

The Western Australian Deaf Society Inc.
(WADS)

Submission to the
Joint Standing Commission on the National Disability Insurance Scheme

On

The provision of hearing services under the National Disability Insurance Scheme
(NDIS)

January 2017

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Introduction

The Western Australian Deaf Society (WADS) thanks the Joint Standing Committee on the NDIS for its inquiry into the provision of hearing services for Deaf and hard of hearing people under the National Disability Insurance Scheme.

WADS, established in 1921, is the peak service provider for Deaf and hard of hearing people in Western Australia. It exists so that the Deaf and hard of hearing people experience full citizenship and enjoyment of life. Deaf people identify as a culturally and linguistically diverse (CaLD) group but are identified by society as a disabled group, so are unique in the fact that they fit under both umbrellas

WADS currently provides a range of individually funded and unfunded/block funded services, including:-

- Community services such as:- assistance with daily living, independence and personal care; support to access community, recreation and employment; coordination of support; Auslan For Families program and Assistive Technology services to support the deaf person's communication and safety in the home, as well as block funded services such as information, advocacy and referral
- Auslan interpreting and translation services
- Specialist employment services for deaf and hard of hearing people (Disability Employment Service funded)
- Auslan classes and Deafness Awareness Training (DAT)
- LEAP (DSS funded bilingual playgroup for families with a deaf child or parent)

There is currently significant inequity in service accessibility and availability due to the limited trial areas that are located primarily within the greater Perth metropolitan area, some adjoining rural communities, and the one country trial site that is situated in the lower south west of the state, approximately two to four hours south of Perth.

There are currently no NDIS funded services available for Deaf and hard of hearing people who live north of the Perth metropolitan area or more than an hour and a half to two hours east of Perth.

We are pleased to provide our submission, responding to the following four terms of reference (TOR):

- TOR 1a: the eligibility criteria for determining access to, and service needs of, deaf and hearing impaired people under the NDIS;
- TOR 1b: delays in receiving services, with particular emphasis on early intervention services;
- TOR 1c: the adequacy of funding for hearing services under the NDIS;
- TOR 1d: the accessibility of services, including in rural and remote areas;

Executive Summary

The Western Australian Deaf Society (WADS) thanks the Joint Standing Committee on the NDIS for its inquiry into the provision of hearing services for Deaf and hard of hearing people under the National Disability Insurance Scheme and for the opportunity to provide a submission that addresses the unique situation in Western Australia where two models of the National Disability Insurance Scheme have been trialled for the past two years.

WADS is aware of the state roll out of the NDIS from July 1st 2017 that will see the formation of a new WA model of the NDIS, administered locally in Western Australia. We are very grateful for the continuation of a local state administered national disability insurance scheme, however, we remain concerned that the issues raised in this submission will continue to be of concern both until and after the NDIS is fully rolled out across WA.

WADS is concerned that the current model for assessing deafness is still often viewed from the impairment model, that see deafness as principally 'the loss of hearing', and does not always include an holistic approach to the individual's experience of disability.

The consequent restricted interpretation of hearing services, being principally directed towards auditory services and specifically the focus on auditory-verbal early intervention services that aim to 'fix' the hearing loss, is one that needs addressing through a multi-tiered approach.

Additionally, the lack of accessible information in Auslan, and the required level of support for adult Deaf participants to identify barriers to their participation and relevant strategies, needs addressing.

WA Deaf Society (WADS) recommends:-

- (1)** Regular updated Auslan accessible information about the NDIS must be provided and clearly promoted on the NDIS/WA NDIS websites, to explain about the transition to the one state-based model, and provide current information into the future under the one model.
- (2)** Well promoted information about the evidence that supports the learning of sign language as part of the bilingual communication for a deaf child, regardless of whether the aim is to be an oral communicator, must be available at all levels of the early intervention pathway. Adequate NDIS plan funding must be available to support this, from point of diagnosis and complementary to any auditory-verbal therapy program funding

- (3) While waiting for the state-wide roll out of the NDIS, it is imperative that deaf children and their family have the same access to funding for Auslan training programs as for auditory-verbal programs through other government funding such as Better Start.
- (4) NDIS staff should be provided adequate pre-training, including Deafness Awareness Training, and be encouraged to contact an appropriate service provider before developing a deaf person's NDIS plan, to ensure adequate funding is being calculated and allocated and not just guessed or anticipated. The same degree of care should be shown to the deaf person's planning as for a hearing person, or person without a disability but in need of other care plan.
- (5) It is vital the NDIS is rolled out as swiftly as possible, so deaf and hard of hearing people throughout the state are able to access the same degree of service as those living in Perth in an NDIS trial site.

Terms of Reference 1a:

The eligibility criteria for determining access to, and service needs of, deaf and hearing impaired people under the NDIS

Issues

Two main issues interplay and influence the perceived eligibility of culturally Deaf people, whose primary mode of communication is Auslan (Australian Sign Language).

- Historic approach by society that is one of neglect about one of the most populous disability groups in Australia
- Historic approach by members of the Deaf community that they are Deaf and not disabled, and so do not need disability service
- Historic approach, engendered by the medical model of deafness that deafness can be fixed and that deaf people therefore do not need disability service
- Historic view by 'hearing' people, including the disability services system and NDIS planners, that deafness is a loss of hearing that needs to be fixed.

Consequences

- Deaf adults often have limited awareness of the functional impact of their deafness. In their effort to not be classed as disabled, they have not accessed disability services and have not learnt to recognise barriers and advocate for their own needs. Until recently there has been a lack of Auslan accessible information about the NDIS, Deaf people have been restricted in their opportunity to learn about the NDIS, how to access it and what is involved in the planning process. Without the relevant support, Deaf people struggle to connect with the NDIS and the opportunity to develop a plan. Due to the historic lack of services other than primary medical, police or court services,

when the deaf person does finally get to the planning stage, they are often overwhelmed at receiving any amount of service that supports family and social life, and are at risk of accepting a significantly less amount of service than what they really require eg. Auslan interpreting.

Deaf people in WA are worried about the change of model come 1st July 2017 and how that may impact on them and their funded programs, specifically their ability to access funding for Auslan interpreters.

WA Deaf Society has recently run a successful WA Deaf NDIS Peer Support Group that aimed to inform and encourage Deaf Auslan users to connect with the NDIS. There is risk of misinformation if there is no 'official' up-to-date NDIS Auslan translated information to refer to. Deaf people are entitled to the same level of current information as a hearing person.

WA Deaf Society supports Deaf people with the completion and professional sign-off for their Access Request Form. Without this direct support many Deaf people would be significantly delayed accessing the NDIS scheme .

- There is acknowledgment by the disability system of the need and allocation of significant funding for auditory-verbal early intervention services for deaf babies/young children, with the aim for the deaf child, who is typically born into a hearing family, the opportunity to learn to speak and communicate with their hearing family.

Unfortunately there has often been a lack of relevant information and evidence to inform the parents of newly diagnosed deaf babies/infants that incorporating the learning of Auslan as part of a bilingual communication early intervention program, will not negatively impact on their child's ability to learn to speak , but may assist it. Some auditory-verbal service providers still actively, but misguidedly, promote to parents and the health system that the learning of Auslan should not be undertaken if a deaf child is to learn to speak.

Even with early diagnosis through the Newborn Hearing Screening program (NHS) and early fitting of assistive listening devices (hearing aids and/or cochlear implants and associated auditory-verbal program) deaf children are at risk of not being immersed in accessible language during the critical early language learning period. For some children, they learn to speak, but do not continue to develop age-appropriate language skills, which impacts on their future learning, social skill development, communication, education, employment and civic participation.

There is evidence to suggest severe and profoundly deaf children benefit from accessing sign language as part of bilingual communication. It provides a linguistic 'safety net' in case the child is unable to achieve the expected outcomes from spoken language development. (1) (2) (3)

WA Deaf Society is registered to provide its Auslan For Families program, a unique evidenced-based program for families with a deaf child, but requires funding to provide this service.

Recommendations

(1) Regular updated Auslan accessible information about the NDIS must be provided and clearly promoted on the NDIS/WA NDIS websites to explain about the transition to the one state-based model and provide current information into the future under the one model.

(2) Well promoted information about the evidence that supports the learning of sign language as part of the bilingual communication for a deaf child, regardless of whether the aim is to be an oral communicator, must be available at all levels of the early intervention pathway. Adequate NDIS plan funding must be available to support this, from point of diagnosis and complementary to any auditory-verbal therapy program funding.

References:

(1) Davidson, K., Lillo-Martin, D. & Chen Pilcher, D. (2013). Spoken English Language Development in Native Signing Children With Cochlear Implants. *J Deaf Stud Deaf Educ* (2013) 19 (2): 238-250.

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<https://academic.oup.com/jdsde/article/19/2/238/377174/Spoken-English-Language-Development-Among-Native>

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Retrieved January 20, 2017 from

<http://www.newbornhearingscreening.com.au/newborn-hearing-screening-conference/anhsc-2015/>

(3) Lloyd, K. (2009). Policy on Early Intervention for Deaf and Hard of Hearing Children. *Advice to the Minister for Families, Housing, Community Services and Indigenous Affairs / Parliamentary Secretary for Disabilities and Children's Services*, Deaf Australia.

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www.aph.gov.au/DocumentStore.ashx?id=e8cbc1dd-6a5d-4f25-9a66...subld

Terms of Reference 1b:

Delays in receiving services, with particular emphasis on early intervention services

There is significant research plus anecdotal evidence that supports families with a deaf child accessing Auslan training as soon as their child has received a diagnosis of deafness, whether before, while or after the child undergoes cochlear implantation.

Sign language is recognised as the only truly accessible language for a severely-profoundly deaf child, and having access to strategies that supports the typically hearing family to interact with their deaf child may help reduce family stress, the immediate panic to choose either this or that communication modality and facilitate family cohesion. (4)

Issues

- With the anticipated full state roll-out of the NDIS not to be complete until 2019-2020 (or later in WA), WADS is concerned that many deaf children and their families will miss out on the necessary funding to allow their accessing Auslan For families during their child's critical early intervention years of 0 - 3 years and up to 5 years.
- Delay in the full state roll out of the NDIS will also affect opportunity for older deaf children and deaf adults from accessing often critically needed funding to support a range of services including support to access learning, education and training programs, recreational programs, life skills and independence.

See TOR 1d for further information on this issue.

Consequences

- Families may be able to access auditory-verbal programs through other funding, and so pursue this pathway, but as noted earlier in TOR 1a, severe to profoundly deaf children are at risk of not growing up with fully developed spoken language, with impact to their social skill development, education and ultimately employment options.

There is evidence to suggest severe and profoundly deaf children benefit from accessing sign language as part of bilingual communication. It provides a linguistic 'safety net' in case the child is unable to achieve the expected outcomes from spoken language development. (1) (2) (3)

WA Deaf Society is registered to provide its Auslan For Families program, a unique evidenced-based program for families with a deaf child, but requires funding to provide this service.

- Currently there is significant inequity between funding available for a child who lives in an NDIS/WA NDIS trial site and has an NDIS plan and those that don't.

- Deaf children with an NDIS/WA NDIS plan are able to access up to 36 x2 hour sessions, enabling them to participate in Auslan For Families sessions throughout their twelve month plan.
 - Deaf children who live outside of a trial site but are able to access Auslan Training under their Better Start Resource funding or carer respite funding may have up to 12 x2 hour sessions within the one year
 - Deaf children who live outside a trial site and do not qualify for other funding options just go without.
- A major barrier to deaf children being able to access more funding under Better Start, is the lack of recognition of the Deaf Auslan teacher as the rightful person to teach Auslan as a first language. WADS has recognition by DSS as an approved Auslan Training Provider, but not as a registered Service Provider. Deaf children who want to access the Auslan For Families program can only access up to a maximum of \$2,100 in any one year, as opposed to a maximum of \$6,000 for the same child to access auditory-verbal therapy.

Recommendations

(3) The right of the deaf child, and family, to be taught Auslan by a native Deaf Auslan teacher should be recognised and reflected with access to similar levels of funding as when participating in a spoken language program provided by a hearing professional.

While waiting for the state-wide roll out of the NDIS, it is imperative that deaf children and their family have the same access to funding for Auslan training programs as for auditory-verbal programs through other government funding such as Better Start.

References:

(4) Spencer, P. E. (2001) *A Good Start: Suggestions for Visual Conversations with Deaf and Hard of Hearing Babies and Toddlers*. Laurent Clerc National Deaf Education Center, Gallaudet University, Washington DC.
Retrieved August 16, 2013, from <http://clerccenter2.gallaudet.edu/KidsWorldDeafNet>

Terms of Reference 1c:

The adequacy of funding for hearing services under the NDIS

WA Deaf Society is concerned about the amount of funding that is often offered to the Deaf person, which is often not a true reflection of their need and ability to meet their identified goals. With lack of understanding by many of the planners, WADS is concerned that with the pressure on the NDIS to maintain a sustainable scheme and the issue of 'reasonable and necessary', there will be further pressure to reduce the

amount of funding, particularly in the area of Auslan interpreting and support for families to access programs such as Auslan For Families.

Issues

- Culturally Deaf people, for whom Auslan is their primary mode of communication, do not grow out of their deafness, they just grow older. If provided with the right amount of support at the right time, they are enabled to access communication, education, learning and ultimately employment and opportunity to live independently and participate in community and civic life.

Reducing the amount of funding for critical programs, that enable deaf children, and deaf people of all ages, to grow to be independent and economic contributors, does not save the government money in the long term.

- The amount of funding available to a Deaf person is often a reflection of the planner's understanding and willingness to engage with relevant agencies such as the state Deaf Society, to identify the real needs of that person and not just "guess" at what the need might be.

Consequences

- Funding that is capped for Auslan education is not reflective of the nature of language acquisition. To learn a language such as Auslan is a life-time enterprise, like English is for many people.
- As Auslan is not yet recognised as a mainstream language like it is in some countries around the world (Ireland, New Zealand to name some), greater investment is required to ensure that the deaf child is put at the centre of 'everything', including his/her family, school, community and peers, so that these stakeholders have the opportunity to learn Auslan and ensure that the deaf child is able to experience life like any other child.

Recommendations:-

(4) NDIS staff should be provided adequate pre-training, including Deafness Awareness Training, and be encouraged to contact an appropriate service provider before developing a deaf person's NDIS plan, to ensure adequate funding is being calculated and allocated and not just guessed or anticipated. The same degree of care should be shown to the deaf person's planning as for a hearing person, or person without a disability but in need of other care plan.

Terms of Reference 1d:

The accessibility of services, including in rural and remote areas

Issues

- Currently there is a postcode lottery situation where residence determines the level of supports that a deaf individual receives. A deaf child born in rural Australia has a far less chance of an 'ordinary life' than a child born in Perth.

Consequences

- Historically this has seen many families leave their hometowns and move to city centres so their deaf child is able to access supports. In the past, this has meant many children, some as young as 3, go to 'specialist' deaf boarding schools. These Deaf residential schools no longer exist in WA and so a deaf child born in rural and remote WA must wait until the NDIS is progressively rolled out to their area/postcode.
- A similar situation exists for deaf youth and adults, who due to lack of local funding, must wait for the NDIS to come to them before they are able to access that range of services that can be provided by the specialist staff employed by WA Deaf Society.
- WADS has been contacted by a range of Disability Services in the Pilbara and goldfields, wanting to access services for deaf Indigenous youth on their books. Their enquiries stop when told funding is required for WA Deaf society services.

Recommendations:-

(5) It is vital the NDIS is rolled out as swiftly as possible, so deaf and hard of hearing people throughout the state are able to access the same degree of service as those living in Perth in an NDIS trial site.