Submission to Senate Inquiry:
Prevalence of different types of speech, language and communication disorders and speech pathology services in Australia

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Down Syndrome Australia

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This document summarises the needs and experiences of children and adults with Down syndrome relating to speech pathology services in Australia in 2014.

Down Syndrome Australia would like to thank Rebecca Kelly from the Down Syndrome Tasmania Committee of Management for her work as the primary author of this report.

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Summary and recommendations

This section provides an overview of the general state of speech therapy support for children and adults with Down syndrome and recommendations on improvements to the system endorsed by Down Syndrome Australia. Detailed data and case studies are provided later in the report to illustrate the issues raised here.

Current situation

- Almost all children with Down syndrome will require speech therapy services for speech and communication issues. Almost 40% will require assistance with feeding issues, with many of these issues requiring assistance until the child is over 5 years of age.
- Support for breastfeeding is critical and speech pathologists can provide important assistance to new mothers who wish to breastfeed their baby with Down syndrome. It appears this assistance in the early days is not consistently provided. There is also a disturbing trend in some states of not supporting breastfeeding in favour of the immediate introduction of nasal gastric tubes. In fact the introduction of a NGT almost creates a self-fulfilling prophecy, as the insertion of a tube in babies with already small airways compromises their ability to breathe and feed at the same time. It also prevents further development of an adequate sucking motion because the tube ensures the newborn is never hungry.
- Current access to speech therapy services is based on arbitrary criteria relating to age, the state in which a child resides, whether they live in a regional centre or major urban area and the type of school they attend. Adults with Down syndrome often have issues with speech that would benefit from ongoing therapy. Currently there appears to be no source of funding to allow for this.
- Many parents of children with Down syndrome supplement government provided services (in some cases no publicly funded service) with private speech therapy. Parents generally perceive private therapy as expensive. Many parents also believe that the costs of private speech therapy have risen in response to Better Start funding being available.
- Most parents of children with Down syndrome are not entirely satisfied with their access to speech therapy services. The greatest discontent is expressed over a lack of services and the cost of services. Some parents also complain of poor quality service (although in most cases parents talk very highly of their therapists) and the distance they have to travel to access services.
- The variety of funding sources being accessed for speech therapy means that in many cases children are using multiple providers. Parents report a lack of consistency in their child’s speech therapy program and wasted resources from doubling up on things like assessments as issues with this approach to accessing services.
- There is a high cost associated with failure to provide adequate speech therapy services. These costs include: direct financial costs of therapy services to families; the opportunity cost for families and children of insufficient service provision which leads to poorer quality life outcomes for children; additional medical expenses associated with ongoing feeding issues not adequately addressed during baby and toddlerhood; and, additional costs to the education system of supporting students with poor communication skills, including the learning and behavioural issues arising from this, as well as providing feeding support for children whose feeding issues extend into their school years.

Down Syndrome Australia Recommendations

1. Speech pathology services should be provided based on the needs of the child or adult rather than arbitrary criteria such as the age of the child or the type of school they attend. No child with substantial needs should be denied access to speech pathology. There should not be an arbitrary age based cut-off for the provision of services. The system should allow for situations in which people with Down syndrome would benefit from additional speech therapy into adulthood.
2. New mothers should receive adequate support to breastfeed their newborn with Down syndrome, including the assistance of a speech pathologist where necessary.
3. Families should receive adequate support for the transition to cup drinking (from breast, bottle, NGT or PEG feeding tubes), including the assistance of a speech pathologist where necessary, without age restriction.
4. There needs to be greater consistency of provision of services and funding models between states and territories.
5. Speech patholgy should be regarded and funded as a health issue. In general, tying provision of speech therapy to the school system is unsuccessful. Experiences indicate a lack of services in government schools where available funding is spent on aid time or is allocated based on arbitrary criteria. Students in independent and private schools generally receive no allocation for speech therapy regardless of need. It is vital that access to speech therapy should be provided based on need. The situation where families are asked to choose between speech therapy or learning support time should never arise.
6. A cap should be set on out of pocket expenses for parents who access private speech therapy. Parents should not be forced to choose between the needs of their child for therapy and meeting the basic financial needs of their families.
7. The impact of government funding on prices must be carefully considered in the design and roll out of the NDIS. There should be a direct process available to parents who wish to complain about price increases or other exploitative practices they currently see occurring to take advantage of the availability of funding via Better Start or the NDIS trial sites.
8. Speech pathologists should have improved access to professional development opportunities to develop skills in specialised areas such as assisting children with Down syndrome, cleft palate speech or signing.

What is Down syndrome?

Down syndrome is the most common genetic cause of intellectual disability and the second largest specific childhood disability (after autism spectrum disorder) in Australia.

Down syndrome is the world's most common chromosomal disorder and cause of intellectual disability. It is not an illness or disease, and occurs at conception. It occurs in one of every 700 to 900 births worldwide and affects people of all ethnic and social backgrounds. In Australia approximately 270 babies are born each year with Down syndrome.

The human body is made up of millions of cells, and each cell there are 23 pairs of chromosomes, or 46 chromosomes in each cell. Down syndrome is caused by the presence of an extra chromosome, chromosome 21 (Down syndrome is also known as trisomy 21). People with Down syndrome therefore have 47 chromosomes in their cells instead of 46. This results in a range of physical characteristics, health and development indications and some level of intellectual disability. Down syndrome is usually recognisable at birth and confirmed by a blood test.

Health

Many babies with Down syndrome are born without any health problems at all. However, some newborns with Down syndrome may experience some health complications, such as:

- low muscle tone
- a heart defect
- digestive or feeding issues
- ear, nose or throat issues
- vision problems
- thyroid disease
- slow or delayed growth and development.

Population data

There are currently more than 13,000 Australians with Down syndrome. This number continues to increase due to steady birth numbers and increasing life expectancy. The greater availability of prenatal testing has not significantly altered the numbers of babies born with Down syndrome, while life expectancy continues to increase with improved medical care.

However, because of poor life expectancy in the past, the proportion of children and young adults is still believed to be higher in the population of people with Down syndrome than in the general population. Down Syndrome Australia estimates* that over 30% of the population of people with Down syndrome is under 18 (compared with around 26% in the general population).

*based on a community research project conducted in South Australia in 2013 indicating that the proportion of children (17 and under) could be as high as 40% and current WA data indicating a proportion of around 31%.

Intellectual disability

Down syndrome is the most common cause of intellectual disability that we know of. Everyone who has Down syndrome will have some level of intellectual disability. There will be some delay in development and some level of learning difficulty. Because everyone is unique, the level of delay will be different for each person.

When a baby is born, there is no way to tell what level of intellectual disability the child may have. Nor can we predict the way in which this may affect a person's life. However, we do know that having Down syndrome will not be the most important influence on how that person develops and lives their life. Instead, what happens after birth will be much more important and family, environmental, cultural and social factors will shape their life, just like everyone else.

For many people with Down syndrome, speaking clearly can be difficult. Although a lot of people with Down syndrome speak fluently and clearly, many will need speech and language therapy to achieve this. Very often, people with Down syndrome can understand a lot more than they can express with words. This often means that their abilities are underestimated, which can make them feel frustrated.

Some people with Down syndrome will find it very difficult to develop language skills and speak clearly. This may be made worse by hearing loss.

We are still learning about the potential of people with Down syndrome. The first generation of people who experienced the advantages of early intervention, mainstream schooling and transition to work programs are still in young adulthood. And while early intervention and education outcomes continue to improve in research and practice, the old data on life expectation and functionality cannot be relied on to predict future demand for services.

What we do know is that people with Down syndrome continue to break down barriers as their contributions to their families and the broader community are recognised.

Down Syndrome Australia online survey

In order to provide factual information about the needs for speech pathology and experiences of people with Down syndrome, a brief online survey of parents of people with Down syndrome was conducted. Data provided below summarises the responses of 38 members of our community who completed this survey. While this is a limited sample size, we feel the data collected presents a good indication of the prevalence of issues and the experiences of people with Down syndrome in accessing speech pathology services.

The prevalence and incidence of different types of speech, language and communication disorders and swallowing difficulties in Australia amongst young people with Down syndrome

Children and adults with Down syndrome commonly suffer from a number of issues relating to speech and feeding. Children with Down syndrome typically have low muscle tone which affects their fine motor and gross motor control. Almost half of children with Down syndrome have heart defects. For these reasons, babies with Down Syndrome are frequently sleepy and difficult to rouse for feeds. They have less success with breast and bottle feeding and frequently need assistance with commencing on solid foods. It is also common for children with Down syndrome to have multiple disabilities and serious medical conditions which affect their ability to feed and speak – including but not limited to hearing and vision loss, congenital heart disease, autism, ADHD, cleft palate, leukaemia, a tendency to aspirate on fluids and epilepsy.

For these reasons babies with Down syndrome and their mothers sometimes require additional assistance to establish breastfeeding. While some experience challenges, breastfeeding is successfully established with many babies with Down syndrome. The health and wellbeing benefits of breastfeeding are well documented, and are no different for babies with Down syndrome. In particular, the exercise of breastfeeding itself improves muscle tone, and can help with speech and tongue control in the future.

For this reason it is important new mothers receive adequate support when breastfeeding, including the assistance provided by a speech pathologist where necessary. Unfortunately this assistance is not consistently provided across the country. In fact in at least one state there appears to be a disturbing trend of medical professionals recommending to families the immediate introduction of a nasal gastric tube rather than support for breastfeeding. Evidence of the challenges some babies face is presented to families as evidence that breastfeeding will not be successful before it is even attempted.

Figure 1 shows the responses of survey participants when asked about whether their child had experienced issues relating to speech and feeding, either current or in the past.

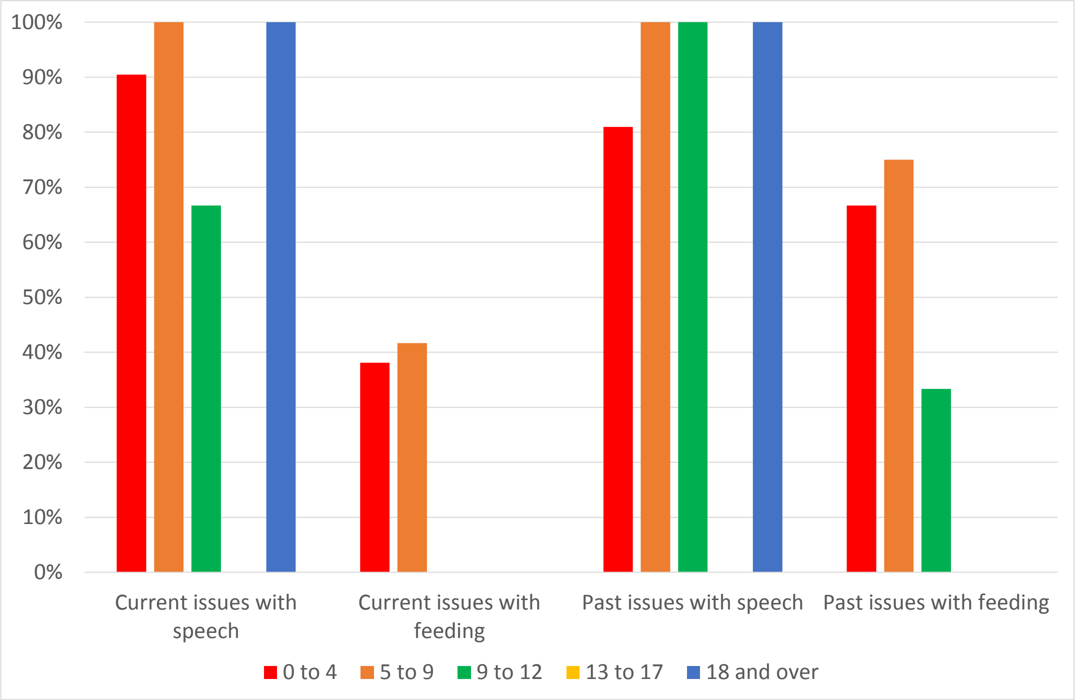

Figure 1. Prevalence of speech and feeding issues past and present amongst survey participants

These results are indicative of the general prevalence of these issues amongst people with Down syndrome. Almost all children under the age of 10 are currently experiencing issues with their speech. Close to 40% of children in these age groups currently experience issues with feeding. Effectively all children with Down syndrome have in the past experienced issues with speech with the only survey participants indicating no issue being 1 and under. Well over half those in the 0 to 4 and 5 to 9 age groups have had issues with feeding in the past.

Availability and adequacy of speech pathology services provided to people with Down syndrome

As is shown in Table 1 access to speech therapy is very variable. People access a mix of government and private providers, with some people accessing therapy through both government and private providers. Some of those who require speech therapy also indicate that they currently receive no service. These responses were given by those with older children (18 and 22).

Table 1. Access to speech therapy services by those with current speech difficulties

Type of service accessed	Proportion
None	6%
Government provider	18%
Private provider	52%
Both government and private	21%
Other	9%

Table 2 shows access to services for those whose children have current feeding difficulties. Only 15% of these children access government providers only, with the largest proportion accessing private services.

Table 2. Access to speech therapy services by those with current feeding difficulties

Type of service accessed	Proportion
Government provider	15%
Private provider	46%
Both government and private	38%

Survey participants were asked about how satisfied they are with their children’s access to speech therapy services. 26% of respondents were ‘not at all satisfied’, with a further 47% ‘somewhat satisfied’. 26% of parents indicated they were ‘entirely satisfied’. Reasons for a lack of satisfaction are shown in Figure 2. This Figure shows that the lack of service and cost of service are major drivers of lowered satisfaction. Comments provided under ‘Other’ also demonstrate some of the issues:

- *‘There is no service available in the public system for school aged children with a disability attending Catholic and private schools in Tasmania. Paying for private speech therapy is our only option.’*
- *‘We attend fortnightly. Would love to do it weekly but due to distance travelled and the fact our speechie wasn't a Better Start provider till late 2013, cost has been prohibitive’.*
- *‘Not sure what speech services are available now he has left school’.*
- *‘There is no option other than private therapists in our area’*
- *‘We start next month. But would have liked access earlier as R. is trying to communicate but we have been left to find information on our own’.*

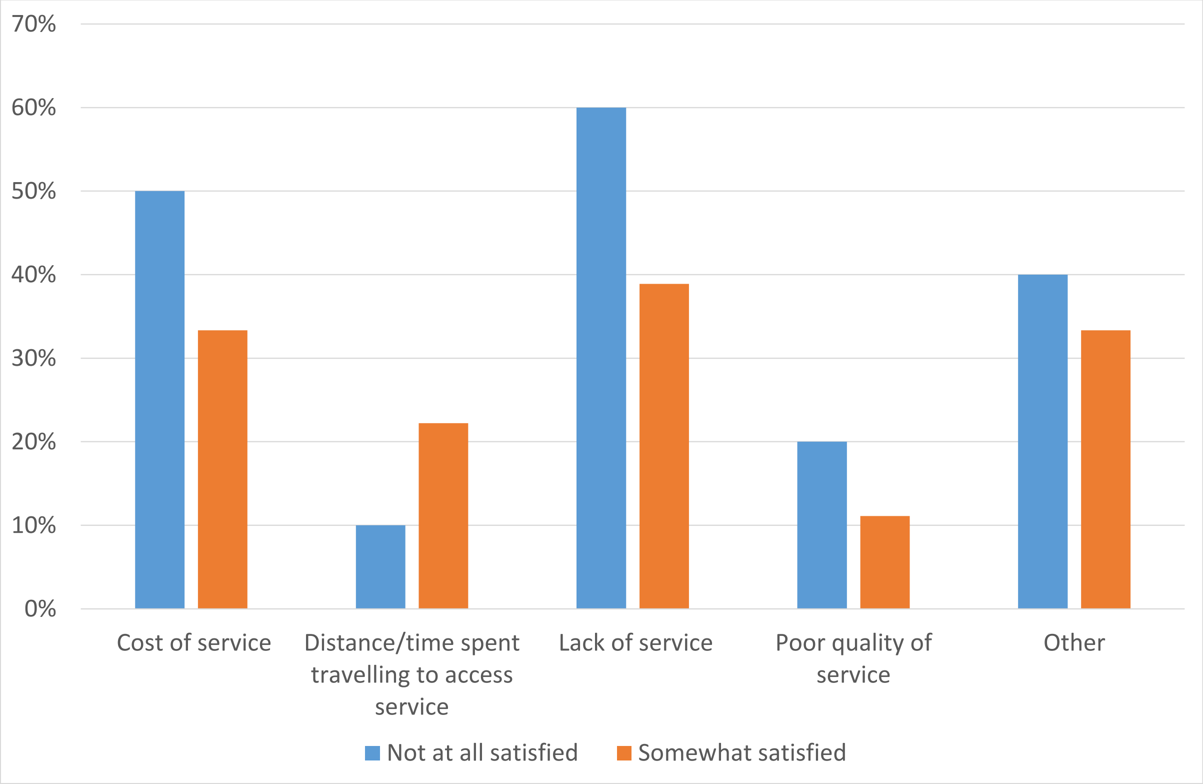

Figure 2. Reasons for lowered satisfaction with speech therapy services

Parents were also asked about the out-of-pocket expenses that they typically face in a year for accessing speech therapy. The majority of families pay less than $50 a year, with nearly 70% of families paying less than $200 a year. Over 20% pay between $200 and $800 a year, and 11% pay over $1,000 a year with half of these paying between $2,000 and $5,000 a year.

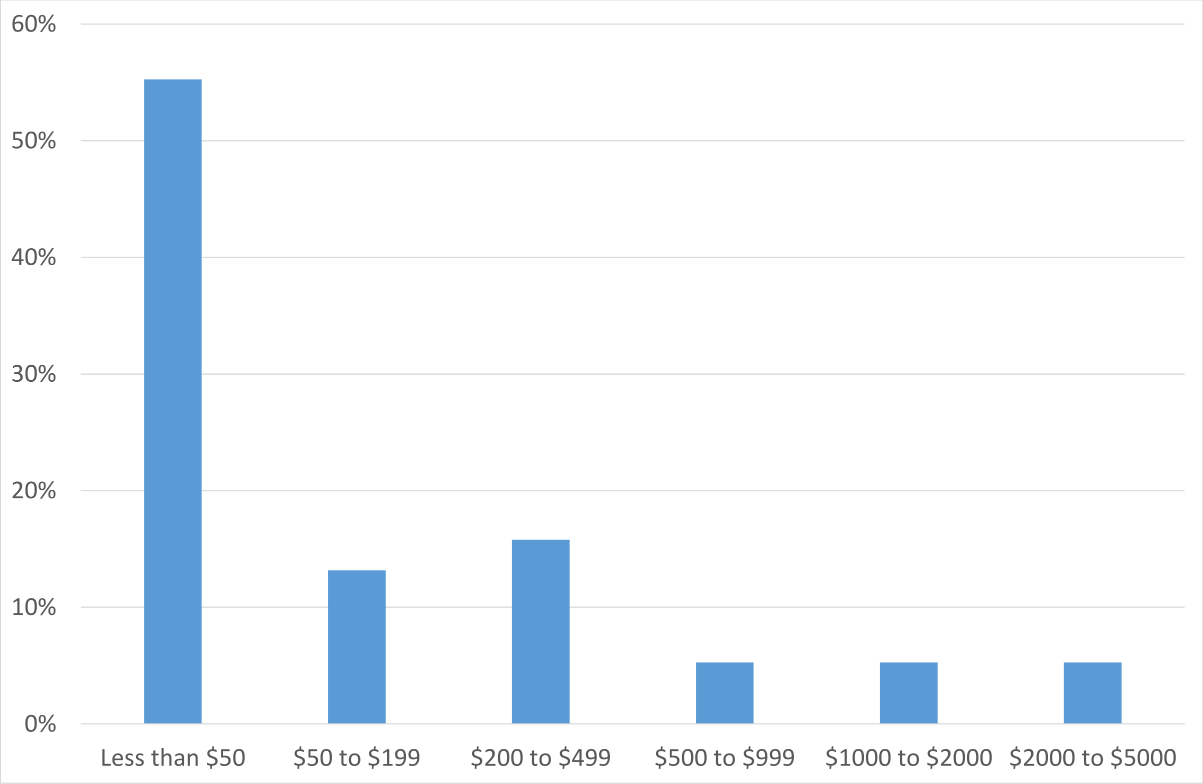

Figure 3. Out-of-pocket expenses for speech therapy services faced by families of children with Down syndrome

Positive experiences with accessing services

In many instances, parents report very good experiences with accessing services:

‘Our Speech Therapist has been excellent and on the ball from when my son was 3 months of age. We saw her every month and assisted with feeding issues (suggested different bottles for our baby and use of thickener which definitely made a positive difference in his weight gain). She suggested I do a signing course to assist with communication. Has also assisted with self-feeding and currently working on communication techniques.’

‘We were referred to our speech therapist from our paediatrician and there was no waiting list. We've had no issues with our experiences with our speech therapist.’

‘We needed assistance with feeding when our child was born prematurely and with a disability. With the assistance of a feeding team made up of speech and occupational therapists we were able to eventually establish a feeding routine that allowed us to leave hospital 42 days after the birth of our daughter. The speech therapist was very helpful in monitoring progress during our first 6 months and assisted us to achieve our goal to move from a nasal gastric tube in hospital to bottle and breast feeding and eventually full breast feeding. We transition from services provided by the local children's hospital to a Government provided early intervention service. We found the services at the hospital provider much better in terms of assistance to the family and regular follow up. Since transitioning to the early intervention services we have had assistance with early communication and cup drinking. I must say I would never have imagined that such a simple task would be so overwhelmingly challenging and know that the support we have received really did help. We also have attended a training course (Hanen) run by our speech therapist that was very beneficial to our family.’

‘My daughter was discharged from hospital at 6 weeks with a nasogastric tube. The Eastern Health feeding clinic immediately contacted me to circumvent any feeding problems in the future. They followed up at 6 months when she was starting solids. They're available should I need them at any time. I also have an appointment with Early Intervention to assess my daughter's speech and feeding in a few weeks.’

‘Ageing Disability and Home Care have been involved with my little girl for nearly 2 years. The speech therapist has assisted with feeding issues as she had a nasogastric tube for 16 months and a g-tube for another 12 months. The ST assisted with her oral aversion and then with getting her to eat. She has been an amazing resource, not only with ideas, but also with tools such as spoons, teats, bottles cups etc. The ADHC speech therapist also set up PECS and PODD for communication. She comes to see us about every 3 weeks or sooner if I have an issue. Communication has been very easy between us, using email or phone calls. I always get an answer within a day or two. We also see a private speech therapist who is doing Prompt Speech with her. This has been accessed via our GP management plan. We had five sessions last year, and we will have another five this year, before we start using our Better Start Funding. As my little one is becoming better with her sounds, and clearer with her speech, we will be accessing this speech therapist more this year.’

Arbitrary criteria for access to services

There is substantial evidence that provision of services is based on relatively arbitrary criteria such as age, State of residence and the school a child attends, rather than the needs the child has for a service. An example illustrating this is provided by a parent of a 5 year old girl living in Tasmania:

‘We were entirely satisfied with our initial access to speech therapy before V was even a week old and still in Neonates. We saw a speechy daily to help with feeding issues until V was discharged at 6 weeks old. We had regular appointments with her until feeding via bottle was well established around 9 months. V accessed speech therapy at early intervention from around 1 year until she transitioned to school. This was for speech side of therapy. And we accessed (or tried to) speech therapy for ongoing feeding issues with our local core Paediatric rehab provider.

At the end of 2013, we received a speech pathology report from our core service provider for our daughter who is 5 and half, and heading off to full time school this year (2014). The report states:

- *V has a severe speech and language delay*
- *V has a severe delay in receptive language (comprehension)*
- *V has motor impairment in speech pronunciation*
- *Oromotor difficulties related to a diagnosis of Down syndrome and cerebral palsy. These difficulties affect her speech as well as her eating and drinking.*

The outcome of this report is that our daughter was discharged from speech therapy as she no longer meets the criteria to access speech therapy at our local core service provider. Even though it is documented in the report that she would benefit from further speech therapy.’

In this case, regardless of the obvious very high need this child has for speech therapy, access to this was denied because she attends an independent school. Her parents have used almost all the funding available to them from other sources (such as Better Start, GP Management Plans and private health) and face the choice of paying substantial amounts for speech therapy for their daughter (on top of needing to fund other therapies such as physiotherapy and occupational therapy) to address her obvious high needs or to deny her access to these services with life limiting consequences. It is likely that the cost to them for accessing therapy at the levels she requires would amount to many thousands of dollar per year.

Age barriers to accessing speech therapy are also illustrated by several parents of school age children:

‘Services are not really offered through the school and unless there is a strong medical need, it is hard to secure services for a child. Services are limited in the area as well because of the rural setting.’

‘Our son had speech therapy until he started Kinder at a therapy centre. Since starting school though, there have not been regular therapy sessions which is so disappointing. Learning to speak is a life skill should be accessible and within reach for families and individuals who require this therapy. I am now the speech therapist!!!!’

The arbitrary nature of age cut-offs for accessing services and funding was also illustrated by a parent of a 2 year old boy who said:

‘Our son has a cleft palate and hearing loss on top of extremely low muscle tone associated with Down syndrome. At birth he had severe issues with feeding, requiring a nasogastric tube and the use of a special needs feeder. We commenced speech therapy when he was 7 weeks old, initially for feeding then following this until the current day for speech. At the age of 1 he was also diagnosed with leukaemia and undertook 7 months of chemotherapy during which time he had no access to speech therapy services while also experiencing additional developmental delays relating to his treatment.

Our current access to speech therapy services in Tasmania is excellent. We have had access to high quality therapists with very low costs for specialist speech programs we have attended and no cost for appointments. In the past his access to speech therapy services has been poor during two phases of his life: immediately after his birth when we ideally would have accessed assistance with feeding him while he was still in hospital; and, while he was at the Royal Children's Hospital in Melbourne undertaking treatment. At both these times the system failed to provide any support to him.

I also have serious concerns about his access to speech therapy once he commences school in two years time. At the moment he is well covered by Better Start and our local provider. However as we intend to enrol him at the same Catholic school his sister attends he will not qualify for any speech therapy as soon as he starts school. He has a major speech impediment caused by his low tone and late cleft palate repair (it was delayed until he was almost 2 due to his cancer diagnosis). He is likely to need intense therapy well into high school to achieve his full potential. Our access to Better Start funding will cut out at 7 and even then is unlikely to stretch as far as that give his very high need. I am extremely worried about the pressures this will put on our family, either to find the money to pay for this therapy or else deny him access and see his ability to communicate diminished for the rest of his life. Given we already have several major health issues to contend with, this adds a significant burden of stress and likely financial cost on our family.'

Lack of government provided services and high cost of accessing private providers

General lack of access to government provided services and the high cost of accessing private therapists were highlighted by many:

'Our daughter was assigned a Speech Therapist through the state provider but they only visited 4 times over the course of a year. We would have liked a session once a month, which is what had been promised. The private sessions are quickly chewing through the Better Start funding.'

'My son can't speak very well, yet he has been signed off from his "allocated " time with his speech therapist. We now have to wait another year before we can access this service again. I find it to be a poor service that can sign off on a child who can't speak properly, as there isn't enough speech therapists in the area, to accommodate the amount of disabled children.'

'Our child essentially missed out on early intervention for speech therapy due to excessive waiting lists, despite this being important for a child with Down syndrome. We lived in a major regional city in NSW at the time. The waiting list for early intervention through the government provider DADHC was so long our child only received one block of 3 sessions in a 6 year period. We placed our child's name on the waiting list as a baby. At 3 years of age we received 3 sessions of speech therapy and were then put on the waiting list for another 3 years at which time our child had turned 6. We only received 4 sessions of speech therapy through Better Start as our child turned 7 a month or so after the first provider was set up in our regional area. We handed back several thousands of dollars that we were simply unable to use. We have used all of our Medicare/Better Start sessions which are meant to cover the ages 7-15. We used these all in one year, rather than the seven years they were designed to be spread over. We currently pay for private speech therapy for 2 children with disabilities and the cost of this is huge.'

'My son has Down syndrome, he aspirates on thin fluids and has required considerable intervention with feeding. We were accessing speech therapy through Disability SA, a Govt funded provider, since birth. Upon the introduction of Better Start, I felt their hands were tied somewhat. They weren't able to approve funding for equipment and services. We were forced to

access private speech therapy in order to purchase education and resources. I found the cost of this private therapy ridiculous. It took 40 minutes for me to drive there and, despite saying exactly why I was there, I was told that I would need at least 5 sessions before they could approve anything. It was a lot of tax payers money spent so that we could get funded for a book and a communication course. During this time I was told that I couldn't access our Disability SA Speech therapist because I was 'doubling up'. I am now back with the Disability SA speech therapist who knows our son best and I understand that they will be able to register as a provider under the NDIS. While I am extremely grateful that we are able to access 'free' services, the whole process has been time consuming and costly.'

'Early intervention offered me a speech therapist when my son was a baby. We accessed her twice in a 12 month period even though he displayed delayed speech and feeding issues. When revisited by the same therapist at the age of two I was told my son was on par developmentally therefore she saw no need to continue. My son is now 8 and still has a speech delay. Lucky for him we sent ourselves broke and paid for private speech therapy. We accessed Better Start for a little over 12 months until the age of seven when apparently the issues disappear. We used our thirteen sessions until the age of 14 (I think it is) within the first fourteen weeks of turning seven. What to do now? School funding goes towards aid time so there is no more money for therapies (State school). We are currently 60K in debt, have no home, barely make ends meet so our son can be an active member of society. All worth it but honestly should be paid for.'

'While we are very happy with the quality of service we have so far received from our EI providers, the lack of necessary quantity of services which we feel our son needs to help his speech development & feeding issues, has forced us to seek the services of a private Speech Pathologist. We fund this primarily using our Better Start funding (& only recently also with some private health extras cover rebates) which sadly is quickly diminishing as we need to also use it for private Occupational & Physio therapy. While I understand the point of the Better Start funding is to supplement public services, I believe better public services (longer, more regular consultations, & not in a group setting) should be made available.'

'We have no government provided speech services via disability services that is available elsewhere. We access speech via cerebral palsy league, and it is only lucky that their books aren't full of their own clients that they take others like us without CP.'

'We had speech in EIP which was included in fees and speech at school, no private service. We haven't applied for funding at any stage for speech. Not sure what speech services exist for those that have left school.'

'Our local disabilities service (DSQ) has no speech therapist available for us to access. We just got private health insurance as we knew that we would have to pay privately for speech services. It distresses me to think that families may miss out on speech services because they can't access private services.'

'They give us good ideas but it can be hard to keep up the time to do everything in our busy lives. Would be good if these services where in our schools and private schools. Professionals are needed in our schools for our children to have daily services with everything they need.'

'Only access through early intervention. Basic baby sign. Would have preferred a more intense program. Speech is very important and a child's way of communication especially our children.'

Poor quality services

Responses also highlighted in a few cases there have been issues with accessing ongoing, good quality therapy services, with some parents indicating that speech therapists they had consulted in some cases had little or no knowledge of issues and techniques relating to children with Down syndrome:

'We initially used the hospital speech therapist when we had feeding issues at 5 weeks old, these were rectified and we were fine for a while. The original SLP went into private practice but was with the Better Start funding, so we used the hospital again with swallowing issues. The Qld health SLP was young and ignorant to my son diagnosis, in fact she was no help at all. The SLP was very rude and told us to teach our son to sign as he would never speak. My son only has Down syndrome, he is neither deaf or mute! We had been without a SLP for 2 yrs he is now 2 and half yrs, and then we were accessing through FECs team which lasted one term when their therapist resigned. Until recently we were without a SLP and have been able to secure a wonderful lady who travels 3 hours from the Brisbane city to see us and 4 others, she is wonderful and specialises in Aspraxia which is common in our kids. I look forward to securing a long term in Speech with this SLP......until our funding runs out!'

'We use Better Start and without this our son would not get speech services. He is non-verbal and does some Makaton. We are searching for an instructor to teach the school and his some more Makaton but have been looking for the past 12 months with no luck. Due to our living area we found it hard to find someone willing to attend our son's school for speech therapy. We love our speechie, but she is not that great at Makaton.'

'Speechie wanted to send us for a barium swallow then when we agreed she told us she should do an assessment first, in hind sight surely she should have done this before suggesting the swallow. Our son had raspy cough with shadows on chest x-ray the time to access the swallow was several months and we had to make a lot of phone calls as referrals were lost then found. Then another one from paediatrician was needed. Doesn't sound like a big deal but it is exhausting when you are just trying to do the best for your child.'

Provision and adequacy of private speech pathology services in Australia to people with Down syndrome

Many families access private speech therapy services, either as an adjunct to their government provided services or as their sole access to speech therapy. There was a general perception amongst parents that the cost of private speech therapy is unreasonable (quoted as being between $150 and $200 an hour). It is also generally perceived that private speech pathologists have in many cases raised their fees to take advantage of the Better Start Initiative. This means that even with Better Start funding parents are often only able to access very limited speech therapy services without incurring substantial out-of-pocket expenses. As an example, at $200 an hour the annual maximum allocation of $2,000 would fund 10 allied health sessions, which for a child with Down syndrome would typically need to be split between speech therapy, occupational therapy and physiotherapy at a minimum. Many of these children require speech therapy on a weekly to fortnightly basis.

'We have always gone private for speech since my daughter was 2 (she is now 6), when she was 3/4 just before Better Start funding came in we were lucky to access fortnightly private speech (in our home) from ADAHC but had to give it up when we were granted Better Start funding. I'm very happy with our private ST but extremely pissed at the amount they charge once you are

using BS funding :(‘

‘We have been very happy with the private speech therapy services that we have accessed over the past few years (since our daughter left early intervention and started school). We are again looking to access some private therapy to reinforce and help her continue to build on the skills that she currently has. However to do this, we need to take her out of school (which isn't always convenient and means that she is missing out on valuable learning time). Whilst we are happy to pay the cost of these sessions, we do find them to be extraordinarily expensive and are disappointed that the management plan only offers limited services at a reduced rate.’

Other issues raised with accessing private speech therapy relate to the lack of continuity between service providers. People are often forced to access multiple providers, with resources often wasted on each of these conducting their own assessments before starting any therapy. There are also implications for the consistency and effectiveness of any program if the same methods are not being applied by the various providers being accessed.

Difficulties in accessing good quality providers with Better Start funding have also been highlighted. In some cases parents could not access their first choice of therapist due to them not being registered with Better Start.

‘We started with access to a speech therapist through Disability Services Queensland. When this person left her position we accessed private speech therapy with our Better Start funding but we found the quality of service to be poor and the cost of the service to be exorbitant. We then had no access to speech therapy for almost 12 months and eventually tried another speech therapist and paid privately to see her. She was great, but with no Better Start registration and us not having private health insurance we were unable to continue to see her because of the cost of her appointments. We have been doing a lot of work at home ourselves and having to do research and attend training myself as a parent to learn ways of developing speech at home as we have not had access to good or consistent speech therapy.’

‘We have accessed Better Start funding to travel 350km to access a speech therapist for our son. That therapist realised the need to support the north west of Tasmania and began traveling. She now employs someone at this end of the state but not to the standard of the original therapist we were using. There are only 2 speech therapists on the Better Start program, these have recently employed other people but accessing has been a nightmare.’

‘When we had Better Start funding, we had very limited access to Speech Therapy as not all Speechies are registered. Then once you get a Speech Therapist, they charge a substantial Admin fee for Better Start clients. Not good. Once Better Start funding stopped, we pay $100/week for Private Speech. Very expensive. We also have to travel over 50kms (round trip) to access our Speech therapy. Very difficult.’

‘We only had access to speech thanks to the Better Start funding, this has been a heaven's gift. After this stops I don't know how we will proceed as the Department of Education does not provide sufficient speech therapy. It also is hard work to make sure everybody keeps everybody in the loop. It also took time for the private speech therapist to get up to speed with Down syndrome issues. She didn't know that our children can learn to read before they can talk and that learning to read will help them talk. This has been a steep learning curve but taken with much enthusiasm from the speech therapist's point of view. She also decided to specialise in this reading program which is developed by Down Syndrome South Australia. Hopefully we can find other financial recourses as I can't afford private speech therapy although this is an ongoing benefit for my son and will help him to have a more independent life later.’

‘We have to accessed two providers to access better start funding - very disjointed and time consuming. The private Better Start funded provider is not as good as our early learning provider and we waste time having two assessments. This is costly to the community, we feel guilty about this but have no option. There is no Down syndrome specific service like in UK or US and as our [support group] reveals the information and service available is practitioner and area dependant and doesn't have a framework despite Down syndrome being the most prevalent cause of Chromosomal intellectual disability in the world. To access a UK based language development program we had researched and then was reviewed by our ELC service for us, we then had to go to our Better Start service provider, pay for a session fee, they ordered it charging Better Start a fee to do so and then it was mailed and we had to go and collect - they didn't even open the box and look at it or make suggestions on the best way to use it. It was ridiculous - $160 ordering service for something I could have ordered myself and have attended webinar on to learn how to use it prior to asking about it.’

Evidence of the social and economic cost of failing to treat communication and swallowing disorders

Social and economic costs of a failure to treat communication and swallowing disorders amongst children with Down syndrome are many:

- The direct monetary cost to families of accessing additional services. These can amount to many thousands of dollars a year if adequate services are accessed. In most cases parents are not able to afford the level of service their children require. There is a general perception amongst many parents of children with Down syndrome that private speech therapists have raised their fees to take advantage of the Better Start Initiative and that as a result these services are now overpriced and largely unaffordable,

- Additional costs in the education system of supporting children through behavioural and learning issues caused by a lack of speech, or medical issues caused by feeding difficulties.

- The loss of potential in children with Down syndrome. Our ability to communicate with others is fundamental to how we interact with society: our ability to access services; our ability to hold down a job and to engage with sporting and other recreational activities. It is likely that a failure to provide adequate speech therapy services to children with Down syndrome limits their ability to work in adulthood and creates a higher care need for these individuals. This amounts to both a personal tragedy to these adults and their families as well as a substantial economic cost to Government and the broader community.

- Additional medical costs associated with long term feeding and swallowing issues. Children who do not learn to feed well as infants often require long term medical intervention to attain adequate nutrition. This comes at both a cost to the health care system, and a cost in time, money and stress to the families involved.

Projected demand for speech pathology services in Australia

It can be expected that with the introduction of the NDIS and more close targeting of service provision to need, the demand for speech therapy services amongst people with Down syndrome will expand substantially. At present there is a clear lack of services provided to:

- Children over the age of 7 who have no access to Better Start funding
- Children at independent and private schools in some states and territories
- Teenagers and adults with Down syndrome who would benefit from speech therapy but currently have little or no access to services
- Toddlers and babies in some states or territories where access to early intervention, particularly for children under the age of 2 is lacking.

In many cases even where speech therapy is currently provided to a child, there is a clear need for access to a greater level, consistency or quality of service than is currently available. All these factors indicate a large demand for speech pathology services into the future amongst children and adults with Down syndrome.

Down Syndrome Australia

Down Syndrome Australia (DSA) is the only national voice for people with Down syndrome and their families. DSA was established by the eight state and territory associations which provide support, information and resources to people with Down syndrome and their families across the country. The associations came together to ensure a strong national voice represents the needs, interests and aspirations of people with Down syndrome and those that support them. Down Syndrome Australia is completely reliant on funding by the state and territory associations and receives no government funding as a peak body.

Catherine McAlpine
Chief Executive Officer

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