Chapter 2

Why is early and effective intervention in speech, language and communication disorders so important?

2.1 It is fundamental to this inquiry's interest in speech, language and communication disorders to ask why it is so important that these disorders are treated promptly and effectively. What are the costs of doing nothing? More particularly, what are the benefits of early and effective treatment, not only for the individual sufferer but for society as a whole and the Australian taxpayer?

The costs of not acting or delaying intervention

2.2 It is clear from the evidence before the committee that failing to treat childhood speech, language and communication disorders contributes to significant lifelong problems. These include limited employment options often leading to periods of unemployment, a dependence on welfare, the psychological and emotional distress to the sufferer and their family and carer, and in many cases interactions with the justice system. Accordingly, diagnosing and addressing speech, language and communication problems in childhood are crucial to an individual's wellbeing and to the level of services and supports that society must provide.

2.3 Many submitters identified the societal costs from failing to address speech and language disorders. Speech Pathology Australia (SPA) wrote in its submission:

> Communication and swallowing disorders are largely invisible (even silent), poorly understood by the general community, and rarely addressed in public policy. The cost to affected individuals is measured in dollars, limitations to participation in the wider society, and in negative impacts on social and emotional wellbeing.
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> There is a cost also to the wider community, a cost which can be measured in many ways. Untreated swallowing disorders give rise to increased costs in terms of length of hospital stay and people with undiagnosed difficulties are frequently referred to other health practitioners – often for expensive and invasive investigations – when a speech pathologist could readily manage the problem. Failure to adequately remediate communication problems in childhood adds to the support costs required throughout schooling. It also has implications for future employment, with associated costs likely in welfare payments. Problems related to over-use of the voice lead to costs associated with sick leave. Failure to recognise the high levels of communication problems in individuals within the justice system may contribute to increased costs associated with recidivism.[1]

1 *Submission 224*, p. 6.

2.4 Professor Mark Onslow, the Foundation Director of the Australian Stuttering Research Centre, explained the importance of early intervention in treating stuttering in children:

> Stuttering is a prevalent and disabling disorder of verbal communication that begins during the first years of life. If not controlled at that time it has subsequent educational, occupational, social and psychiatric consequences.
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> Clinical trials have established an effective early intervention for pre-school children younger than 6 years that speech pathologists can use successfully during everyday clinical practice. This treatment can prevent these lifetime problems occurring later in childhood and during adolescence and adulthood. However, speech pathologists with their current level of service provision cannot meet the clinical needs of this prevalent patient population, and immediate planning for adequate health care services is essential for this public health problem.[2]

2.5 Professor Onslow emphasised that it is clear from recent research that psychiatric problems in adult stuttering patients have origins during the school years of life. In his submission, he noted that the speech pathology profession is not equipped to manage the psychiatric issues encountered by adult patients. He argued that 'immediate planning is required…so that these patients have ready access to clinical psychology services'.[3]

2.6 The Centre for Excellence in Childhood Language[4] wrote in its submission that 'early detection and intervention programs have economic and social benefits at the individual, familial, community and national level'.[5] Associate Professor Sheena Reilly was awarded the National Health and Medical Research Council (NHMRC) grant to establish the Centre in 2012.[6] At the public hearing in Melbourne, Professor Reilly gave evidence that adults (aged 34 years) who had a language

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2 Australian Stuttering Research Centre, *Submission 188*, p. 1.

3 *Submission 188*, p. 1.

4 The Centre for Excellence in Childhood Language incorporates research by the Murdoch Children's Research Institute, Deakin University and the Parenting Research Centre in Melbourne, as well as international collaborators at the University of Newcastle in the United Kingdom and the University of Iowa in the United States. The project is funded by the National Health and Medical Research Council until 2017.

5 *Submission 161*, p. 2.

6 Associate Professor Reilly currently holds various positions. She is Associate Director of Clinical and Public Health at the Murdoch Children's Research Institute, Professor of Paediatric Speech Pathology at the University of Melbourne, and Honorary Speech Pathologist at the Royal Children's Hospital. She has held an NHMRC Practitioner Fellowship since 2008 and is a Fellow of the Australian Academy of Social Sciences, the UK Royal College of Speech and Language Therapists and Speech Pathology Australia. Professor Reilly is also an Honorary Professor with the Australian Stuttering Research Centre at the University of Sydney, a Visiting Professor at the Neurosciences Unit with Institute of Child Health at the University of London and a Visiting Fellow at the University of Newcastle upon Tyne. *Submission 161*, p. 17.

impairment at the age of five have up to seven times higher odds of poor reading, five times higher odds of mental health difficulties and three times higher odds of unemployment.[7]

2.7 The Centre for Clinical Research Excellence on Aphasia Rehabilitation drew on various sources of clinical research to identify the impact of failing to treat aphasia. These are that:

- stroke patients with aphasia experience longer length of stays, greater morbidity, and greater mortality than those without aphasia and therefore incur greater costs;
- language and cognitive impairment have been found to be highly associated with difficulty communicating healthcare needs. The ability to communicate with healthcare staff is essential if patients are to receive adequate, appropriate and timely healthcare. People with aphasia are less able to communicate with healthcare staff and therefore less able to receive adequate, appropriate and timely healthcare in hospital;
- patients with aphasia have a higher incidence of depression (62 per cent to 70 per cent) than stroke survivors without aphasia. Caregivers of people with aphasia also have significantly worse caregiver outcomes than caregivers of non-aphasic stroke patients, with the increased risk of depression persisting over time;
- people with aphasia are much more likely to lose friends after stroke and social exclusion has been found to be a common experience for people with severe aphasia. Loss of friendships post-stroke has been found to contribute to long-term psychological distress; and
- research has revealed that family members of people with aphasia also experience changes to their functioning and disability as a result of their family member's aphasia.[8]

2.8 Brain damage from stroke and traumatic brain injury are the leading causes of aphasia. The National Stoke Foundation identified a range of potential side-effects from failing to treat swallowing problems following a stroke:

> Poorly managed acute swallowing care relating to stroke can lead to severe complications such as aspiration pneumonia, dehydration and malnutrition. This in turn can lead to chest infections, death, disability, longer hospital stays and increased number of discharges to nursing homes… This in turn has significant social and economic cost. Not treating communication deficits such as aphasia can lead to increased isolation and depression also increasing social and economic costs of stroke.[9]

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7 *Committee Hansard*, 11 June 2014, p. 17.

8 *Submission 169*, p. 5.

9 *Submission 233*, p. 5.

2.9 The committee received a submission from a group of researchers from the University of Sydney and the Murdoch Children's Research Institute which focussed on childhood apraxia of speech. This is a lifelong condition where the sufferer has difficulty learning to say new sounds and consistently use the sounds that they have learnt. The researchers' submission provided the following case study highlighting the impact of this condition on the sufferer:

> Trent (pseudonym) recently completed high school and received an excellent university entry rank, however, he has decided to become a dental appliance maker so that "I don't have to talk to anyone". Throughout his life Trent has had difficulty with verbal communication, despite above average intelligence and an intense desire to communicate. At 3 years of age, when his peers were starting to talk in simple sentences, Trent was only able to say 'ma' and 'da'. As the research literature repeatedly suggests, this very delayed oral communication was followed by delayed expressive language development, psycho-social distress, and bullying at school. At 18 years, he has had 1000s of hours of speech pathology treatment. His speech is now 80% intelligible to a stranger but only when he is concentrating, alert and calm. When he is tired or upset most people cannot understand him. His parents estimate that they have spent over $30,000 on private speech pathology treatment on top of maximum contributions from both their health fund and the public health system.[10]

2.10 The Peninsula Model for Primary Health Planning—Children's Health Alliance[11] (Alliance) and the Frankston–Mornington Peninsula Medicare Local emphasised the significant effects on the individual in later life from even mild to moderate speech and language delays in childhood. As it explained:

> Longitudinal studies demonstrate that delays set a poor trajectory for later learning across all areas of development. Communication skills are essential in all aspects of life including health and wellbeing, education and training, family and social relationships, recreation, and work. It has been documented that difficulties in communication skills may have major implications for school success, self-esteem, independence, teacher-student relations, peer relations, literacy and numeracy development, behaviour and problem solving, occupation, economic self-sufficiency and costs to society. The impacts on later life include early pregnancy, incarceration and poor vocational outcomes.[12]

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10 Associates Professors Patrica McCabe and Kirrie Ballard; Drs Angela Morgan, Elizabeth Murray and Alison Purcell; Ms Donna Thomas, Ms Jacqueline McKechnie and Ms Jacqui Lim, *Submission 225*, p. 1.

11 The Peninsula Model is a partnership model to support local service providers and other stakeholders work together in planning and improving primary health services across the Frankston and Mornington Peninsula catchment. The Model initiated the Children's Health Alliance. *Submission 134*, p. 3.

12 *Submission 134*, p. 15.

2.11 The Alliance emphasised that where intervention does take place, the benefits will be greater the earlier that it occurs:

> Interventions at a later stage are more costly and less effective. Early Speech Pathology interventions have been shown to result in significant improvements in a child's speech, language and self-esteem; foundations for successful longer term outcomes.[13]

2.12 Many submitters with children with speech and language disorders, as well as adults reflecting on their childhood, explained the effect of the disorder on the child. The mother of twin boys, both diagnosed with autism, Attention Deficit Hyperactivity Disorder (ADHD) and anxiety, wrote in her submission:

> Due to their lack of age-appropriate speech my boys were bullied, teased and often ostracised. Making friends was extremely difficult and the lack of communication often meant they would lash out physically, which in a mainstream school meant they would spend many a lunchtime in detention.[14]

The cost of inaction in Aboriginal communities

2.13 The committee heard that there are particular challenges in diagnosing and seeking treatment for speech and language disorders in Indigenous communities. Ms Sonia Schuh, a teacher-director at the Napranum Preschool in Weipa, told the committee:

> …there is something wrong with these kids. They are not speaking. Because it is not a physical disability or anything like that, I guess in our culture we do not see special needs as a big thing; we just take care of it. It is only that we have to diagnose it and label it before they go to school, so the school can get some funding to deal with our troubled kids. The parents would generally say: 'He's just a little bit off. He's a little bit crazy. Don't worry about him, as long he's not hurting anyone.' About 80 or 85 per cent of our kids have some kind of learning difficulty, and that is not to mention the big language barrier before going to school, because our community is Aboriginal English, not standard Australian English.[15]

2.14 In its submission to this inquiry, the Apunipima Cape York Health Council highlighted the links between communication impairments and incarceration rates in Indigenous communities in Australia. It wrote:

> The effects of communication impairments for people in the criminal justice system are linked with staggeringly high rates of hearing impairments. In correctional facilities in the Northern Territory, 94% of Aboriginal inmates had a significant hearing loss and 76% of these inmates reported communication difficulties with the criminal justice system as a

13 *Submission 134*, p. 15.

14 Name withheld, *Submission 95*, p. 1.

15 *Committee Hansard*, 27 June 2014, p. 53.

> result (Vanderpoll and Howard, 2012). Communication difficulties and inadequate verbal responses in criminal justice systems can be misinterpreted as rudeness or willful non-compliance and serve to further marginalise offenders. The high rates of hearing loss in the Northern Territory correctional facilities is likely related to there being more hearing loss and general disadvantage among Aboriginal people from remote and regional areas of Australia.[16]

2.15 The Apunipima Cape York Health Council argued the need for early intervention to focus on children at risk 'to ensure they have the best possible start in life and are provided with the foundations for future education'. It added:

> The social and economic costs of failing to provide early intervention for language disorders and the subsequent effects on poor education, poor employment prospects, disengagement and impacts on the health, welfare and criminal justice systems are huge. Comprehensive speech pathology intervention early in life in at risk populations provides an opportunity to reduce these costs in a preventative framework.[17]

The cost of inaction among young people

2.16 The committee received evidence of the high incidence of speech and language disorders among juvenile offenders. This subject is considered in chapter 3 of this report. It is important here to acknowledge the following evidence from Associate Professor Pamela Snow, a speech pathologist and psychologist from Monash University:

> Between 46 and 52% of young male offenders have clinically significant (yet previously undiagnosed) language disorders; such deficits tend to "masquerade" as poor motivation, disengagement, rudeness, and inattentiveness…
>
> The best "early intervention" that a child can receive is evidence-based reading instruction. Academic success can mitigate some of the other adversities present in the lives of vulnerable young people and promote their chances of breaking inter-generational cycles of poverty and social marginalisation. Speech Pathologists have knowledge and expertise that is directly relevant to the training of pre-service teachers and to the support of teachers in classroom settings, particularly with respect to children who struggle to make the transition to literacy.[18]

2.17 Associate Professor Snow added:

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16 The Apunipima Cape York Health Council, *Submission 126*, p. 14. Vanderpoll, T., & Howard, D. (2012). Massive Prevalence of Hearing Loss among Aboriginal Inmates in the Northern Territory. *Indigenous Law Bulletin*, pp 3–7.

17 The Apunipima Cape York Health Council, *Submission 126*, p. 14.

18 *Submission 32*, pp 2–3.

> There are many young people whose circumstances do not result in youth justice involvement but who never-the-less are educationally and socially marginalised and developmentally vulnerable as a result of undiagnosed or mis-attributed communication impairments. Such young people fail to achieve their potential and will make disproportionate demands on government-funded services, such as housing, mental health, substance abuse, and vocational training programs. Although prevention and early intervention are optimal, intensive and specialist services must be made available to vulnerable young people in their still formative adolescent and early adult years.[19]

The impact on older workers

2.18 In her evidence to the committee, Professor Reilly provided a graph showing the shift in the structure of workforce professions since the mid-1960s. In the mid-1960s, roughly 55 per cent of the Australian workforce was employed in blue-collar occupations, with 45 per cent of workers in white collar positions. By 2011, the proportion of blue-collar workers had progressively declined to around 30 per cent while the proportion of white collar positions had increased to around 70 per cent. Of course, the direction and the dimensions of this shift are common to most Western industrialised countries.[20] Professor Reilly told the committee:

> We talk about it being the shift from brawn to brain. There were a lot of jobs you could do if you did not have good language or you could not read. But those jobs have almost disappeared with automation. You cannot stack shelves now without using a scanner. You cannot drive a truck without reading a GPS.[21]

Committee view

2.19 The committee is concerned at the impact of these economy-wide changes on the employment prospects of older manual workers with language difficulties. It notes the comments of Dr Julia Starling, a lecturer in speech pathology at the University of Sydney, who told the committee that older people with language disorders may well have faced discrimination from school and throughout their working lives.[22]

Weighing the benefits against the costs of intervention

2.20 On the basis of the immediate and the long-term costs of failing to intervene, submitters underlined the importance of early and effective intervention. For example, the Centre for Cerebral Palsy (Western Australia), put the following argument:

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19 *Submission 32*, p. 4.

20 *Committee Hansard*, 11 June 2014, p. 17.

21 *Committee Hansard*, 11 June 2014, p. 17.

22 *Committee Hansard*, 12 June 2014, p. 22.

> The provision of speech pathology services is by no means a cheap option. The labour intensive interventions are resource intensive. However, on balance the provision of speech pathology services to those who need them is a less expensive option than the impact created by those who should receive the services but either opt not to have them or are unable to access them.[23]

2.21 The committee received some submissions that were glowing in their praise for the role of the speech pathologist. These accounts—as much as the costs of inaction—underline why early and effective intervention in speech language disorders is so important. A mother, whose daughter was diagnosed with the metabolic illness galactosaemia, wrote in her submission:

> The speech pathologist to whom I was referred was excellent. I honestly do not know what we would have done without her. She provided us with support in so many ways. In regard to my daughter's feeding she monitored her growth, health and nutrition intake, she answered the questions I had, she suggested techniques to try, she held a feeding group in order that my daughter may interact with her peers while eating, and she kept up to date with new treatments both nationally and internationally and applied these to the consultations. In addition, she suggested other avenues that may benefit such as meeting with an occupational therapist for example. When our family went overseas to follow a treatment in a clinic in the Netherlands she gave us much practical support and advice.
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> In relation to my daughter's speech and language delay, the speech pathologist was extremely effective in improving my daughter's speech and language. The fortnightly consultation and the group consultations had a very positive effect in both areas. In addition, the speech pathologist provided me with the tools, techniques and activities for me to do at home with my daughter which was very helpful. My daughter started prep this year and had she not had the assistance of this speech pathologist her communication would have been far poorer and would have had a severe impact on her learning and socialising at school.[24]

2.22 Chapter 6 of this report returns to this issue of the social and economic cost of failing to treat communication and swallowing disorders. Chapter 7 makes a key recommendation to publicise the costs of inaction and the benefits of early and effective intervention. It is important here, at the outset, to recognise that the benefits of early and effective treatment of speech and language disorders extend not only to the individual and their family and carers. There are also benefits to society in terms of forgoing the costs that can arise from these disorders throughout life.

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23 Centre for Cerebral Palsy, *Submission 117*, p. 3.

24 Name withheld, *Submission 115*, p. 1.