Cleft PALS
The Sharing Helps

Give our Kids A Voice

Policy Discussion Paper

To have Speech Pathology (speech therapy) added to the Medicare Cleft Lip and Cleft Palate Scheme.

Executive Summary

- Most children born with a Cleft Palate will require speech pathology (speech therapy).
- Early assessment and intervention is critical to the success of speech therapy.
- The Public system is overloaded with patients waiting between 6 months and 2 years for treatment.
- The Private system is currently prohibitively expensive which makes it difficult for families to access.
- Effective speech skills are critical for oral communication, language development and literacy
- Poor speech intelligibility has a negative impact on self-esteem, confidence and social skills
- Approximately 300 new families each year will seek speech pathology services for their child with a cleft
- The infrastructure needed to support these children already exists in the Medicare Cleft Lip and Cleft Palate Scheme

The Issue

More than 385 babies are born with a cleft condition every year in Australia, and of these children up to 75% will have a severe defect that will require significant surgery, dental and orthodontic work, and ongoing speech therapy.

The treatments required by children with clefts can be costly and ongoing. For this reason the Australian Government has put in place the *Cleft Lip and Cleft Palate Scheme* which subsidises care for children with clefts through Medicare. This scheme alleviates some of the financial burden of ongoing dental and orthodontic procedures throughout the child's life, and allows all children within Australia to access necessary treatments.

However, a key part of the necessary treatment, which is still missing from the Medicare Scheme, is speech pathology.

Speech pathology is available to children through the public and private systems throughout Australia. The expertise of the professionals within these systems is of equal standard, and therefore in high demand and greatly sought after.

The differences lie in the availability of services to children in need, and the cost to families who strive to provide the help they need in a timely manner.

Although the service of the public system is adequate, the system is overloaded and waiting lists are becoming detrimental to the individuals on those lists. CleftPALS has documented cases of children asked to wait between six months and two years to begin their treatment. When it comes to speech pathology, immediate attention is essential. Children cannot wait until they have started school before they learn to speak clearly, without being severely disadvantaged throughout their school years. Early intervention is critical to success.

Meanwhile, the private system is prohibitively expensive for many families, embarking on therapy plans of two or more years. Some families have private health insurance which covers speech therapy, but there is an annual limit to the claims that can be made, and this limit is often reached within a couple of months.

The issue is simply that the public system is overloaded and cannot attend to the needs of all children when needed, and the private system is too expensive for long term therapy for most families in Australia. Australian families striving to help their children need financial assistance in order to achieve the best outcomes.

The Impact

The issues facing a child with a cleft are not only their scars and teeth but also their speech and ability to communicate effectively in society. Adequate speech is so important in every day life, but is often taken for granted.

It is understood in the cleft community that a child whose hard palate did not fuse, will not only need corrective surgery in the first year, but that they will also need some measure of speech therapy before they go to school. Of course they will also need ongoing dental and orthodontic work during their school years, but the most urgent and time critical issue for parents of a cleft child is speech therapy.

Most babies are listening and imitating sounds from an early age, and able to name items, people, places, and communicate basic needs or ideas by the time they are 2 or 3. A baby with a cleft palate is prone to chronic ear infections due to the inability to clear the ears (we use the soft palate for this). Even with the insertion of grommets to assist drainage, these children are audibly disadvantaged and tend to begin verbalising later. A speech difficulty may not be identified until a child is approximately three years old, and so these children who are beginning preschool programs are already significantly behind in terms of their communication skills.

With only 2 or 3 years before a child must attend primary school, parents find themselves in an urgent predicament, frantically searching for specialists that will provide the programs relevant to their child. In essence, what most children learn in 5 or 6 years, cleft children need to learn in 3 years.

So being placed on a waiting list that is already two years long is completely unacceptable, and our families are forced to endure the financial pressure that comes with private speech therapy.

Children with speech and language disorders are at significantly increased risk of literacy difficulties, poor academic outcomes, social, emotional and behavioural difficulties, and ultimately reduced life choices.

It is imperative that we enable a system that prepares and equips our children for the social and educational demands of school life and beyond.

A child born with a cleft will have already been through a lot of pain, stress and frustration by the time they start school. But all that is necessary to fully equip them for the challenge of school life. At a new school they will need to

- make new friends,
- answer questions in class,
- read and comprehend,
- obey the rules,
- demonstrate good behaviour,
- resist bullying,
- develop personal values and a social conscience,
- learn and grow.

This is a difficult task for most children. Children who have communication issues and have difficulty speaking and being understood will really struggle with many of these goals.

The worrying part is the psychological impact that this can have on a young person.

- Will they be confident and outgoing or timid and shy?
- Will they participate in class or retreat into seclusion?
- Will they avoid their problems or become aggressive?
- Will they overcome their challenges as they have before or give up on life?

The Proposed Solution

We propose that the Government extend the Medicare Cleft Lip and Cleft Palate Scheme to include Speech Pathology. Furthermore, we propose that this extension cover both individual and group sessions, given the improvements promised by a diversity of approaches.

This policy change would provide Medicare coverage for private Speech Pathology, making the service affordable and more accessible. This would in turn alleviate some of the pressure that is currently placed on the public scheme, and minimise waiting lists.

Speech Pathology Australia extends its support to this policy submission, reinforcing that accessible and timely speech pathology intervention is essential to the development of optimal speech and language skills; and in order to minimise the social, emotional, educational and employment disadvantage borne by this group of children, which ultimately will result in long term economic benefit to the community.

The Medicare Cleft Scheme is already a very effective and successful program supporting approximately 12,000 people around Australia. Most of those enrolled in the Medicare Cleft Scheme have a cleft palate, as this is the major reason for extensive dental and orthodontic treatment currently covered by the program. If the palate is affected, then these same children will need some degree of speech therapy in their preschool years, and perhaps supplementary treatment later in life.

The major costs involved in establishing, promoting, staffing, educating, and administering the scheme have already been incurred. Subsequent additions to the program would be incidental in the overall costs, but the value to its members will be immeasurable.

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Supporting Information:

Research

- **19% of 5-year-olds and 4% of 12-year-olds were judged to be impossible to understand or just intelligible to strangers. 34% percent of 5-year year-olds and 12-year-olds had consistent hypernasality of mild, moderate, or severe degree. Approximately 30% of both age groups had NOT undergone speech therapy.**

Sell, D. et al. Cleft lip and palate care in the United Kingdom--the Clinical Standards Advisory Group (CSAG) Study. Part 3: speech outcomes Cleft Palate-Craniofacial Journal. 38(1):30-7, 2001 Jan

- **Despite advances in surgical management and the advantages offered by team care, the majority of preschoolers with cleft palate continue to demonstrate delays in speech sound development that require direct speech therapy. An optimal treatment regimen for these children is one that includes primary palatal surgery no later than 13 months of age.**

Mary A. Hardin-Jones, Ph.D.David L. Jones, Ph.D. Speech Production of Preschoolers With Cleft Palate The Cleft Palate-Craniofacial Journal: Vol. 42, No. 1, pp. 7–13.

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Survey

CleftPALS surveyed their members and received a response rate of approximately 10% of our current financial members. The results of this survey confirmed our beliefs of the speech therapy system in Australia. Although the systems vary in each state, our families are struggling to find and/or afford the best treatment for their child.

The following summarises the results of our survey:

- 100% of respondents stated that their child was under 5 when they began speech pathology – 47% were 2 years old or younger, and 53% were 3 or 4 years old.
- 90% of respondents stated that their child attended speech therapy for 4 years. However, 66%of the respondents' children were still attending.
- One of our members told us that the family was out of pocket over $4,700 with her two children needing speech therapy in the private system.
- 1/3 of the respondents said that their child received speech therapy when they could afford it, and that speech therapy put a financial strain on the household, and
- 50% said that their child could have benefited from more speech therapy.
- Of those that chose the private system
  - 92% of respondents stated that the reason was because their child's needs were immediate and they didn't want to wait for treatment, and
  - 73% said they believed they would receive the best treatment in the private system.
- Of those that chose the public system
  - 60% of respondents believed that professionals with cleft experience was necessary for their child. (Cleft Clinic)
  - 40% said that it was what they could afford.
  - 50% said they believed they would receive the best treatment in the public system.
  - Other reasons included private speech therapists in the area lacked cleft experience, private therapy unavailable for up to 100kms.
- When asked what age limit should be placed on the availability for Medicare benefits for speech therapy, only 14% said it should be 10 or under. 86% believed it should be between 15 and 25 years old.

Petitions

We have begun to rally support from the community through petition signing and press attention. As at the end of August, we had secured over 230 signatures on our petitions representing parents, nurses and speech pathologists. This number will continue to grow as we actively make the broader community aware of our organisation and goals.

CleftPALS Australia has committed to focus our National Cleft Awareness Week activities on this campaign every year until we are successful. These activities include both the community and press as participants and supporters of our cause.