

## **Submission to:**

# **The Productivity Commission Inquiry into Long Term Disability Care and Support**

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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 and four speech pathologists 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.

## **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'<sup>1</sup>
- Research suggests that the overall prevalence of stuttering is approximately 1%<sup>2</sup>. Australia's population is currently 22.5 million, which would suggest that there are approximately 225,000 people who stutter in Australia.
- Current prospective studies in Australia indicate a much higher incidence in young children<sup>3</sup>, suggesting there are as many as 8.5% of children who stutter by three years of age.

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<sup>1</sup> World Health Organisation ICD-10 F98.5 – Stuttering

<sup>2</sup> 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)

- Early intervention indicates a good prognosis for recovery, with about 65% of pre-schoolers recovering from stuttering<sup>4</sup> and about 74% recovering by early teens<sup>5</sup>.
- Effective treatment is available for young children<sup>6</sup>, however there is no known cure for adult stuttering<sup>5</sup> but severity and impact can be reduced with treatment<sup>7,8,9</sup>.
- Many adolescents who stutter and continue to stutter into adulthood are managing a chronic condition with extremely significant negative implications<sup>10,11</sup>.
- People who stutter can struggle to express themselves. This includes word avoidance, writing what they want to say on paper, facial contortions and unintended body movements.
- 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<sup>12,13</sup> and a substantial negative impact on Quality of Life<sup>14</sup>.
- Relapse is a risk following treatment for stuttering<sup>15,16</sup> in adults 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 disease<sup>15</sup>.

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<sup>3</sup> 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

<sup>4</sup> 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

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

<sup>6</sup> 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.

<sup>7</sup> 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)

<sup>8</sup> 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

<sup>9</sup> 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

<sup>10</sup> 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.

<sup>11</sup> 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

<sup>12</sup> MB Stein, A Baird and JR Walker, *Social phobia in adults with stuttering*, Am J Psychiatry 1996; 153:278-280

<sup>13</sup> 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

<sup>14</sup> 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.

<sup>15</sup> Craig, A.R. (1998). *Relapse following treatment for stuttering: A critical review and correlative data*. Journal of Fluency Disorders, 23, 1-30.

<sup>16</sup> 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.

## Who should be eligible?

### Who should be in the new scheme and how could they be practically and reliably identified?

Two groups of people who stutter should be targeted in the new scheme;

- 1) Pre and primary schoolers who exhibit stuttering behaviour, identified by school staff, parents and speech pathologists, based on a standard definition of stuttering<sup>17</sup>.
- 2) Adolescents (secondary school and above) and adults who stutter, again, identified by school staff, parents and speech pathologists – confirmed by measures of amount of stuttering (e.g. % syllables stuttered or severity) and its impact on the individual<sup>18</sup>.

### Which groups are most in need of additional support and help? What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

Prevention is better than cure. Early intervention (pre and primary schoolers) has a good prognosis for recovery<sup>19</sup> and a reduced cost on the health system<sup>20</sup>. Furthermore, evidence indicates that early stuttering, if left untreated can have significantly negative impacts on young children who stutter<sup>21</sup>.

Because of the chronic nature of stuttering in adolescents and adults, ongoing treatment programs may be necessary to achieve fluent, natural sounding speech<sup>22</sup>. 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 this<sup>23</sup> and reduce the impact of social anxiety and isolation.

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<sup>17</sup> World Health Organisation ICD-10 F98.5 – Stuttering

<sup>18</sup> O'Brian, S., Packman, A. & Onslow, M. *Measurement of stuttering in adults: comparison of stuttering-rate and severity-scaling methods*, Journal of Speech, Language, and Hearing Research Vol.47 1081-1087 October 2004. doi:10.1044/1092-4388(2004/080)

<sup>19</sup> 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

<sup>20</sup> Packman, A. & Kuhn, L. *Looking at stuttering through the lens of complexity*, 2009, Vol. 11, No. 1, Pages 77-82 (doi:10.1080/17549500802630039)

<sup>21</sup> 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.

<sup>22</sup> Finn, P. *Stutterers' self-ratings of how natural speech sounds and feels*, Journal of Speech and Hearing Research Vol.37 326-340 April 1994

<sup>23</sup> 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)

## Who gets the power?

**How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)?**

Increased availability of treatment for people who stutter of all ages would provide more flexible treatment options. They would have increased choice regarding who they could seek treatment from, when they had it and where it was available.

Including representatives of the Australian Speak Easy Association in the decision making process for service delivery and availability would increase the power of those who stutter.

Given that there is no known cure for stuttering, most treatments require self-help organisation support and self-control skills. Self-help is considered an important and desirable component in managing chronic disease and disability<sup>24</sup> and stuttering is no different<sup>25,26</sup>.

It is important to empower people who stutter to make their own decisions about their treatment in collaboration with their service provider. In achieving this aim it is essential to provide the person who stutters with as much information as possible to support this aim.

People who stutter are, by the nature of the disability, restricted in their ability to lobby publicly on their own behalf. Advocacy services are needed to help support people with communication disabilities.

It is important to establish a complaints and appeals process, similar to Medicare Australia. Such a complaints and appeals system should be based on a recognised standard (eg. AS ISAO10002 Guidelines for complaints handling in organisations) and providing information to individuals on their rights in relation to complaints and appeals.

**How should the amount of financial support and service entitlements of people be decided (and by whom)?**

The amount of financial support and service entitlement for the person who stutters should be managed by a collaboration between the person who stutters and the service provision agencies, which might include the co-ordinating GP, their speech pathologist and potentially their psychologist. The amount of funding available should relate to the severity of the stuttering and its impact – and it should be sufficient to allow for the need for ongoing treatment.

The current Medicare Benefits Schedule - MBS (formerly Enhanced Primary Care Program) funding model doesn't enable sufficient funding for different treatments for the same conditions (i.e. speech and psychology for the same person at the same time), which places a greater financial burden on those with co-morbid conditions. It does not adequately cover those with

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<sup>24</sup> National Health and Hospitals Reform Commission, (2009). *A healthier future for all Australians – Final report June 2009*. Canberra: Commonwealth of Australia.

<sup>25</sup> 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.

<sup>26</sup> 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.

multiple complex related conditions. Five treatment sessions per year does not enable the adequate or appropriate treatment of stuttering or the often resultant Social Anxiety Disorder.

Recent research has revealed that stuttering is also associated with economic consequences that may challenge quality of life<sup>27</sup>. Findings from this study indicated that the average total cost was around \$AUD5,500.00 (median cost \$4,165) in 2007/08 over a 5-year period.

The amount of financial support required can depend on the type of treatment used and when the intervention is applied.

Typically, early intervention involves regular sessions with a speech pathologist (approximately 12-20 sessions may be required).

Treatment for adults who stutter can vary;

- Face to face or telehealth treatment with an individual (typically 30-60 minutes in duration per session; 10-30 sessions can give a person useful fluency, 15-50 sessions can give a person 'good' fluency)
- Intensive group treatment (can vary between one day and one week of intervention). The level of fluency achieved can vary greatly and depends on attending regular maintenance sessions for the following two years (recommended).

## **What services are needed and how should they be delivered?**

**What kinds of services particularly need to be increased or created? How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?**

Speech pathology services in schools should be increased. At present, priority is given to younger children, but children can start to stutter throughout their school years and in adolescence. In most states, treatment for stuttering is almost impossible to access in the later school years and in adulthood.

Increased speech pathology services should be provided in community health centres – and assurance should be given that these services will include treatment provision for adults who stutter.

Increased number of sessions should be included under the Government MBS Medicare rebate system for speech pathology and psychology services. This might take the form of subsidised packages of comprehensive multidisciplinary services, including speech pathology.

Service delivery could be improved by using technologies such as telehealth, which can improve accessibility to services, particularly for rural and remote people.

Advocacy services are needed for people with communication disabilities who need assistance

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

to communicate their choices, decisions and wishes.

Access to indirect treatment has 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<sup>28,29</sup>.

### **Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?**

Early intervention (pre and primary schoolers) can lead to complete recovery<sup>30,31</sup>. This requires early identification of individuals exhibiting stuttering behaviour. Stuttering can be identified by school staff, parents and speech pathologists, based on a standard definition of stuttering<sup>32</sup>. More funding is needed to increase availability of speech pathology services to pre and primary school children.

Left untreated until late adolescence and adulthood, stuttering can become a relapsing chronic condition<sup>33,34</sup> with significant impact on Quality of Life<sup>35</sup> and resulting in severe anxiety (Social Anxiety Disorder)<sup>36</sup>.

Even after treatment, stuttering can be physically and emotionally exhausting because for many individuals, it requires constant monitoring to control speech fluency<sup>37,38</sup>.

### **How could a new scheme encourage the full participation by people with disability and their carers in the community and work?**

Untreated people who stutter typically avoid social interaction and many types of speaking situations. By providing treatment, people who stutter who are treated have improved health outcomes, are more likely to participate in social activities with others and are more likely to seek employment opportunities and community activities. People who stutter who are untreated may have significantly reduced psychological, emotional and mental functioning

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<sup>28</sup> 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.

<sup>29</sup> 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.

<sup>30</sup> Jones, M., Onslow, M., Packman, A., Williams, S., Ormond, T., Schwarz I., Gebiski V., *Randomised controlled trial of the Lidcombe programme of early stuttering intervention*, BMJ 331 : 659 doi: 10.1136/bmj.38520.451840.E0 (Published 11 August 2005)

<sup>31</sup> Lincoln, M., Onslow, M., *Long-Term Outcome of Early Intervention for Stuttering*, American Journal of Speech-Language Pathology Vol.6 51-58 February 1997.

<sup>32</sup> World Health Organisation ICD-10 F98.5 – Stuttering

<sup>33</sup> 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.

<sup>34</sup> 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.

<sup>35</sup> 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

<sup>36</sup> Kraaiaat, F., Vanryckeghem, M., Van Dam-Baggen, R., *Stuttering and social anxiety*, Journal of Fluency Disorders, Volume 27, Issue 4, December 2002, Pages 319-331

<sup>37</sup> Kalinowski, J., & Dayalu, V.N. (2002). *A common element in the immediate inducement of effortless, natural-sounding fluent speech in people who stutter.* The second speech signal. Medical Hypotheses, 58, 61-66.

<sup>38</sup> O'Brien, S., Packman, A., Onslow, M., & O'Brien, N. (2003). *Generalizability theory 11: Application to perceptual scaling of speech naturalness in adults who stutter.* Journal of Speech, Language, and Hearing Research, 46, 718-723.

and will frequently avoid these types of situations.

Findings show that people who stutter often work in positions below their potential<sup>39</sup>, or that they often do not choose the career they actually want<sup>40</sup>. It would be helpful for people who stutter to have a structured transition from treatment into the workforce possibly through employment agency services.

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 to increase treatment opportunities for those who stutter.

### **How can a new system ensure that any good aspects of current approaches are preserved?**

There are currently limited accessible treatment options for teenagers and adults who stutter. The MBS Medicare rebate provides for five treatment sessions, however this model is limited and does not provide adequate treatment, particularly for those with severe stuttering and severe Social Anxiety Disorder. The current model would be significantly enhanced by revising the criteria used for determining access to and benefit from the MBS Medicare rebate and also by increasing the number of services possible.

### **What should be done in rural and remote areas where it is harder to get services?**

Urgent upgrades to reliable and accessible broadband web access (for example, the National Broadband Network) are required for those in rural and remote areas, together with the provision of webcams for those requiring treatment for stuttering. This would enable the telehealth provision of speech treatment services for which there is increasing evidence for effective treatment outcome<sup>41</sup>. This would also enable those in rural and remote areas to access specialists in the treatment of stuttering.

Provide incentives to encourage health professionals to take jobs in hard to staff areas.

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<sup>39</sup> 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.

<sup>40</sup> Peters, H.F.M., & Starkweather, C.W. (1989). *Development of stuttering throughout life*. Journal of Fluency Disorders, 14, 303-321.

<sup>41</sup> Carey, B., O'Brian, S., Onslow, M., Block, S., Packman, A., & Jones, M. (2010). *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.

### **How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?**

Minimise the requirement for detailed assessment by a GP for speech pathology (or other) service referral for the MBS service.

Withdraw the requirement for an MBS referral to need more than solely a stuttering diagnosis/or treatment by more than one professional.

Invest in supporting e-Health and move towards technologies to support these systems, which can be accessed by a multidisciplinary team, to ensure no duplication, paper burdens or overlapping of services. Some of the strategies coming out of the National e-Health Transition Authority (NeHTA) which could help include Personally Controlled Electronic Health Record (PCEHR), e-Referrals, Healthcare Identifiers and Terminology.

This needs to be supported by ICT infrastructure and software support from state governments to enable seamless integration and accessibility of this information.

## **Funding**

### **How should a new scheme be financed?**

The most practical funding option would seem to be as part of the Medicare Levy.

The draft report talks about options around private health insurance. This may disadvantage those with severe stuttering who may also be suffering from social anxiety and may be unable to gain employment or afford private health insurance.

Other options are also practical, including;

- Adding a levy on the tax system (for example, a specific disability tax)
- Surcharge on the Resource Super Profits Tax or Minerals Resource Rent Tax

### **How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?**

Funds for the scheme needs to be adequately isolated and protected from other funding sources to ensure they are not diverted to other government funding commitments.

Ideally the funding model to be implemented should take into account the impact of the disability, together with typical service demand to secure adequate budget to support ongoing funding for the scheme.

This might be achieved through detailed analysis of current usage of services, which would need to be offset with predictive models of the potential increase of services based on the outcomes of this inquiry.



# Organising and implementing a new disability policy

## **What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?**

The process to access treatment needs to be simple and straight-forward. If it is complicated for patients and healthcare practitioners it will lead to an administrative burden and delays in accessing treatment services.

If the scheme is rolled out in stages, target the early intervention group first, as the outcomes can be significantly greater than in other groups.

Seek broad consultation with relevant professional bodies, in particular Speech Pathology Australia, and include some of this representation in the implementation and governance of the scheme.

## **How long would be needed to start a new scheme, and what should happen in the interim?**

Thorough consultation is required with many stakeholders in the development of a new scheme, including health professionals and members of the Australian Speak Easy Association.

Implementation of the scheme could take a number of months. This might begin with a number of pilot sites to test systems and iron out process issues. This could then be expanded to include a greater number of areas and services. Ideally the implementation shouldn't take longer than 24-36 months.

In the interim, improved accessibility to services for children by providing more speech pathologists in schools would be a great start to improving outcomes and providing early interventions for children who stutter.

## 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 work can fill a person who stutters with fear, panic, 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 life of the person. 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 MBS which only provides five treatment sessions per calendar year. This is inadequate to treat both the stuttering and the sometimes resultant 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 research<sup>42</sup> 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.

For further information about this submission, please contact

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<sup>42</sup> Blumgart, E., Tran, Y., & Craig, A. (2010). *An investigation into the personal financial costs associated with stuttering*. Journal of Fluency Disorders, 35, 203-215.