

Chapter 3

The prevalence of speech, language and swallowing disorders in Australia and the incidence of these disorders by demographic group

- 3.1 This chapter addresses the first two terms of reference for this inquiry:
- 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 (paediatric, Aboriginal and Torres Strait Islander people, people with disabilities and people from culturally and linguistically diverse communities).

The lack of national data on the incidence of speech and language disorders

3.2 Data on the prevalence of speech and language disorders in Australia is patchy. The 2012 *Australian Survey of Disability, Ageing and Carers* conducted by the Australian Bureau of Statistics (ABS) found that there were 215 000 Australians under 65 years of age with a disability who require assistance with communication.¹ These are people with profound or severe core activity limitation.

3.3 The peak professional body, Speech Pathology Australia (SPA), which represents around 70 per cent of speech pathologists in Australia, estimated that there are over 1.1 million Australians with a communication disorder (around five per cent of the population).² It added:

We consider that this is likely to be an underestimation, given that we have not included in this figure disorders where there is a known (or likely), but as yet unquantified, overlap with disorders that were counted. Within these figures, there is evidence that some specific groups—for example, Australians of Aboriginal or Torres Strait Islander descent, and people who are socio-economically disadvantaged—are over-represented. It is clear also that the figures will likely increase exponentially as the population ages.³

3.4 SPA argued in its submission that a figure on the prevalence of communication disorders across Australia is difficult because of the number of

1 Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia, Summary of Findings 2012*, Catalogue Number 4430.0, <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0> (accessed 28 August 2014). Speech Pathology Australia, *Submission 224*, p. 21.

2 Speech Pathology Australia, *Submission 224*, p. 21.

3 Speech Pathology Australia, *Submission 224*, p. 21. See also Ms Gail Mulcair, *Committee Hansard*, 11 June 2014, p. 3.

specific disorders and the potential for overlap between these disorders.⁴ SPA noted that there are many people who have difficulty communicating that do not have profound or severe core activity limitation. As the President of SPA, Professor Deborah Theodoros, explained at the Melbourne public hearing:

One of the big problems with the collection of data is that communication disorders or swallowing disorders are not seen as the primary disability, and a lot of the data sets might be for people with hearing loss or the deaf population, or for the cerebral palsy population, or the autistic population, but the actual communication disability is the primary. Disability is embedded within those broader types of disability, and what we would like to see is that it becomes the primary disability and we get some data on the actual prevalence of that particular type of disorder. Clearly you cannot separate it entirely from the overarching disability, but I think that is part of the reason why we do not have that data—because communication disabilities and swallowing problems are embedded in other data sets.⁵

3.5 The Chief Executive Officer of SPA, Ms Gail Mulcair, told the committee that the organisation was 'doing a lot of work' with the ABS on the upcoming survey of people with disability in ageing and carers. She explained that the point of these discussions was to try to adapt some of the questions, or introduce others, such that information is gathered on the specifics on the communication disorder that people may have.⁶

3.6 SPA did note in its submission that there have been many 'high quality research studies' that have estimated the prevalence of a disorder by age group or disorder type.⁷ The committee received submissions from the researchers involved in several of these studies, which noted and discussed the findings. This chapter and later chapters of this report draw on this evidence.

The need for improved data on the incidence of speech and language disorders

3.7 SPA argued in its submission that there is a need for better data on the incidence of speech and language disorders in Australia. It noted that while there are significant gaps in data for many populations, 'there is an even greater paucity of data for groups such as Aboriginal and Torres Strait Islanders, culturally and linguistically diverse populations and populations in correctional institutions'.⁸ In evidence to the committee, Ms Mulcair stated:

What we believe is necessary is, firstly, some comprehensive work across the whole of the Australian population in terms of identifying people who

4 Speech Pathology Australia, *Submission 224*, p. 21.

5 *Committee Hansard*, 11 June 2014, pp 10–11.

6 *Committee Hansard*, 11 June 2014, p. 4.

7 *Submission 224*, p. 21.

8 *Submission 224*, p. 79.

have speech, language, communication and swallowing problems, to fully understand the scope of the needs of people across Australia.⁹

Box 3.1: Speech Pathology Australia: recommendations on data resources

1. The Australian Government develop a framework to support collaboration across existing Centres of Clinical Research Excellence and other research groups which focus on specific cohorts, including, but not exclusively:

- Centre of Clinical Research Excellence: Aphasia;
- Centre of Clinical Research Excellence in Childhood Language;
- Australian Stuttering Research Institute;
- Centre for Community Child Health;
- Telethon Institute for Child Health Research; and
- Centre for Research Excellence in improving health services for Aboriginal and Torres Strait Islander Children.

2. The Australian Government commits to developing an approach to collection of data on communication and swallowing disabilities so that every individual who has a communication and/or swallowing disability is identified and may receive the supports needed to participate in life.

3. [T]he Australian Government work with Speech Pathology Australia to ensure that communication disability is conceptualised and adequately captured in National Minimum Data Sets and other universal standardised data collection methods relevant to the disability, education, health, aged care and justice sectors.

4. The Australian Bureau of Statistics in consultation with Speech Pathology Australia develops and includes questions in the National Census to gather data about the prevalence of communication and swallowing disability.

5. The Australian Institute of Health and Welfare works with Speech Pathology Australia and other stakeholders to improve the specificity of the data collected in the Disability Services National Minimum Data Set.

6. The Australian Bureau of Statistics work further with Speech Pathology Australia to refine categories and questions around communication limitation and primary disabilities, as they relate to communication in the Survey of Disability, Ageing and Carers.

7. The Commonwealth Department of Education review the Nationally Consistent Data Collection on School Students with Disability tool and explicitly include communication (including speech and language) disorders, recognised as a primary disability in their own right.

8. The Commonwealth Department of Health endorse the National Framework for Self Regulating Health Professions (which will include speech pathology), once this is finalised and released.

9. The Australian Bureau of Statistics includes an individual category of Speech Pathologists in the occupation data section of the National Census. Revision of the Australian and New Zealand Standard Coding of Occupations coding is required to separate Speech Pathology and Audiology at the Unit Group Level.

10. Health Workforce Australia and/or the Australian Institute of Health and Welfare (AIHW) determine/s that Speech Pathology is a priority profession for comprehensive workforce data collection and demand projections, and undertake a comprehensive analysis of the speech pathology workforce, including the availability (taking into account part time working), demand (current and future) and geographic spread of speech pathologists in Australia.

3.8 SPA argued the need for a 'standardised, coordinated and congruent approach to data collection'. To this end, it made ten recommendations which are presented in Box 3.1 (above).

3.9 The first of these recommends that the federal government develop a framework for the various research centres to collaborate on their findings. SPA told the committee that there are research centres around the country with 'very good data': '[W]hat is missing is an overarching framework or body who is able to pull that research material together.'¹⁰

Committee view on the need for more data

3.10 The committee believes that this is a practical, common sense and necessary recommendation that deserves the attention of government. Without question, the work and research output of these Centres is of an extremely high standard and should be used as much as possible.¹¹ However, it appears that what is lacking is a mechanism for these Centres to communicate in a structured way on—among other things—the data requirements of the profession. If the community is to benefit from the skill and professionalism of speech pathologists, it is crucial that there is accurate data on the prevalence of speech and language disorders, and the incidence of specific disorders by location and demographic group. The recommendations made later in this report underscore this imperative.

3.11 The federal Department of Health should consider—among other matters—the data that is currently available through research Centres and academic studies, and the data that is necessary to identify the areas of current and prospective need. It should then consider where there are gaps, the need and the benefit of filling these gaps and how this information could best be gathered.

3.12 As part of this discussion, the Department of Health should assess the need, the practicality and the likely cost of gathering further data through the ABS. In particular, the committee recommends that the Department of Health carefully consider SPA's proposals to gather more specific data on communication disabilities through:

- the National Census (point 4, Box 3.1);
- the Disability Services National Minimum Data Set (points 3 and 5, Box 3.1); and
- Nationally Consistent Data Collection on School Students with Disability tool (point 7, Box 3.1).

10 Ms Gail Mulcair, *Committee Hansard*, 11 June 2014, p. 3.

11 The committee has received written submissions and taken verbal evidence from many of these Centres and has been impressed with their work programs and detailed research output. It was particularly impressed with the work of Professor Mark Onslow of the Australian Stuttering Research Centre.

Recommendation 1

3.13 The committee recommends that the federal Department of Health in collaboration with key stakeholders consider the data that is currently available through the Research Centres, and the data that is necessary to identify the areas of current and prospective need. It should then consider where there are gaps, the need and the benefit of filling these gaps, and how this information could best be gathered.

3.14 The committee recommends that the federal Department of Health assess the need, the practicality and the likely cost of gathering further data through the Australian Bureau of Statistics. In particular, the committee recommends that the Department of Health carefully consider Speech Pathology Australia's proposals to gather more specific data on communication disabilities through:

- the National Census;
- the Disability Services National Minimum Data Set; and
- Nationally Consistent Data Collection on School Students with Disability tool.

3.15 The committee notes that some submitters expressed scepticism that government would address the need for Australia-wide data on the prevalence of speech and language disorders. Notably, the Australian Education Union (AEU) argued that governments are reluctant to discover the level of unmet need for speech pathology because 'this knowledge would create a public expectation that they do something about it'.¹² The committee does not believe that this is the case. It hopes that the government's positive response to the recommendations made in this report will demonstrate the federal government's commitment to understanding the dimensions of speech and language disorders in Australia.

The incidence of speech and language disorders by demographic group

3.16 The committee has received considerable evidence on the impact of speech disorders among children, Aboriginal and Torres Strait Islander people, people with disabilities and people from culturally and linguistically diverse (CALD) communities. Analysing these disorders by demographic group is important to identify the dimension and nature of the problem and to inform a public policy response.

Speech and language disorders among children

3.17 The ABS has gathered data on children with disability. *Children at School with Disability* (4429.0, Profiles of Disability, 2009) has a 'Core Activity Limitation' category titled 'communication difficulties'. It reported that 64 400 children with

12 *Submission 257*, p. 7.

disability attending school between the ages of 5 and 20 experienced 'communication difficulties'. The same survey also presents data by 'disability group' where one group is titled 'sensory and speech'. It found that there were 99 600 children between 5 and 20 years of age with a speech and sensory disability.¹³

3.18 The lack of ABS data and State data on children with speech and language disorder was a source of frustration for some submitters and witnesses. The AEU, for example, observed in its submission:

There appears to be a lack of comprehensive national data on the extent of children and young people experiencing speech disorder problems and the level of access to speech pathology services. ABS data (such as Children at School with Disability 4429.0, Profiles of Disability, 2009) runs together sensory and speech disability into a single category group for data collection purposes. Data about the demand for speech services collected by Education Departments as part of their disability funding policies are a significant under-estimation of need. Students with speech difficulties who fall outside of the criteria for funding are not included in Departmental statistics. There is also no documentation of levels of parental use of private providers. Often parents use these providers because there is no timely access to publicly-funded providers.¹⁴

3.19 The AEU also noted the conclusion of Victorian Auditor-General's report into Programs for Students with Special Learning Needs that:

DEECD (Department of Education and Early Childhood Development) does not know how many students in Victoria have unfunded special learning needs. It cannot identify these students nor can it determine if they are being adequately supported by schools.¹⁵

3.20 There have been some significant studies in Australia into the prevalence of speech and language disorders among children. In one of her submissions to the inquiry, Professor Sharynne McLeod of Charles Sturt University, summarised the findings of her study of 14 514 children across 44 schools in New South Wales. The study was conducted in two waves. Professor McLeod found that:

There were 14 514 students in the first year of data collection (wave 1) and 14 533 students two years later (wave 2). Overall 5 309 (36.57%) students were identified as having some area of learning need in the first year and 4 845 (33.33%) students were identified 2 years later. Specifically, the areas of learning need (in order) were:

- specific learning difficulty (17.93% in wave 1; 19.10% in wave 2)

13 Australian Bureau of Statistics, Profiles of Disability—Australia, 2009, Catalogue No. 4429.0, <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4429.02009?OpenDocument> (accessed 16 August 2014).

14 *Submission 257*, p. 7.

15 *Submission 257*, p. 7.

- communication disorder (13.04%; 12.40%)
- English as a second or other language (9.16%; 5.80%)
- behavioural/emotional difficulty (8.16%; 6.10%)
- early achiever/advanced learner (7.30%; 5.50%)
- physical/medical disability (1.52%; 1.40%)
- intellectual disability (1.38%; 1.20%)
- hearing impairment (0.96%; 0.80%)
- visual impairment (0.16%; 0.30%).¹⁶

3.21 Professor McLeod provided a table in her submission summarising the findings of 15 Australian studies on the prevalence of children with speech, language, and communication needs. The largest of these studies, in terms of sample size, was conducted by the Centre for Community Child Health and Telethon Institute for Child Health Research using the Australian Early Development Index. Using teachers' reports of 261 203 students, it found that 8.9 per cent of four to five year olds were developmentally vulnerable to language and literacy disorders, and 9.2 per cent were developmentally vulnerable to communication disorders.¹⁷

3.22 The Peninsula Model—Children's Health Alliance drew on various findings of Professor McLeod's research (published in 2007, 2008, 2009 and 2011) to present the following picture:

The prevalence of speech and language impairment in school aged children is significant, with studies revealing that 13% of children at primary & secondary schools in Australia have communication impairment.¹⁸ Other studies put this figure at a higher level (see below).¹⁹ Communication difficulty in pre-schoolers predicts poorer educational and social outcomes at school age. Based upon 2013 Australian school enrolments approximately 474 000 school children currently suffer from communication impairment. Australian teachers report that 21% of school students have an expressive language difficulty upon entering schooling.

16 *Submission 72*, p. 2.

17 *Submission 72*, p. 2.

18 McLeod, S., & McKinnon, D. H. (2007), 'The prevalence of communication disorders compared with other learning needs in 14,500 primary and secondary school students', *International Journal of Language and Communication Disorders*, 42 (S1), 37–59.

19 Harrison, L. J., McLeod, S., Berthelsen, D., & Walker, S. (2009). Literacy, numeracy and learning in school-aged children identified as having Speech and language impairment in early childhood. *International Journal of Speech-Language Pathology*, 11(5), 392–403.
McCormack, J., Harrison, L. J., McLeod, S., & McAllister, L. (2011). A nationally representative study of the association between communication impairment at 4-5 years and children's life activities at 7-9 years. *Journal of Speech, Language and Hearing*, 54(5), pp 1328–1348.

Furthermore, 16% have a receptive language difficulty.²⁰ Australian data also estimates that 14% of 15 year olds are unable to read at even a baseline level of proficiency, and 21% have only minimal reading proficiency.²¹

3.23 The Centre of Research Excellence in Child Language noted in its submission that the incidence of obesity in Victorian children (under the age of 14) is as high as the incidence of language impairment: 5 000 cases per 100 000 children. Further:

Among four year olds, this can be as high as one in five (20 per cent), which equates to 50 000 Victorian children—the same number of obese children. These figures are thought to be nationally representative, equating to some 220 000 language-impaired Australian children. While obesity has been a National Health Priority area since 2007, Language Impairment is often not viewed as a disability of consequence, despite costly, persistent and far-reaching consequences...

Of those four year olds with Language Impairment, around 2 per cent also have general learning disabilities while 7.5 per cent have a specific Language Impairment. Although children with Language Impairment come from all socio-economic backgrounds, Language Impairment is more common in children who live in a vulnerable or disadvantaged community. In the most socially disadvantaged populations, up to 50 per cent of children can have Language Impairment. For Aboriginal and Torres Strait Islander children, the figure may be higher still. We also know that more and more Australian children are being raised in culturally and linguistically diverse environments and that the wide heterogeneity in bilingual children's communication skills may also represent a subset of children with unique language needs.²²

Speech and language disorders among young offenders

3.24 The committee received evidence on the high incidence of speech and language disorders among juvenile offenders both in Australia and internationally. Associate Professor Pamela Snow of Monash University, presented to the committee the following findings from her research:

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. These language disorders are pervasive, compromising expressive and receptive language skills across all domains – vocabulary, narrative skills, ability to understand figurative (non-literal) language...

20 Harrison, L. J. & McLeod, S. (2008, November). *School adjustment and achievement in children identified as having speech and language impairment at age 4-5 years*. Australian Association for Research in Education, Brisbane.

21 *Submission 134*, p. 8.

22 *Submission 161*, p. 5.

There is a relationship between severity of offending (in particular convictions for violent offences) and the severity of language impairment...Young people who have been in out-of-home care via Child Protection orders face an elevated risk of language impairment (62%).²³

3.25 In her testimony to the committee, Associate Professor Snow expanded on the motivation for, and implications of her research. In so doing, she noted that her findings were consistent with similar international research:

Our research in Australia resonates very strongly with the international research carried out in the United States and in the UK that indicates that around 50 per cent—the percentages vary slightly, but broadly around 50 per cent—of young males in the youth justice system have a clinically significant but previously unrecognised language impairment. So they are actually operating in a clinical range when we administer standardised measures of everyday expressive and receptive language skills.

Now that has clear implications in a number of realms. A key one for me, and a key one that informs some of the current research that I am doing, is around strengthening that early transition to literacy...

But there are also implications for how we manage young people in the youth justice system with respect to the counselling services that they are provided with. Most forms of counselling are verbally mediated. Cognitive behaviour therapy is an evidence based counselling approach, but it does not get much more verbal than being asked to sit down and think and talk about your thinking with a very articulate clinician. So we operate therapeutically in a very verbal space with young people of whom 50 per cent, at least, have significant but unrecognised verbal deficits. One of the problems in classroom situations is that communication difficulties often masquerade as other behaviours, so they masquerade as disinterest, poor motivation, disengagement or rudeness, and then that can stand to further disadvantage the young person with respect to how they are viewed, how they are managed, how their behaviour is interpreted in the classroom. So we see very high rates of suspension and exclusion.²⁴

3.26 Ms Laura Caire, the speech pathologist at Parkville College in Melbourne (see Box 3.2), noted in her submission that juvenile offenders with communication impairment face discrimination at every stage of the justice process, from when they are questioned by police, to when they are arrested and then in court. She noted the huge challenge of her role as a speech pathologist in a juvenile detention centre:

Every day I come into work, I feel overwhelmed by the need I see around me, from the classroom to therapeutic interventions to the care provided in the residential units. Staff have genuine care and concern for the children in their care, and a strong desire to help these young people get back on track and create happy and productive lives for themselves, however often lack

23 *Submission 32*, p. 2.

24 *Committee Hansard*, 11 June 2014, p. 12.

the awareness, knowledge and skills required to fully understand the extent of a young person's communication difficulties, the impact these difficulties have on their everyday functioning, and how to best facilitate optimal communication. Speech pathologists can help improve this situation through provision of assessment, consultation, training and treatment/intervention but only if there are enough to go around. Until more speech pathologists are employed, young people with communication impairment involved in the justice system will miss out on the intervention and support they desperately require.²⁵

Box 3.2: Parkville College

On the recommendation of Speech Pathology Australia, on 11 June 2014, the committee had the opportunity to visit Parkville College in Melbourne. The College is a school for juvenile offenders, up to the age of 18, who have been remanded or sentenced to Custody by the Court. There are currently around 80 students.

The committee had the opportunity to speak with the College's speech pathologist, Ms Laura Caire. Ms Caire noted the high incidence of speech and language disorders among the student population. The committee commends the work that SPA and Parkville College have done in identifying the importance of how speech, language and communication difficulties are treated in youth justice systems.

Speech disorders among Aboriginal and Torres Strait Islander people

3.27 There have also been important studies into the incidence of speech and language disorders in rural and Aboriginal communities. Ms Debra Jones, Professor Michelle Lincoln and Assistant Professor Maeva Hall from the Broken Hill University Department of Rural Health, noted that 'rural and remote Australian children are more likely to be identified as experiencing developmental vulnerabilities that impact on education and health attainment on entry into primary school than their metropolitan counterparts'.²⁶ They observed that Indigenous children are particularly vulnerable to language and learning difficulties:

Indigenous children face elevated risks for delayed acquisition of Standard Australian English language and literacy (De Bortoli et al 2004) and may experience poorer health than their non-Aboriginal counterparts (Standing Council on Health 2012). Aboriginal children may experience Standard Australian English as a second or third language, or speak a Kriol language, placing them at a high risk for delayed oral English language development and educational disengagement (Parlington et al 2005). Aligning this to the cultural determinants of communication behaviour (Eades 2000) these

25 *Submission 26*, p. 4.

26 *Submission 105*, p. 12.

young people are particularly vulnerable in their interface with mainstream English language dominant education systems.²⁷

3.28 Several submitters highlighted the higher incidence of ear disease in Aboriginal communities than in the general Australian population. *Deadly Ears*, a Queensland-wide Aboriginal and Torres Strait Islander ear health program, noted in its submission that Aboriginal children experience ear disease earlier, and that the disease is more severe, persistent and frequent than their non-Indigenous peers.²⁸

3.29 The Apunipima Cape York Health Council wrote in its submission that:

14.7% of children in remote Far North Queensland communities had Chronic Suppurative Otitis Media, with almost 25% of the children in Aboriginal predominant communities affected. World Health Organization (WHO) identifies an incidence greater than 4% as a public emergency and a massive public health problem requiring urgent attention.²⁹

3.30 Ms Sonia Schuh, the Teacher-Director of Napranum Preschool in Weipa, told the committee that hearing and speech impairments are common among students at the school. As she explained:

A lot of our children—I would say about 80 per cent—have some kind of learning difficulty related to hearing impairment and speech. With the otitis media, our wet season goes for six months, and you can tell the parents, 'Don't let them play in the sprinklers; keep them out of the rain,' but that is not going to happen. Usually all the surgery happens just before the wet season...and there is no way you can keep the kids out of the water at that time. So there is the hearing impairment with the kids, the runny ears and all that kind of stuff. It is all about the parents, for early intervention with the little ones—the nose blowing, all that stuff. You can only do so much of it when they are with you for, say, five hours a day at the school but then going home, going down the beach, playing in the sprinklers 24/7, at night-time, not blowing their noses properly. I would say it is about 80 per cent.³⁰

3.31 A 2014 study by Professor Sharynne McLeod and Ms Sarah Verdon of Charles Sturt University found that there is a similar prevalence of speech, language and communication need for Indigenous and non-Indigenous Australians. In a joint submission to the inquiry, Professor McLeod and Ms Verdon contrasted the findings of this study with the findings of a 2009 study with Professor Linda Harrison. The 2014 Longitudinal Study of Indigenous Children (LSIC) was based on data from 692 three to five year-old Indigenous children; the 2009 Longitudinal Study of Australian

27 Flinders University, *submission 75*, p. 2; Broken Hill Rural Department of Health, *Submission 105*, p. 12.

28 *Deadly Ears, Submission 130*, p. 1.

29 *Submission 126*, p. 11.

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

Children (LSAC) was based on data from 4,983 four to five year-old Australian children. Professor McLeod noted that:

A similar number of parents of Indigenous Australian 3- to 5-year-olds in LSIC had concerns about speech and language skills compared with parents of 4- to 5-year-olds in LSAC (LSIC: 24.3% versus LSAC: 25.2%). “Speech not clear to others” was the area of highest concern for both groups (LSIC: 13% versus LSAC: 12.0%).³¹

Speech & language disorders in the culturally and linguistically diverse community

3.32 The committee received a second submission from Ms Sarah Verdon and Professor McLeod which concluded that:

...there is a mismatch between the languages and locations in which speech pathology services are offered in Australia and the languages spoken by Australian children. Therefore, there is an inequity in the services available for Australian children who speak language other than English.³²

3.33 The academics found that while 20.9 per cent of Australian paediatric speech pathologists in the study offered services in languages other than English, the languages spoken by these speech pathologists 'are not reflective of the most common languages spoken by Australian children'. Specifically, they note that 'multilingual speech pathology services were often not offered in the location of the children who speak those languages'.³³

3.34 The Multicultural Disability Advocacy Association of New South Wales (Association) focused in its submission on the challenge of ensuring that people from a non-English speaking background are made aware of the speech pathology services that are available. The Association noted that currently:

People from CALD / NESB [non-english speaking background] with disability, their families and carers often are not aware of the availability of supports and services due to a lack of culturally appropriate information available. The role of the service providers, who are the first point of contact, is essential in ensuring that pathology services are utilised to full capacity. Such service providers for example, general practitioners (GPs), need to have the ability to identify when there is a need for pathology services, then appropriately communicate the options that are available so as to get the best possible outcomes for each individual.³⁴

3.35 The Association also emphasised that ongoing support is crucial to ensuring the best outcomes for people from CALD communities. It noted that one challenge in

31 *Submission 73*, p. 1.

32 *Submission 187*, p. 1.

33 *Submission 187*, p. 2.

34 *Submission 191*, p. 3.

this regard is to ensure that strategies designed by speech pathologists for the home environment are properly communicated to carers.³⁵

Prevalence by type of speech or language disorder

3.36 The committee also received evidence noting the prevalence of particular types of speech and language disorders in the Australian population. The Centre for Clinical Research Excellence Aphasia Rehabilitation, for example, made the following observation on the prevalence and incidence of stroke and aphasia in Australia:

- in 2012, 25 831 Australian males and 23 235 Australian females had a stroke;
- Aphasia has been estimated to affect approximately one third of first ever stroke survivors (Disability Policy and Research Working Group, 2011; Frattali, 2013);
- a recent Australian study reported that 37.2 per cent of acute stroke admissions to the Royal Perth Hospital over a ten month period had a confirmed diagnosis of aphasia;
- based on an incidence of 37.2% it is estimated that in 2012, there were 18 253 new cases of aphasia in Australia;
- in 2012, 420 000 people (1.77 per cent of the Australian population) were living with the effects of stroke; and
- assuming that Aphasia affects approximately one third of stroke survivors, and 60 per cent of this number still experience the effects of aphasia 12 months after their stroke, it is estimated that in 2012 between 93 744 and 156 240 Australians were living with the effects of aphasia.³⁶

3.37 Professor Mark Onslow from the Australian Stuttering Research Centre noted in his submission that the first prospective cohort study of childhood stuttering was recently completed in Melbourne. Children were assessed before the onset of the disorder and cases of stuttering were diagnosed by experts. It found that at four years of age, one in nine Australian preschool children is stuttering. A United States Government report published in 2011 found that—from a sample size of 119 367 children—stuttering was present in two per cent of 3–10 year olds and 1.2 per cent of 11–17 year olds.³⁷ Professor Onslow noted that the lifetime cumulative stuttering

35 *Submission 191*, p. 3.

36 Centre for Clinical Research Excellence Aphasia Rehabilitation, *Submission 169*, p. 2.

37 Boyle, C., Boulet, S., Schieve, L., Cohen, R., Blumberg, S., Yeargin-Allsopp, M., et al. (2011). Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*, 34, 385–395. Referred to in submission from Professor Mark Onslow, *Submission 188*.

incidence—the risk of being affected at some time during life—was estimated as 'at least as high as 10 percent'.³⁸

3.38 Professor Leanne Togher, a speech pathologist at the University of Sydney, provided the committee with information on communication disorders from traumatic brain injury (TBI). She wrote:

In Australia, there are more than 2 500 cases of moderate-severe TBI each year...Overall, TBI is most common in the very young (0–4 years) and the elderly (65+). Falls are a common reported cause in these groups (32%) as are sporting injuries (18%) (especially in school aged children). However, more serious brain injuries show a different distribution. In this case, males outnumber females 1:2 and the highest incidence occurs in the 15–24 year age group. Motor vehicle accidents are by far the most common cause of serious TBI in general and specifically in the peak (18–25) age group.

...

Communication disorders following severe TBI comprise a range of problems, the most common of which is cognitive communication disorders, which occur in up to 70% of cases. Cognitive-communication disorders are “communication impairments resulting 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, organization, information processing, problem solving and executive functions)”. This definition is based on the premise that basic language functions such as syntax and semantics are intact, by contrast to disorders such as aphasia and developmental language impairments, in which impairments in basic language functions are the defining characteristic.³⁹

3.39 The Melbourne Cleft Service at the Royal Children's Hospital noted in its submission that in 2008, the Victorian Birth Defects Bulletin stated that clefting occurs in Victoria at a rate of 1 in 531 births. The number of cases per year ranged from 110 to 150. The Melbourne Cleft Service estimated that 'at any one time there are over 6000 individuals under the age of 18 born with CL/P receiving some form of treatment across Australia'.⁴⁰

Committee view

3.40 The committee notes that considerable research has been undertaken in recent years in Australia into the prevalence of particular speech and language disorders and the incidence of these disorders among various demographics.

38 Bloodstein, O, & Bernstein Ratner, N. (2008). *A handbook on stuttering* (6th Edition). Clifton Park: Delmar. Referred to in submission from Professor Mark Onslow, *Submission 188*.

39 *Submission 81*, p. 5.

40 *Submission 90*, p. 2.

3.41 It is clear from the committee's inquiry, however, that there needs to be greater capacity to consolidate these findings and assess the areas of overlap and where there are gaps. In the committee's view, this need is clearly indicated by the lack of Australia-wide data on the prevalence of speech, language and communication disorders.

3.42 Collecting and analysing Australia-wide data serves a clear policy objective and need. As the following chapters of this report emphasise, one of the key challenges for the speech pathology profession in Australia is to identify the areas of current and prospective unmet demand within schools, hospitals, aged care facilities, correctional services, and rural and remote communities (see chapter 4). The related challenge is to use this information to ensure there are adequate numbers of speech pathologists with the appropriate skills to meet this demand (see chapter 5 and 6). Both these challenges will require careful planning. The committee foresees an important role for the federal and state governments in collaboration with key stakeholders to lead in these processes.

