

NDIS Hearing Stream

What is working well, what is not working well, where are the barriers,
where are the risks, where are the opportunities?

The perspectives of participants, parents & carers and providers

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Report to the National Disability Insurance Agency

Prepared by Deafness Forum of Australia, July 2019

This Report

The National Disability Insurance Agency (NDIA) commissioned Deafness Forum of Australia to form a Community of Practice-Hearing Stream comprising representatives of NDIS participants, families & carers and sector providers to investigate best practice: what is working well, what is not working well, where are the barriers, where are the risks, where are the opportunities?

To commence this project, a workshop was held at the Australian Hearing Hub in Sydney on 1 March 2019. In the months that followed to the end of June, workshops, teleconferences and out of session discussions were held on specific topics nominated by the NDIA, vis:

- Children learning Auslan
- Best practice for early intervention including options for mode of communication
- NDIS Access requirements
- Interpreter availability, market gaps, communication assistance
- Hearing devices and rehabilitation
- Deafblindness
- Family & carer perspective

Reports on each of these seven topics investigated are the subjects of this report.

Community of Practice

Community of Practice members were experts in their respective fields within the sector: persons living with disability and their representative organisations are regarded as being *expert*. Individuals representing the members of the Community of Practice were at the most senior levels: CEOs, managing directors, executive officers, chairpersons and topic/program managers who were nominated by their organisation's senior officer.

1	ABLE Australia	Carla Harper	VIC
2	ABLE Australia	Meredith Prain	VIC
3	Access Plus (formerly WA Deaf Society)	David Gibson	WA
4	Australian Sign Language Interpreters Assn	David McQuiggin	NSW
5	Audiology Australia	Marion Jones	VIC
6	Aussie Deaf Kids	Ann Porter	NSW
7	Aussie Deaf Kids	Roslyn Wyburn	NSW
8	Australian Hearing (renamed Hearing Australia)	Samantha Harkus	NSW
9	Australian Hearing (renamed Hearing Australia)	Alison King	NSW
10	Better Hearing Australia	Caitlin Barr	VIC
11	Can:Do Group	Heidi Limareff	SA
12	CHARGE	Madeline Rich	VIC
13	Cochlear Ltd	Janet Menzies	NSW

14	Deaf Children Australia	Roz Keenan	VIC
15	Deaf Society	Leonie Jackson	NSW
16	Deaf Society	Genevieve Roberts	NSW
17	Deafblind Australia	David Murray	VIC
18	Deafblind Australia	Viki Cox	NSW
19	Deafblind Association NSW	Irene McMinn	NSW
20	Deafblind Association NSW	Trish Wetton	NSW
21	Deafblind Newcastle	Stephen Hallinan	NSW
22	Deafblind Victoria	Heather Lawson	VIC
23	Deafblind Victoria	Trudy Ryall	VIC
24	Deafblind West Australia	Eddie Szczepanik	WA
25	Deafness Council Western Australia	Barry MacKinnon	WA
26	Deafness Forum Australia	Margaret Dewberry	NSW
27	Deafness Forum Australia	Steve Williamson	NSW
28	Deaf Services	Brett Casey	QLD
29	Deaf Services	Jen McKee	QLD
30	Deaf Services	Michelle Stark	QLD
31	Expression Australia	Brent Phillips	VIC
32	First Voice	Jessica Balfour Ogilvy	QLD
33	Hear For You	David Brady	NSW
34	Hearing Business Alliance	Josephine Khairy	NSW
35	Hearing Business Alliance	Jane McDonald	NSW
36	Hearing Care Industry Association	Ben Hoddinott	NSW
37	Hearing Care Industry Association	Nina Quinn	NSW
38	Hearing Matters Australia	Christine Hunter	NSW
39	Independent Audiologists Australia	Louise Collingridge	NSW
40	Independent Audiologists Australia	Celene McNeill	NSW
41	Melbourne Polytechnic	Leslie Pulanco	VIC
42	National Hearing Care	Adam Redman	VIC
43	National Hearing Care	Shirley Pratap	VIC
44	NDIA	Louise Jago	VIC
45	NDIA	Kathy McEwan	VIC
46	NDIA	Ingrid Woodger-Brown	VIC
47	NDIA	Alex Jones	NSW
48	Parents of Deaf Children	Fleur Henderson	NSW
49	Royal Institute of Deaf and Blind Children	Greg Leigh	NSW
50	Royal Institute of Deaf and Blind Children	Breda Carty	NSW
51	Royal Institute of Deaf and Blind Children	Harzita Hashim	NSW
52	Royal Institute of Deaf and Blind Children	Inge Kaltenbrunn	NSW
53	Royal Institute of Deaf and Blind Children	Eleanor McKendrick	NSW
54	Royal Institute of Deaf and Blind Children	Louise de Beuzeville	NSW
55	Royal Institute of Deaf and Blind Children	Natalie Lubrano	NSW
56	Senses Australia	Karen Wickham	WA
57	Senses Australia	Melanie Robartson	WA

58	Shenton College Deaf Education Centre WA	Raelene Walker	WA
59	Speech Pathology Australia	Maree Doble	VIC
60	Speech Pathology Australia	Erin West	VIC
61	Sydney Cochlear Implant Centre and CICADA	Sue Walters	NSW
62	The Shepherd Centre	Jim Hungerford	NSW
63	Usher Kids Australia	Emily Shepard	VIC
64	Usher Kids Australia	Hollie Feller	VIC
65	Victorian Deaf Education Institute	Dr Elizabeth Levesque	VIC



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COMMUNITY OF PRACTICE - HEARING STREAM FIRST WORKSHOP, 1 MARCH 2019

To commence this NDIS Hearing Stream project, a workshop was held at the Australian Hearing Hub in Sydney on 1 March 2019.

The workshop began with the NDIA providing an outline of progress to date in the hearing stream. Attendees took the opportunity to raise some general issues with the NDIA team.

One of the key issues that attendees wanted to have resolved as quickly as possible was the management of hearing services once the in-kind arrangements with Australian Hearing cease in June 2020. Attendees were keen to know: will services, particularly for the 0-26 year olds, become competitive, what happens to Australian Hearing if services are contestable, what happens to the Community Service Obligations Program – what will it look like in future? The answers to these questions could impact on the referral pathway, timeliness of services, access to skilled audiologists, on site services at schools and there was potential for market failure particularly in rural and remote areas. If services become contestable there is not much time left for other providers to prepare to take on this new work and meet the NDIS requirements.

There was general discussion about the availability of interpreters, particularly interpreters for Deafblind people, support for culturally and linguistically diverse clients, availability of grants to provide interpreters and captioners for groups of deaf and hard of hearing people.

The workshop then focussed on three topics:

1. Children Learning Auslan
2. Early Intervention / Modes of communication
3. Interpreter availability, market gaps, communication assistance

A 4th item had been listed for discussion which was “Deafblind and other co-morbidities” but this was deferred as representatives from the Deafblind community were not available for this workshop. It was agreed that agencies working with and supporting Deafblind people would have a separate workshop. Parents would also be included in that session.

Some issues raised during the workshop were common across the 3 above-mentioned topics including:

- The need for families to receive comprehensive, accurate, unbiased information so they can make informed decisions
- The need to ensure the quality of services, programs and practitioners including interpreter services, early intervention programs, audiology and speech pathology services
- Issues with NDIS processes, practices, eligibility and funding and the need for further staff training
- Accessibility in terms of availability of programs as well as access for Aboriginal and Torres Strait Islander people, Culturally and Linguistically Diverse people and for people living in rural and remote areas.

Particular themes emerged from the discussion of each of the areas:

1. For Children learning Auslan the themes were:
 - Information and accessibility
 - Parents need to be fully informed
 - Parents need access to unbiased information

- Whole family needs to learn Auslan not just the child
- Auslan programs not always available in all areas
- Quality of programs
 - Training and development of Auslan tutors
- Planning and funding
 - Funding needs to be adequate to support all requirements of participants
 - Planners and ECEI partners require further training
- Support for culturally and linguistically diverse families

The specific issues captured via post it notes are shown in Attachment 1.

2. For Early Intervention/Modes of Communication the themes were:

- Aboriginal and Torres Strait Islander people, culturally and linguistically diverse (CALD) communities, remote communities
 - Availability of programs particularly in rural and remote areas
 - Are individual programs culturally appropriate and do they deliver the best outcomes in Aboriginal and Torres Strait Islander communities?
 - How will CALD families be supported?
 - Increase in number of refugees and migrants seeking support
- Choice and control/capability to use NDIS
 - Children should receive supports they need. Should not rely on parent's ability to advocate
 - Families need independent advice to support their decisions
 - Participants may need help to understand the program, the website, their plans
 - Families in complex circumstances not engaging in the pathway. Does NDIS choice process disadvantage isolated, low socio-economic groups including people with mental health issues?
 - Providers particularly small providers are withdrawing from NDIS or closing due to onerous process to comply with quality and safeguarding requirements and changes to funding stream
 - What happens when in-kind arrangements cease in June 2020?
- Professional skills
 - Benchmarking, accreditation and training of professionals
 - NDIS staff turnover and training needs
- Eligibility
 - For people over 26 years with mild to moderate hearing loss Intervention should occur earlier rather than waiting until person has a more severe loss and becomes eligible for NDIS funding
 - Eligibility for over 26 years should be based on functional need, not thresholds
 - Some refugees and migrants not eligible for government funded services
- Assistive technology
 - Level of technology provided needs to meet individual's needs

The specific issues captured via post it notes are shown in Attachment 2.

3. For interpreter availability, market gaps, communication assistance the themes were:

- Access to interpreters
 - Availability particularly in rural and remote areas
- Market gaps
 - Need to invest in capacity building
 - Availability of training courses

- Poor utilisation of community organisations
- Interpreting for languages other than Auslan
- Captioning
- Issues relating to NDIS plans
 - Staff turnover and training needs
 - Appropriate funding
 - Clarification of cross-jurisdictional responsibility between Health, Education and NDIS

The specific issues captured via post it notes are shown in Attachment 3.

Attendees were invited to put forward any additional questions, feedback and concerns in writing during the workshop. Some of the broad themes that emerged from the written notes covered:

- Device range
- Eligibility
- Involvement of consumer organisations
- NDIS issues
- Provider issues

The specific questions and feedback are shown in Attachment 4.

1. CHILDREN LEARNING AUSLAN

THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Information and accessibility to support choice of Auslan	Families need to be informed. Parent choice and informed decision making		Access to accurate unbiased information
	Difficulty providing parents/carers with balanced views of communication modes when competing with major corporations providing devices/services for a fee – major conflict of interest		
	Benefits of Auslan are generally not promoted – why? Greater promotion of bilingualism needed rather than either/or		
	Need adequate access to a language to learn the language – parent training - Access to Deaf community (less than 5% born to Deaf parents)	Parents need to learn Auslan fluently to support their child's language and ongoing mental health. This is certainly a barrier. They need funding and access to learn Auslan in the family environment	
	If deaf children don't get Auslan or language training they have no way to uniformly communicate thus getting further and further behind their hearing peers	Availability of programs is an issue	
	How can families be supported to access sign language for their newly diagnosed children as well as spoken language?		Clear pathway for family with newly diagnosed child to courses etc for whole family
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Information and accessibility to support choice of Auslan (cont)			Families need to be exposed to Deaf professionals throughout their journey
	Auslan course availability for whole family taught by Auslan users Families need to be offered course instruction but courses		Access to agencies with expertise in Auslan

	need to be available taught by Auslan users		
	Parent training in Auslan ongoing		
	Whole family need to learn Auslan to reduce isolation of child. It is difficult for families to learn Auslan but it is not enough for one parent to learn to provide a vibrant language/communication home environment. In order for the child to learn Auslan, the whole family need to learn. This is often misunderstood	Children who require Auslan need parents who can communicate with them. Poor communication will impact on them	For success the family needs to be involved
	Long term mental health issues for the child		
	How can NDIS support Aboriginal kids in remote communities to learn Auslan or community sign and connect with other kids like them?	Accessibility in rural and remote areas and for those in low SES	
			NDIA needs to look at best practice models overseas and facilitates implementation of families to be bilingual
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Information and accessibility to support choice of Auslan (cont)	Clear pathway to building Auslan development		
			Online programs – VRI?
			Auslan interpreters need to be extended to the school environment
			Community focus- Auslan playgroups
			Social opportunities for Auslan users in regional and remote areas
Quality of Auslan programs	How to ensure availability and capability of trained interpreters for specific purposes eg education, medical	Lack of training opportunities for Deaf/Auslan tutors	Auslan tutors are trained
	How to ensure community of practice in low incidence areas of support eg bilingual, deafblind across the country		Ongoing flexible learning programs available that focus on whole family not just child

	Auslan language models especially for hearing families with L1 Auslan child		
	Quality of educators		
	Need to ensure quality of program is appropriate		
			Appropriate assessment tools are available
	Equity of quality resources to learn at family's pace		
			Auslan as a language needs to be respected and taught by Auslan users
			Video relay needs to be improved
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Planning/funding	How does funding for interpreters, Auslan training for families work?	No line item or group registration to teach Auslan. What do you bill for? Where does the funding sit?	
	Funding needs to be made available for both interpreters and devices. It shouldn't be either/or		
	NDIS has difficulty understanding bilingualism and the benefits and choice of families. It's been either/or devices or Auslan not both		
	Planning has to be face to face and NDIS funding required to support education – provided learning		
	Planners see funding for Auslan as only needed in Year 1 and not as lifelong learning		Adequate funding for Auslan in the home and funding for parents to develop Auslan skills if that is their goal
			Ensure funding for interpreter requirements included in plan Stated funding in plan for Auslan interpreting
			Funding in plan for families to learn Auslan
			Interpreter needs to be funded in child's plan if

			parent requires Auslan interpreter
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Planning/funding (cont)			Interpreter needs to be funded in child's plan if parent requires Auslan interpreter
			More funding for Deaf mentors in home for child and family
	Funding in initial plan has maximum number of hours funded that have to be shared between Auslan and therapy ie half a service in both		Adequate funding for children who would like to develop spoken language and Auslan – emphasis on each
	Cost allocation to this service when more children/participants are requesting other supports		
	ECEI planners require a “test” they can apply to children who use Auslan as part of NDIS plan review – highly specialised skill by Teacher of the Deaf	Difficult to assess language skills and to develop goals due to lack of Auslan assessment tools and guidelines for learning Auslan	
	ECEI partners who are providing information to families on options need to meet Deaf people and understand the issue more clearly		
	ECEI partners: Auslan should not be portrayed to parents as an option if the child is slow to learn spoken language. How options are provided to parents is very important		ECEI partners need to be clear that Auslan in an option – they need to be careful how they impart the information to ensure bias is not an issue
			Clear pathway to Auslan development
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Planning/funding (cont)	ECEI partners <ul style="list-style-type: none"> - Skills - Guidance - Content 		Funding needs to be provided to support organisations (ILC) to assist in choosing providers under the EI including Auslan – stated support

CALD	How do newly arrived families who have multiple languages get help with Auslan?		CALD interpreters available so that families can make informed decisions
			Interpreting services for all families who require support. Many families/participants with CALD background
Other	Need for total communication – access all areas		
	Schools need to offer bilingual/bicultural students and choose what they want		
	Auslan interpreting – extended to translation in the school environment		
	Community empowerment and knowledge		
	Interface with roadmap?		

2. EARLY INTERVENTION AND MODES OF COMMUNICATION

THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Aboriginal and Torres Strait Islander people, Culturally and Linguistically Diverse communities and remote communities	How will NDIS fund service providers to deliver programs in remote communities	Children in remote areas may need services but none are available	Access to regular high quality EI services and health education for families in rural and remote areas
	Will EI agencies step in to deliver appropriate speech and language programs for 0-6 year olds Aboriginal and Torres Strait Islander children in remote communities	Limited access to speech and language programs for Aboriginal children in remote areas	EI providing regular service for families. Health education for families
	Choice and control and Individual program may not be the best approach in Aboriginal and Torres Strait Islander communities – may need programs that support the larger community		
	Migrant families and refugees with children newly diagnosed with hearing loss need intervention and support services	Not eligible for NDIS	CALD families need information in their language to make informed decisions and understand the early intervention process
	How does deaf child of new migrants receive the intensive English support? How is the family supported? Who provides interpreters?		
Theme	Issues	Barriers	Opportunities/Best practice
Aboriginal and Torres Strait Islander people, Culturally and Linguistically Diverse communities and remote communities (cont)			Qualified interpreters available in person and remotely

Choice and control/ capability to use NDIS	Families in complex circumstances not engaging in the pathway. Does NDIS choice process disadvantage isolated, low socio economic groups including people with mental health issues	People who may struggle to access the website, understand it, navigate the system, organise themselves or transport have difficulty with the choice and control aspect of NDIS	
	Families may not feel confident to advocate for their child during the planning process. Some families are not able to utilise the “choice and control” of the NDIS due to mental health issues and therefore may not be in a position to make good choices		Children should receive the services and support they need – it should not rely on the family’s ability to advocate to get appropriate funding in the child’s plan
	Families need access to the full range of information at the time of diagnosis		Professionals need to be knowledgeable on the full range of programs and services to assist families with the planning process
	Participants need more choice and control regarding the level of device being provided during transition		
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Choice and control/ capability to use NDIS (cont)	With the early plans families were told they could use the funding for communication but not OT or PT despite families wanting to start those programs early		
	Choices should be based on professional recommendations with a second opinion. Funding should be sought after clinical recommendations	Professionals are often approached after the plan has been approved	
	Families want independent advice and not to come from service	Families do not trust the information provided to	

	providers. Strong feedback from families that above all they want independent balanced support	them. They want independent information	
	Families are having to make choices about language choices “blind” – don’t know what to do, what is “best”	Families can’t make choices about services they don’t know about – weighted towards bigger organisations	Informed parent choice. Family support to explore all options then fast track through hearing stream OHLFSS model which provides info on all services and all communication options best practice
	Ensuring funding predictions/estimates take into account the growing commitment to EI/hearing with 2 ears		
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Choice and control/ capability to use NDIS (cont)	EI – informed and realistic funding and realistic expectations of providers and families		
			Benchmarking of all modes of communication
			Early assessment of outcomes required to ensure that children who need (not only those who want) alternatives to spoken language identified early
Choice and control – potential market failure	In terms of modes of communication, some options may disappear completely because there isn’t the capability and they are pushed to the margins so longer term it may limit choice		Need to ensure system capability to support intervention options – market failure will exist if all services seek to focus on auditory oral intervention exclusively
	EI services losing block funding – unstable financial stream resulting in closure of services and market failure		

	What is happening post June 2020 for 0-26 age range?		Ensuring NFPs have sufficient funding to help organisations to transition from AH without going broke
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
	Providers are withdrawing from the NDIS or leaving the market completely due to the cost of meeting the quality and safeguarding requirements	NDIS quality assurance needs a rethink. It's too expensive and orgs are pulling out because of cost	NDIA needs to identify market gaps to avoid market failure which will have life-long impacts on some people. The risk of market failure must be addressed to ensure it doesn't occur
Eligibility	NDIS for over 26 years is aimed at profound hearing loss yet economically it would be better to start intervention before the loss becomes severe		
Professional skills - quality			EI is evidence based and whole of child outcomes focussed
			7-25 years – funded groups in the community to support transitions
			Timely EI maintaining 1-3-6 guidelines. Ensure children progress all stages
			Maintain high quality AH services. Don't water it down or put it at risk, it's the best in the world
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Professional skills (cont) - quality	Risk – appropriately qualified staff at all agencies		Need for benchmarking professionals to ensure they are well trained and have specialist skills
			Professional training and accreditation required for all options – not just

			spoken language intervention
	Importance of information counselling – ongoing, not just at diagnosis		Best practice – Qld model of family support post diagnosis
			Unbiased independent person/agency to provide ECI information
			Well trained, competent ToD and speech pathologists across all communication modes
Professional skills – NDIS issues	Families able to advocate for their child		Families have confidence the system will give what they need – funding not related to ability to advocate
	NDIS staff turnover, need to continually build skills in new people. Families continually retelling their story		
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Professional skills (cont) – NDIS issues	Audiological diagnosis should not be only factor determining NDIS funding when other disabilities/ factors present		
	Families with children across ECEI and LAC pathway – 1 st plan only for communication, 2 nd plan with other therapies may be delayed but can't access other therapies without 1 st plan		
	Requests often dismissed as not “reasonable and necessary”. Won't consider trial of a device or hiring a device		
	Although reports available to planners they are still relying on		Training of ECEI planners and LACs needs to highlight

	reference packages in funding the number of hours available eg 10 hours for speech and out of that will be travel expenses, report writing which will dwindle down to 4 hours of support		importance of reading reports and taking on professional advice on what the child and family need to support that child to develop their communication
	Families with complex situations may struggle to engage with planners		Benchmarks for engagement
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Professional skills (cont) – NDIS issues	Sometimes mis communication by ECEI partner that families can only seek specialised service until client has plan is in place	Potential delay in EI access	
	Confusion over line item for “transdisciplinary services”		
	What is the pathway after newborn hearing screening? Are families being guided to EI services – EI provider in WA has no babies this year? Are families being guided straight to NDIS or other rehab/ emotional support offered first?		
Assistive technology	Will participants be able to access high level technology in order to gain connections to mobiles, laptops	Limited access to technology creates limited inclusion	High performance technology for young children, school aged children and adults to fully participate in education, work and community

3. INTERPRETER AVAILABILITY, MARKET GAPS AND COMMUNICATION ASSISTANCE

THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Access to interpreter	Unprecedented access to interpreters thereby increasing need. Has caused confusion for Deaf people and their ability to engage and access interpreters	TIS availability when participant wants support delivered or interpreter cancels at short notice	Interpreting in NDIS plan (not just via TIS) to allow choice of provider
	Health interpreter access can use up NDIS funding if health care doesn't provide support		
	Risk of using communication support vs qualified interpreters	Issues particularly in regional, rural and remote areas	Need to empower people to use Skype or online where they can use an interpreter as none available in rural and remote areas. When formulating the plan NDIS need to consider whether the person has the infrastructure and equipment at home to access an interpreter in another city.
	Without language either spoken or manual interpreters cannot be used		
Market Gaps	Market gap big concern. Need to reduce training length		
	Need to ensure "specialist" interpreting capability in different areas eg tertiary education, medical etc		
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Market gaps (cont)	Lack of focus from government to invest in capacity building for Auslan workforce		Interpreter availability should be a priority investment for workforce capacity

	As more deaf students entering TAFE/Uni bigger demand for support ie interpreters. Need more courses to meet demand		
	Major shortage		
	Availability of interpreters for Aboriginal languages and emerging communities		
	Lack of courses, Cert II, III, IV Diploma that lead to interpreting courses and qualified interpreters. Interpreting courses not offered every year		Requirement for guidelines that set requirements ie Cert II Auslan not enough
	Auslan career development		
	Service closures – limited choice		
	Facilitating choice and empowering consumers/ families – NFPs, charities, non vested orgs at risk of disappearing but will be needed here		
	Insufficient pre and post assessment counselling for individuals and families		
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Market Gaps (cont)	Insufficient utilisation of experts in the field eg consumer organisations who can provide services of rehab and liaising between services available		
	Lack of community available interpreters in WA because with NDIS people have \$\$ to book but at one event 4 people each book own interpreter. Need centralised system		
	There are many market gaps in terms of support outside of device fitting eg		

	rehab, management strategies		
NDIS Plans		Ability for families to understand plan. Website high level language translation	
			Support children with bilingual approach (families being told they need to choose one)
	Plan reviews – phone plans not asking for goals or changing goals reflecting goals		
	ATS- need quality technology quickly		Support choice of provider – evidence of multi D response
	Better fund group interpreting needs (rather than individual funding)		ILC funding to pay for interpreters/captioning for events for registered organisations
THEME	ISSUES	BARRIERS	OPPORTUNITIES/BEST PRACTICE
NDIS Plans (cont)	Clarity of who funds what eg Education, Health, NDIS	7+ years: intersection in mainstream – education, health slows process down	
	Seen big improvement in speed of plans for HI but difficulties with children with co-morbidities, have to wait for a plan for the “rest” – can be quite difficult with families as may not be the most pressing immediate concerns		
	Most families rely on Audiologists (AH) for advice on next stages after diagnosis. Most families do not know about options (focus on AVT)	Pathways to try different strategies if the family’s first option didn’t work is not available in most areas	Support family to make informed choices is vital early in their journey after diagnosis (this is not reflected in the current pathway)
	Funding for non device related services		

Interpreting for languages other than Auslan	If self managed, need to know to ask for interpreters in the plan. Non registered providers cannot access interpreters	If simply CALD cannot access interpreters as not related to disability. Can only access services through registered provider	Include need for ESL interpreter in the participant's plan
	Accessible language for CALD communication		
Captioning	Number of hours for captioning is confusing		
	Fee for set up ie phone, internet and devices to make it happen		

4. OTHER ISSUES, FEEDBACK AND QUESTIONS

THEME	ISSUE	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Devices	Hearing device provision should reflect hearing loss not market price/affordability		Set plan for devices upgrade and provision 3-4 years
	FM/assistive device should be for whole life not partitioned – NDIS/ education/employment		
	ATS: need quality technology in a timely manner		
	Types of device provided should not be around “standard stock” but for “individual need” ie AH needs to be able to use NDIS/Vouchers to purchase the right model hearing device		
Deafblind and other co-morbidities	Deafblind: important to realise the complex interaction between the two conditions		
	Understanding needed that 1 disability plus 1 disability does not equal 2. Losing 2 senses or having another disability plus deafness huge problems		
THEME	ISSUE	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Consumer organisations	Representation of wider consumer group in pathway progression. Only have Deafness Forum and Deaf Australia		
	Consumer organisations that support those with hearing loss are ignored and unfunded yet they play a vital supporting		

	role. Why are they not in the equation?		
	How are orgs who provide information and advocacy support for adults being considered?		
	Ensure conversation is focussed on consumer choice and empowerment not ease/convenience for providers. Need orgs to support choice		
	Peer to peer mentoring programs for teens and adults in person and on line		
	Historically some services especially cochlear implant counselled against certain modes of communication. Need unbiased information counselling		
THEME	ISSUE	BARRIERS	OPPORTUNITIES/BEST PRACTICE
26 + years	For 26+ years focus is on devices. All evidence is that more needed than devices for best outcomes. How is this supported?		
	For 26+ years where their services are covered under the Voucher Program. It is critical that through the CSO/AH program to NDIS process that the additional funding be contestable. Most of our HSP complex clients choose to stay with use sacrificing additional \$\$		
	Where is conversation about eligibility criteria for 26+ years? Deaf, Auslan speakers, co-disabilities important but not whole picture		

	Disappointed by lack of discussion on older kids and adults. Needs to be more attention paid to how children progress/ graduate through to being productive supported adults.		
	Please take time as process evolves to give due attention to the transition of CSO funding for adults		
	Lack of support to develop spoken communication for DHH people who may have lesser hearing loss		
THEME	ISSUE	BARRIERS	OPPORTUNITIES/BEST PRACTICE
NDIS issues	Eligibility not focussed on functioning. Get away from threshold		
	The focus needs to move away from a threshold of hearing determination of access to communication assessment and needs. This would encompass all communication modes. In turn will lead to better assessment of outcomes		
	What amount of focus do planners/assessors take of how well a person can FUNCTION with their level of hearing loss eg can they perform in their chosen job?		Opportunity to move away from “threshold” to functional assessment and measurement of outcomes
	Assessment skill of planners. What training do they have to make an accurate assessment of a person’s hearing loss?		
	Variance in planner skill/power over plans goes against consumer centred approach	Risk that planners (non experts) have more control than anyone else across system	
	Risk that consumers will be under immense		

	pressure and stress to make decisions if not facilitated by unbiased but expert support		
	Inconsistency across planner actions/ decisions		
THEME	ISSUE	BARRIERS	OPPORTUNITIES/BEST PRACTICE
NDIS issues (cont)	High turnover of LACs, planners, ECEIs leads to lack of consistency. Lack of knowledge. Having to tell their story from the beginning		
	EI: Initial plan should consider that child may not have hearing loss only needs. Increase in services funding required to address other needs		
	Keyworker model service delivery requires adequate funding for keyworker to collaborate with other support services involved		
	Families with more than one deaf child		Best practice to look at family needs as a whole. Include supports co-ordinator to assist with juggling required supports. If children are split across ECEI/LAC pathway better to have 1 planner with experience/expertise in deafness not different planning conversations with different outcomes. This provides less stressful experience for families
THEME	ISSUE	BARRIERS	OPPORTUNITIES/BEST PRACTICE
NDIS issues (cont)	Hearing pathway has been great but we have had families with children with hearing loss AND		

	additional disabilities. These families need to have a planning meeting after access to the hearing stream so they can access funds for other disabilities ASD, CPL, other physical and sensory issues impacting functional needs		
	Disconnect between Agency, LACs and ECEI partners in approach and in understanding disability supports. Seeing less than satisfactory outcomes due to planners understanding of deafness and what reasonable and necessary supports are		
	Support choice of participants to choose providers – evidence of multi D approach		
	Goals not being asked about or adapted in line with family wishes		
	Interaction with mainstream has declined significantly since NDIS		
	More than 1 planner/ case manager for each client		
	Takes 4-5 weeks to hear back from NDIA. Clients not happy		
THEME	ISSUE	BARRIERS	OPPORTUNITIES/BEST PRACTICE
NDIS issues (cont)	Educating case planners on adult hearing concerns and needs		
	Giving providers a choice to recommend before planning		
	Clients > 26 not kept in the loop on how claim is going and moved from one person to the other to get information		

Provider issues	Will providers be able to access portal at an easier mode?		
	How can consumers recognise providers who are registered? There is no regulation!		Yes there is. Self regulation for both speech pathology and audiology
	Accreditation of providers – when, where, how?		Opportunity to use Audiology Australia?
	Cost of registration process is onerous and prohibitive. Happy to be regulated but might cost their business		
	No other providers other than AH can register under the “Hearing Services” category. This is unfair and other hearing services providers should be able to provide this service		
	NDIA referring to AH – clients to be given choice of provider so they have a variety to choose from		
THEME	ISSUE	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Provider issues (cont)	Better education to providers about the NDIS process		
Other	Poorer socio-emotional outcomes when children cannot communicate with their families. Communication is key to building attachment. Impacts on later mental health		
	0-26 years: Why are we asking the questions in the hearing stream when we already have the resources/models in AH?		
	In future will there be any funds made available for individuals and orgs to		

	attend these forums? They are extremely valuable but costly for service providers/advocates		
	Topic selection too constrained and does not consider quite a large group of people with different configurations of hearing loss but in particular significant communication difficulties in their daily lives.	Having only Deafness Forum and Deaf Australia involved/ consulted to “progress the pathway” is extremely limited with regard to input and understanding of processes	
			Training programs for families, professionals and participants need to be best practice and with a research approach
THEME	ISSUE	BARRIERS	OPPORTUNITIES/BEST PRACTICE
Other (cont)			Certification levels achieve and outcomes measured
			Benchmarking of specialist early intervention programs and benchmarking of qualified clinicians to provide support in the area of hearing loss
	Different service delivery options not always individualised eg working within CALD and ATSI communities, working with individual child and immediate family, may not achieve best outcomes		
	More specialists supporting participants to transition to high school, post school options		
		Risk: unqualified providers, don't understand scope of practice	Audiology Australia to educate and accredit
	Unqualified/unskilled assessors and providers.	Barriers exist in understanding by	Best practice: Assessment be well

	Many providers have targets to achieve	assessors etc of how hearing loss interacts with how well a person can function in employment and everyday life. This impacts negatively on the type of assessment provided	qualified audiology and also correct and optimal device fitting. Consistent follow up and support re rehabilitation after fitting, communication techniques etc
THEME	ISSUE	BARRIERS	OPPORTUNITIES/BEST PRACTICE
		Risk: Insufficient support, very poor overall plan, wrong focus of plan. Inability of client to reach their potential	Opportunity: For better collaboration between services and for better liaison. Opportunity for the utilisation of services like rehab and information/education for clients
	Hearing tests for people 50-55 rather than 65 for early identification and intervention. Consumers want to be able to access independent providers		

COMMUNITY OF PRACTICE – HEARING STREAM CHILDREN LEARNING AUSLAN

DESTINATION: For families who have chosen for their child to learn Australian Sign Language (Auslan), the child will grow up having access to Auslan and access to their community. They will be able to use Auslan for communication in order to develop relationships, to gain an education and employment and enjoy a good quality of life. Families will be supported to learn Auslan in order to communicate with their child.

This body of work was facilitated by Leonie Jackson, chief executive officer The Deaf Society.

BEST PRACTICE APPROACH

Moeller et al., (2013) indicate a number of best practice principles when working with families who choose to communicate with their child using sign language:

1. Providers of early intervention services are trained professionals, usually with graduate degrees in their fields (which include deaf education, early childhood special education, speech/language pathologists, audiologists, counsellors/social workers and psychologists.) They receive regular additional in-service training
2. Services are provided to parents – the focus is on facilitative family-child interactions, rather than child-directed therapies. Families require 1 to 1.5 hours weekly and include information on child development, communication strategies etc. to build competence and provide the child with language-rich stimulations during natural interactions with the family (parents, siblings, extended family members).
3. Families are supported to gain the necessary knowledge, information, and experiences to make fully informed decisions
4. Families are contacted immediately after the diagnosis and the professionals who work with the parents are specially trained to provide emotional support, as needed, to deal with their responses
5. Family Support Facilitators/Regional Co-ordinators provide information and the guidance necessary to assist parents in choosing an initial approach to language use. This initial decision can be modified when appropriate. Options for various language approaches are available, and decisions may be changed over time
6. Children's developmental progress is assessed twice yearly and results are used to help parents make or revise decisions on how to support their child's development

ISSUES

- Given the disparity among the different approaches, parents need access to balanced information from an unbiased source in order to make an informed decision on the mode of communication they want their child to use. There is evidence that parents are not receiving enough information on bilingual communication i.e. Auslan and English as an option for their child
- There is evidence in the literature that parents can experience negative emotions when service coordination is provided by individuals without the core knowledge and skills for working with children (Yoshinago-Itano, 2014). ECEI partners do not have this core knowledge
- NDIS plans need to contain enough funding to allow for the intensive exposure to Auslan that the family needs in order to learn the language and become fluent. This also needs to be ongoing as language development will take time and needs individualising as skill levels increase

- It is critical for the child’s family to learn Auslan otherwise the child becomes isolated from their family
- Children need access to a community of language users
- Children who communicate using Auslan are usually bilingual (i.e. use Auslan and spoken English) and will need continued access to hearing services
- Families should be given access to Auslan as a language option, even if they are choosing English as their child’s first language
- While opportunities currently exist for families to learn Auslan, this is an area that has been deficient for families who choose Auslan and there is a need for clearer pathways to be established

Some issues exist for all deaf children regardless of choice of first language access:

- Regional and remote families need solutions that provide them with equitable access to the support services that they require in order to pursue their chosen approach to early intervention e.g. Auslan at Home, speech therapy, device support
- Families who do not speak English will need additional supports
- Language exposure needs to begin early, and meaningful, accessible and ongoing interactions need to occur in order to learn the language
- Access to English is important – for some children this will be through spoken English; and for all deaf children, it will be with written English

RECOMMENDED PATHWAY

Attachment 1

FURTHER WORK REQUIRED TO SUPPORT THE PATHWAY

Work that needs to be done/funded to better support the pathway includes:

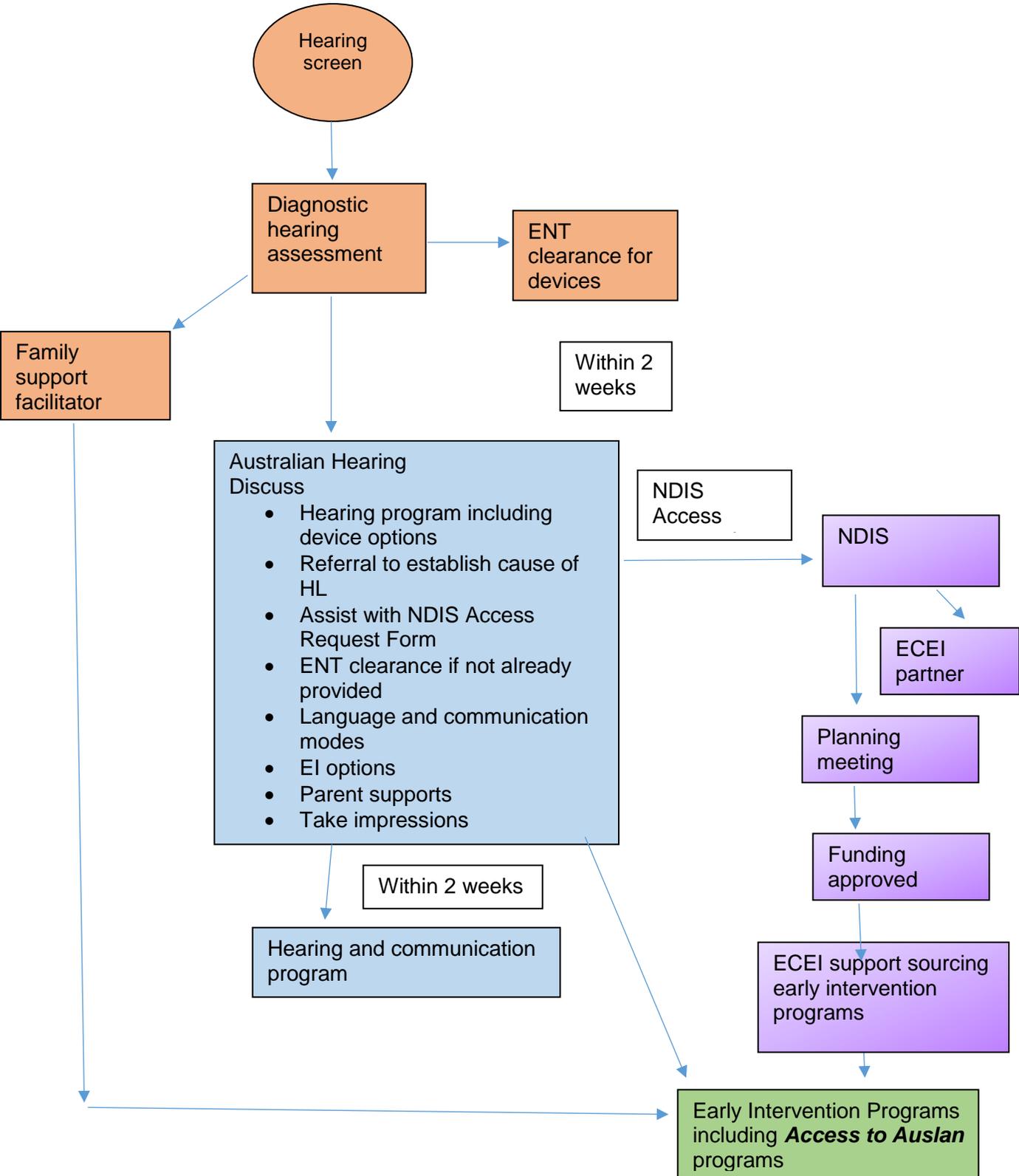
1. Language assessment
It is important to maintain a focus on acquiring more information on early language acquisition in Auslan. There is a need for more quality evidence-based information about infant development of Auslan skills and there is also a need to build professional capability in monitoring, sampling, and analysing language abilities as well as the capability in intervening in language acquisition based on that analysis
2. Resources for families
3. Workforce capacity
 - a) Conduct a needs assessment to determine (1) the number of available sign language instructors with the qualifications in sign language and family/infant education and (2) available funding sources
 - b) Develop systems that ensure that neither geographic location nor socioeconomic status limits access to competent and skilled sign language instructors. State systems should consider utilisation of all technology, including computer and videophones, to support teaching families
 - c) Establish and conduct training for Auslan instructors that includes strategies and techniques for teaching sign language to families of infants and toddlers
 - d) Establish a quality assurance program for Auslan instructors of parents/families. The program should (1) assess their fluency in and knowledge of Auslan and (2) determine

their ability to tailor the instruction so that families are prepared to communicate with infants and very young children

- e) Conduct a needs assessment to determine the number of professionals with the qualifications and skills required to serve as an Auslan instructor for families/parents of infants

Example of an Access to Auslan program - see Attachment 2.

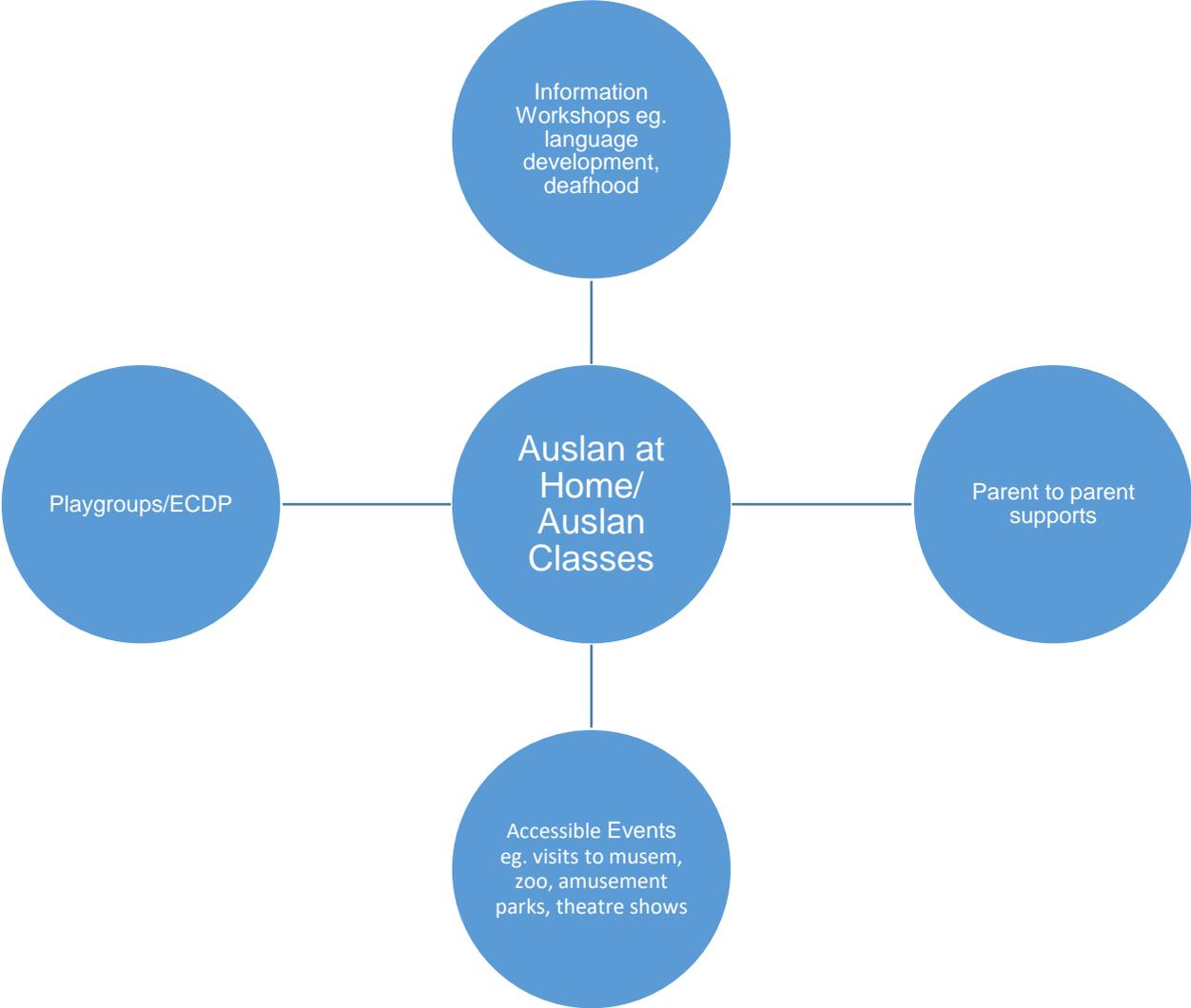
PROPOSED PATHWAY MODEL - ALL CHILDREN 1-6 YEARS OLD



ACCESS TO AUSLAN

The proposed pathway will lead to a whole range of Early Intervention choices. The Access to Auslan model is one of these choices and proposes to provide a number of services for the Deaf child and their families. This may include but not limited to:

- Auslan at Home or Auslan classes
- Early Childhood Development Programs (ECDP)
- Information workshops around language development, living with deafness, deafhood, Deaf gain etc
- Parent to parent support programs
- Accessible community events and playgroups for the child.



COMMUNITY OF PRACTICE – HEARING STREAM BEST PRACTICE FOR EARLY INTERVENTION INCLUDING ALL OPTIONS FOR MODES OF COMMUNICATION

DESTINATION: Families are well supported on their pathway to accessing the supports they need and receive timely services irrespective of mode of communication or geographical location.

This body of work was facilitated by Leonie Jackson, chief executive officer The Deaf Society.

MODES OF COMMUNICATION:

- Oral/aural
- Bilingual – spoken English and Australian Sign Language (Auslan)
- Auslan only

CURRENT PATHWAY ISSUES

- The pathway from diagnosis to Hearing Australia and early intervention providers is different in each state
- An additional element has now been added which is the pathway into the NDIS in order for funding to be secured to access early intervention services. Hearing Australia is currently assisting with that process in order to fast track the child's access to the NDIS but that may change in July 2020 when competition is scheduled to be introduced for audiological service provision for children
- Currently the NDIS funding package does not need to include audiological rehabilitation services as this covered under the Australian Government Hearing Services' Community Service Obligations (CSO) program but that will need to be incorporated into the pathway from July 2020 as children transition from the CSO Program to the NDIS for their audiological program needs
- There are many steps in the pathway with the family interacting with different agencies which increases the risk of families falling through the gaps
- Information on early intervention services and communication options is provided by Hearing Australia but this is not always done well. Families need complete, balanced information from an unbiased source delivered in a way that is comfortable for them
- The needs of children with other disabilities is not well managed. There is poor support in funding and process
- The pathway will change in July 2020 but it is not yet clear how it will change because no information has been provided on whether audiological services to children will be made competitive

The current pathway for different age groups is shown in Attachment 1.

BEST PRACTICE PATHWAY ELEMENTS PATHWAY

- There is a need for a national guided referral pathway and a single point of entry to service provision. This is currently being provided by Hearing Australia but the continuity of that role is in question if/when the delivery of paediatric hearing services becomes contestable in July 2020

- The pathway needs to be clear and timely regardless of whether the child's hearing loss is diagnosed at birth or later
- The pathway needs to be clear and timely regardless of whether the child lives in an urban, rural or remote area of Australia
- Timing benchmarks from newborn hearing screening – identified by 1 month, completed diagnosis by 3 months, intervention before 6 months of age must continue to be met
- Timing benchmarks of fitting within 2 weeks of diagnosis for children diagnosed through mechanisms other than newborn hearing screening also need to be met
- Families need assistance in getting streamlined access to the NDIS so they can minimise the time between funding approval and the ability to access the services they need
- The pathway needs to work seamlessly and in a timely way and support all families, regardless of where they live or what language they use. The pathway needs to address the risk of families falling through the gaps as they transition between services or at different life events

RECOMMENDATION 1

That a streamlined access pathway continues to be provided beyond June 2020 when services to children with hearing loss are expected to become contestable

RECOMMENDATION 2

That the NDIA ensures that the change from the in-kind arrangements with the Australian Government Hearing Services Program in July 2020 do not negatively impact on the timeliness of children being provided with hearing rehabilitation services including device fitting

RECOMMENDATION 3

That Hearing Australia remains the sole provider of hearing services to children (with the exception of those fitted with cochlear implants) to mitigate the risks of delays in accessing the NDIS, delays in fitting devices and market failure due to the lack of providers of paediatric hearing services

FAMILY SUPPORT

- After the child is diagnosed with hearing loss families need access to independent balanced information on all intervention options available from appropriately skilled people
- Information needs to be provided in a variety of formats so it is as accessible as possible
- Ongoing parental support is needed for emotional wellbeing as well as support and service delivery in relation to the child's hearing loss. The support is needed not just at diagnosis but at every transition point in the child's life
- Families need access to mentoring and support
- The NDIS ECEI partner that provides the family with unbiased information and links them to services needs to be well informed and provide a timely service. The model for this service recommended by professionals and parents is that provided by the Family Support Facilitators linked to the newborn hearing screening program in Queensland who meet with the family soon after diagnosis. Families gain impartial and balanced information on the range of communication options and providers available to them from the family support facilitators. The support workers are trained psychologists or social workers who are able to provide impartial and balanced information and support from birth to 6 years of age, supporting the family on the journey to primary school. These

roles are State funded. The ECEI partners do not have the skills or expertise to undertake these roles.

RECOMMENDATION 4

That Family Support Facilitators are funded by the NDIS and made available nationally

- It can take time to gather information on the child's abilities. The reference packages provided to families need to be reviewed as more information on the child's needs becomes available

RECOMMENDATION 5

That reference packages be reviewed as more information on the child's needs becomes available

CHILDREN WITH ADDITIONAL NEEDS

- Where a child has additional needs families should not have to nominate a primary disability. Each condition makes the impact on the child and family more complex and the disability causing the most impact may change depending on the stage of development or the situation the child is in
- The system needs to support children with additional needs. Consideration needs to be given to support families with several children with different disabilities who may have different NDIS workers for each child and need to meet with a variety of service providers

RECOMMENDATION 6

The NDIA reconsiders the need for families to nominate a primary disability for the child with hearing loss and additional needs

WORKFORCE CAPACITY

- There is a need to identify service providers with appropriate cultural competency to deliver services to Aboriginal and Torres Strait Islander children. It is important for these service providers to establish linkages with other services such as RFDS and Aboriginal Community Controlled Health Organisations to support early identification and intervention
- All frontline NDIS staff should have a high level of Deaf cultural awareness and undertake Deafness Awareness Training and National Relay Service (NRS) training and training in working with interpreters and captions.
- Families need access to deaf professionals as role models along their pathway and building capacity in this section of the workforce needs support
- Families living in rural and remote areas need access to high quality intervention services

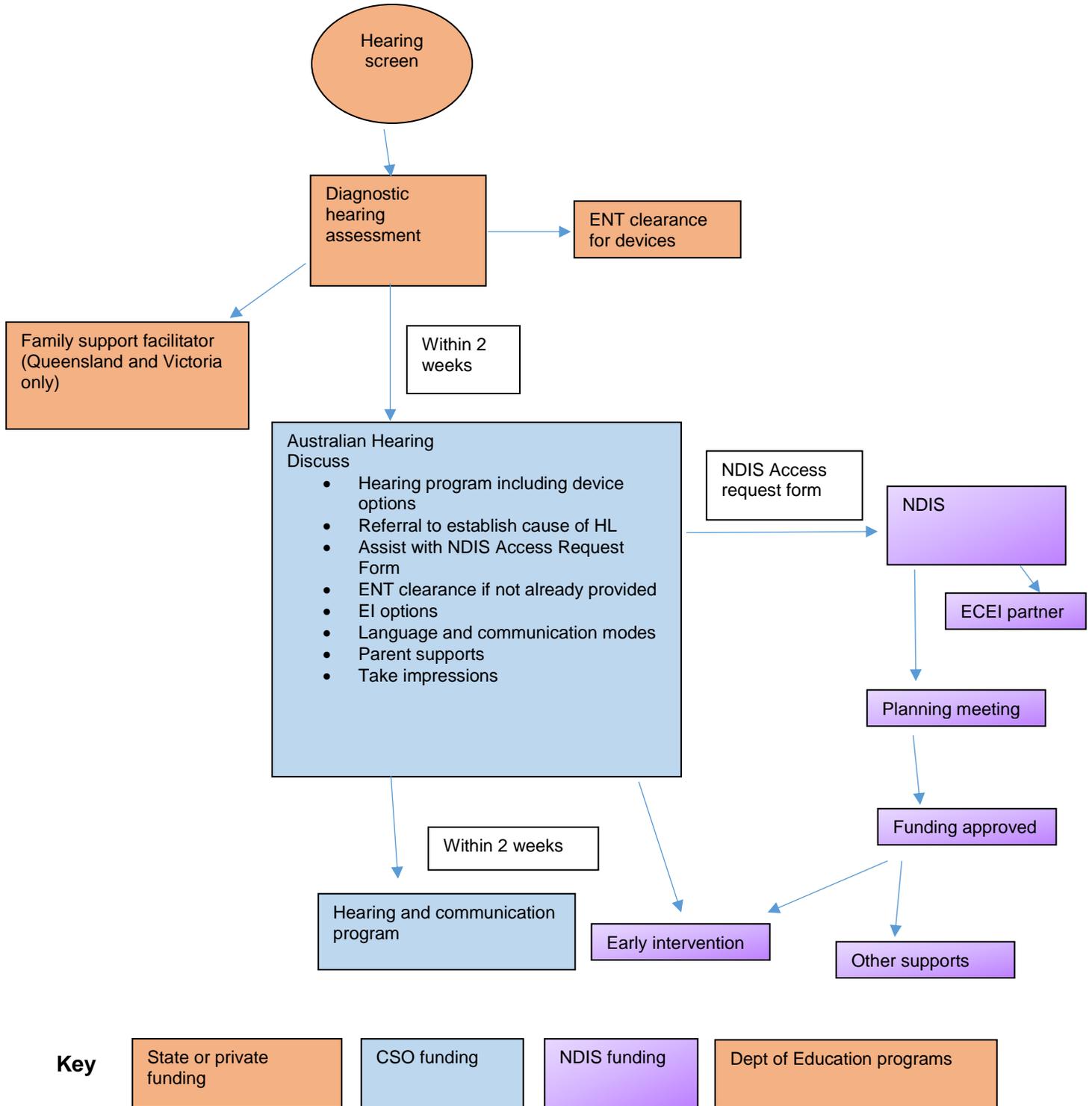
RECOMMENDATION 7

That the NDIA ensures that there is an appropriate skilled workforce available to meet the needs of a culturally diverse population

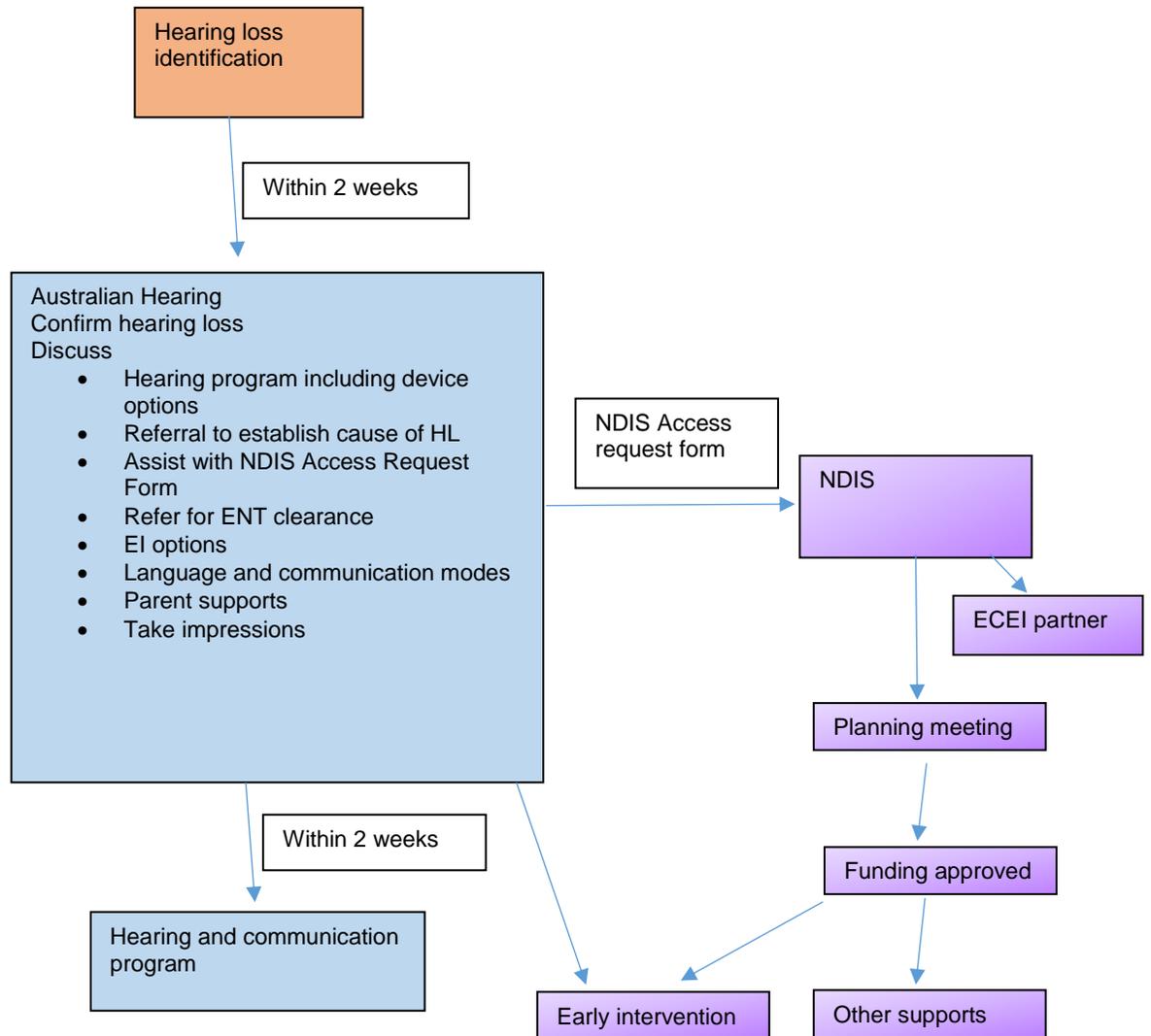
RECOMMENDATION 8

That families are able to exercise choice and have access to high quality intervention services regardless of where they live

CURRENT PATHWAY - NEWBORNS



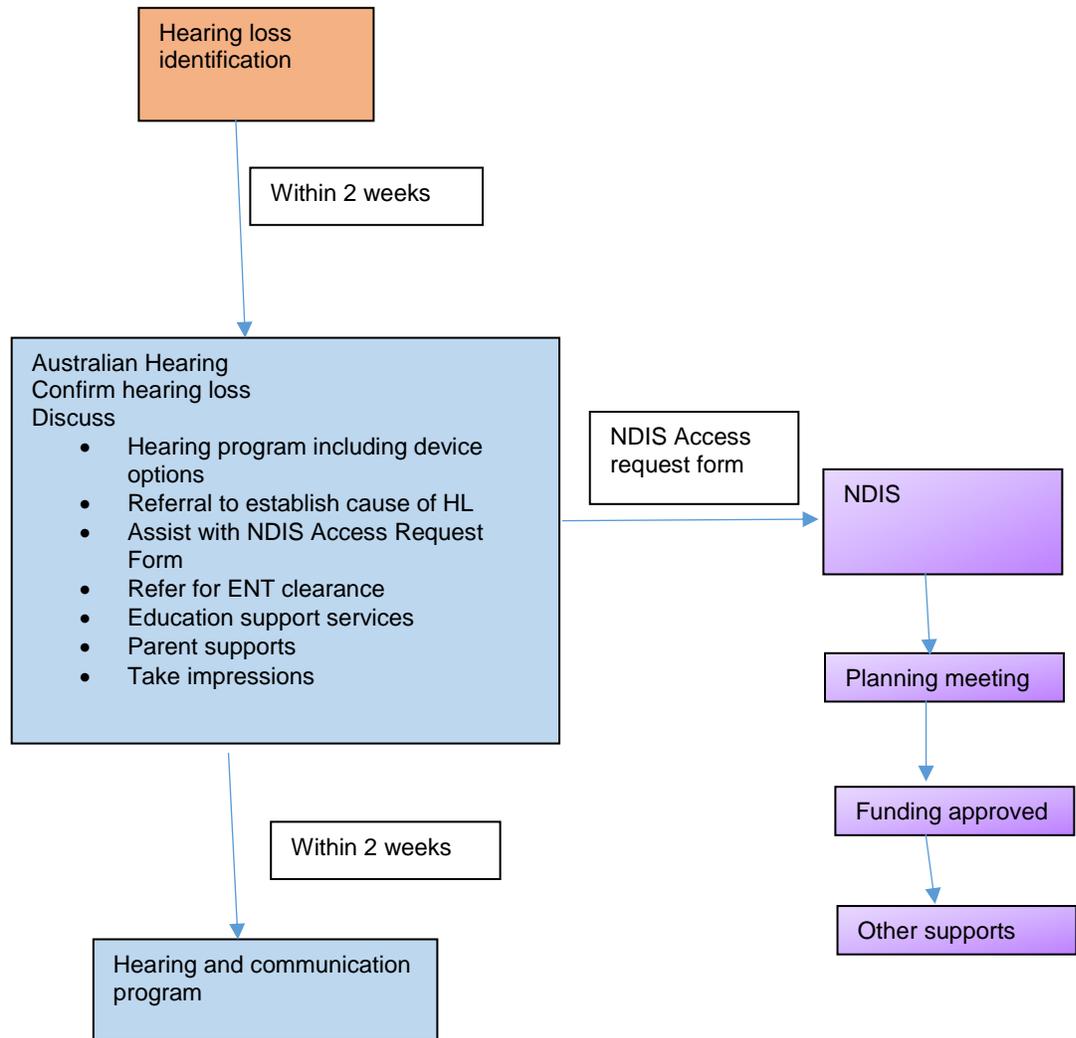
CURRENT PATHWAY – 1 to 6 years



Key



CURRENT PATHWAY - 6 to 25 years



Key



COMMUNITY OF PRACTICE – HEARING STREAM NDIS ACCESS REQUIREMENTS

NDIS access is dependent on a person's age, residency status and disability.

To access the NDIS a person must satisfy the following 3 conditions:

1. be aged under 65 years AND
2. live in Australia and be an Australian citizen or hold a permanent visa or a Protected Special Category visa AND
3. have a permanent impairment that significantly affects your ability to take part in everyday activities, or have a developmental delay

Applicants must complete an Access Request Form and provide supporting evidence of their disability. Once a person has been accepted into the NDIS they meet with a planner to discuss their needs and goals and then a funding plan is developed which must be approved prior to the person accessing the supports they require.

The access pathway is not working well for people with a single sensory impairment, a dual sensory impairment or for those people with a sensory impairment and other disability for the following reasons:

1. OPERATIONAL GUIDELINES

The NDIA developed operational guidelines to help streamline access for people with hearing loss. The guidelines are not well understood by NDIS staff, professionals working with people with hearing loss or by potential NDIS participants. The guidelines are being interpreted as if the four-frequency average hearing loss in the better ear is the criteria for access, whereas the guidelines were intended to identify the level of evidence required to support the access request for people with hearing loss.

The recent case at the Administrative Appeals Tribunal (AAT) (*Evans vs NDIA* (2019)) clarified the use of the Operational Guidelines for hearing services. The AAT determined that the NDIA could not apply its Operational Guidelines as a 'threshold' in a way that meant that anyone whose hearing was reduced by less than 65 decibels did not have a substantially reduced capacity to communicate. Instead, the relevant question was whether a person's hearing impairment resulted in a substantially reduced capacity to communicate, which required the NDIA to look at a person's subjective evidence about how their hearing loss impacted on their ability to communicate. On that basis, the AAT determined that Ms Evans satisfied the "hearing impairment" access criteria to become a NDIS participant.

The following examples highlight where the operational guidelines are not being applied as intended:

- a) According to the NDIS guidelines people with hearing loss greater than 90dB (4FAHL BE) are not required to prove that their hearing loss has substantially reduced their functional capacity. Yet there are examples where people with this degree of hearing loss have not been accepted into the NDIS
- b) People with hearing loss less than 65dB (4FAHL BE) and have reduced functional capacity are not applying for the NDIS as they assume their hearing loss is not severe enough to qualify or they have been told by the NDIS and professionals that their hearing loss is not "bad" enough for them to qualify so they don't even try, even though

they could provide evidence of the reduced functional capacity that is caused by their hearing loss

The operational guidelines were meant to provide clarity regarding access to the NDIS but unfortunately that has not been the case. The guidelines are causing concern and anxiety and are being applied inappropriately within the NDIS and externally.

RECOMMENDATION 1

That the NDIS undertakes a campaign targeting various referral points to raise awareness of the access criteria for the NDIS for people with hearing loss so that potential participants do not mistakenly self-exclude themselves from applying for the NDIS

RECOMMENDATION 2

2a. That staff who determine whether a person is accepted into the NDIS, are aware of the access requirements and operational guidelines relating to hearing loss and apply them appropriately and consistently across locations

2b. That such staff be provided with training given by hearing-related therapy providers so they can understand the actual services offered in each state and territory

2. ACCESS REQUEST FORM AND SUPPORTING EVIDENCE

The amount of documentation required to apply to the NDIS is substantial and overwhelming for both professionals and potential participants. The Access Request Form is a generic form to be used by all applicants regardless of their disability. It is not well designed to capture the impact of a sensory impairment. This can lead to people being unfairly excluded from the NDIS because they are unable to represent the impact of their hearing loss on the form. The NDIS Access Request Supporting Evidence Form which has to be provided along with the Access Request Form is also a generic form. Professionals have been provided with little guidance on how to complete the form for someone with a sensory loss and they are not clear on what evidence the NDIS needs in order to determine the functional impact of the disability. Professionals find it difficult to complete the form and if the supporting evidence is not completed appropriately it may lead to the person not being accepted into the NDIS when they should have been.

The Access Request Form and Supporting Evidence forms needs to be supported by an Auslan translation and available in a centralised accessible location.

RECOMMENDATION 3

That the Access Request Form be reviewed to ensure that it is not, through its design, leading to people with sensory impairment being excluded from the NDIS

RECOMMENDATION 4

That the form for providing supporting evidence be simplified and guidelines developed to assist professionals to complete the form when providing evidence for people with sensory impairment

Obtaining the evidence required by the NDIS to demonstrate the functional impact of the disability can be time consuming for the applicant and for the professional. It may take several appointments with a professional and none of these services are covered by NDIS funding. This means the individual may have substantial out of pocket expenses in order to complete the documentation required by the NDIS. Consideration needs to be given to reviewing the level of

evidence needed by applicants (and its resultant costs) and providing financial support to people, particularly those on low income, to obtain the evidence needed to apply to the NDIS.

RECOMMENDATION 5

That the level of evidence needed to support access requests be reviewed and financial support provided, particularly for people on low income, to cover out of pocket expenses relating to the assessments needed to obtain evidence to support their NDIS Access Request.

3. PRIMARY DISABILITY

The Access Request Form asks for the person's primary disability. It can be difficult for people with multiple disabilities to nominate a primary disability. It implies that one condition has more impact or is somehow more important than others, whereas for the individual, the presence of more than one disability makes the impact more complex so that it may not be possible to identify a "primary disability". The disability causing the most impact may change depending on the situation the person is in.

Nominating a primary disability can mean that the person's plan is total focussed on addressing the needs of that disability whereas the person needs a more holistic approach to be taken to address the overall impact of the multiple disabilities.

This is clearly at odds with a person-centric approach and the NDIS' mission to treat each applicant and participant as an individual.

RECOMMENDATION 6

That the NDIA reconsiders the need to nominate a primary disability for people who have multiple disabilities

People with deafblindness are being told that they cannot list deafblindness as the primary disability, they have to elect either hearing or vision impairment. The needs of a person who is deafblind are very different to the needs of a person with a vision or hearing impairment so it misrepresents the person's situation to have to elect either hearing or vision impairment as the primary disability. It may also mean that the person does not receive all of the supports that they need in their plan if the supports are only addressing the primary disability.

It is important for the NDIA to capture data on the number of people with deafblindness who are registering for the NDIS as it will help to monitor the access rates for people with deafblindness. The data could also assist with workforce planning as the market is currently unable to meet the demand for the supports being funded through the NDIS and these workforce shortages need to be addressed.

RECOMMENDATION 7

That deafblindness be accepted as a primary disability on the Access Request Form

4. COMMUNICATION WITH PARTICIPANTS WITH HEARING LOSS

There have been examples of people with hearing loss being told by the NDIS that communication must be done by telephone. While some people with hearing loss are able to communicate by telephone, many are not. When the NDIS staff have been asked to use alternative communication methods the person has been told that the contact must be by telephone. This is not acceptable.

The Access Request Form asks the individual to indicate their preferred method of communication. It may be that this information is not being accessed by the people organising the planning meeting or other contacts and consequently they are using an inappropriate method of contacting the individual. If the reason for the contact is to arrange a planning meeting, hearing impaired and Deaf people would find it easier if there was an option to arrange the appointment through an on-line booking process. Also, many hearing impaired and Deaf participants prefer to communicate via SMS. It would be helpful to have a dedicated SMS line to support this method of communication.

RECOMMENDATION 8

That NDIS uses an appropriate form of communication when liaising with participants with hearing loss and consider implementing online bookings for appointments and a dedicated SMS line to communicate with participants with hearing loss

There have been instances of participants having planning meetings where they were not fully aware of the decisions being made to quarantine funding to a single provider or agreeing to undertake self-management of their plan. These situations result in confusion, poor or no services being delivered and ultimately a lack of choice and control as the NDIA has not communicated effectively with the participant.

NDIS staff who have contact with these participants should have a high level of deaf cultural awareness and undertake deafness awareness training, the role of the National Relay Service and captions; and training in working with interpreters.

RECOMMENDATION 9

That NDIS staff be provided with training in Deafness Awareness, using the National Relay Services and working with interpreters

5. SUPPORT FOR VULNERABLE PEOPLE

The access pathway is complex and confronting. The individual who is applying for the NDIS needs resilience, determination, significant self-advocacy skills and a high level of education.

More vulnerable people such as people from culturally and linguistically diverse backgrounds, and people with low literacy or low health literacy levels are at risk of being excluded from accessing the Government funded services and supports they need as they are unable to navigate the system. People in these circumstances need a support worker, and in some cases, a funded interpreter to help them navigate the pathway successfully.

This is obviously exacerbated for participants in regional and remote areas. The difficulties in accessing the NDIS for Aboriginal and Torres Strait Islander peoples has been well documented.

RECOMMENDATION 10

That the NDIS provides funded support workers and interpreters to assist people who may have difficulty accessing the NDIS and monitor take up rates to ensure more vulnerable groups are gaining access to the services they need

6. TIMELINESS OF SERVICES FROM THE NDIS

The NDIS access process has several steps and each of the steps currently appears to have delays leading to people waiting months if not years to access the scheme.

The time to be notified of registration to the NDIS has been reported to take several months. Similarly, the time to receive an appointment with a planner or an early childhood early intervention partner can take additional months.

It is unreasonable to have people with hearing loss or deafblindness waiting months to receive the supports they need. These delays leave the individual and providers in a difficult situation. Individuals are left to decide whether to try to fund their supports themselves. Providers cannot be paid retrospectively yet find it difficult to leave a person with a disability without the supports they need due to administrative delays in the NDIS so they are left with the decision of whether to provide assistance without being reimbursed.

The NDIS has performance indicators on the timeliness of service but there do not appear to be any consequences for the NDIS when these timeframes are not met.

RECOMMENDATION 11

That the NDIA addresses the delays in potential participants accessing the NDIS as a matter of urgency

7. ACCESS FOR CHILDREN AND YOUNG ADULTS

Currently, Hearing Australia is the sole provider of hearing services to children with hearing loss - it is assisting families to register with the NDIS. A streamlined pathway has been developed to ensure there are no delays in families receiving the supports they need. The child's audiological needs are still being met under in-kind arrangements with the Australian Government Hearing Services Community Service Obligations Program. It is not clear how the process will be managed from July 2020 when the in-kind arrangements cease and audiological services for children and young adults are expected to become contestable.

The changes that are to be implemented in July 2020 will also impact on the timeliness of audiological services. These services are currently provided outside of the NDIS through in-kind arrangements with the Hearing Services Community Service Obligations Program. Once that arrangement ceases, the hearing rehabilitation program including device fitting will be delayed until the person has their NDIS plan approved. Any delay in device fitting is likely to have an adverse impact on a child's development.

RECOMMENDATION 12

That a streamlined access pathway continues to be provided beyond June 2020 when services to children with hearing loss are expected to become contestable

RECOMMENDATION 13

That the NDIA ensure that the change from in-kind arrangements in July 2020 does not negatively impact on the timeliness of children being provided with hearing rehabilitation services including device fitting

RECOMMENDATION 14

That Hearing Australia remains the sole provider of hearing services to children (with the exception of those fitted with cochlear implants) to mitigate the risks of delays in accessing the

NDIS, delays in fitting devices and market failure due to the lack of providers of paediatric hearing services

8. ACCESS FOR ADULTS

Adults with a sudden hearing loss need immediate assistance to support their needs. If the hearing loss is such that they require hearing rehabilitation services, they need to be able to access these services without delay. The current waiting times for adults to access the NDIS would leave people with sudden hearing loss unable to function at work or socially. There needs to be a mechanism to give these people priority to access NDIS funded services.

The current in-kind arrangements between the NDIS and the Hearing Services Program are not working well for adults who choose not to access services from Hearing Australia under the Community Service Obligations component of the Hearing Services Program. These clients are only able to access the services that are approved under the Voucher Program. The Voucher Program is designed to meet the needs of people with non-complex hearing rehabilitation needs whereas the needs of NDIS participants are more complex. Under the Voucher Program, NDIS participants only have access to a limited range of services and devices and they may be seen by a practitioner who does not have the expertise required to provide the rehabilitation services they require. The changes to the in-kind arrangements that will occur in July 2020 will allow these issues to be addressed.

NDIS participants will need to have rehabilitation services included in their plans as well as appropriate assistive technology. They will also need to be able to identify the practitioners with the competencies to deliver the hearing rehabilitation services they need. As this represents a significant change to current arrangements, NDIS staff, particularly planners, will require training to ensure they understand the new supports that will need to be included in plans for people with hearing loss or deafblindness.

The status of existing NDIS participants who also meet the eligibility requirements for the Australian Government Hearing Services Program needs to be clarified. It is not clear whether a person who is already a NDIS participant when they apply for a voucher in the Hearing Services Program will be permitted to access to that Program. There does not appear to be anything to exclude their access so they could in theory access hearing services under the Hearing Services Program and the NDIS, yet the draft legislation for the Hearing Services Program indicates that the same is not true for people already in the Hearing Services Program who become NDIS participants. The exposure draft of the *Hearing Services Program (Voucher) Instrument 2019* (Clause 13 (6)) indicates that a voucher issued under the Hearing Services Program will cease if the person becomes an NDIS participant.

RECOMMENDATION 15

That the NDIA institutes streamlined access to the NDIS for adults with sudden hearing loss

RECOMMENDATION 16

That planners receive training in the new range of supports that need to be included in plans for adults with hearing loss once the in-kind arrangements cease in July 2020

RECOMMENDATION 17

That the NDIA clarifies whether a person can be provided with hearing services under the NDIS and the Australian Government Hearing Services Program

9. NDIS PLANS

It appears that the discussion of what supports to include in an individual's plan can be heavily influenced by the planner they see. There are cases where the recommendations of the professional who provided the supporting evidence on the functional impact of the hearing loss are not being taken into account leading to the participant having inappropriate supports included in their plan. This varies across planners and locations.

It also appears that the participant does not always see the plan that is submitted for approval so there is no opportunity for them to indicate that the supports that have been included are not appropriate for them until after the plan has been approved and the funding allocated to a support they do not want. It is not uncommon for hearing impaired participants to receive a substantial allowance for Auslan services when they do not communicate in Auslan but listen and hear - their need is for new or better hearing devices, or captions.

Deaf participants – those whose first language is Australian Sign Language (Auslan) - should have their plan provided in both Auslan and English. The current documentation can result in Deaf people not understanding the terminology used or the supports that have been funded.

If a Deaf participant requires an Auslan interpreter at their planning meeting the NDIS needs to ensure that the interpreter is arranged well before the meeting to ensure their availability. There is a significant shortage of qualified Auslan interpreters and Deafblind interpreters. Interpreter booking services need appropriate notice to ensure an interpreter can be provided. The notice period also means that meetings cannot be changed at short notice. If an interpreter cannot be made available then the meeting should not proceed.

RECOMMENDATION 18

That planners use the advice and recommendations that have been provided by the participant's professionals when determining what will be included in a participant's plan

RECOMMENDATION 19

That participants be given a copy of the plan that is being submitted for approval

RECOMMENDATION 20

That participants whose primary language is Australian Sign Language (Auslan) be given the option of having their plans provided in Auslan

RECOMMENDATION 21

That the NDIS arranges Auslan interpreters and deafblind interpreters for planning meetings well in advance to ensure that the interpreter will be available for the planning meeting

10. PLAN REVIEWS

Participants who are attending plan reviews are being asked to again produce evidence of their disability as if the participant's situation had improved since their last plan review. This is time consuming and is not contributing to an improved outcome for the participant or their families and carers. The criteria for accessing the NDIS is that the person has a permanent disability. On this basis it is unlikely to improve. However, it may deteriorate or the person's circumstances may change such that they need different supports. This is a different conversation and currently the reviews are not being approached on this basis.

RECOMMENDATION 22

That the NDIS removes the requirement for people to continually provide evidence of their disability at plan reviews and ensure the process is more positive and productive for participants, their families and carers

11. PEOPLE WHO DO NOT QUALIFY FOR THE NDIS

There will be people with hearing loss who apply for the NDIS who do not meet the access criteria. In the case of children, they would have previously been covered by the Australian Government Community Service Obligations Program or by Hearing Australia (in the case of temporary residents) but it is not clear what will happen to these children after June 2020.

For adults with hearing loss who do not meet the eligibility criteria for the NDIS or for the Australian Government Hearing Services Program, there is currently no alternative to receiving Government assistance with the supports they need. They may have difficulty finding or retaining employment or in maintaining social contact if they are not aided optimally. There needs to be a safety net for people with hearing loss, particularly those on low income, who do not meet the access criteria for the NDIS or the eligibility criteria for the Australian Government Hearing Services Program but still need support with their hearing needs. The eligibility criteria for the Australian Government Hearing Services Program should be reviewed to determine what changes are needed to allow it to address the needs of people with hearing loss who do not qualify for the NDIS.

RECOMMENDATION 23

That a pathway to Government funded hearing supports be identified for people with hearing loss who do not qualify for the NDIS.

12. REGISTRATION AND ACCREDITATION REQUIREMENTS FOR PROVIDERS

It is not clear where services will be available to NDIS participants once the in-kind arrangements with the Australian Government Hearing Services Program cease in June 2020.

The availability of providers could be impacted by the NDIS registration and accreditation requirements. Providers are reporting NDIS requirements for registration and ongoing accreditation are expensive and onerous and make it difficult particularly for small businesses to register and provide services to NDIS participants. This may cause existing providers who are no longer able to continue to be registered to leave the market, and new providers may not have the resources or financial capital to enter the market. The loss of these providers to the system will impact choice and control, particularly in rural and regional areas.

RECOMMENDATION 24

That the NDIA ensures that the registration and accreditation requirements support quality care to clients, while also supporting the ability of service providers to register and provide NDIS participants with access to services particularly in rural and regional areas.

13. END OF IN-KIND ARRANGEMENTS WITH THE AUSTRALIAN GOVERNMENT HEARING SERVICES PROGRAM

Once the in-kind arrangement ceases in June 2020 there will be a need for a significant education program to help planners, providers and participants understand the options for accessing hearing services. In particular, participants who have been familiar with receiving services under the Australian Government Hearing Services Community Service Obligations Program will need advice on how to manage their own funding for hearing services in the future.

RECOMMENDATION 25

That the NDIA provides clear information to planners, providers and participants about options for accessing hearing services after transition is complete in mid-2020. This should include individualised advice for those who have been eligible for Community Service Obligations-funded services under the Hearing Services Program.

NDIS ACCESS REQUIREMENTS FOR HEARING LOSS Deafness Forum plain language version

NDIS access is dependent on your age, residency status and disability.

To access the NDIS you must satisfy the following 3 conditions:

4. be aged under 65 years AND
5. live in Australia and be an Australian citizen or hold a permanent visa or a Protected Special Category visa AND
6. have a permanent impairment that significantly affects your ability to take part in everyday activities, or have a developmental delay

The first two criteria are straightforward. The third point requires further explanation. The NDIA has provided guidelines to clarify the access arrangements in relation to point 3, the disability requirements.

The easiest way to look at the requirements relating to disability is firstly by age and then by hearing loss.

1. People aged 0-26 years

Access is streamlined for people in this age group in recognition of the evidence that shows that early intervention support up to age 26 is critical for people with hearing impairment as the developing brain requires consistent and quality sound input and other support over that period to develop normally and ameliorate the risk of lifelong disability.

For this age group the evidence from an audiologist that shows:

- auditory neuropathy or hearing loss equal to or greater than 25 decibels in either ear at 2 or more adjacent frequencies, which is likely to be permanent or long term; and
- the hearing loss necessitates the use of personal amplification

should be sufficient to satisfy the access requirements without the need for further assessment.

2. People aged 26 – 65 years

The level of evidence required to support an access request for people in this age group varies according to the degree of hearing loss.

- i) The NDIA has developed a list of conditions which are designed to streamline the access process. For hearing loss, a person with a permanent hearing impairment of greater than 90 decibels in the better ear (pure tone average of 500Hz, 1000Hz, 2000Hz and 4000Hz) is eligible to join the NDIS without the need to prove that their disability has substantially reduced their functional capacity. It is accepted that this degree of hearing loss will have a significant impact on the person's functional capacity.

For people with hearing loss less than 90 decibels, the NDIA has given further guidance on what information is required of the applicant.

- ii) People with a permanent hearing impairment of 65 decibels or greater in the better ear must provide evidence that the disability results in substantially reduced functional capacity to undertake communication, social interaction, learning or self-management activities.

- iii) Hearing impairments of less than 65 decibels in the better ear in conjunction with other permanent impairments (for example vision or cognitive impairments), or where there is evidence of significantly poorer than expected speech detection and discrimination outcomes, may also be considered to result in substantially reduced functional capacity to undertake relevant activities. People in these circumstances may also be eligible to join the NDIS.

Providing good evidence will help the NDIA make the right decision about your eligibility for the NDIS. The evidence should demonstrate the impacts of your hearing impairment on different areas of your life. It could relate to the communication challenges you experience in relation to your employment, education and training, social participation, independence or health and well-being. Your audiologist may be required to provide the evidence to support your NDIS Access Request so you need to ensure your audiologist fully understands how your hearing loss is impacting on your daily life.

COMMUNITY OF PRACTICE – HEARING STREAM INTERPRETER AVAILABILITY, MARKET GAPS, COMMUNICATION ASSISTANCE

DESTINATION: People have access to an appropriately skilled interpreter when required.

This body of work was facilitated by Leonie Jackson, chief executive officer The Deaf Society.

ISSUES:

- NDIS has created increased demand for interpreters and there is not the workforce available to meet the demand leaving vulnerable people underserved, unsupported and isolated
- The shortfall will increase as the NDIS continues to roll out, increasing the pressure on the workforce, creating a thin market and setting it up to fail
- NDIS is promoting choice and control without ensuring the sector has the infrastructure to support it. It is leading to thin markets and the potential for market failure
- Participants cannot fully utilise the funding in their packages due to the lack of interpreters which is likely to lead to less funding being made available in future years
- Difficulty accessing interpreters in rural and remote areas
- Shortage of deafblind interpreters or interpreters skilled in deafblind communication
- Casualised workforce – no permanency, annual leave, so some people must supplement it with other employment which in turn reduces their availability for interpreting
- Different pay rates used in education, community interpreting. People with self-managed plans can negotiate rates directly with the interpreter which is driving up the cost
- Need strategies to maintain the existing workforce of interpreters as well as attracting new people to the profession
- The accreditation process is slow and causing delays in people obtaining their interpreter qualification
- After the interpreters qualify, they need time to gain experience before taking on more challenging situations such as interpreting for people requiring mental health services
- Different individuals may organise an interpreter for the same event leading to unnecessary duplication and tying up interpreter time that could have been used elsewhere
- Individuals have used NDIS to book an interpreter for events where interpreters have already been provided eg the Royal Commission into Aged Care
- Use of family members as interpreters particularly in planning sessions may not be supporting true individual choice and control
- Lack of understanding of consumer needs and access to interpreters
- Interpreters need upskilling and refresher courses to ensure they retain competency and proficiency
- Individuals who are deafblind can find it difficult to book an interpreter
- Interpreting bookings for deaf people appear to be prioritised over bookings for deafblind people
- The Australian Sign Language Interpreters Association proposes that only interpreters with NAATI qualifications be permitted to provide services to NDIS participants, including self-managed participants.
 - The National Accreditation Authority for Translators and Interpreters, known as NAATI is the national standards and accreditation body for translators and interpreters in Australia.
- The Australian Sign Language Interpreters Association proposes the creation of an independent registration board to address unethical behaviour and ensure quality access

DATA

Victoria: Currently has 16 full time interpreters. Demand is increasing by 2% so will need 33 full time interpreters. Currently 10% of bookings unfilled.

Queensland: 40% of interpreters have indicated they are considering leaving the profession in the next 6 years.

NSW: Current request for services fulfillment rate is 70%.

Of the numbers of students who start the Certificate II courses only 1 in 7 will complete the Diploma of Interpreting course. If all of the courses were running back to back it would take 7 years to gain the qualification as a paraprofessional level interpreter.

CURRENT STRATEGIES

- Fast track courses have been developed in some states. Unfortunately, the trainee needs to wait until June to take the National Accreditation Authority for Translators and Interpreters examination and then it takes another 3 months to learn of the results. Demand to undertake the training has been strong but the pathway to qualify needs to be improved
- Increased use of affordable technology to provide interpreter services in rural and remote areas
- In Victoria there are about 100 schools teaching Auslan. By Year 6 some children are doing Certificate II and III courses which may lead to a long term career as an interpreter. If the Certificate courses can be incorporated within the high school curriculum, then the Diploma can be completed at TAFE which would help to fast track the qualification process
- Online classes to teach Auslan are being investigated in rural NSW
- In NSW there is a closed Facebook group where people attending the same event can organise captioning or an interpreter to avoid duplication in bookings
- Use of communication support workers or unaccredited interpreters in very specific low risk situations

RECOMMENDATIONS:

- Quantify the shortfall in the interpreter workforce in all states
- Provide “fast track” courses with a shared curriculum in all states
- Address delays in timing of examinations and availability of results from National Accreditation Authority for Translators and Interpreters
- Investigate potential to make Auslan available in more schools
- Develop an award for interpreters to improve employment conditions and help to make interpreting a more attractive career choice
- Provide more education for participants on situations where an interpreter would be made available outside of NDIS funding to avoid duplication
- Develop mechanisms for co-ordinating interpreters for events to avoid duplication
- Develop guidelines for the use of communication support/unaccredited interpreters
- The NDIS needs to help the sector put the infrastructure in place to support participants with the services they need

COMMUNITY OF PRACTICE – HEARING STREAM HEARING DEVICES AND REHABILITATION

Currently, NDIS participants with hearing loss are accessing hearing services through the in-kind arrangements with the Australian Government Hearing Services Program. These arrangements are working well for children but are not always providing the level of support that is needed by adults. The in-kind arrangements are due to cease in June 2020 and therefore planning is needed regarding the inclusion of hearing supports into NDIS funding plans in relation to:

- The rehabilitation programs that will be needed and funded for NDIS participants
- The range of assistive technology that will be funded
- How NDIS participant will be able to identify practitioners with the competency to deliver services for people who have complex hearing rehabilitation needs

The issues that need to be considered apply differently to children and adults.

CHILDREN

It is not yet clear whether hearing services for children will become contestable once the in-kind arrangements cease or whether paediatric hearing services will remain with as the sole provider. Consumers, particularly parent groups, are very keen for Hearing Australia to be nominated as the sole provider of hearing services for children under the NDIS for reasons of expertise, access and equity, clinical standards and independent advice. Hearing Australia would also act as a safety net to ensure that children did not fall through the gaps. The only exception to the sole provider arrangement would be for children with cochlear implants as these children currently receive their clinical services from an implant clinic audiologist rather than Hearing Australia and it is expected that this arrangement would continue. Regardless of whether Hearing Australia remains as the sole provider of hearing services to children with hearing aids, the child's NDIS plan will in future need to include funding for hearing rehabilitation, assistive technology, repairs, device replacements and batteries.

The NDIS plans for children need to fund a hearing and communication program that allows the child and their family to access their paediatric audiologist at regular intervals. The number of appointments needed varies according to the age of the child, the age of onset of the hearing loss and whether the child has other disabilities.

The hearing rehabilitation program needs to commence as soon as the family are ready and should not be delayed by the NDIS access pathway.

The hearing aids and other assistive technology required by children needs to maximise the child's residual hearing and also contain appropriate safety features particularly for very young children. The child's family, carers, teachers and other professionals working with the child need to not only understand how the device functions, but also what to expect from the child when they are wearing their devices. Some of this support is provided by the audiologist visiting the child's school.

The devices need to be replaced at regular intervals due to normal wear and tear or when new technology becomes available that provides significant clinical benefit to the child. Devices also need to be replaced due to loss or damage. This occurs quite regularly for children compared with adults and needs to be factored into the child's NDIS plan. Funding also needs to be available for batteries and device repairs.

If services do remain with Hearing Australia it is expected that the arrangement would ensure that children are seen by an audiologist with appropriate expertise. If services become contestable then families need a mechanism to easily identify audiologists with the competencies required to provide services to children. These services should not be provided by audiometrists as it would be beyond their scope of practice.

The funding arrangements will be more complex for children with cochlear implants as their services will be funded partly through Medicare and partly through the NDIS. The initial cochlear implant would be funded as per existing arrangements however replacement speech processors and upgrades to new technology would need to be funded under the NDIS. Cochlear implant replacement processors and upgrades including repairs and replacement parts are currently funded under the Australian Government Hearing Services Community Services Obligations Program and administered by Hearing Australia. Once the in-kind arrangements cease Hearing Australia would no longer have a role in these arrangements and the funding for these items would need to be included in the child's NDIS plan and they would access these items through their cochlear implant centre. Children with cochlear implants also need some additional assistive technology funded in the NDIS plan such as remote microphones which they would also access via their implant clinic audiologist.

While the mapping of the speech processor is covered under Medicare, there would be a need for the child to have some rehabilitation services funded in their NDIS plan such as fitting and review appointments for additional assistive technology.

ADULTS

Once the in-kind arrangements with the Hearing Services Program cease, adults with hearing loss will need to have rehabilitation programs and assistive technology included in their NDIS plans.

The hearing rehabilitation program needs to commence as soon as the individual is ready to proceed and should not be delayed by the NDIS access pathway.

Many NDIS participants with hearing loss will require intensive communication programs supported by an appropriate level of technology. They will need to be able to identify the audiologist with the appropriate expertise to provide the clinical services they need. The person's plan will need to include funding for hearing rehabilitation programs, hearing aids and other assistive technology, device repairs, replacements and batteries as well as other supports required by the participant such as interpreting services, speech pathology and occupational therapy.

The range of hearing supports required by a person with complex hearing rehabilitation needs is currently provided through the Australian Government Hearing Services Community Service Obligations Program. The services and devices provided under the Community Service Obligations Program are vastly different to what is available under the Australian Government Hearing Services Voucher Program so the Voucher Program should not be used as the basis for funding an NDIS plan for a person with hearing loss. It will be critical for NDIS planners to receive advice from the participant's audiologist and other professionals working with the person to ensure that the participant's plan contains sufficient funding for the person to access the clinical services, assistive technology and other supports that the person requires.

It is not clear how the level of technology that will be funded under the NDIS will be determined. Under the Community Service Obligations Program, Hearing Australia determines the level of technology that can be funded under the fixed funding allocation they receive each year. The level of technology and the range of devices is very different to what is available under the Voucher Program as is appropriate for clients with more complex hearing rehabilitation needs. It is expected that clients will continue to be able to access a range of devices that will best meet their needs.

As with children, the funding arrangements will be more complex for adults with cochlear implants as their services will be funded partly through Medicare and partly through the NDIS. The initial cochlear implant would continue to be funded as per existing arrangements however replacement speech processors, upgrades to new technology and repairs and replacement parts would need to be funded under the NDIS. Currently, the Hearing Services Community Service Obligations Program has only been funding repairs and replacement parts for eligible adults with cochlear implants. Replacement speech processors and technology upgrades for adults have not been funded under the Community Service Obligations Program. Hearing Australia has had no role in managing a funding allocation for cochlear implant speech processors for adults or determining clinical protocols for adults with cochlear implants to access upgraded technology.

While the mapping of the speech processor would continue to be funded under Medicare, other components of the person's rehabilitation program would need to be funded in their NDIS plan including additional technology.

In addition to accessing rehabilitation services from an audiologist, adults with hearing loss may need other supports to be funded in their plans including interpreters, speech pathology, occupational therapy, as well as ongoing support from organisations such as Hearing Matters Australia or Better Hearing Australia.

TRANSITION FROM IN-KIND ARRANGEMENTS

The changes in support arrangements for people with hearing loss that will commence in July 2020 are significant. The new arrangements will need to be supported with an education campaign that targets NDIS staff, professionals working with people with hearing loss, consumer organisations, referrers including medical practitioners and specialists and people with hearing loss.

In particular, participants who have been familiar with receiving services under the Australian Government Hearing Services Community Service Obligations Program will need advice as to how to manage their own funding for hearing services in the future.

RECOMMENDATION

That NDIA provides clear information to planners, providers and participants about options for accessing hearing services after transition is complete in mid-2020. This should include individualised advice for those who have been eligible for Community Service Obligations-funded services under the Hearing Services Program.

COMMUNITY OF PRACTICE – HEARING STREAM DEAFBLINDNESS

The functional impact of deafblindness is not just the sum of two single sensory disabilities. It is more complex than this.

This body of work was facilitated by Meredith Prain, director of Deafblind Australia, deafblind facilitator.

1. TERMINOLOGY AND ACCESS

There are several conditions that cause deafblindness including Usher Syndrome (I, II, III), CHARGE syndrome, Congenital Rubella Syndrome, Norrie Disease and Ageing. Some of these conditions are progressive and can also impact on other senses such as balance and can cause developmental delays.

There are a range of terms used to indicate that a person has a disability that affects more than one of their senses including deafblindness, dual sensory impairment and multisensory impairment.

As there is no single, accepted term to describe a disability that affects hearing, vision and potentially other areas of a person's functional ability there is no clear, consistent way to flag to the NDIS planners that the participant is going to have quite complex needs.

Additionally, not all individuals with vision and hearing impairment use the same terminology to describe their disability and it is important for people to be able to identify in the way that they want. However, it is critical that as soon as NDIS staff see someone with a combined vision and hearing loss, it is understood that this individual's needs will be different to a person who is blind or deaf.

The NDIS is using a medically based definition of deafblindness which is "permanent severe to profound vision impairment combined with a permanent severe to profound hearing impairment". This definition is not consistent with the international or Australian definition of deafblindness, and the application of this definition as a criteria for access to the NDIS is not consistent with the WHO International Classification of Functioning, Disability and Health (ICF) which is used as the basis for NDIS access in other areas of disability.

The definition used by not for profit body Deafblind Australia looks at the functional impact of deafblindness.

*"Deafblindness is described as a unique and isolating sensory disability resulting from the combination of both hearing and vision loss or impairment. This has a significant effect on communication, socialisation, mobility and daily living."
Deafblind Australia (2018)*

The NDIS definition is restrictive and is not supporting early intervention in cases such as Ushers Syndrome where there is likely to be a progressive loss of hearing and vision and early intervention is key to helping the individual prepare for the future.

There is also inconsistency in the NDIS access criteria for people with a single sensory impairment of hearing loss or vision loss.

Where an individual has a hearing loss alone the access criteria is clearly defined and allows for people up to the age of 26 years with milder losses to receive supports through the NDIS.

Where an individual has a vision loss alone the access criteria is more restrictive. Even children who have structural abnormalities, eg, born without eyes, are not consistently accepted by the NDIS. NDIS is looking for a visual acuity of 6/60 or worse and it can be difficult to obtain a visual acuity measurement in a young child or for those that cannot fix and follow. Children with vision impairment are needing more streamlined access to the NDIS similar to the arrangements for children with hearing impairment.

The functional impact of deafblindness is not just the sum of two single sensory disabilities. It is more complex than that. The person will require different supports to those participants with a single sensory disability. In some cases of deafblindness, the hearing or vision impairment and its impact can change over time. NDIS staff need to be aware of that and be prepared to regularly review and update the participant's plan to reflect any new supports that are required.

Additionally, the NDIS requires people to nominate their primary disability and does not accept deafblindness as a term to describe the primary disability. This needs to change. If the cause of deafblindness also results in other physical, sensory or cognitive impairments then it would be difficult for the individual to nominate a single disability as their primary disability. There is a risk that the application process could contribute to the lack of understanding of the impact on the individual who has deafblindness and could lead to people with deafblindness not having all of their needs met in the NDIS plans. The listing of deafblindness as the primary disability should immediately direct the planner to reference material outlining the range of usual supports required. This would save the participant from having to educate and advocate for even the most basic supports with a planner who has no understanding of the challenges faced by a person with a dual disability.

RECOMMENDATION 1

That the NDIA adopts an acceptable criterion that measures the functional impact of deafblindness

RECOMMENDATION 2

That the NDIA reviews the access criteria for vision impairment, particularly for children, to ensure they are able to access early intervention supports in a timely manner

RECOMMENDATION 3

That the NDIS allows participants to describe their primary disability as deafblindness or multisensory impairment

RECOMMENDATION 4

That there be a process to flag to the Local Area Coordinator (LAC) and NDIS planner that the needs of an NDIS participant with deafblindness will be different to an individual who is deaf or blind

RECOMMENDATION 5

That in situations where the condition is progressive, that NDIS planners and plans are flexible and responsive in providing early intervention supports to assist the person to prepare and adapt to changes in their functional ability

2. KNOWLEDGE AND EXPERTISE

Potential NDIS participants with deafblindness and their families and carers need information on what the NDIS can do to support their needs, and the information needs to be in a format that makes it accessible. Potential deafblind participants need to be able to include the supports they need in their plan in a streamlined way without having to explain and advocate for even very basic supports because they are different to those used by people with a single sensory impairment. Deafblind participants may not always be aware of the full range of supports available and NDIS planners may not understand the range of supports that would help the participant achieve their goals. There needs to be mechanisms to ensure that participants do not miss out on supports through lack of knowledge either in themselves or in their planner.

The level of knowledge of deafblindness is very limited and mostly non-existent among professionals and NDIS staff. People in very vulnerable situations are required to constantly educate and strongly advocate to gain access to the supports they need and they are expected to do this repeatedly due to the constant changes in LACs and planners. This should not be necessary. Action is needed to ensure more streamlined access to support services for people who are deafblind. This will mean educating professionals as well as NDIS staff on the functional impact of deafblindness and the range of supports that are available to assist deafblind people in various aspects of their life.

Parents of newly diagnosed children are particularly vulnerable and unlikely to be in a position to outline needs and goals to an NDIS planner. This situation is further complicated if the NDIS planner has no understanding of deafblindness. While the NDIS may have a standardised list of questions for planners to use, not all planners seem to be aware that the questions exist or understand the complexity of the disability resulting in plans that are unlikely to include all of the supports that are needed by the participant.

Given staff turnover levels in the NDIS there is a need for constant upskilling of new recruits. Even when staff have been trained, it is hard for them to retain knowledge of a disability that they will not see frequently. Therefore, it would be beneficial if people with deafblindness were immediately referred to a senior planner who understands the complexity of their needs. If deafblind participants could be seen by a senior planner with knowledge of deafblindness instead of having to be initially seen by a Local Area Coordinator and a planner with no knowledge of the particular needs of a deafblind person it would save time, money and avoid frustration for staff and participants. It would also avoid the participant having to constantly explain and justify their needs. This constant need for the participant to prove what they can't do is confronting and disheartening especially for those whose condition is progressive. Having access to a senior planner who is going to immediately understand the needs of a deafblind participant would make the interaction more positive and less time consuming.

It would also be helpful for the NDIS to engage subject matter experts, either internally or externally, to advise NDIS staff on how they can best support an NDIS participant with deafblindness.

Similarly, professionals working with people with hearing or vision impairment may not have a good understanding of deafblindness. These professionals also need access to deafblind consultants to help them provide effective programs and supports for their clients who are deafblind. There is a need for professional development programs for allied health professionals working with deafblind clients and allied health discussion groups where professionals can support each other to provide the best programs for deafblind clients.

RECOMMENDATION 6

That the NDIS takes action to ensure that potential NDIS participants with deafblindness, their families and carers are aware of the NDIS, understand what the NDIS can do to support their needs and are able to access the supports they need in a streamlined way

RECOMMENDATION 7

That the NDIS educates staff in deafblindness, provide support materials and access to advisers with expertise in deafblindness to ensure that the NDIS plans contain appropriate supports

RECOMMENDATION 8:

Given the diversity of the deafblind population and the complexity of their needs, NDIS participants should be referred to a senior planner with knowledge of deafblindness as soon as they are accepted into the NDIS

RECOMMENDATION 9:

That professionals who are working with deafblind clients have access to education, support materials and subject matter experts to ensure they are able to provide effective programs and supports to clients with deafblindness

3. DEAFBLIND CONSULTANTS

People with deafblindness including multisensory impairment need the support of someone with knowledge of deafblindness to help them to navigate the NDIS, to understand the supports that are available and then to help them access those supports. Programs in the UK and the USA use a model of deafblind specialists to support people with deafblindness. This model needs to be adopted in Australia.

When using a consultant it is important that the participant retain choice and control. The consultant provides independent, unbiased advice to the participant to help them to obtain the full range of supports they need. They are there to support the participant, not to decide for the participant.

RECOMMENDATION 10

That NDIS participants with deafblindness have access to deafblind consultants to help them to access the NDIS effectively and to access the supports that are included in their plans

4. SPECIALIST SUPPORT CO-ORDINATION

Families with a child with deafblindness have to act as advocates, teachers, interpreters, communication guides and carers. It is challenging to fulfil all of those roles without a trusted ally to help them on their journey. Families need access to independent, unbiased support that they know they can trust as they try to work their way through the various medical, allied health, early intervention, education and NDIS pathways to access the services their child needs. Similarly, deafblind adults need support to navigate the same pathways as well as employment and Centrelink services. There needs to be a key support worker with specialised knowledge of deafblindness that the family or individual can access to guide them through and help them navigate the various systems that are there to support them.

Families and individuals also want to have contact with other deafblind people for support, socialising and mentoring.

People with deafblindness including multisensory impairment can find it difficult to co-ordinate all of the supports that they need so that they gain the maximum benefit from the NDIS plans. It can also be difficult to find providers with the expertise needed to work with people with deafblindness. Deafblind people would benefit from having a specialist support co-ordinator such as a social worker to help them to link with appropriate providers, peer groups, information and research.

RECOMMENDATION 11

That people with deafblindness have access to a specialist support coordinator with knowledge of deafblindness to ensure they gain the maximum benefit from their NDIS plans

5. PEER SUPPORT

An important way for a person with a disability to find support, reassurance, advice, information and a social connection with people with the same disability is through a peer support network. Social groups and peer mentoring programs are fundamental in encouraging and supporting the mental health of its members and should be included in NDIS Plans. Representative organisations and peer groups also play a role in empowering and supporting participants to get the most out of the NDIS.

While there are a few organisations that fulfil this role for people with deafblindness including multisensory impairment, many are run by volunteers and do not have ongoing funding to make the organisations sustainable. The NDIS provides some funding to organisations through ILC grants but these are time limited and project specific and require significant work to complete the grant application which is often beyond the capacity of small voluntary organisations. Peer support is vital to deafblind people and their carers as it helps to build capacity and resilience. It is important that NDIS funding is available to ensure support/representative organisations are sustainable so they have the ability to run the types of activities that provide peer support such as conferences and camps for deafblind children and their siblings. Without ongoing funding there is a high risk that existing representative organisations will close. There is already evidence that activities that have been valued over the years eg the National Deafness Sector Summit will cease due to the lack of funding.

RECOMMENDATION 12

That the NDIA ensures that NDIS funding is available to build capacity in the deafblind sector and support the sustainability of existing support/representative organisations

6. INTERPRETERS AND COMMUNICATION GUIDES

There is not a good understanding of the difference between the various supports used by people with deafblindness. There is a workforce shortage of interpreters generally, but especially interpreters for deafblind participants, and a shortage of communication guides. Consequently, interpreters are at times working outside of their role and also acting as communication guides to fill a need. Similarly, because of the shortage of interpreters, participants are using communication guides alone when they should also have an interpreter present. These workforce issues need to be addressed.

Interpreters for deafblind participants require additional skills to Auslan interpreters, and communication guides need different skills to a disability support worker. The higher-level skills required by both professions need to be recognised by the NDIS and remunerated appropriately.

The pathway into the workforce supporting deafblind people needs to be strengthened. Communication guiding is a new field and requires formalised training and accreditation to be established. There is also a need for more consistent training programs and accreditation standards for deafblind interpreters.

The lack of understanding of deafblindness by NDIS planners is reflected in some current NDIS plans in relation to the provision of interpreter hours. Some participants have had occupational therapy or occupational mobility training included in their plans but not the interpreter hours to allow the participant to utilise these supports. NDIS planners need to understand that interpreters need to be included for deafblind participants to access some of the supports included in their plan. Planners also need to understand how communication guides build capacity and therefore need to be included as part of funded activities.

Due to workforce shortages some deafblind participants are using family members as interpreters in their planning meetings. Using a person who is not a professional interpreter means they are not bound by a code of conduct on how to interpret in that setting. At times family members are putting their own advice and opinions into the discussion which can mean the participant misses out on funding for a professional interpreter.

Communication guiding is a new role and deafblind people may not be aware of its existence. They need information as to how this role can assist them in daily activities and ensure it is something that is included in their NDIS plans. The role is particularly important for people in group homes or supported accommodation who can feel particularly isolated. Communication guides would play an important role in helping deafblind people to socialise which could improve their mental health and well-being as their feeling of isolation would be reduced.

RECOMMENDATION 13

That a workforce strategy be developed to address the shortage of deafblind interpreters and communication guides. The strategy needs to commence with an audit of the workforce working with people with deafblindness including interpreters, communication guides and support workers to quantify the shortages by State. The strategy needs to identify the action needed to address the skills shortage including the need for more formalised and consistent training and accreditation of interpreters and communication guides

RECOMMENDATION 14

That deafblind interpreters and communication guides be recognised by the NDIS as distinct professions and remuneration rates that recognise the additional skills required of these roles be included in the pricing guide

RECOMMENDATION 15

That NDIS planners be trained in the need for interpreters and communication guides to be routinely included in the participants plan in order for a deafblind participant to access certain supports

RECOMMENDATION 16

That professional interpreters rather than family members be used in NDIS planning sessions with deafblind participants

7. THIN MARKETS

There is a serious lack of allied health professionals and educators with the expertise needed to support children and adults with deafblindness including multisensory impairment. Western Australia offers the best range of supports followed by Victoria. Royal Institute for Deaf and Blind Children (RIDBC) has expertise in early intervention for children with multiple sensory impairment. These services need to be supported to grow their capacity and other states need programs to help to develop the expertise that will be needed in order to meet the growing demand that has been generated by the NDIS. Able Australia and Senses Australia recognise the need to build capacity across the sector and are developing training packages. Additional funding would help to speed up the process.

NDIS participants may have particular supports approved in their plans but they cannot find the providers with the appropriate expertise to deliver the service. There needs to be a strategy that helps to build expertise in the market to provide the specialist services needed by deafblind people.

RECOMMENDATION 17

That the NDIA reviews the level of support available for people with deafblindness including multisensory impairment in each state and take the necessary action to build the expertise required to meet the needs of people with deafblindness including multisensory impairment

In the allied health area, the professional organisations need to be made aware of the gap in knowledge and expertise in working with people with deafblindness including multisensory impairment among audiologists, optometrists, orthoptists, speech pathologists, physiotherapists, occupational therapists, counsellors, social workers, psychologists, early childhood teachers, teachers of the deaf and specialist teachers of vision impairment.

RECOMMENDATION 18

That professional organisations be made aware of the gap in knowledge and expertise in working with people with deafblindness including multisensory impairment so they can take the necessary action to build capacity within the membership of the various professions

The NDIS promotes choice and control but the market is experiencing a reduction in the number of providers so in some cases choice has been reduced since the NDIS has been introduced. Some small early intervention providers have not been able to cope with the change from block funding to fee for service funding arrangements and have either closed or been subsumed by larger providers leaving less choice for families. If State Governments decide to discontinue their involvement in the provision of early intervention programs the market will be even more limited. Programs required by children with deafblindness including multisensory impairment are not widely available, require high level expertise and are costly to deliver. These programs could disappear completely if they are not adequately funded through the NDIS leaving families with no appropriate early intervention options for their child.

Additionally, the NDIS requirements for registration and ongoing accreditation are expensive and onerous and make it difficult particularly for small businesses to register and provide

services to NDIS participants. The loss of these providers to the system will impact choice and control, most acutely in rural and regional areas.

RECOMMENDATION 19

That the NDIA reviews the changes in the market that have been caused by the introduction of the NDIS and take the necessary action to ensure that market is not reduced to the point where there is no real choice of provider and that small specialised programs, such as those required by children with deafblindness, continue to be available

RECOMMENDATION 20

That the NDIA ensures that the registration and accreditation requirements support quality care to clients, while also supporting the ability of service providers to register and provide NDIS participants with access to services particularly in rural and regional areas

8. 0-6 YEAR PATHWAY ISSUES

HEARING IMPAIRMENT

A pathway has been established to ensure a smooth and rapid entry into the NDIS for children diagnosed with hearing loss, particularly through newborn hearing screening programs. Hearing Australia plays a major role in the pathway by helping families with the access process and by providing the evidence required by the NDIS to show that the child meets the access requirements. Because of the in-kind arrangements between the Australian Government Hearing Services Community Service Obligations Program and the NDIS, Hearing Australia can proceed with device fitting prior to the child being accepted into the NDIS and having a funded plan approved. These in-kind arrangements cease in June 2020. At that time, it is possible that the audiological services will become competitive which will put the facilitated pathway at risk. The device fitting could also be delayed from that time as the provider will need to wait until the child has an NDIS plan approved before proceeding with device fitting. Any delay in device fitting could have a significant impact on the child's development.

Hearing Australia also has a role in providing independent, balanced advice to families on early intervention programs, technology options and other support services without being influenced by sales targets or commissions. This role is valued by families and needs to continue in some form from July 2020 when the in-kind arrangements cease.

As Hearing Australia has been the sole provider of services to children requiring device fitting for approximately 70 years, it is not clear whether the market would be able to offer the same level of service in the same locations should services become contestable. There is a risk that providers will limit services to areas which are easy to service i.e. urban areas, so that children in rural and remote areas may be left without services or have to travel considerable distances in order to access the expertise they require.

Families need clarity on how hearing services will be delivered from July 2020. Parent groups want services to remain with Hearing Australia.

RECOMMENDATION 21

As a matter of urgency, the NDIA retains Hearing Australia as the sole provider of services to children requiring device fitting, and provide information on how hearing services will be delivered under the NDIS from July 2020

VISION IMPAIRMENT

Currently vision impairment eligibility criteria for children 7 years and over is applied to children 0 – 6 years as well, i.e. permanent blindness in both eyes, diagnosed and assessed by an Ophthalmologist as follows:

- Corrected visual acuity (extent to which an object can be brought into focus) on the Snellen Scale must be less than or equal to 6/60 in both eyes; or
- Constriction to within 10 degrees or less of arc of central fixation in the better eye, irrespective of corrected visual acuity (i.e. visual fields are reduced to a measured arc of 10 degrees or less); or
- A combination of visual defects resulting in the same degree of visual impairment as that occurring in the above points.

Under early intervention there are broader opportunities for developmental concerns to be funded over a straightforward diagnosis. The child can meet eligibility for the NDIS if they are identified as being at risk of developmental delay that has a functional impact on their communication, social interaction, learning, mobility, self-care or self-management. Vision impairment is also a low incidence disability, and when there are no obvious structural abnormalities it can often be overlooked. In addition, the cause of vision impairment can take some time to diagnose in young children under the age of 3 years. Vision impairment also frequently occurs with other disabilities such as cerebral palsy or seizures. In many cases treatment or intervention for these other coexisting conditions or disabilities is prioritised before a vision impairment is suspected. This can then result in a delayed referral for early intervention for vision impairment or if the child has already met access request to NDIS with another disability their package will not reflect the supports they require for early intervention to address their vision needs. This may also translate to children with deafblindness 0 – 6 years, as their hearing impairment is what they would first gain access to NDIS.

RECOMMENDATION 22

That the NDIS works with Vision2020, Deafblind consultants and the health sector to put in place a consistent approach for identifying children 0 – 6 years with atypical visual behaviours that may be at risk of developmental delay and benefit from early intervention supports funded by NDIS

9. EARLY INTERVENTION

State Government Early Intervention programs have provided a safety net in offering services in locations where there are no other providers and offering programs that are not otherwise available including programs for children with deafblindness or multisensory impairment. State Government programs are not funded through the NDIS and may not continue once the NDIS is fully implemented. If they cease these programs then families could be left with no early intervention options that meet the needs of their child. In Victoria, the State Government funded early intervention program at Aurora which offers programs for children with deafblindness is overwhelmed with the demand for service. It is not clear where these families would access services if the programs at Aurora were not available.

RECOMMENDATION 23

That State Government early intervention programs continue to be funded as they offer essential programs particularly for children with deafblindness or multisensory impairment and children living in rural and remote locations

Families need access to unbiased, independent advice in order to make an informed choice about their child's early intervention program. They also need advice on what should be included in their child's NDIS plan. Most parents will not have the knowledge particularly in the early years to know what is available and what to ask for during the meetings with the NDIS planner. In some cases it appears that decisions are being made by the NDIS planner rather than the participant or their carer as to what therapies or assistive technology would be appropriate. A family support worker with expertise in deafblindness or a deafblind consultant would ensure that the child and their family is well supported through the medical, allied health and education pathways that they will need to navigate so they are able to make informed decisions and not have decisions made by others.

RECOMMENDATION 24

That families have access to independent, balanced advice and support from a family support worker with expertise in deafblindness or deafblind consultant

Currently, some supports such as occupational therapy, orientation and mobility training and communication training have not been included in NDIS plans yet, these supports would be routinely required by people recently diagnosed with deafblindness or who have a progressive condition. The participant may not have sufficient knowledge of deafblindness to know what to ask for, or what options are available unless they have access to an advocate such as a deafblind consultant, and the NDIS planner may not have the knowledge to inform the participant and their carers of the various options. NDIS planners need information on best practice early intervention programs to ensure that all necessary supports are included and funded.

RECOMMENDATION 25

That NDIS planners have access to information on best practice early intervention programs in order to ensure that all necessary supports for people with deafblindness are funded

Some children with deafblindness or multisensory impairment may need regular medical treatment due to other health conditions. This can affect their progress. The medical condition can cause setbacks which means that some intervention services may need to be reintroduced to the child's plan. Once an intervention program has been included in a child's plan it should continue even if the child goes to hospital.

RECOMMENDATION 26

That NDIS planners be made aware that the needs of children with deafblindness including multisensory impairment can change due to other health factors and the child's plan may need to be adjusted accordingly

RECOMMENDATION 27

That intervention programs that have been included in a child's plan continue to be provided wherever the child needs to access the program including during hospital admissions

With deafblindness there can be changes in the person's hearing and vision over time. For example, with Usher syndrome, hearing loss is present at birth and vision problems occur later. It is important for individuals to have access to programs such as orientation and mobility training as early as possible to build capacity so they are well prepared for the future. If the individual is prepared to start these programs before the vision impairment starts to have a significant impact then it should be possible to factor that funding into their NDIS plans. Helping

the individual accept that their circumstances will change over time would also help reduce feelings of depression and anxiety in the longer term.

RECOMMENDATION 28

That the NDIS plans allow for early access to programs that will address the impact of conditions that change over time

NDIA/NDIS has endorsed the Best Practice guidelines as set out by Early Childhood Intervention Australia (ECIA), in which family centred practice, key worker model and team collaboration are core components. Currently the funding packages for children with vision impairment and additional disabilities do not appear to adequately fund the non-face to face intervention time to work with such complex children and service providers are finding it challenging to adhere to these best practice principles while remaining sustainable.

RECOMMENDATION 29

That NDIS planners, LACs and ECEI partners have some consistent training around ECIA best practice principles and how these should be considered and reflected in the recommendation for an early intervention NDIS package.

10. EDUCATIONAL SETTINGS

There is inconsistency with the funding of technology to support children and young adults in their educational setting. Some planners are including goals that are education related in the participant's plan, whereas other participants are told that NDIS does not fund anything relating to education. There are differences with what is funded by State education services to support a child with a disability, and what is available through Catholic and independent school systems. The provision of equipment funded through state school systems may be linked to age rather than need which can be limiting for the individual. Some equipment might benefit the child at home as well as school so in these cases it is likely to fit within NDIS guidelines. Participants should not be left in a position where they are left without the technology support they need due to different interpretations of the funding arrangements for equipment used in educational settings.

RECOMMENDATION 30

That the NDIS consults with various education systems and develop clear guidelines on the provision of equipment to ensure that children and young adults have equipment to use in the environments where they need to use it

There is often a need for allied health professionals to work with children in a school setting. The service is funded under the participants NDIS plan but not all schools will allow allied health professionals to work on school premises. It is recognised that the health professional would need to undergo working with children checks and other safety training which can slow down the provision of services in a school setting. However even after that training is completed it doesn't guarantee access to the school. It is then left to the family to educate and negotiate with the school on the need for the allied health professional to be able to work in the school environment.

RECOMMENDATION 31

That education systems be briefed on the importance of allowing allied health professionals to support children in a school setting where that support has been included in a participant's plan

and develop guidelines so that it is clear what requirements allied health professionals need to satisfy in order to provide services in a school setting

The supports available in school for children with a disability varies widely across educational systems and across states. Some families are having to move states in order to access the educational support their child needs. There needs to be more consistency in what educational services are providing to support children with a disability, particularly sensory disability.

RECOMMENDATION 32

That standards be developed on the support services that should be available in all educational settings and education systems be funded appropriately so that children can access the support services they need regardless of where they live or the educational system their family chooses for their child. This needs to be communicated clearly to parents, NDIS planners, LACs and schools

11. MENTAL HEALTH AND DEAFBLINDNESS

There is significant evidence to show that the levels of depression and anxiety in children with deafblindness are higher than the general population. Adults with deafblindness also experience depression and anxiety due to their disability particularly when the level of disability changes over time. For some people with deafblindness, their mobility changes over time, their hearing changes over time, the environment becomes more challenging and communication becomes more difficult. The person's community participation and employment may be affected by the changes in their abilities. The person can become anxious and depressed as they come to terms with their change in circumstances.

It is essential that NDIS planners recognise that the anxiety and depression is directly related to the participants disability and therefore appropriate supports whether they be seeing a psychologist or accessing programs such as creative arts therapy that address the anxiety and depression need to be included in the participant's plan. Some participants have been able to access professionals and programs that support their mental health and wellbeing whereas other participants have been told it is a health issue and therefore not covered by the NDIS. As these mental health issues are directly related to the participant's disability there should be no question that the supports required should be included in the participant's NDIS plan.

RECOMMENDATION 33

That NDIS planners are trained on the impact of deafblindness on the participant's mental health and wellbeing and support the participant in having any needs relating to depression and anxiety addressed through their NDIS plans

The parents of children with deafblindness including multisensory impairment may also find their mental health and wellbeing is affected from the demands of their role as a carer, advocate, teacher and parent of a child with deafblindness. If the well-being of the parent is affected to the point where they are unable to cope, then the implications for the child and family are significant. Where the effect on the parent's mental health is directly related to their child's disability the NDIS should provide the supports needed to help families to stay well in order to support their child.

RECOMMENDATION 34

That the NDIS provides mental health and wellbeing support for families with children with deafblindness including multisensory impairment

12. GROUP HOMES AND DAY SERVICES

People with deafblindness who are living in group homes or using day services often do not receive the supports they require as the impact of the dual disability is not well understood. There is a risk for people in these settings to become isolated. Deafblind people in group homes have the potential to engage more in the community but because they did not have someone to advocate on their behalf at the planning session their plans are not supporting them to reach their potential. For example, some people who had the ability to communicate in Auslan will lose that skill if there is no one in the home who can communicate using Auslan. There are people who would benefit from orientation and mobility training but it has not been included in their NDIS plans.

People with deafblindness in group homes often do not have family who are engaged in their lives. They need to have an advocate to work with them to ensure they are reaching their potential and have a good quality of life.

The staff in supported accommodation need to be appropriately trained and remunerated. There needs to be more than one staff member with relevant training. It may be easier to achieve this if people with similar needs can be accommodated in the same premises or close by so resources can be shared, thus reducing load on individual staff and likelihood of undesirable turnover of staff. The shortage of appropriately trained communication guides and interpreters is major problem for deafblind people living independently so it is also likely to be a problem for those living in supported accommodation.

RECOMMENDATION 35

That deafblind people living in group homes have access to an advocate with an understanding of their circumstances to ensure they have appropriate supports included in the NDIS plans

13. TRAINING

There is potential to develop online training materials that would help professionals, parents, carers and NDIS staff to have access to up to date information on disabilities particularly those with low incidence. The CHARGE Syndrome Association of Australia is investigating the use of a massive open online course (MOOC) to develop a 6 week course on understanding CHARGE Syndrome. This model could be applied to other conditions that cause deafblindness as a way to access the latest information on rare conditions. However, as the support organisations already work at capacity, many on a voluntary basis, they would require funding to help to develop the materials and place in a common area online. As this would be of significant benefit to NDIS staff it could perhaps be considered for funding outside of the usual ILC grants process.

RECOMMENDATION 36

That the NDIA considers funding the development of online materials to provide information on deafblindness for use by NDIS staff, parents, carers and professionals

14. ASSISTIVE TECHNOLOGY

People with deafblindness benefit from the use of a broad range of technology. The technology plays an important role in supporting the communication and information needs of deafblind people, including through text/video phone, visual or vibrating alarms and alerting devices. Some of the devices have been developed specifically for use by deafblind people. However, as technology is now more software driven, developers are expanding the function of mainstream devices in order to incorporate applications that assist people with deafblindness. This is to be encouraged and should be supported by the NDIS. Using a mainstream device has the advantage of being:

- More easily supported with a repair service than a niche product
- More likely to be updated regularly to incorporate improved functionality than a niche product
- More flexible so that the individual may be able to replace several niche products with one mainstream device
- Easier to manage due to size and more robust when transported than a niche product
- More accepted by the user and therefore used more consistently than a niche product
- Mainstream technology options can also facilitate greater inclusion within the community and may be provide greater access across a range of environments
- Can at times be more cost effective than a disability specific piece of equipment

The NDIS appears to be declining requests for mainstream products to be funded for people with deafblindness possibly because planners do not understand the advantages these devices bring.

RECOMMENDATION 37

That NDIS planners be made aware of the advantages of mainstream devices over niche products for deafblind participants and allow these devices to be funded in NDIS plans

It is important to ensure that the participant receives the training they need to get the most from the assistive technology that is provided in their plans. The training needs to be provided at the pace that the deafblind person is able to work at. The participant also needs access to troubleshooting and other technical support to ensure that the device is functioning optimally.

RECOMMENDATION 38

That participants' plans include training and technical support for any assistive technology that is provided.

SENSES AUSTRALIA information sheet**Deafblind Consultant**

Deafblind consultants work with clients to build their capacity to clearly express their individual access, mobility and communication needs, at the same time recognising this is challenging for many people with deafblindness so providing a conduit between the person with deafblindness and the service provider to minimise misunderstandings and communication break downs and optimise service outcomes.

Deafblind consultants specifically:

- provide consultation, assessment, technical support, service coordination, training, transition planning, job placement and development;
- provide support to assist individuals to find suitable employment and/or increase their level of independence within the home and community;
- engage and connect individuals and families by developing peer-to-peer support networks and other networking opportunities;
- identify information and training opportunities to provide to individuals and families and to advance own professional development (e.g., related to evidence-based practices in deaf-blindness; educational and family engagement systems; local, state, and national resources);
- collaborate with other deafblind consultants to share knowledge and skills regarding client engagement, resources, and best practice;
- undertake and collaborate with others on research projects to build the evidence base of best practice in deaf-blindness;
- use distance communication technology (e.g., social media, web conferencing, telephone) to engage individuals and families;
- assist in developing, delivering, and evaluating training for individuals and mainstream services;
- facilitate individual and family participation in conferences and other training events (i.e., help them identify relevant opportunities, obtain funding to attend, and subsequently share what they've learned with other families); and
- adapt informational materials into deafblind and family friendly documents and formats

COMMUNICATION GUIDES

Communication Guides provide practical help with everyday tasks and access to community services. The role of this specialised support is very complex, requiring constant observation and interpretation of behaviour of individuals who they support to determine what information is needed, the best way to convey it, and if it has been clearly received.

Supporting communication, access to information and mobility, the Communication Guide is the deafblind person's link to the world, providing one-to-one support in the preferred communication mode of the deafblind person they are supporting, along with information and resources to enable the person to be fully informed about their environment and their circumstances, have choices and make decisions. Communication Guides need to be trained to work specifically with people who are deafblind and have a clear understanding and knowledge of dual sensory impairment, how to work with that population along with the impacts of

deafblindness. The Communication Guides provides practical support with everyday tasks such as: facilitating communication in the preferred communication mode, sighted guide, facilitating access to information, facilitating inclusion/access to recreational/social/community activities, facilitating access to public transport, providing vital visual and auditory information, providing environmental information, assistance with shopping, attending appointments, practical help with everyday tasks along with social support.

COMMUNITY OF PRACTICE – HEARING STREAM PARENTS AND CARERS

DESTINATION: That NDIS staff and providers follow best practice principles when working with families and carers

WORKING WITH FAMILIES – BEST PRACTICE

The following characteristics are common to all family-based models:

- 1) the child cannot be viewed apart from the family
- 2) services cannot be provided without considering the family context
- 3) the family is the primary unit of intervention
- 4) practitioners strengthen family competencies
- 5) practitioners provide resources as well as informational and emotional supports

Reference: Rhoades, E. A. (2017). Toward family-centred practice. In E. E. Rhoades & J. Duncan (Eds.), *Auditory-verbal practice: Family-centred early intervention* (2nd ed., pp. 133-150). Springfield, Illinois, USA: Charles C Thomas.

The International Consensus Statement on Best Practices in Family-Centered Early Intervention for Children Who Are Deaf or Hard of Hearing recommends the following in relation to informed choice and decision making, and family social and emotional support.

Informed Choice and Decision Making

Professionals promote the process wherein families gain the necessary knowledge, information, and experiences to make fully informed decisions. This includes educating families regarding special education laws and their rights as defined by these laws. Decision making is seen as a fluid, ongoing process. Families may adapt or change decisions in response to the child's and families' changing abilities, needs, progress, and emotional well-being.

1. Recognise that ultimately, decision-making authority rests with the family; collaborate with families to support their abilities to exercise this authority
2. Adopt open and flexible policies that effectively endorse a range of communication possibilities
3. Share information and experiences from a variety of sources that are comprehensive, meaningful, relevant, and unbiased to enable informed decision making
4. Keep in mind that "informed choice" is not synonymous with information that is neutral or functionally descriptive. Rather, evaluative information is essential in that it draws attention to the various risks, benefits, and uncertainties related to particular options
5. Inform families about expectations for them that are inherent in implementing various approaches, as well as potential benefits and challenges
6. Actively support the family in processes of decision making and self-determination
7. Assist families to identify and successfully rely on their abilities and capabilities
8. Support families to reach decisions in ways that reflect their individual strengths, resources, needs, and experiences
9. Support families to create a vision and plan for their child's future; assist them in understanding that plans and visions can be altered, if needed
10. Provide resources and support family members' decisions
11. Recognise that informed choice is not a one-time decision but an ongoing process
12. Fully inform families of their rights ensured by law

Family Social & Emotional Support

Families are connected to support systems so they can gain the necessary knowledge and experiences that can enable them to function effectively on behalf of their children.

1. Build upon and use both formal (systematic parent–professional partnerships and parent-to-parent support networks) and informal (community organisations, friends, extended family, religious affiliations, play groups) support systems
2. Understand the ways in which natural networks support the health and wellbeing of families
3. Assist families to identify what resources their informal support networks can provide to meet specific needs/concerns
4. Ensure that families have access to a range of supports so that supports can be individualised to the unique needs of the family
5. Understand and actively model the practices of reciprocity in order to build networks
6. Facilitate contacts between families and their communities as a way of strengthening informal capacity
7. Ensure that all families have access to parent-to-parent support from other families of children who are hearing impaired or Deaf. Recognise the key role of parent-to-parent support in promoting social and emotional well-being for families
8. Support connections between families and adult role models who are hearing impaired or Deaf
9. Provide social and emotional supports to promote the wellbeing of parents and siblings. Inform parents about and refer them to professional mental health services, if considered appropriate. Recognise the importance of family well-being for child development.

Reference: Moeller, M. P., Carr, G., Seaver, L., Stredler Brown, A., & Holzinger, D. (2013). Best practices in family centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education*, 18, 429-445. doi:10.1093/deafed/ent034

KEY ISSUES

- After the child is diagnosed with hearing loss families need access to balanced, unbiased information on all options from appropriately skilled and unbiased people

RECOMMENDATION 1

That families and carers have access to independent, balanced advice that is free of commercial bias and influence

- Ongoing parental support is needed for emotional wellbeing as well as support and service delivery in relation to the child's hearing loss. The support is needed not just at diagnosis but at every transition point in the child's life
- Families need access to parent-to-parent mentoring and support
- The NDIS ECEI partner who provides the family with unbiased information and links them to services needs to be well informed and provide timely services. The model for this process, recommended by both professionals and parents, is that provided by the Family Support Facilitators linked to the newborn hearing screening program in Queensland, who meet with the family soon after diagnosis. Families gain impartial and balanced information on the range of communication options and providers available to them from the family support facilitators. The support workers are trained psychologists or social workers who are able to provide impartial and balanced information and

support from birth to 6 years of age, supporting the family through the journey to primary school. These roles are State funded. The ECEI Partners do not have the skills or expertise to undertake these roles and service providers are not independent

There is evidence in the literature that parents can experience negative emotions when service coordination is provided by individuals without the core knowledge and skills for working with children who are D/HH" (Yoshinago-Itano, 2014)

RECOMMENDATION 2

That Family Support Facilitators are funded by the NDIS and made available nationally

MENTAL HEALTH AND WELLBEING OF PARENTS AND CARERS

Parents of children with hearing loss or deafblindness including multisensory impairment may find their mental health and well-being is affected from the demands of their role as a carer, advocate, teacher and parent. If the wellbeing of the parent is affected to the point where they are unable to cope, then the implications for the child and family are significant. Where the effect on the parent's mental health is directly related to their child's disability the NDIS should provide the supports needed to help families to stay well in order to support their child.

RECOMMENDATION 3

That the NDIS provide mental health and wellbeing support for families with children with hearing loss or deafblindness including multisensory impairment

ASSISTIVE TECHNOLOGY

People with hearing impairment and who are Deaf benefit from the use of a broad range of technology. The technology plays an important role in supporting the communication and information needs of people, including through text/video phone, visual or vibrating alarms and alerting devices. As technology is now more software driven, developers are expanding the function of mainstream devices in order to incorporate applications that assist people with hearing impairment or who are Deaf. This is to be encouraged and should be supported by the NDIS. Using a mainstream device has the advantage of being:

- More easily supported with a repair service than a niche product
- More likely to be updated regularly to incorporate improved functionality than a niche product
- More flexible so that the individual may be able to replace several niche products with one mainstream device
- Easier to manage due to size and more robust when transported than a niche product
- More accepted by the user and therefore used more consistently than a niche product
- Mainstream technology options can also facilitate greater inclusion within the community and may be provide greater access across a range of environments
- Can at times be more cost effective than a disability specific piece of equipment

The NDIS appears to be declining requests for mainstream products to be funded, possibly because planners do not understand the advantages these devices bring.

RECOMMENDATION 4

That NDIS planners be made aware of the advantages of mainstream devices over niche products for hearing impaired and Deaf participants and allow these devices to be funded in NDIS plans

TRANSITION FROM IN-KIND ARRANGEMENTS

The changes in Australian Government support arrangements for people with hearing loss that will commence in July 2020 are significant. The new arrangements will need to be supported with an education campaign that targets NDIS staff, professionals working with people with hearing loss, consumer organisations, referrers including medical practitioners and specialists and people with hearing loss.

RECOMMENDATION 5

That NDIA provides clear information to planners, providers and participants about options for accessing hearing services after transition is complete in mid-2020. This should include individualised advice for those who have been eligible for Community Service Obligations-funded services under the Hearing Services Program