

Submission to:

Community Affairs References Committee
Department of the Senate, Parliament of Australia

Regarding:

Prevalence of different types of speech, language and communication disorders and speech pathology services in Australia

Prepared by:

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Introduction

The Australian Speak Easy Association (ASEA) is the only volunteer run national self-help group representing people who stutter around Australia. The Association has the purpose of supporting those who stutter of all ages; educating the community about stuttering and its treatment; providing a supportive environment to encourage the maintenance of fluency; and advocating for those who stutter. There are active branches in Queensland, NSW, Victoria, South Australia and Western Australia, with a re-emerging presence in Tasmania. State branches of ASEA are supported by a national council of the ASEA. The national council primarily provides support and advice to state branches, together with resources and national insurance. Its membership includes representatives from each state branch, life members, speech pathologists and other professionals who form an advisory board for the association. The groups represented by the ASEA in each state are principally made up of adults who stutter, who meet in small groups on a regular basis to provide support to each other and to practise the fluency techniques they have learned in speech treatments.

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Stuttering

- Stuttering is commonly defined as ‘a speech disorder in which the flow of speech is disrupted by involuntary repetitions and prolongations of sounds, syllables, words or phrases and involuntary silent pauses or blocks in which the stutterer is unable to produce sounds’¹
- Research suggests that the overall prevalence of stuttering is approximately 1%². Australia’s population is currently 23.3 million, which would suggest that there are approximately 233,000 people who stutter in Australia.

¹ World Health Organisation ICD-10 F98.5 – Stuttering

² Craig, A; Tran, Y (2005). "The epidemiology of stuttering: The need for reliable estimates of prevalence and anxiety levels over the lifespan". *Advances in Speech–Language Pathology* 7 (1): 41–46. PMID 17429528)

- Current prospective studies in Australia indicate a much higher incidence in young children³, suggesting there are as many as 8.5% of children who stutter by three years of age.
- Early intervention indicates a good prognosis for recovery, with about 65% of pre-schoolers recovering from stuttering⁴ and about 74% recovering by early teens⁵.
- Effective treatment is available for young children⁶, however there is no known cure for adult stuttering⁵ but severity and impact can be reduced with treatment^{7,8,9}.
- Many adolescents who stutter and continue to stutter into adulthood are managing a chronic condition with extremely significant negative implications^{10,11}.
- People who stutter struggle to express themselves, commonly resulting in word avoidance, needing to write what they want to say and may involve involuntary face, head and body movements¹².
- A significant proportion of people who stutter will develop social phobia (fear and avoidance of social situations) resulting in self-imposed isolation, anxiety, stress, shame^{13,14} and a substantial negative impact on quality of life¹⁵.
- Relapse is a risk following treatment for stuttering in adults^{16,17} and a predominant number of people need to return to treatment to manage their chronic condition.
- Stuttering was found to increase risks of reduced vitality (increased levels of fatigue), as well as reduced social, emotional and mental health functioning. The negative impact of stuttering in these four domains was equivalent to the impact in these same domains from chronic disorders such as spinal cord injury, diabetes, and heart disease¹⁵.

³ Reilly, S., Onslow, M., Packman, A., Wake, M., Bavin, M., Prior, M., Eadie, P., Cini, E., Bolzonello, C. & Ukoumunne, O. 2009. *Predicting stuttering onset by the age of 3 years: A prospective, community cohort study*. Pediatrics. 123; 270-277

⁴ Yairi, E; Ambrose, N (1992). "Onset of stuttering in preschool children: selected factors". Journal of speech and hearing research 35 (4): 782-8. PMID 1405533

⁵ Ward, David (2006). *Stuttering and Cluttering: Frameworks for understanding treatment*. Hove and New York City: Psychology Press. ISBN 9781841693347

⁶ Jones, M., Onslow, M., Packman, A., Williams, S., Ormond, T., Schwarz, T., & Gebiski, V. (2005). *Randomised controlled trial of the Lidcombe Programme of early stuttering intervention*. British Medical Journal, 331, 659-661.

⁷ M Blomgren, N Roy, T Callister, *Intensive stuttering modification therapy: A multidimensional assessment of treatment outcomes*, Journal of Speech, Language, and Hearing Research Vol.48 509-523 June 2005. doi:10.1044/1092-4388(2005/035)

⁸ Block, S., Onslow, M., Packman, A., Gray, B. & Dacakis, G. (2005). *Treatment of chronic stuttering: outcomes from a student training model*. International Journal of Language and Communication Disorders. 40, 455-466

⁹ Carey, B., O'Brian, S., Onslow, M., Block, S., & Jones, M. (2009) *A randomised controlled non-inferiority trial of a telehealth treatment for chronic stuttering: the Camperdown Program*. International Journal of Language and Communication Disorders, 45, 108-120

¹⁰ Iverach, L., O'Brian, S., Jones, M., Block, S., Lincoln, M., Harrison, E., Hewat, S., Menzies, R., Packman, M., & Onslow, M. (2009). *Prevalence of anxiety disorders among adults seeking speech therapy for stuttering*. Journal of Anxiety Disorders, 23(7), 928-934.

¹¹ Iverach, L., Jones, M., O'Brian, S., Block, S., Lincoln, M., Harrison, E., Hewat, S., Cream, A., Menzies, R.G., Packman, A., & Onslow, M. (2009). *The relationship between mental health disorders, stuttering severity and treatment outcome among adults who stutter*. Journal of Fluency Disorders, 34, 29-43

¹² Mulligan, H., Anderson, T., Jones, R., Williams, M., Donaldson, I. (2001) *Dysfluency and involuntary movements: a new look at developmental stuttering*. The International Journal of Neuroscience 2001 Jul; 109(1-2):23-46

¹³ MB Stein, A Baird and JR Walker, *Social phobia in adults with stuttering*, Am J Psychiatry 1996; 153:278-280

¹⁴ Tran, Y., Blumgart, E., Craig, A., *Subjective distress associated with chronic stuttering*, Journal of Fluency Disorders, Volume 36, Issue 1, March 2011, Pages 17-26

¹⁵ Craig, A., Blumgart, E., & Tran, Y. (2009). *The impact of stuttering on the quality of life in adult people who stutter*. Journal of Fluency Disorders, 34, 61-71.

¹⁶ Craig, A.R. (1998). *Relapse following treatment for stuttering: A critical review and correlative data*. Journal of Fluency Disorders, 23, 1-30.

¹⁷ Iverach, L., Jones, M., O'Brien, S., Block, S., Lincoln, M., Harrison, E., et al. (2009). *The relationship between mental health disorders and treatment outcomes among adults who stutter*. Journal of Fluency Disorders, 34, 29-43.

Summary

Effective verbal communication is essential for individuals to function in society. Everyday tasks such as answering the telephone, ordering a meal, buying a train ticket or talking at a meeting can fill a person who stutters with dread, fear, shame and embarrassment.

Treatment of social anxiety as well as stuttering need to be adequately addressed to give people who stutter the best chance to reach their potential, to feel that they are a powerful contributing force and to integrate into society.

Early intervention for people who stutter has good success, but where treatment is unsuccessful or no treatment is given, stuttering can become a chronic condition that requires ongoing treatment throughout the person's lifetime. Some people who stutter also commonly suffer from Social Anxiety Disorder. This can have significant impact on the well-being and quality of life of the person who stutters.

The current funding model for treatment is limited to the Chronic Disease Management program, which only provides five treatment sessions per calendar year. This is inadequate to treat both stuttering and associated Social Anxiety Disorder.

The financial burden for treatment, apart from the first five sessions, must be borne by the person who stutters. Evidence from recent research¹⁸ suggests that 36% (n=65 of 181) of people who stutter spent more than \$1000 per annum on stuttering related expenses, with the remaining 64% (n=116) spending up to \$1000 per annum.

18 Blumgart, E., Tran, Y., & Craig, A. (2010). *An investigation into the personal financial costs associated with stuttering*. Journal of Fluency Disorders, 35, 203-215.

Addressing the Terms of Reference (in relation to stuttering):

- a. **the prevalence of different types of speech, language and communication disorders and swallowing difficulties in Australia;**
 - Research suggests that the overall prevalence of stuttering is approximately 1%¹⁹. Australia's population is currently 23.3 million, which would suggest that there are approximately 233,000 people who stutter in Australia.
- b. **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);**
 - As indicated above, the overall prevalence of stuttering is approximately 1%.
 - More adult males stutter than adult females, with an estimated ratio of 4 (males) to 1 (female)²⁰.
 - Current prospective studies in Australia indicate a much higher incidence in young children²¹, suggesting there are as many as 8.5% of children who stutter by three years of age.
 - Some research does suggest that stuttering occurs more frequently in first degree relatives of stutterers.
 - The Australian Speak Easy Association is unaware of any specific increased risk factors for Aboriginal or Torres Strait Islander people or people from culturally and linguistically diverse communities. Studies suggest that there are no racial or ethnic differences related to stuttering prevalence²².
- c. **the availability and adequacy of speech pathology services provided by the Commonwealth, state and local governments across health, aged care, education, disability and correctional services;**
 - Public treatment options that were previously made available by Commonwealth, state and local governments (between 1975-1995) across Australia have been withdrawn. These treatments were expensive to operate as they frequently involved an equal ratio of speech pathologists to stutterers in small groups of around five individuals for a period between one and three weeks. Treatment outcomes for stutterers were significant and long lasting.
 - Some universities, for example La Trobe University, University of Sydney and the University of Queensland run Student-delivered treatment programs, often as a part of funded

¹⁹ Craig, A; Tran, Y (2005). "The epidemiology of stuttering: The need for reliable estimates of prevalence and anxiety levels over the lifespan". *Advances in Speech-Language Pathology* 7 (1): 41-46. PMID 17429528)

²⁰ Craig, A, Tran, Y., Craig, M. & Peters, K. (2002). *Epidemiology of stuttering in the communication across the entire life span*. *Journal of Speech, Language, and Hearing Research*, 45, 1097-1105

²¹ Reilly, S., Onslow, M., Packman, A., Wake, M., Bavin, M., Prior, M., Eadie, P., Cini, E., Bolzonello, C. & Ukoumunne, O. 2009. *Predicting stuttering onset by the age of 3 years: A prospective, community cohort study*. *Pediatrics*. 123; 270-277

²² Proctor A., Duff, M.. and Yairi, E. (2002). *Early childhood stuttering: African Americans and European Americans*. *ASHA Leader*, Vol. 4, # 15, 102.

research into stuttering. However, they are not always ongoing long-term treatment programs, due to lack of funding²³.

- An essential part of management of stuttering is the ongoing maintenance of fluency by attending support groups run by self-motivated individuals or speech pathologists.
- It is unclear what type of services the National Disability Insurance Scheme will offer to people who stutter when it is fully rolled out.
- Stuttering identification and treatment in educational facilities needs improvement. Early intervention (pre and primary schoolers) has a good prognosis for recovery²⁴ and a reduced cost on the health system²⁵. Furthermore, evidence indicates that early stuttering, if left untreated can have significantly negative impacts on young children who stutter²⁶.
- The Australian Speak Easy Association does not have up-to-date information about stuttering treatment in correctional or aged care facilities. However, there have been occasions when speech pathologists have treated adults in correctional facilities at the request of staff in the facilities. This treatment has been intermittent and is expensive to provide.

d. the provision and adequacy of private speech pathology services in Australia;

- While there are a large number of private speech pathologists in Australia, their services are not inexpensive.
- The Department of Health's Chronic Disease Management program only allows five treatment sessions per calendar year. This is inadequate for not only the treatment of stuttering, but also the associated Social Anxiety Disorder. The amount of financial support required can depend on the type of treatment used and when the intervention is applied.
- Appropriate intervention involves regular sessions with a speech pathologist. Sessions (face to face or telehealth) of 30-60 minutes in duration for 15-50 sessions usually achieve good levels of fluency. Intensive group treatments of a week in duration, in combination with attendance at regular maintenance sessions, can also achieve good levels of fluency.
- In spite of initial fluency, relapses for adults and adolescents are highly likely if stuttering associated social anxiety disorder has not been identified and treated. At this time few clinicians are experienced in the use of assessment screen for social anxiety disorder or its treatment.

²³ Block, S., Onslow, M., Packman, A., Gray, B. & Dacakis, G. (2005). *Treatment of chronic stuttering: outcomes from a student training model*. International Journal of Language and Communication Disorders. 40, 455-466.

²⁴ Yairi, E; Ambrose, N (1992). "Onset of stuttering in preschool children: selected factors". Journal of speech and hearing research 35 (4): 782-8. PMID 1405533

²⁵ Packman, A. & Kuhn, L. *Looking at stuttering through the lens of complexity*, 2009, Vol. 11, No. 1, Pages 77-82 (doi:10.1080/17549500802630039)

²⁶ Langevin, M., Packman, A., & Onslow, M. (2010). *Parent perceptions of the impact of stuttering on their preschoolers and themselves*. Journal of Communication Disorders, 43, 407-423.

e. evidence of the social and economic cost of failing to treat communication and swallowing disorders;

Recent research has revealed that stuttering is also associated with economic consequences that may challenge quality of life²⁷. Findings from this study indicated that the average total cost was around \$A5,500.00 (median cost \$4,165) in 2007/08 over a 5-year period.

Early intervention indicates a good prognosis for recovery, but if left untreated until late adolescence and adulthood, stuttering can become a relapsing chronic condition^{28,29} with significant impact on quality of life³⁰ and resulting in severe anxiety (Social Anxiety Disorder)³¹.

Because of the chronic nature of stuttering in adolescents and adults, ongoing treatment programs may be necessary to achieve fluent, natural sounding speech³². This necessitates increased speech pathology services in schools and community centres, together with increased support for self-help groups. A multidisciplinary approach to the treatment of all aspects of the impact of the stutter is required. Increased access and numbers of speech pathologists and psychologists are required to help these older people who stutter cope with the constancy of the disability as well as to minimise the likelihood of relapse. Relapse in adults who stutter is common; however ongoing access to treatment can help to manage this³³ and reduce the impact of social anxiety and isolation.

Findings show that people who stutter often work in positions below their potential³⁴, or that they often do not choose the career they actually want³⁵. Enabling people who stutter to choose their preferred career by providing adequate and timely treatment would help them to better integrate into society and increase feelings of self-worth.

Minimising the 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 and opinions, would enable people who stutter to participate more fully in community and employment activities. Such barriers are caused by a person with a disability being unable to communicate effectively. Minimising these barriers could begin by developing resources to aid people who stutter. Such resources could be integrated into community services and employment activities and processes. However, more immediate and cost-effective ways of minimising such barriers would be

²⁷ Blumgart, E., Tran, Y., & Craig, A. (2010). *An investigation into the personal financial costs associated with stuttering*. Journal of Fluency Disorders, 35, 203-215.

²⁸ Howie, P., Tanner, S., Andrews, G., *Short and Long-Term Outcome in an Intensive Treatment Program for Adult Stutterers*, Journal of Speech and Hearing Disorders Vol.46 104-109 February 1981.

²⁹ Boberg, E., Kully, D., *Long-Term Results of an Intensive Treatment Program for Adults and Adolescents Who Stutter*, Journal of Speech and Hearing Research Vol.37 1050-1059 October 1994.

³⁰ Craig, A., Blumgart, E., Tran, Y., *The impact of stuttering on the quality of life in adults who stutter*, Journal of Fluency Disorders, Volume 34, Issue 2, June 2009, Pages 61-71

³¹ Kraaimaat, F., Vanryckeghem, M., Van Dam-Baggen, R., *Stuttering and social anxiety*, Journal of Fluency Disorders, Volume 27, Issue 4, December 2002, Pages 319-331

³² Finn, P. *Stutterers' self-ratings of how natural speech sounds and feels*, Journal of Speech and Hearing Research Vol.37 326-340 April 1994

³³ Cream, A., O'Brian, S., Onslow, M., Packman, A. & Menzies, R. *Self-modelling as a relapse intervention following speech-restructuring treatment for stuttering*, 2009, Vol. 44, No. 5, Pages 587-599 (doi:10.1080/13682820802256973)

³⁴ Craig, A.R., & Calver, P. (1991). *Following up on treated stutterers: Studies of perceptions of fluency and job status*. Journal of Speech and Hearing Research, 34, 279-284.

³⁵ Peters, H.F.M., & Starkweather, C.W. (1989). *Development of stuttering throughout life*. Journal of Fluency Disorders, 14, 303-321.

to increase treatment opportunities for those who stutter.

f. the projected demand for speech pathology services in Australia.

Many people who stutter do not seek treatment because they do not know treatment is available or they have tried one therapy which was unsuccessful and did not try another. Stuttering in adults is commonly a chronic relapsing condition that requires ongoing active management to maintain fluency.

It is important to let people know that stuttering treatment is available and is successful.

Even with successful treatment options, stuttering is a chronic condition requiring ongoing treatment. Additional public speech pathology services or programs specifically focussed on stuttering would help to manage the needs of the stuttering community.

In most states, public treatment for stuttering is almost impossible to access in the later school years and in adulthood.

Increasing services to treat stuttering early (pre and primary schoolers) can reduce the long-term burden on the health system for treatment of chronic stuttering³⁶.

Increased speech pathology services should be provided in community health centres as part of the National Disability Insurance Scheme – and assurance should be given that these services will include treatment provision for adults who stutter.

More services should be offered for the treatment of stuttering under the National Disability Insurance Scheme or as part of the Chronic Disease Management program through the Department of Health.

Some consideration also needs to be given to indirect treatments, which have also been found to benefit treatment of stuttering. Examples of indirect treatments for stuttering include cognitive behaviour therapy, pharmacology, as well as individual counselling. Self-help support groups have also been shown to help people who stutter maintain their fluency^{37,38}.

³⁶ Packman, A. & Kuhn, L. *Looking at stuttering through the lens of complexity*, 2009, Vol. 11, No. 1, Pages 77-82 (doi:10.1080/17549500802630039)

³⁷ Ramig, P.R. (1993). *The impact of self-help groups on persons who stutter. A call for research*. Journal of Fluency Disorders, 18, 351-361.

³⁸ Yaruss, J.S., Quesal, R.W., Reeves, L., Molt, L.F., Kluetz, B., Caruso, A.J., et al. (2002). *Speech treatment and support group experiences of people who participate in the National Stuttering Association*. Journal of Fluency Disorders, 27, 115-134.