

**House of Representatives  
Standing Committee on  
Health, Aged Care and Sport**

**Inquiry into the Hearing Health and  
Wellbeing of Australia**

**Children and Young People with Disability Australia  
Submission – December 2016**

## INTRODUCTION

Children and Young People with Disability Australia (CYDA) welcome the opportunity to contribute to the House of Representatives Standing Committee on Health, Aged Care and Sport *Inquiry into the Hearing Health and Wellbeing of Australia*.

CYDA supports the submission provided by Deafness Forum of Australia and has drawn heavily upon their work and organisational expertise in developing this submission. This submission focuses on key issues of importance to children and young people aged 0 to 25 and responds to relevant terms of reference.

Currently in Australia, between nine and 12 children per 10,000 births will be born “with a moderate to great hearing loss in both ears.”<sup>1</sup> A further 23 children per 10,000 will “acquire a hearing loss that requires hearing aids by the age of 17.”<sup>2</sup>

CYDA acknowledges the significant diversity among people who experience deafness\* in terms of identity and preferences for support. It is critical that people with deafness, including children and young people, are able to access appropriate services and supports that meet their individual needs, circumstances and preferences.

## CHILDREN AND YOUNG PEOPLE WITH DISABILITY AUSTRALIA

CYDA is the national representative organisation for children and young people with disability, aged 0 to 25 years. The organisation is primarily funded through the Department of Social Services and is a not for profit organisation. CYDA has a national membership of 5500.

CYDA provides a link between the direct experiences of children and young people with disability to federal government and other key stakeholders. This link is essential for the creation of a true appreciation of the experiences and challenges faced by children and young people with disability.

CYDA’s vision is that children and young people with disability living in Australia are afforded every opportunity to thrive, achieve their potential and that their rights and interests as individuals, members of a family and their community are met.

CYDA’s purpose is to advocate systemically at the national level for the rights and interests of all children and young people with disability living in Australia and it undertakes the following to achieve its purpose:

- **Listen and respond** to the voices and experiences of children and young people with disability;
- **Advocate** for children and young people with disability for equal opportunities, participation and inclusion in the Australian community;
- **Educate** national public policy makers and the broader community about the experiences of children and young people with disability;

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\* Throughout this submission, CYDA uses the term ‘deafness’ to refer to people who: are born deaf; Deaf people who communicate using Auslan; people who are hard of hearing; or have hearing loss.

<sup>1</sup> Australian Hearing 2014, *Causes of Hearing Loss in Australia*, North Ryde, viewed 22 December 2016, <https://goo.gl/juYZmH>.

<sup>2</sup> Ibid.

- **Inform** children and young people with disability, their families and care givers about their citizenship rights and entitlements; and
- **Celebrate** the successes and achievements of children and young people with disability.

## RESPONSES TO THE INQUIRY TERMS OF REFERENCE

### 2. Community Awareness, Information, Education and Promotion about Hearing Loss and Health Care

There is currently no consistent approach to community awareness and education programs around hearing. An awareness raising and education campaign with consistent messaging is key to improving the community's knowledge and understanding of this issue. This should include:

- Information for families around recognising the signs of deafness; and
- Information about the risks of hearing loss through noise in leisure activities such as concerts.

Making hearing a National Health Priority would allow a more coordinated communication strategy to facilitate better understanding of deafness, its effects and the options for support and strategies for preventing hearing loss particularly among younger people.

**Recommendation 1:** Include hearing as a National Health Priority to ensure a coordinated communication strategy to increase community understanding of deafness and hearing loss.

### 3. Access to, and Cost of Services, which include Hearing Assessments, Treatment and Support, Auslan Language Services, and New Hearing Aid Technology

Paediatric hearing assessment services may be provided by Australian Hearing under the Australian Government Hearing Services Community Service Obligation Program funding. This access has been restricted to children who have had an initial assessment elsewhere. Australian Hearing also offers assessment services for a fee. As a Commonwealth Government Agency, Australian Hearing is unable to offer clients the option of a Medicare rebate.

Some Audiologists in not for profit organisations and private providers may provide a hearing assessment under Medicare. They may also charge the individual (approximately \$140) for a hearing assessment. Depending on the arrangement at the clinic it may be possible for the client to receive a Medicare rebate for the hearing assessment.

The availability of hearing assessment services is currently confusing and disjointed. Outside of the newborn period, there is no clear pathway for families to access a hearing assessment when needed. Not all hearing professionals provide services to children so service availability can be limited. Some clinics only offer assessment services to older children due to the specialised and costly equipment and expertise needed to assess children aged less than three years.

The situation has been exacerbated by the closure of some audiology clinics at public hospitals, the demise of the nurse audiometrists service at community health centres, the withdrawal of school hearing screening programs and the gradual reduction in access to hearing assessments for children at Australian Hearing under the Community Service Obligations Program.

**Recommendation 2:** Provision of clear and accessible information about the availability of hearing assessment services and the signs of deafness to children, young people and families.

#### **4. Current Demand and Future Need for Hearing Checks and Screening, Especially for Children (12 Years and Younger) and Older Australians at Key Life Stages**

##### **Newborn Hearing Screening Program**

Australia's current newborn hearing screening program ensures that every newborn (approximately 300,000 births annually) has the opportunity to have their hearing screened soon after birth. Feedback from representative organisations for people with deafness indicates that the program has a robust referral pathway from screening to diagnosis and audiological intervention where indicated.

There is currently a single provider of audiological services to children, Australian Hearing. This will change with the roll out of the National Disability Insurance Scheme (NDIS) where services will be contestable. This is discussed further under term of reference 10 in this submission.

##### **Older children**

For older children, it is essential to identify deafness or hearing loss as early as possible as early intervention leads to the best outcomes for the child. However it can be quite difficult for families to locate services with the expertise, facilities and equipment needed to test children especially those aged under three years.

Australian Hearing is well placed to offer this service due to its national network of hearing clinics across urban, rural and remote areas of Australia, however they will only accept referrals of children who have been initially assessed by another service provider. Some private hearing services providers will test the hearing of older children but most do not have the facilities to test children under three years.

Hospital audiology clinics where they exist can provide hearing assessment services for children but a number have closed, for example, Hornsby and Mona Vale hospitals in Sydney. There has been no coordinated approach to employ appropriate numbers of diagnostic audiologists in hospitals in metropolitan or rural and remote areas.

When children are being assessed in relation to speech development or behaviour support needs, medical practitioners often refer children for a hearing assessment as the first step in establishing a diagnosis. It can be difficult for families to find an appropriate testing facility in these circumstances.

Data from Australian Hearing shows that the largest number of children fitted with devices per birth year are under 12 months of age which demonstrates the effectiveness of newborn hearing screening programs.<sup>3</sup> The next peak occurs at school entry. As state based school hearing screening programs are no longer routinely provided, these children are likely to be first identified by teachers who suggest that children who are showing signs of hearing loss. It is likely that many of these children had hearing loss prior to starting school. There is a need to educate parents and others such as child care workers on the signs of deafness in young children and to improve access to hearing assessment services for young children to allow for early intervention. Hearing screening programs could be implemented at pre-school or school entry as a safety net for children who have not been identified earlier.

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<sup>3</sup> Australian Hearing 2015, *Demographic Details of Young Australians aged less than 26 years with a Hearing Impairment, who have been Fitted with a Hearing Aid or Cochlear Implant at 31 December 2014*, North Ryde.

### **Aboriginal and Torres Strait Islander Children**

Aboriginal and Torres Strait Islander children have been found to experience high rates of hearing loss, particularly due to otitis media, a middle ear infection. While rates vary according to different studies, the 2012–13 *Aboriginal and Torres Strait Islander Health Survey* found that “7% of Indigenous children aged 0 to 14 in Australia had ear or hearing problems.”<sup>4</sup> Rates in some communities have been found to be as high as 90%.<sup>5</sup>

Given this high prevalence, there is a need for better access to hearing assessment services, hearing rehabilitation services and access to medical specialist services. Currently this appears to occur in an ad hoc manner. Coordination seems to be poor and there does not appear to be a cohesive management strategy in place for identification and management of hearing loss in Aboriginal communities.

*The Recommendations for Clinical Care Guidelines for the Management of Otitis Media in Aboriginal and Torres Strait Islander Populations* recommend that ear examination should be part of the clinical assessment of Aboriginal and Torres Strait Islander children and that health staff should undertake ear examinations when they do regular child health checks.

**Recommendation 3:** Hearing screening programs be supported by a referral pathway to allow people to access appropriate diagnostic assessment and treatment services.

**Recommendation 4:** The national newborn hearing screening program continue to be supported.

**Recommendation 5:** Consideration of mechanisms to ensure state and territory health services be encouraged to provide hearing screening and assessment services for children.

**Recommendation 6:** Development of requirements for general practitioners to include a basic hearing screen into general medical reviews.

**Recommendation 7:** Hearing assessments be made available for people in prison, including youth justice settings.

### **9. Whether Hearing Health and Wellbeing Should be Considered as the Next National Health Priority for Australia**

CYDA supports making hearing health a National Health Priority area. A significant percentage of Australians experience hearing loss, are Deaf or deafblind, live with chronic ear disorders or tinnitus. This represents a larger number of people impacted than in relation to existing National Health Priority Areas such as asthma, diabetes and musculoskeletal conditions.

People with hearing disability report barriers in access to health care and poorer health outcomes across a range of domains. It has been reported that people who experience deafness are higher users of general practitioners, more likely to be taking prescribed medications and at a higher risk of mental health issues<sup>6</sup>.

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<sup>4</sup> Australian Institute of Health and Welfare, Australian Institute of Family Studies 2014, *Ear Disease in Aboriginal and Torres Strait Islander Children*, Commonwealth of Australia, Canberra, p. 5.

<sup>5</sup> *Ibid*, p. 5.

<sup>6</sup> A Hogan et al. 2015, ‘Higher Social Distress and Lower Psycho-Social Wellbeing: Examining the Coping Capacity and Health of People with Hearing Impairment,’ *Disability and Rehabilitation*.

A large proportion of acquired hearing loss is highly preventable. There is a need for community education programs to promote understanding of the effects of noisy occupations and recreational loud noise from personal music devices, clubs and concerts. A nationally integrated policy approach to research, early interventions, holistic services, prevention, and community education would therefore be highly beneficial.

**Recommendation 8:** The Australian Government make hearing health and wellbeing a National Health Priority.

## 10. Any Other Relevant Matter

### **The implementation of the National Disability Insurance Scheme**

The Australian system for providing disability services and supports is currently undergoing unprecedented reform with the implementation of the NDIS. The NDIS represents a significant shift from the previous model of block funding disability services to providing portable funding packages, with a focus on enabling people with disability to exercise choice and control in relation to supports received.<sup>7</sup>

Each eligible person will have their own 'Individual Funding Package' that will fund supports that meet the specific needs and goals of each person. This package is developed through a planning process with the National Disability Insurance Agency (NDIA), the body charged with administering the Scheme.

The NDIS will involve rolling in the many different disability funding programs that currently exist into a single scheme. This includes the Australian Government Hearing Services Program. However, representative organisations for people who experience deafness have raised ongoing concerns regarding risks posed by the transition of this program to the NDIS. There is a prevailing concern that the transition could lead to reduced quality of service and poor outcomes for clients unless these risks are managed very carefully.

There are some highly vulnerable client groups within the Australian Government Hearing Services Program. These groups are identified as Community Service Obligations (CSO) within the program and include infants, children and young people up to age 26. The CSO Program also funds a culturally sensitive outreach service for Aboriginal and Torres Strait Islander peoples in urban, rural and remote areas of Australia. The responsibility for service delivery to these clients is currently assigned to the government hearing services provider, Australian Hearing. With the rollout of the NDIS, services to these client groups will become contestable.

The introduction of contestability in hearing services poses the following risks:

- Changes to the streamlined approach to providing appropriate support and programs for infants and children with deafness with the introduction of multiple providers;
- Loss of independent, unbiased advice regarding clinical programs, devices and educational program options for children as potential providers in a contestable environment are likely to be aligned with particular educational programs or hearing aid manufacturers;
- Australian Hearing has been the sole provider of services to children with deafness for over 70 years. The private sector has not been required to deliver hearing rehabilitation services to infants and children in the past, so the ability and interest of the private sector to provide these services is unknown. The move to contestability in the delivery of services to children

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<sup>7</sup> *National Disability Insurance Scheme Act 2013 (Cth)*, s. 2.3.

could result in market failure leaving children with deafness and their families without the critical services they need;

- Reduced access to services for people in regional and remote areas;
- Barriers in accessing services for people from culturally and linguistically diverse backgrounds;
- Loss of a culturally sensitive service delivery model for Aboriginal and Torres Strait Islander people in urban, rural and remote areas;
- The client groups in the CSO Program are very small so the fragmentation of these groups that will occur with contestability may make it difficult for audiologists to maintain their skill levels; and
- Increase in the cost of delivering hearing services in the commercial market as opposed to service provision in a CSO Program where the government provider achieves cost efficiencies through its economies of scale and bulk purchasing arrangements.

Australian Hearing plays a pivotal role in the current arrangements as the sole service provider under the CSO Program. Clients are expected to transition from the Hearing Services Program to the NDIS in 2019.

By that time the following issues need to be resolved:

- Identifying the eligibility criteria for the NDIS for people with deafness or hearing loss;
- Identifying how services will be delivered to vulnerable groups who do not qualify for the NDIS and remain within the Australian Government Hearing Services Program;
- Identifying the quality framework that will be applied to service delivery for all government funded hearing programs;
- Identifying the service delivery arrangements for people in rural and remote areas;
- Identifying a new referral pathway for infants diagnosed with deafness through newborn hearing screening programs that ensures timely service provision;
- Ensuring that the hearing services market has the interest and expertise to provide services to infants and children; and
- Ensuring that the client groups do not become so fragmented that it is not possible for clinicians to maintain their skill level.

It is critical that the safety net of Australian Hearing remain until there is confidence that clients will not be worse off under the new arrangements.

In February 2016 the Government announced it was investigating a proposal from a consortium consisting of the Royal Institute for Deaf and Blind Children, Macquarie University and Cochlear Ltd to transfer Australian Hearing to non-government ownership. Presently limited details have been released on the proposal from the consortium.

**Recommendation 9:** Development and implementation of management strategies to mitigate the risks that arise from the transfer of clients from the Hearing Services program to the NDIS, particularly in relation to the CSO Program.

**Recommendation 10:** The Australian Government Hearing Services CSO Program with Australian Hearing as the sole provider remain in place until the transition issues associated with the transfer of services from the Australian Government Hearing Services Program to the NDIS are resolved.

## SUMMARY OF RECOMMENDATIONS

**Recommendation 1:** Include hearing as a National Health Priority to ensure a coordinated communication strategy to increase community understanding of deafness and hearing loss.

**Recommendation 2:** Provision of clear and accessible information about the availability of hearing assessment services and the signs of deafness to children, young people and families.

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