Submission regarding the Service Delivery Framework for the Hearing Services Program – Voucher Scheme for the Office of Hearing Services undertaken by Australian Healthcare Associates July 2015



P: 02 6684 2571 M: 0419 495 032 E: <u>info@aussiedeafkids.org.au</u> ABN: 39 127 705 793 Thank you for the opportunity to make a submission regarding the Service Delivery Framework for the Hearing Services Program.

Aussie Deaf Kids is a not-for-profit organisation providing online information and support to families raising children with hearing loss in Australia. The proposed changes to hearing services for children and their families has caused considerable concern amongst the hundreds of parents who are members of our online groups. The majority are strong supporters of the services provided by Australian Hearing. They know how fortunate their family has been to have a child identified with a hearing loss in Australia where they have access to quality services and support to guide them throughout their journey.

The core principles laid out in this Service Delivery Framework were designed for the Voucher component of the Scheme. We believe they are too general for the CSO component of the Hearing Services Program where failure to provide a services that meets the needs of children and their families will have lifelong consequences for a child, their family and society as a whole.

We note one of the goals of this Service Delivery Framework is to minimise red tape for service providers. This cannot be at the expense of providing high quality, family-centred services to children and their families. Minimum standards, as laid out in this Framework, will not optimise the outcomes for children with hearing loss and their families — which we believe should be the goal for every child participating in the Hearing Services Program provided by the Australian Government.

Our views of a National Framework has been coloured by our experience with the National Framework for Neonatal Hearing Screening. We were involved in consultation for this document in 2009. The document was finally released in August 2013 and, to date, there is little evidence of compliance or consequences for newborn hearing screening programs. We hold grave fears that this could be the fate of a Service Delivery Framework for the Hearing Services Program. Newborn hearing screening programs are provided by State Governments where there is some rigour around quality assurance. In a contestable environment, where service provision is self-regulated, the adverse consequences of poor compliance for the deaf child and their family cannot be overstated.

Aussie Deaf Kids does not support the sale of Australian Hearing or moving the Community Service Obligations component of the Hearing Services Program to a contestable environment. We believe that Australian Hearing should be the sole provider for children under the age of 18 transitioning to the National Disability Insurance Scheme.

However, it is through the lens of a possible sale of Australian Hearing and move to a contestable marketplace that we address our comments below.

Note: we have used the terms 'deaf' or 'child with hearing loss' to mean all types of permanent childhood hearing loss.

Yours sincerely

APorter

Ann Porter AM

CEO

Are there other features that should be included in a Service Delivery Framework for Hearing Services?

1. The whole child

Central to the Service Delivery Framework is the child – not a deaf child or a hard of hearing child - but a child. His hearing loss should not define him. His identity will be forged by many of his talents and characteristics – hearing loss will only be one of them. The way service providers portray hearing loss has a profound impact on the family and how they will parent their deaf child (Bosteels et al., 2012).

2. Continuum of Care

The Hearing Services Program is part of a continuum of care required for a deaf child and their family.

- A clear and timely pathway from newborn hearing screening to hearing services and the NDIS must be available to every family whose child is identified with a hearing loss.
- Hearing services should be part of a holistic approach to supporting deaf children and their families and be part of an interdisciplinary service delivery model including the health, early intervention, education and social services required by the child and family.
- The Service Delivery Framework for Hearing Services should embrace a broader social model of deafness. Parental attitudes can be complex and include compliance as well as opposition to medical and normalising strategies for the management of hearing loss (Bosteels et al., 2012). A pathway that integrates a medical and social model of care will assist parents to see the chances and opportunities for their deaf child rather than the doubts and uncertainties that often define the views of hearing parents about their child's future.

3. Family-centred services

Family-centred practice is essential for improving learning outcomes in children (Cohrssen, Church, & Tayler, 2010).

Considerable effort has gone into best practice guidelines for early intervention services (both audiological and educational) for deaf and hard of hearing children and their families in recent years (Moeller et al., 2013; "Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation that a Child is Deaf or Hard of Hearing.," 2013; Yoshinaga-Itano, 2014)

Leading academics, professionals and parents from around the world have endorsed the principles that promote best practice for children identified with hearing loss. These include:

- Families need a clear, timely and equitable pathway from newborn hearing screening to diagnostic audiology, appropriate fitting of listening devices and early intervention services.
- They need information that is balanced, meaningful and relevant to their needs and situation and allows them to participate in shared decision making with professionals who assist them to make informed decisions about the management of their child's hearing loss.
- Services must be provided by qualified professionals, who work regularly with babies and children and whose goal is to optimise the child's ability to communicate, learn and participate fully in the life of their family and community.

- Children need access to listening devices that will optimally support the development of their communication and language skills at home and school.
- And families need emotional and practical support from family, friends, professionals and other parents of children with hearing loss so they can gain the necessary knowledge and experiences to confidently parent their child with a hearing loss.

When any of these principles is compromised, the result is likely to lead to poorer outcomes for the wellbeing of both the child and family.

The Service Delivery Framework for Hearing Services Program must embed family-centred principles into the provision of hearing services to deaf children and their families.

4. Provision of information and informed decision making

The process of making an informed decision is a complex one involving information provision and shared decision making with the audiologist.

To promote informed decision making, parents need balanced, meaningful and relevant information at multiple points in the child's life. The audiologist at Australian Hearing currently undertakes a large part of this process. The "Choices" booklet has provided the context for shared decision-making between parents and providers.

It is not clear how this will be managed under the National Disability Insurance Scheme (NDIS) and particularly if the CSO clients move to a contestable marketplace. The possibility of new parents being lured by glossy brochures and unrealistic promises must be avoided.

The International Patient Decision Aids Standards (IPDAS) Collaboration has outlined the components of "balance" as well the type of information likely to hinder informed decision making. Parents can be influenced by subtle cues in the content, presentation and display of information. "If information is presented in a non-neutral manner, that can stimulate a range of cognitive biases that can unduly affect people's knowledge, their perceptions of risks and benefits, and, ultimately, their preferences (Stalmeier et al., 2012)."

As the Hearing Services Program transitions to the NDIS, it is an opportunity to revisit the information provided to families in light of the considerable body of work that has been undertaken by IPDAS in recent years. This would ensure the information complies with the definition of 'balance' and facilitates parents' knowledge acquisition and informed decision-making.

5. Measurement of client outcomes

"The measurement of client outcomes needs to be broader than the fitting of a device...The way in which these outcomes are measured needs to be consistent across the sector."

- Our concern is that outcomes for children are very different to adult clients. Children need to *develop* language and their audiological needs change over time. We believe that appropriate measurement of outcomes for children will not fit into a sector-wide outcome measures framework.
- A child's progress must be regularly monitored and adjustments made if the child fails to master the skills appropriate for his age and cognitive functioning. Clear guidelines for monitoring progress of deaf children have been detailed in recent publications (Moeller et al., 2013; "Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation that a Child is Deaf or Hard of Hearing.," 2013; Yoshinaga-Itano, 2014)

6. Prescription and provision of devices

The prescription and provision of devices in this Framework appears to rely on identified client outcomes and the integrity of the provider. In a self-regulated marketplace, this does not provide the protection the child and family needs to optimise outcomes and ensure appropriate allocation of the child's NDIS funding package to devices that will meet the needs of the child.

The Office of Hearing Services must be certain that the issues of over-servicing and upselling highlighted in a recent Radio National report are not a feature of any Hearing Services Program for children.

We believe the integrity of the CSO program must be maintained with protocols and guidelines for:

- Prescription and provision of devices
- Monitoring to ensure equipment and devices are meeting the communication and educational needs of the child
- Review protocols and frequency
- Verification of proximity of fitting to prescriptive targets
- · Repairs, replacement and upgrades.

Compliance requires rigorous quality assurance procedures and a regular national audit of services is required to ensure the Hearing Services Program funding is allocated to meet the audiological needs of the child.

7. Data management

One of the strengths of the current CSO program is that children and young people have equitable access to hearing devices provided by a single provider using rigorous quality assurance measures. This has provided an invaluable longitudinal database of CSO clients and their outcomes.

One of the high-level principles for newborn hearing screening outlined in the National Framework for Neonatal Screening published in 2013 includes "Systems exist to provide accurate, reliable and consistent data collection and reporting(National Framework for Neonatal Hearing Screening, 2013)." To our knowledge no national database or registry has been implemented which means that the only way we have of tracking babies from newborn hearing screening to audiological management and beyond is through Australian Hearing.

With the considerable changes occurring within the disability sector and hearing services at present, it is critical that a national dataset is established to ensure appropriate monitoring and engagement with services at each step of the pathway. A national dataset will also permit national benchmarking against quality standards for consistent quality service provision for all children.

The Australian Hearing database has provided unprecedented opportunities for research into children with hearing loss which has benefitted children in Australia and overseas. A national dataset must continue to allow access to data for ethically approved research projects.

Considering the proposed service delivery principles, are the proposed client and service outcomes appropriate? Are there any gaps?

PRINCIPLE 1: SERVICES ARE ACCESSIBLE AND Principle	Comment
Clients can access the services most appropriate to their hearing loss in a timely manner	 Services for children must be timely, accessible and equitable. However, choice of provider should not be based on <u>level of hearing loss</u> but on expertise and ability of provider to deliver appropriate paediatric services. Timeliness of appointments, fitting of devices and timely repairs are critical throughout the life of the child in order for them to maintain communication development and learn.
Services access is equitable and transparent for all clients	 One of the strengths of the current CSO program is that every child, irrespective of their socioeconomic and cultural background and geographic location has access to quality paediatric services and devices, which optimise their ability to listen and learn. The CSO program must continue to ensure the same or improved level of service for all children. We do not want to see a system where children are disadvantaged because of their socioeconomic or cultural background or their geographic location.
Clients and their families have a clear understanding of the type and quality of service they can expect and their rights and responsibilities when accessing the service.	 Families will need balanced information that should include: the pathways from diagnostic audiology to hearing services and early intervention the core knowledge, skills and competencies required to provide quality paediatric audiological services to ensure families choose a provider with the appropriate expertise. the process for device prescription, provision, reviews and upgrades including how frequently they should expect review appointments. their responsibility to take every reasonable care of their device(s) and the replacement and repair policy of the provider, including any out-of-pocket expenses they might incur. (It is our contention that repairs and replacements for children should be free of charge if they are not lost or damaged through neglect or misuse.) their right to change providers with a smooth and comprehensive handover between service providers.

PRINCIPLE 2: SERVICES ARE FOCUSED ON A Principle	Comment
Clients (and their families) are assisted to identify individual communication goals aimed at maximising their independence and opportunities for community participation	 Families are integral to the process of identifying communication goals and children should be encouraged to participate as they start to better understand their listening and access needs. However, families need to know from the outset what all the options are with regards to communication and their child. "In the deaf child context, the essential question of what is and what is not amenable to informed choice is played out in highly politicized terms (Young et al., 2006)." Information, therefore, needs to be balanced and comprehensive. It must be recognised that providing information does not equate to understanding and simply providing written information about options does not mean the family will be able to make an informed decision. It should be also recognised that "Decision-making does not occur in one-off events, but rather is distributed over people, places, and time. Decisions emerge, transform, and solidify through multiple interactions, over a period of time, over multiple places (Edwards & Elwyn, 2009)." Parents need to revisit their decisions throughout their child's life as the needs of the child change as they grow. It is recommended that The Office of Hearing Services and the National Disability insurance Agency (NDIA) consult and collaborate with parents regarding What the information should contain, Who will provide the information and assist the family to understand its implications for their child and family and Where on the pathway this information should be provided.
Clients (and their families) are supported to participate in decision making process so that they can make informed decisions about their care	 Informed decisions are only possible when parents understand the information provided to them. Informed decision-making requires balanced information and a shared decision process between parents and audiologists where options are discussed and the values and preferences of the parents are considered (Hoffman et al., 2014). Families, including Deaf parents and parents from Aboriginal and Torres Strait Islander background, require culturally appropriate services and interpreters so they are able to understand their options and make informed decisions.

Individual communication goals are The current CSO program is integrated with the evidence and outcomes identified by the National achieved through provision of evidence-Acoustics Laboratories (NAL). It has been one of the strengths of the CSO program. based clinical assessment, support, • The assessment, support, training and selection of devices must be undertaken by qualified training, referral and the selection of audiologists with the skills, competencies and capacity to provide paediatric services. fitting devices as appropriate See Page 4 point 6 for additional comments regarding the selection and provision of devices for children Providers must keep up-to-date with current literature, guidelines and standards to ensure evidence-based practice. Minimum number of hours of Continuing Professionals Development must be a requirement of ongoing practice. Referral to other appropriate services or providers must be timely and seamless for the child and family. Service delivery is focussed on building In the context of the young child, service delivery should focus on building the capacity and the capacity of Clients (and their confidence of the family to manage the child's hearing loss. families) to manage their hearing loss The role of managing the child's hearing loss will evolve as the child grows and understand their and achieve their communication goals. needs and preferences. Children and young people should be fully supported to make decisions about their communication goals and the management of their hearing loss within their capacity.

Principle	Comment
There is clarity of roles for practitioners, development and retention of critical skills and accountability to support a professional, capable and diverse workforce.	 Hearing services for babies and children must be undertaken by qualified audiologists with specialis paediatric skills. "The consensus of professionals who specialize in intervention for listening and spoken language for children who are D/HH is that these skills are frequently not mastered in typical preservice training programs of educators of the deaf, speech-language pathologists, or audiologists (Yoshinaga-Itano, 2014). "To maintain competence and continually update skills in assessment and habilitation, individual audiologists need to assess 20-30 new cases per year to ensure best practice and improve expertise. This has a key impact on the quality of the service provided and is particularly important in low volume specialist activity such as early electrophysiological assessment of babies, early hearing aid fitting and habilitation (Transforming Services for Children with Hearing Diffi culty and their Families: A Good Practice Guide, 2008)." Additional core competencies required by providers to optimise a child's development and child-family well-being have been comprehensively detailed in recent position papers and guidelines and should form the foundation of any standards for the Hearing Services Program for children (Moellei et al., 2013; "Supplement to the JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention After Confirmation that a Child is Deaf or Hard of Hearing.," 2013; Yoshinaga-Itano, 2014). There is currently no course for audiologists to specialise in paediatric practice although we are aware that Audiology Australia are reviewing this situation. In keeping with the principles of family-centred practice, the development of quality standards and practice guidelines for paediatric service provision should be guided by consultation with parents and parent groups. The current self-regulation of audiological services is of considerable concern with regards to paediatric service delivery. Quality, outcomes and effectiv

PRINCIPLE 4: SERVICES ARE ORGANISED FOR SAFETY, EFFECTIVENESS AND EFFICIENCY		
Principle	Comment	
The service monitors its performance by collecting and analysing safety and quality data to improve service delivery	 Robust audit and quality assurance procedures are required to ensure compliance and optimal level of service quality for paediatric hearing services. Aussie Deaf Kids believes a regular auditing process should be undertaken by an independent body to ensure consistency and quality. Non-compliance must be dealt with immediately so outcomes are not compromised. The current system for CSO clients results in a longitudinal database of children in the CSO program. This is invaluable in looking at trends and issues such as loss to follow up. In a contested marketplace, provision must be made for the ongoing collection of data for all children in the hearing services program. 	
Governance and management processes support the delivery of safe and high quality services	 All audiological testing must be performed in soundproofed rooms built to current ISO standards for acoustic testing of children Audiological services should be delivered in an environment that is safe, engaging and family-friendly Governance and management processes should outline best practice principles and quality assurance monitoring for all program elements including child and family outcomes, knowledge of skills of providers and include parent feedback mechanisms beyond satisfaction surveys(Moeller, Carr, Seaver, Stredler Brown, & Holzinger, 2013). Working with Children checks are required 	

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