

Chapter 1

Introduction

An overview

1.1 The capacity to communicate verbally is fundamental to a person's development and wellbeing. The ability to learn effectively, to form meaningful and supportive relationships, to influence others, and to obtain and maintain employment can be significantly affected if a person is unable to verbally communicate. Undiagnosed or untreated, a person who suffers from a speech or swallowing disorder is susceptible to poorer educational outcomes, reduced employment prospects and increased likelihood of social, emotional and mental health issues.¹ The personal cost to the individual, and to society at large, can be significant.

The establishment of this inquiry

1.2 On 9 December 2013, the Senate referred to the Senate Community Affairs References Committee (committee) an inquiry into the prevalence of different types of speech, language and communication disorders. A parliamentary inquiry along these lines had been advocated by the national peak body, Speech Pathology Australia (SPA), for some time. In June 2011, SPA National President, Ms Christine Stone, wrote to the committee noting that without Australian data on the prevalence of speech, language and communication disorders, 'it is impossible for government and health professionals to adequately plan and provide comprehensive prevention, promotion and therapeutic services to those individuals with communication and swallowing impairments'.² Ms Stone suggested that a parliamentary committee would be the right forum to advance these inquiries, and offered SPA's help in refining the scope and terms of reference for the inquiry.

The committee's areas of interest

1.3 The terms of reference for this inquiry are presented at the front of this report. In the first instance, this inquiry is concerned with the dimensions of speech and swallowing disorders in Australia. What are the types and symptoms of these disorders, and how do they affect the person's ability to function in everyday life? How prevalent are these types of disorders among children, among Aboriginal and Torres Strait Islander people, among people with disabilities and among people from culturally and linguistically diverse backgrounds? What data are available on these issues, and what is needed for policy makers and governments to understand the dimensions of the problem and frame an appropriate response?

1 Speech Pathology Australia, *Submission 224*, p. 5.

2 Letter from Ms Christine Stone, National President of Speech Pathology Australia to the Committee Secretary, Senate Community References Affairs Committee, dated 24 June 2011.

1.4 The inquiry is also concerned with how effectively current demand for speech pathology services is being met. Are publicly funded and operated speech pathology services offered within Australian hospitals, clinics, schools, nursing homes and correctional centres, and are these adequate to meet current demand? What is the cost and the adequacy of private speech pathology services? And, moreover, what is the projected demand for speech pathology services in Australia?

1.5 These questions raise several others: how are families and carers alerted to the types of speech pathology services that are available in Australia; are they able to access speech pathology services when they need to; what are their travelling times to these services, particularly for people in remote regions; are they satisfied with the quality of the service that they receive; what are the out of pocket costs of private speech pathology services; how are people made aware of ancillary services?

The conduct of this inquiry

1.6 Shortly after the referral in December 2013, the committee called for written submissions by 21 February 2014. It received 305 submissions, which are listed at Appendix 1. Submissions were received from a wide range of stakeholders:

- the parents and grandparents of infants and children with speech and swallowing disorders;³
- adults who have either had a speech or swallowing disorder since birth or childhood, or who have acquired a disorder as a result of injury or stroke;⁴
- SPA, the peak body representing 70 to 80 per cent of practising speech pathologists in Australia;⁵
- speech pathologists operating in both the public system and in private practice;⁶
- leading Research Centres specialising in particular speech and language disorders and/or the incidence of these disorders among a particular demographic;⁷
- various Centres, Societies, Associations and Services representing a range of interests associated with speech and swallowing disorders, as well as disability advocacy groups;⁸

3 See submissions 89, 95, 103, 106, 108, 113, 115, 119, 166, 167, 179, 181, 183, 184, 189, 193, 198, 207, 211, 215, 219, 237, 241, 248, 249, 251, 252, 254, 281, 287–298.

4 See submissions 88, 102, 154, 162, 200, 205, 206, 246, 255, 267.

5 Submission 224

6 See submissions 62, 64, 83, 86, 91, 93, 94, 96, 99, 104, 127, 141, 144, 146, 148, 149, 151, 152, 232, 235, 238, 239, 242, 244, 245, 253, 264.

7 See submissions 121, 161, 169, 188, 263.

8 See submissions 90, 100, 117, 118, 120, 122, 123, 124, 130, 131, 132, 134, 155, 172, 174, 185, 209, 214, 216, 220, 222, 226, 230, 231, 233, 256, 259, 260, 269, 270, 275.

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- a range of academic contributors, often comprised of multidisciplinary teams;⁹
 - school principals, school teachers and representatives of parents associations;¹⁰ and
 - state government departments.¹¹

1.7 These submissions are available on the committee's website. Where a child's name or photo was provided in a submission, it has been redacted to protect the child's identity.

The committee's public hearings

1.8 The committee held four public hearings:

- in Melbourne on 11 June 2014;
- in Sydney on 12 June 2014;
- in Canberra on 20 June 2014; and
- in Brisbane on 27 June 2014.

1.9 The public transcripts from these hearings are available on the committee's website.

The committee's site visits

1.10 The committee also conducted several site visits:

- In Melbourne on 11 June 2014, it visited North Melbourne Primary School where it met with students with developmental delays and several staff members including the school's speech pathologist, Ms Alison Clarke. As chapters 4 and 5 of this report discuss, it is not uniform for Australian states and territories to have a speech pathologist employed within a school. The North Melbourne Primary School demonstrates the progress that can be made where a school commits to funding a speech pathologist, and provides the person in that role with access to the teachers of students with speech, language and communication disorders.
- The committee then visited Parkville College, a school for juvenile offenders up to the age of 18 who have been remanded or sentenced to Custody by the Court. The committee met with the College's speech pathologist, Ms Laura

9 See submissions 15, 32, 53, 72, 73, 75, 81, 85, 97, 98, 105, 139, 160, 161, 169, 202, 203, 213, 217, 225, 234, 236, 257, 261, 262.

10 See submissions 65, 70, 71, 83, 90, 99, 107, 142, 170, 171, 177, 178, 228, 272, 286.

11 See submissions 111 (Tasmanian Education Department), 147 (South Australian Department of Education), 265 (Tasmanian Department of Health), 268 (Queensland Premier), 271 (NSW Health), 273 (ACT Chief Minister).

Caire, who noted the high incidence of speech and language disorders among the student population (see chapter 3). The committee highlights the uniqueness of the Parkville College set-up: it is the only youth custodial education facility to employ a speech pathologist to work on underlying language disorders;

- In Sydney on 12 June 2014, following the public hearing, the committee visited the Australian Stuttering Research Centre. The Centre's Director, Professor Mark Onslow, emphasised the importance of addressing a child's stuttering problem early in life. He noted the high success rate of early intervention and the long-term benefits of intervention, not only to the individual's wellbeing but to society as a whole. The Centre's research is world-leading;
- On 27 June in Brisbane, prior to the public hearing, the committee had the opportunity to visit the Glenleighden School in the suburb of Fig Tree Pocket. The school, which was established in the late 1970s, has as its principal aim to support children and young people with language disorders to achieve their educational and personal potential. At the school, the committee met with the Principal, Ms Cae Ashton, who facilitated a discussion between committee members and several parents of children attending the school. The committee was very impressed with the level of care provided by staff, and the range of multi-disciplinary programs offered by the school.

Acknowledgements

1.11 The committee is grateful to people and organisations that have helped the committee with its deliberations.

- Firstly, the committee extends its sincere thanks to the many individuals, parents, grandparents, family members and carers who made a submission to this inquiry. It appreciates their willingness to share personal accounts. These accounts are often heart-wrenching, but they also offer hope that early and effective diagnosis and intervention can provide positive outcomes for both the sufferer and their family.
- Secondly, the committee thanks SPA for arranging the site visits and the organisations themselves for giving their time and insights. It is particularly grateful to the parents of students at the Glenleighden School who came to share their personal experiences with the committee (see above).
- Thirdly, the committee thanks SPA for its leadership during this inquiry. As mentioned earlier, the organisation proposed this inquiry in 2011 and since the referral late last year, has made itself available on many occasions to discuss matters of interest and concern with the committee and has provided written information on request.
- Finally, the committee thanks all those organisations who gave submissions and verbal evidence to the committee. The level of engagement from a wide range of stakeholders throughout this inquiry has been impressive.

Background

1.12 This report presents the key issues and themes that emerge from the submissions against each term of reference. The central themes are the strong demand for speech pathology services in Australia, the long waiting lists in the public system and the need to target speech pathology services to areas of high current and projected demand.

Types and causes of speech, language and swallowing disorders

1.13 Box 1.1 sets out the main types of speech and language disorders, and some of the possible causes of these disorders.

Box 1.1: Types of speech, language and swallowing disorders

- voice disorder: production of voice in speaking has disordered pitch, quality, loudness, resonance or when someone cannot sustain their voice
- stuttering: involuntary sound repetition
- cognitive communication disorders: result from underlying cognitive deficits due to neurological impairment. These are difficulties in communicative competence (listening, speaking, reading, writing, conversation, and social interaction) that result from underlying cognitive impairments (attention, memory, organisation, information processing, problem solving, executive function).
- developmental language disorders—trouble understanding others (receptive language), or sharing thoughts, ideas, and feelings completely (expressive language)
- aphasia—impaired ability to understand or use language (such as after a stroke)
- dysarthria—problem with the motor act of producing sounds given neurological disturbance (common among people with TBI, Cerebral Palsy)
- childhood apraxia of speech: problem with planning and programming of sounds, syllables, words
- dysphagia —swallowing disorders
- voice aphasia

Possible causes of these disorders

- cleft palate
- traumatic brain injury (TBI)
- Cerebral Palsy
- progressive neurological diseases: Parkinson's disease, Motor Neurone Disease, Multiple Sclerosis, Huntington's disease
- stroke—can result in aphasia or a language disorder
- head and neck cancers inside the sinuses, nose, mouth, salivary glands, pharynx and larynx
- autism, intellectual impairment,
- developmental delay, sensory impairment
- dementia
- FOXP2 mutation (genetic condition associated with childhood apraxia)

1.14 Box 1.2 summarises the process for accessing and claiming speech pathology services through Medicare Chronic Disease Management Items and the *Helping Children with Autism Package*.

Box 1.2: A general guide to accessing and claiming for speech pathology services

To claim a Medicare rebate for a speech pathology service (Chronic Disease Management Items), you must have received an Enhanced Primary Care Plan from a GP. Eligibility for an Enhanced Primary Care Plan is based on the presence of a chronic condition—one that has been present for six months or longer.

A GP will make the assessment for a Primary Care Plan and then make a referral to a speech pathologist. The client may request to see a particular speech pathologist or the GP may recommend one. (A person can self-refer directly to a speech pathologist but will not then be eligible for the Medicare rebate.)

For a rebate to be claimed, the speech pathologist must be registered with Medicare and have a Medicare provider number. A maximum of five sessions can be claimed per calendar year. These sessions may be with one health professional or a number of allied health professionals. A client may claim a rebate using an invoice provided by the speech pathologist.

The rebate is currently \$52.95 for each 20 minute speech pathology session. The scheduled fee for a 20 minute session is currently \$62.25, with the rebate calculated at 85 per cent of this fee. The speech pathologist may recommend a longer session and charge accordingly. There will be a gap fee—the amount between what the speech pathologist charges and the rebate. Ms Julie Carey (submission 64), a private speech pathologist, has noted that the cost of a standard consultation is around \$180.

The client may not claim a Medicare rebate and a private health insurance rebate for the same service. The client must choose which rebate they are going to claim for a service. The fund *Health.com.au* offers a basic policy—with a fortnightly premium of \$84 a fortnight—which covers 65 per cent of the cost of a speech pathologist up to a maximum of \$200 in a calendar year.

Helping Children with Autism Package

The **Helping Children with Autism Package** is an initiative to assist families with children diagnosed with Autism Spectrum Disorder. Medicare rebates for specialist and allied health services are available to assist in the diagnosis and treatment of children with Autism Spectrum Disorder (ASD), or Pervasive Developmental Disorder [PDD]).

Up to four Medicare Benefit Schedule (MBS) services in total will be available for eligible allied health professionals, including speech pathologists, to collaborate with the referring practitioner in the diagnosis of a child (aged under 13 years) and/or the development of a child's PDD treatment and management plan.

A further 20 Medicare rebate services in total will also be available for eligible allied health professionals, including speech pathologists, to provide treatment to a child (aged under 15 years and who was under 13 years at the time of receiving their diagnosis from the specialist and the PDD treatment and management plan) for their particular condition, consistent with the treatment and management plan prepared by the referring practitioner.

The Medicare rebate for the Chronic Disease Management Items is different from that under the Helping Children with Autism Items. Source:

<http://www.speechpathologyaustralia.org.au/information-for-the-public/frequently-asked-questions>

The structure of this report

1.15 This report has seven chapters:

- chapter 2 looks at why early and effective treatment of speech and language disorders is so important;
- chapter 3 examines the evidence on the prevalence of different types of speech, language and communication disorders and swallowing difficulties in Australia, and the incidence of these disorders by demographic group;
- chapter 4 presents the committee's evidence on the current and projected level of demand for speech pathology services in Australia;
- chapter 5 looks at the availability and adequacy (supply) of speech pathology services in Australia. It notes the evidence of gaps in this supply and the lengthy waiting lists for children to access services in the public system and for those seeking these services in rural and remote areas;
- chapter 6 examines the various factors that affect the supply of speech pathologists in Australia and proposes ways in which these obstacles can be overcome; and
- chapter 7 summarises the committee's recommendations.

