be incorporated into VET and tertiary courses relevant to the field of disability (including medicine, nursing, the health sciences, teaching and support workers) in order to change the prevailing culture, attitudes and understanding about disability.

The sector needs to develop and support the health professional workforce to increase and optimise the capacity to respond to the needs of people with disabilities, and of particular interest to Speech Pathology Australia, communication and/or swallowing impairments.

Chapter 16 A national injury insurance scheme (NIIS)

Speech Pathology Australia supports the establishment of a national framework that would provide fully funded care for all catastrophic injuries on a no fault basis.

Chapter 17 Implementation

Speech Pathology Australia supports the undertaking that A Memorandum of Understanding under COAG be agreed that sets out an in-principle agreement that the NDIS should commence in a staged fashion from 2014. The implementation of the NDIS is an issue for all Australians, not just those Australian who have a disability now.

There will be massive costs in not engaging in this reform. The Commission has already observed that the system is overheating and that there are regular breakdowns - these will continue until appropriate funding and services and systems are put in place.

Conclusion

This submission provides Speech Pathology Australia 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 or limited in their ability to advocate for themselves.

Participation in society must be supported by appropriate access to communication. The ability to communicate effectively – talk with and listen to others easily, learn, share, ideas, express our needs and wants and be part of a social or work conversation – is a basic human right that is often taken for granted.

Speech Pathology Australia supports the government's commitment to ensuring that people with disabilities have the same opportunities as other Australians – to a quality education, to appropriate health care, to have a job where possible and to access buildings, transport and social activities.

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 and fragmented service provision.

Speech Pathology Australia contends that through the National Disability Strategy and the creation of a Disability Care and Support Scheme through a NDIS, recognition be afforded to the complex and variable nature of communication and/or swallowing disability, and its potential to impact social inclusion and participation at many levels and in many diverse ways.

One of the critical tasks of both the Disability Strategy and the Disability Care and Support Scheme will be to secure national agreement on the definitions of disability and to be explicit about inclusions, including communication and/or swallowing impairment.

Speech Pathology Australia looks forward to further consultation as the work for a long term disability care and support scheme progresses. The Association supports the development of an equitable and adequately funded system of providing necessary care and supports to people with disability, including those with communication and swallowing disorders.

The Productivity Commission has produced an excellent report that outlines a way forward to remedy the underfunded and fragmented system currently in place. The Report articulates strategies that affect all Australians in the future not just Australians with a disability NOW and provides some comfort to those who have been labouring under the difficult burdens of disability and care for many years. The recommendations of the report are a social and fiscal imperative for both state and Federal governments that will help to promote the cultural change needed to understand the lives of people with a disability.

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Appendix 1

Statistics on communication and swallowing impairment

A severe communication impairment may affect as many as 8-10 people per 1000 population. (Beukelman, D, R., & Ansel, B.) (1995)

One in seven users of government disability services (over 5 years of age) has little or no effective communication. (Speech Pathology Australia2008) and over 40% of users require assistance with communication. (Australian Institute of Health and Welfare (2005)

18.1% of five year olds are 'developmentally vulnerable' with respect to Language and Cognitive Skills and Communication and General Knowledge outcomes, while a further 29.8% are 'developmentally at-risk' across both these domains. (Australian Early Development Index) (2009)

At 2 years of age, 20% of Australian children have speech and language delay while 50% of this group will have persisting language delay at 4 years. A further 10-15% of children not identified at 2 years will be identified at 4 years with a speech and/or language impairment. (Reilly S., et al 2009)

One in 4 children have difficulty understanding and using language upon school entry. (McLeod & Harrison, 2009)

Speech and oral language difficulties are a significant risk factor in literacy development. Baseline literacy skills are non existent in 14% of children at 15 years of age. (Speech Pathology Australia2008)

Communication impairment is evident in 75% of children with autism; 69% of children with Down syndrome and 55% of children with cerebral palsy. (Speech Pathology Australia2008)

Over 70% of indigenous children in remote communities suffer from chronic otitis media that can cause permanent hearing loss and inhibit language and literacy development. (Department of Education and Training, Western Australia). (2006)

Around 20% of Australians over 50 years of age experience difficulties swallowing food and/or drink. (Speech Pathology Australia2008)

More than 50% of Australians with dementia experience communication difficulties. (Speech Pathology Australia2008)

Of all people who suffer a stroke, 25% develop aphasia (acquired speech and language difficulties) (Speech Pathology Australia2008)

Augmentative or alternate communication devices are used by 13,000 Australians. (Speech Pathology Australia2008)

References

Australian Early Development Index (2009). *A Snapshot of Early Childhood Development in Australia - National Report, re-issue*. Melbourne: AEDI

Australian Government. *National Disability Strategy 2010-2020.* An initiative of the Council of Australian Governments (Draft)

Australian Institute of Health and Welfare: Disability Support Services 2008-2009; Report on services provided under the Commonwealth State/Territory Disability agreement and the National Disability Agreement; January 2011.

(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)

(Australian Institute of Health and Welfare (2004). *Disability and its relationship to Health Conditions and other Factors*. (AIHW CAT No. Dis 37)
Beukelman, DR., & Ansel, B. (1995). Research priorities in augmentative and alternative communication. *Augmentative and Alternative communication, 11,* 131-134

(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)

(Bloomberg, K., & Johnson, H. (1990) A statewide demographic study of people with severe communication impairments. *Augmentative and Alternative Communication 6* (1), 50-60.

(Commonwealth of Australia, Disability Standards for Education, 2006. 2005 Guidance Notes.)

(Conti-Ramsden & Durkin, 2008; Felsenfeld et al, 1994; McCormack, McLeod, McAllister & Harrison 2009 in McLeod, S,. Press, F, & Phelan C. The (In)visibility of Children with Communication Impairment in Australian Health, Education and Disability Legislation and Policies. 2010. Asia Pacific Journal of Speech, Language, and Hearing. Vol 13, No 1 pp.67-75).

(Department of Education and Training, Western Australia). (2006*). Conductive Hearing Loss and Aboriginal Students.* Retrieved from http://www.det.wa.edu.au/education/abled/apac/resources/pdf/conductive%20hearing%20loss.pdf

(ELVS): A prospective, longitudinal study of communication skills and expressive vocabulary development at 8, 12 and 24 month. International Journal of Speech-Language Pathology, 11(5), 344-357

(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

(ICAN 2006). *The cost to the nation of children's poor communication*. I CAN Talk Series – issue 2. London. ICAN

Marsh, K., Bertranou, E., Suominen, H., and Ventatachalam, M. Matrix Evidence. An economic evaluation of speech and language therapy. Final report. December 2010.

McLeod, S and Harrison, L. (2009), Epidemiology of speech and language impairment in a nationally representative sample of 4 – 5 year old children. Journal of Speech, Language and Hearing Research, 52(5), 1213-1229.

McLeod, S., Press, F., & Phelan, C. (2010). The (In)visibility of children with Communication Impairment in Australian Health, Education and Disability Legislation and Policies. Asia Pacific Journal of Speech, Language and Hearing. 13(1), 67-75

(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)

Reilly S., Bavin, E.L., Bretherton, L., Conway, L., Eadie, P., Cini, E., Prior, M., Ukoumunne, O. C., Wake, M. (2009). *The Early Language in Victoria Study*.

Snow, P.C., & Powell, M.B. (2008). *Oral Language Competence, Social Skills and High Risk Boys: What are the Juvenile Offenders Trying to Tell Us*, Children and Society, 22,16-28.

(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 94), 221 -229. Smart, D. et al (2004). Patterns of antisocial behaviour from early to late adolescence. Trends and issues in crime and criminal justice. No. 290)

Speech Pathology Australia. (2008). *Prevalence and implications of communication and swallowing disorders.* Melbourne: Speech Pathology Australia.

World Health Organisation (WHO Workgroup for development of version of ICF for Children and Youth). (2007) *International Classification of functioning, disability and health – Version for children and Youth:* ICF-CY. Geneva: Author