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Introduction

Executive Summary

The Deaf Society of NSW gives in-principle support to the notion of a National Disability Insurance Scheme administered by an independent federal body.

In order to meet Australia's obligations under the UNCRPD to "promote respect for the inherent dignity of persons with disability", such a scheme should give the maximum possible range of choice and control to people with disability, but should be supported by separately funded infrastructure for information, referral and support services to ensure the smooth running of the scheme. The details of how such a scheme may work for deaf and deafblind people need to be carefully considered as the needs of deaf and deafblind people include unique and specialised areas of service provision such as Auslan interpreting and tactile/visual frame interpreting.

This submission outlines the background, scope, definition of terms and a summary of recommendations before discussing design and implementation in detail.

Background

The Deaf Society of NSW (DSNSW) was established in 1913. Our vision is "equity for deaf people", and our mission is to "work in partnership with the Deaf Community to enhance the quality of life of deaf people, strengthen the community and advocate for changes that will ensure fundamental rights and freedoms". All DSNSW offices are bilingual workplaces in which Auslan (Australian Sign Language) and English are valued equally.

Auslan is the language of the Australian Deaf Community. It is a unique language with its own grammar and vocabulary. It does not follow the structure of English. As with any language other than English, it takes years for learners to become fluent. Auslan is distinct from other signed languages (French Sign Language, American Sign Language, etc.) in the same way that English is distinct from other spoken languages.

DSNSW is the largest provider of services to deaf people in NSW who use Auslan as their primary or preferred means of communication. DSNSW also provides some services to hard of hearing people who use speech, listening, and lipreading to communicate.

Our services include consumer and community services, accredited and non-accredited training courses, Auslan/English interpreting, employment and workplace support, and programs for families with deaf children. Many of our services are provided to deaf people with additional disabilities such as vision impairment, mental illness, intellectual impairment and physical disability. However, a large number of our services, especially interpreting services, are provided to deaf people who have no additional disability.

In accordance with our vision and mission, we are excited by the prospect of a National Disability Insurance Scheme as in our view it will bring us closer to achieving our vision of equity for deaf people. However, the details of such a scheme will be critical. This submission aims to provide the information needed to ensure that the scheme has the design features required to meet the needs of deaf people.

Scope

This submission will be restricted to commenting on the design and implementation of a National Disability Insurance Scheme as it relates to deaf people and deafblind people, with some reference to hard of hearing people. In line with our client base, our responses will focus on the needs of deaf people who use Auslan to communicate, and deafblind people who use tactile fingerspelling, hand-over-hand signing and visual-frame signing to communicate. We will also make some reference to hard of hearing people who use speech, listening, and lipreading to communicate. However, it must be remembered that hard of hearing people will have many needs (especially in the area of technology and aids) which we will not note or discuss, as they are not part of our service delivery.

In restricting ourselves to our area of expertise in deafness services, we will also avoid commenting in detail on the macro-economic aspects of the proposed scheme or the eligibility requirements or assessment tools for assessing those who have disabilities other than hearing loss or deafblindness.

Terms

Throughout this document, the term ‘deaf’ will be used to refer to people who use Auslan as their primary or preferred language (this group is also referred to as ‘culturally deaf’, and is a small but significant minority of approximately 2000 people in NSW (Willoughby 2009)). The term ‘hard of hearing’ will be used to refer to those with a hearing loss who prefer to communicate using spoken English – a much larger group (“One in six Australians is affected by hearing loss” (Access Economics, 2006, p. 5)). These groups do overlap to some extent. Where we refer to both groups together, we use the term ‘people with a hearing loss’.

For ease of use, the abbreviation ‘NDIS’ will be used for the proposed National Disability Insurance Scheme. We would, however, recommend a clearer and less negative name for the final scheme be chosen in consultation with disability groups.

Summary of Recommendations

1. That an NDIS be established which has these key features:
    a. Individual funding that is person-centred and broad in scope
    b. Eligibility based on need
    c. No means-testing or co-payments
    d. A contingency payment to be treated as income, over and above service-purchasing funds
2. That assessment for an NDIS comply with the principles of fairness, transparency, consistency, accessibility, trust, and the involvement of people with comparable disability. Assessment should be conducted on the assumption that the applicant is the person best able to determine the support they require.
3. That the NDIS have a majority of people with disabilities involved at all levels of decision-making, and specifically that deaf, hard of hearing and deafblind people are involved at all levels of decision-making which have an impact on deaf, hard of hearing or deafblind people, and that a similar principle be applied for those with other disability.
4. That the NDIS be administered by an independent federal statutory authority.
5. That all information about the scheme be available in Auslan and that the assessment processes be available in Auslan.
6. That the following allocations be made separate to the allocation of individual funds:

    - An allocation for culturally sensitive and accessible referral and information services for deaf, deafblind and hard of hearing people. These services should be provided by existing disability service organisations which already have relationships with the relevant client base.
    - An allocation for ongoing capacity building within the system, including training for specialised professional workers, capacity building for organisations, mentoring and collaboration across sectors, etc.
    - An allocation for local group activities within the system such as computer skills classes, educational excursions, etc.
7. That the NDIS have a quality assurance system that involves the registration of approved providers (including freelance professionals and family members) and that this registration process include review by consumer groups.
8. That there be urgent attention given to the Auslan Interpreting skills shortage as a critical capacity-building measure for the success of the delivery of any National Disability Care and Support program to deaf and deafblind people.

Design

Rationale and Objectives of the Scheme

The Deaf Society of NSW supports the introduction of a long-term disability care and support scheme in principle, pending the details of implementation.

The rationale for such a scheme should be one of fairness. It is simply fair for the whole community to bear the responsibility – economically and practically – of adapting to the needs of persons with disabilities.

If there were nothing to be gained for the Australian community in establishing such a scheme, we should still do it. However, it is our view that the full inclusion of people with disabilities in all aspects of Australian life is also in the national interest – socially, culturally and economically.

The objectives of the scheme should be to:

- **Empower** people with disability
- Adopt a **social model** of disability
- Be **person-centred**
- Be **fair**
- Provide access to **high quality** services
- Be **efficient**

Design Implications of the Objectives

Each of the six objectives listed above has specific design implications.

<u>Empowerment of the Individual</u>

The scheme should empower the individual to choose services which suit them. An individual funding model should be the default system. This is in line with the UN Convention on the Rights of Persons with Disabilities (UNCRPD) Article 3(a) which stipulates “Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”.

<u>Social model of disability</u>

The scheme should assume the social model of disability. Rather than a purely medical model of disability in which impairment is the problem of the individual, a social model sees disability as located to a great extent in the failure of the community to adapt. The social model of disability is consistent with the human rights approach which underpins the UNCRPD. This would have design implications for the financial structure of the scheme. If disability is the responsibility of all Australians, there is an implication that costs should be borne equally by all. Such a model also has implications for assessment and eligibility as circumstantial and functional factors would need to be taken into account in assessing the level of actual disability.

Person-centred

The scheme should be person-centred, and therefore broad in scope. One cannot separate participation in family and community from productivity in the workplace. Shutting a person out from the family or community leads to lost learning opportunities, higher risk of health and mental health problems, and consequently to disadvantage in the workplace. A deaf person who cannot access social and sporting opportunities outside the workplace is a less engaged, less skilled, less healthy employee. The scheme should therefore be designed with as broad a scope as possible to facilitate access across all areas of life. This is in line with the UNCRPD which emphasises rights to access in all areas of life.

Fair

The scheme should be fair. In our view this means:

- eligibility criteria based on need defined as “what is needed to remove the barriers that would not be faced by people without disability in comparable circumstances”. Eligibility would not be based on medical diagnoses only.
- taking into account the compounding effects of multiple disability, e.g. in the case of mild intellectual disability and deafness the actual disadvantage is “more than the sum of its parts”
- taking into account compounding circumstantial factors such as remoteness and history of severe educational deprivation
- taking account of the real cost of the services needed, including the higher cost of purchasing services in remote locations or the need for highly specialised and skilled professional services, such as Auslan interpreting, which are more expensive than less-skilled services
- providing a cash allowance (to be treated as income) above and beyond the service-purchasing or card/voucher system, as a contingency payment for each individual, in recognition that formal services will not solve all the problems that a person with disability will face in the community

High Quality

The scheme should provide for the quality assurance of services through a streamlined and simple quality management system (see below, under *Implementation Issues*).

Efficient

The scheme should be efficient. In our view, the key efficiency features would be:

- distribution of funds directly to people with disability or their representatives for them to purchase services from providers – this could be in the form of a card for use at service outlets
- administration by an independent national statutory authority
- an allocation for culturally sensitive and accessible referral and information services for deaf, deafblind and hard of hearing people. These services should be provided by existing disability service organisations which already have relationships with the relevant client base.

- an allocation for ongoing capacity building within the system, including training for specialised professional workers (e.g. specialised carers, community access workers, mental health workers, Auslan interpreters), capacity building for organisations, mentoring and collaboration across sectors, etc.
- an allocation for group activities within the system such as computer skills classes, educational excursions, etc. It may be possible to pay these funds directly to service providers, but the tender process should be for local activities, not large regional or national schemes. Local projects are more likely to be efficient and targeted than larger projects.

Equal weight should be given to all these design aspects. Without any of them the whole scheme would become ineffective. Economic, social and cultural objectives are strongly interrelated and compromising one would compromise all.

Model of funding

It is our view that fully individualised funding should be the default model for all successful applicants for the scheme. Individualised funding would provide the maximum power of choice to the individuals needing the services. The only exceptions to individualised funding for deaf and deafblind people should be:

- community education programs, support and referral services to facilitate access to the scheme
- capacity building within the system (allocations for professional development, organisational planning, etc.)
- local community-based group activities (e.g. community education programs for particular target groups)

There will also need to be some funding allocated to the body that administers NDIS for:

- National-level research and development
- Administration of assessment and funding allocations
- Administration of the registration of service providers

The individualised funding model could take the form of a card that contained a dollar-value amount, ear-marked for use at registered service providers. The card should be able to be swiped (or card number quoted) at the point of service provision with service providers then claiming payment from the administrative body. The method of using this system would look similar to the use of a credit card.

For Auslan interpreting, a card system with a monthly or annual dollar-value amount would work well as it would maintain a level of healthy competition in the quality and pricing of services. We are not in favour of the establishment of a single government-funded interpreting service as this could reduce quality, reduce the choices available for deaf consumers, and reduce healthy competition. We would not be in favour of the “bank of hours” model if it lead to the fixing of prices. Fixed pricing would inhibit provider’s ability to attract practitioners to the field (see below under workforce issues). If pricing were not fixed, then a bank of hours could be an appropriate model for the funding of Auslan interpreting. Under one international scheme (in Finland), deaf people each receive an allocation of 180 hours of interpreting annually for use at their discretion, with an unlimited number of hours available for educational interpreting.

For those unable to manage their own funds, carers or family members could apply to manage the funds on behalf of the person with disability. Alternatively, people could elect to have their funding managed by an organisation which they trust.

Some payments onto the card could potentially be made monthly rather than on an annual basis, as that could assist clients with limited money-management skills to spread out their usage of services across the year.

For smaller providers without the capacity to swipe cards, paper-based claim systems could be used.

Eligibility

Eligibility is a sensitive area because discussions of eligibility tend to revert to a deficit or medical model of disability rather than bearing in mind the social model of disability. In our opinion eligibility should be based on need as defined and qualified below.

We do note that a scheme based on need/eligibility rather than on a rationing model has inherent economic risks. However, a scheme that is based on rationing also has risks – economic risks associated with lost productivity and moral risks of creating or failing to alleviate human suffering. This creates a tension which we do acknowledge. However, on balance we feel an obligation to advocate for a needs-based scheme as the less risky option.

“Need” should be clearly defined as that which will provide opportunity equal to that experienced by people without disability in comparable circumstances. This should not be narrowed to need purely in the workplace, or need purely in relation to bodily functions, or need purely for access to a limited number of set services. It should be defined as “need in order to remove barriers not experienced by people without disability”.

‘Severe’ and ‘profound’ are somewhat problematic in determining eligibility because the same medical hearing loss can exist in two different people who have vastly different needs. Some of the factors which should be taken into account when assessing for “need in order to remove barriers” are:

- **Education background**. Deaf people in the past (and even now in many cases) have been channelled into programs which did not allow them to develop sign language or to use sign language in the educational context. For those who also failed to develop speech, this often lead to poor educational outcomes, low literacy levels and poor relational skills, and was a compounding factor in the development of mental illness. None of these effects are generally experienced by deaf people with deaf parents who had early language access, even though they may have the same medical level of hearing loss. These effects are, however, severely disabling.
- **Compounding effects of additional disabilities** - ‘Severe’ and ‘profound’ are also problematic because the terms do not take account of the compounding effects of moderate disabilities. Someone with a moderate hearing loss and a moderate intellectual disability could be effectively severely disabled.
- **Compounding effects of circumstantial factors** such as remoteness, linguistic/cultural background, and availability of family support also need to be taken into account in part of any assessment process of the level of disability.
- **Needs of family and carers** will impact on the allocation required by a child or young person with a hearing loss. Around 95% of children with a hearing loss are born to parents who are not deaf, and most are born to people with no experience with deaf people or Auslan. For deaf children and young people, an allocation should be made for parents and carers to receive support, including learning Auslan in order to communicate with their child.

These factors should be taken into account to the extent that they have an impact on a person’s ability to achieve the same quality of life as a person without disability in comparable circumstances. For example, if a deaf person lives in a small town in far Western NSW, they should have the opportunity to achieve at least the same quality of life as a hearing person living in a small town in far Western NSW. In order to achieve this, they will probably need more funding than a deaf person living in Sydney, but their quality of life may not necessarily reach that of a deaf person living in Sydney.

Carers' needs could be factored in to eligibility as part of an assessment of compounding circumstantial factors. A carer should not have to abandon their relative in order to prove the person's need; a desire to re-enter the workforce or retire from caring duties should be taken as a statement that the person with disability does not have care available and the lack of family care should then be taken into account as part of the compounding effects of circumstantial factors.

Eligibility and Visa Requirements

It is a point to bear in mind that visa and citizenship requirements are quite variable across disability service programs generally. We don't have the answer to the problem, but eligibility criteria need to include clear information about visa or citizenship requirements for applicants. There may also be a role for the NDIS administrator in liaising with the Department of Immigration to enhance the accessibility of programs run by the Department of Immigration for new migrants.

What about eligibility and natural ageing?

It is our view that disabilities acquired before the age of 65 should continue to be covered by the scheme after a person turns 65, and that disabilities acquired before 65 should be covered by the scheme, even if the application is made after the person turns 65. The needs of deaf people will not change overnight when they turn 65, and 65 is not the ideal age to begin negotiating a whole new system in any case. The aged-care system is severely under-equipped and under-trained to deal with the needs of signing deaf people. This is already an area in which significant costs are shifted onto the Deaf Society and the families of deaf people, as nursing homes and hostels are frequently unable to provide culturally appropriate care to culturally deaf residents. Age-related hearing loss brings a completely different set of needs to the needs of culturally deaf people and of people who have been hard of hearing from before the age of 65. It is unrealistic to expect the aged-care system to deal with the unique needs of culturally deaf people.

Assessment

Assessment should comply with six main principles:

- Transparency
- Consistency
- Efficiency
- Accessibility
- Trust
- The hands-on involvement of people with comparable disability in each assessment

Transparency

Assessment should be transparent in that detailed criteria should be publically available, processes should be clearly explained *in the language used by the applicant*, and the training, experience and potential conflicts of interest of decision-makers should be fully and publicly disclosed.

As an aid to transparency, individual applicants, service providers, family members, carers, and friends should be able to make recommendations on a person's eligibility and ability to manage individual funding, and these recommendations should be taken seriously by the panel. The panel should have the power to make final decisions about eligibility and about the person's ability to manage funding, but if they do not follow the recommendations of applicants themselves, service providers, or others, they should have a responsibility to explain why they have not followed these recommendations.

Consistency

Assessment should be consistent such that people with comparable need receive comparable levels of support.

Efficiency

For efficiency, we would suggest a tiered approach to assessment as the most likely to save time and money:

1. For people with a hearing loss *without* additional disability or other compounding factors, a base-line allocation of funding annually or monthly to cover those needs which are common to all people with a hearing loss is recommended. The base-line allocation should be a flexible amount for spending on any disability service, but should be sufficient to cover as a minimum:
    - flashing light safety devices (fire alarms, door bells, baby-cry alarms, etc.)
    - interpreting/real-time captioning/notetaking for appointments and events not covered by other schemes (this allocation may need to be "topped up" in any given year if the person's need changes due to circumstance, such as gaining a managerial job where more interpreting is needed, for example)
    - hearing aids
2. For deafblind people and deaf people *with* additional disability or other compounding factors requiring additional services such as case-work, personal care, transport, domestic assistance, etc. additional allocation should be made according to the likely cost of services needed.
3. For deaf children and young people under 18 the needs of the family should also be taken into account, such as the need for parenting support/mentoring or Auslan learning.

Applicants would identify the tier in which they wish to apply. The assessment required for tiers 1 and 3 should be minimal.

There may also need to be a regional loading for those in regional and remote areas.

Applications would be assessed by the panel or committee as outlined below.

Assessment should generally also occur as infrequently as possible. For people with a hearing loss, needs are very unlikely to change. Reassessment should not be required unless need changes, such as in the case that a deaf person moves to a regional area, acquires an additional disability, or has a drastic change in circumstances.

There is likely to be a possibility of removing unnecessary assessment by using assessments previously conducted by other programs such as Disability Employment Services.

Accessibility

For accessibility, we recommend that all information relating to the scheme be made available in Auslan. The assessment process should also be conducted wholly in Auslan for applicants who choose it. This is consistent with Article 21 (b) of the UNCRPD.

Trust

The application process should proceed on the assumption that people with disability themselves know what they need and can best determine their own support needs. This requires a paradigm shift to a basis of trust in the design and implementation of the application process.

Hands-on involvement of people with disability

It is our strongly-held view that persons with disability should be involved at all stages of the assessment process. Persons with the same disability as applicants should be involved and consulted in the drawing up of guidelines for eligibility and assessment of each type of disability, and should also be closely involved in making decisions for individual assessments. That is, for each assessment of a culturally deaf person, a culturally deaf person should be on the panel or committee which assesses. For each assessment of a hard of hearing person, a hard of hearing person should be one the panel or committee which assesses. Assessment should not be left to generalist assessors or medical professionals only, although these people may be involved. Specialist disability service provider reports should be given equal weight to medical reports in order to uphold the principle of functional capacity and “need in order to remove barriers”, rather than need assumed as a result of physical deficit. Neither medical professionals nor disability specialists should make final decisions.

Caveat in relation to Eligibility and Assessment

The above suggestions in relation to eligibility and assessment are offered tentatively as a starting point only. We are very aware that there may be problems and flow-on effects of such a structure that we cannot anticipate, and therefore we strongly recommend:

- further consultation with representative bodies and consumer groups in order to refine the criteria and processes for application and assessment
- openness to feedback and continuous improvement in policies and processes for eligibility and assessment (i.e. people and organisations should be able to suggest changes at any time and see good changes implemented in a timely manner, rather than having to wait for a scheduled review to take place at the end of an arbitrary period)

Current Services

Deaf people are served by a range of service providers including interpreting agencies, dedicated deaf-specific services, general disability services and mainstream service providers. It is not possible to list all the services provided to deaf people, but a summary of some of the key deaf-specific services is contained in the following table.

Service	**Details**	**Currently funded in NSW by:**	**Estimated annual cost for NSW (where known):**
Auslan interpreting services	Employment – job interviews, workplace meetings and training, etc.	Employee Assistance Fund	Not known
	Medical – public	Hospitals	Not known
	Medical – private	NABS	Not known
	Police and court	Community Relations Commission	Not known
	Education – TAFE and universities	Large education providers	Not known

Workplace Modifications	Technology and building modifications for deaf people in the workplace	Employee Assistance Fund	Not known
Independent Living Skills Services	for deaf people requiring support to become independent	Ageing, Disability and Home Care via contract with DSNSW for Sydney Metro area only	approx $350,000
Access and Information Services	for deaf people needing support to negotiate complex issues and systems (e.g. support through legal processes) and for community education and family support	Ageing, Disability and Home Care via contract with DSNSW for Sydney Metro area only	approx $395,000
Employment Services	Support for deaf and hard of hearing people in preparing for and looking for work	DEEWR via contract with DSNSW	approx $590,000
Literacy and Numeracy Training	Classes taught in Auslan for deaf adults wishing to learn written English	Funded by NSW DET ACE Unit via contract with DSNSW education division, Deaf Education Network	approx $63,500
Services for deaf children and their families	A range of auditory-verbal programs are available for deaf children. (Limited support available for parents who choose to use Auslan to communicate with their child.)	Various funding sources	Not known.

All these services are operating well but available resources are limited and the level of unmet need is still relatively high. They would only need to be replaced by the NDIS if current provision ceases. If replacing these services by the NDIS is required, this could be done slowly, after the introduction of the scheme and after its first evaluation so that the process could happen smoothly without loss of skills and staff for organisations.

Services not provided now

Services not provided now which should be part of a national disability insurance scheme include:

- Some interpreting services including, for example, interpreting for funerals, legal advice and civil court proceedings, private financial appointments, weddings, artistic and cultural events (e.g. historical tours, art gallery events, theatre), social and sporting events, strata scheme/body corporate meetings, and community college classes, as well as a range of other areas in which mainstream service providers claim that “undue financial hardship” will result from providing access for deaf people as required by the Disability Discrimination Act. Currently these are not provided, or costs are paid by individuals or covered by Deaf Societies as a charitable activity.

- Support for deaf and hard of hearing people in nursing homes and hostels.
- Interpreting for employment where eligibility criteria for the EAF are not met (e.g. for those working fewer than 8 hours per week)
- Safety devices for the home such as strobe-light or vibrating fire alarms, flashing-light door bells and baby cry alarms are not subsidised by the state government in NSW. The lack of these devices leads to a serious safety risk for deaf people and their families.
- Hearing aids. A hard of hearing person between the ages of 21 and 65 is likely to have to pay thousands of dollars to access sound unless they can prove that the hearing aids are essential for their work. This reduces their safety in the home and restricts their access to family, community and sporting events.
- Deaf-accessible care for those with additional disabilities, e.g. domestic assistance, personal care, communication support, and other community services. Auslan is a unique language with its own grammar and lexicon. Currently deaf people requiring these support services in NSW must go to generic disability service providers which do not have any staff trained in Auslan. An individual funding model would change this situation by allowing deaf-specific service providers to meet the actual needs clients express, rather than sending them to service providers who cannot communicate with them simply because funding doesn’t cover the services they need.
- Services to deaf people in regional areas receive limited funding.
- Auslan translation services for organisations who cannot afford to make their information accessible.
- Services for families of deaf children and young people for whom Auslan is the preferred language – especially services which support parents who choose to use Auslan to communicate with their child.

Details are set out below:

Service	**Details**	**Current status of provision in NSW:**	**Estimated annual cost for NSW:**	**Required in NDIS?**
Auslan interpreting services	Education – small providers	Not provided	Not known	Yes
	Private legal and financial appointments and civil court proceedings	Not provided, or cost covered by Deaf Society as a charitable activity	$4995.66	Yes
	Strata/body corporate meetings	Not provided, or cost covered by Deaf Society as a charitable activity	$405.40	Yes
	Funerals	Cost covered by Deaf Society as a charitable activity	$6479.77	Yes
	Weddings	Not provided, or	Not known	Yes

	Interpreting in Nursing Homes	cost covered by individual Not provided or paid by nursing home	Not known	Yes
Auslan translation services	translation and filming of information into Auslan for websites to facilitate access to services and information in all areas of life	Fee for service – which means very few websites have Auslan available	Not possible to estimate – costs depend on length and complexity of information.	Only where organisations are too small to meet their obligations under the DDA. This could not be provided as an individual allocation as translations are by nature designed to benefit more than one person.
Support for deaf and hard of hearing residents in nursing homes and hostels	Nursing homes frequently unable to provide for the communication needs of culturally deaf residents. Limited or no social opportunities for deaf seniors in residential aged care settings.	Unfunded	Not known	Yes
Accessible support for deafblind people	Transport Social support Support groups	Some funding Unfunded Unfunded	Not known	Yes
Independent Living Skills Services	for deaf people requiring support to become independent	Unfunded for most regional areas	Not known, but numbers are small.	Yes
Deaf-accessible disability support services	for deaf people requiring ongoing care and support to maximise quality of life	Unfunded, or provided with limited communication access by generic disability service providers	Not known, as these clients have piecemeal services from a range of organisations at present.	Yes
Access and Information Services	for deaf people needing support to negotiate complex	Unfunded for most regional areas	Not known, but numbers are small.	Yes

	issues and systems (e.g. support through legal processes)			
Safety devices	Fire alarms and flashing light door bells, baby cry alarms	Unfunded unless covered by small once-off community grants (NRMA, CDSE) or local government in some LGAs.	Not known.	Yes
Mentoring programs for parents of deaf children	For parents wishing to have support in negotiating the maze of services for deaf children	Funded by the Deaf Society as a charitable activity	approx $40,900	Yes
Auslan programs for parents of deaf children	In-home programs for parents who wish to communicate with their child in Auslan	Generally unfunded, except where a parent is able to join a funded accredited evening course (impossible in most cases, especially for new parents).	Not known, but numbers are small.	Yes
Hearing aids	Hearing aids for people between the ages of 21 and 65	Generally unfunded	Not known	Yes

Cost savings

It must be remembered that the services outlined here do not only have costs associated with them but cost-savings as well. Some likely cost savings are:

- providing deaf-accessible services delivered by deaf people who sign means that generic disability service providers do not have to provide interpreters in order to serve deaf clients
- providing interpreters/captioners/note-takers for training in a community college or private RTO allows a deaf or hard of hearing person to become more productive in their workplace and may reduce interpreting costs under the EAF in some cases
- providing funding to cover costs of interpreting in the workplace (in the small number of cases where the allocation of the EAF is insufficient) removes the remaining disincentives for employers to hire deaf people
- providing case-work in rural areas enables better community and workforce participation by deaf and hard of hearing people
- providing safety devices in the home improves the independence of people with a hearing loss and reduces risk of injury and costly medical treatment
- providing support for deafblind people and deaf people in residential aged care reduces risk of mental illness and other costly effects of social isolation
- providing Auslan translation reduces the time wasted by organisations dealing with confused deaf clients
- providing Auslan translation serves more than one deaf person and saves interpreting costs

- providing access to sporting and social opportunities saves on health and mental health costs in the long-term
- providing accessible programs for parents to be supported and to learn Auslan improves long-term outcomes for deaf people through the opportunity for age-appropriate language acquisition, emotional and social development, and development of educational potential

IMPLEMENTATION ISSUES

Should eligibility take account of people’s income or assets?

Means testing for disability care and support would be in effect a tax that was applied only to people with disability and would therefore contravene the principle of fairness. It is our view that eligibility should not take account of people’s income or assets. People with disability should have the same opportunities to prosper as other Australians. However, people with disability should pay the same taxes as everyone else, including any levy that is taken in order to fund an NDIS.

Comprehensive versus narrower coverage

The scheme should apply to all cases of disability and should not be restricted to new cases of disability if it is to meet the principle of fairness. It is our view that eligibility should be given permanently to those with permanent disability, with short-term disability covered by short-term access to the system. For permanent disability a once-off assessment should be all that is required, unless circumstantial factors were significant in the determining of eligibility, in which case the circumstances may need to be re-assessed every three years or when there is a significant change.

Decision making powers

Decision-making powers for eligibility should be vested in independent panels which include at least one (preferably two) people with comparable disability, as outlined above under *Assessment*. That is, culturally deaf people should be strongly involved in the assessment process for culturally deaf people, and likewise for other disabilities.

Administrative decision making should be vested in an independent federal statutory body. This organisation should uphold the principles of a human rights approach to disability insurance, rather than a medical approach to disability. We are not in favour of state-based administration of any kind, as this may compromise consistency.

Cashing out and saving or borrowing

Allowances should be in dollar-value amounts, not vouchers for specific items or services. This will allow a reasonable degree of flexibility. For example, a deaf person could purchase different proportions of community support or interpreting in different years according to their needs and preferences.

Recipients should be able to save current funding to pay for future services, but not to borrow from future funding in order to pay for present services. If current needs are not covered by current allocations, it is likely that a re-assessment of eligibility is required. However, saving for future needs is an appropriate flexibility given that some costs (hearing aids, etc.) are not annual, but occur every few years. Amounts paid could be set to expire, say, 5 years from date of issue to prevent high future liabilities for the NDIS.

Evaluation

Success and failure of the scheme would be tested by asking recipients and service providers if the system is working. Economic measures such as participation in the workforce and average income of people with disability could also be used as measures of the success of the scheme.

Evaluation should also include surveys of people with disability who are not using the scheme as this will give an excellent reflection of improvements needed.

Governance and accountability – risk minimisation

The main risks for an individualised funding model are related to the quality of services and the risk of funds being appropriated by unscrupulous people.

To minimise the risk of poor quality services, a simple quality assurance system should be implemented. The quality assurance system should be no more onerous than the current 12 disability service standards, and auditing requirements should be fewer for smaller providers. However, this system should also contain a mechanism for complaint resolution and de-accreditation of unsatisfactory service providers. Individuals, such as freelance interpreters, disability workers, or family and friends who wish to be paid to care for people with disability could apply to the administrative body to become eligible to receive payments using the funding allocated to the person with disability, without having to go through such rigorous quality assurance processes.

The registration process for service providers should also include review by appropriate consumer groups.

To minimise the risk of funds being misappropriated by individuals, the application process for those who cannot manage their own funding should confirm the availability of independent advocates for the person with disability – other family members or friends or public guardians who are sufficiently close to, but sufficiently independent from the delegated manager of funds. The advocate could raise concerns with the administrative body if there was a need to do so, or submit a brief report on a yearly basis.

Those organisations funded to provide community education, support and referral should also be able to undertake advocacy and support consumers to give feedback and make complaints.

Workforce issues

Accreditation of Practitioners

The requirements for accreditation of individuals should depend on the skill requirements of the work.

In the case of Auslan interpreting, stringent requirements are already in place. Interpreters require accreditation through the National Accreditation Authority for Translators and Interpreters (NAATI), and this system is effective as it is. There is scope for expanded accreditation testing options within NAATI's program but this should remain under the auspices of NAATI. Freelance interpreters should be required to be a member of ASLIA or the equivalent professional organisation, and must have opted in to NAATI's revalidation scheme in order to register to claim payments via the NDIS.

In the case of other people employed to deliver services to deaf children and adults (case workers, teachers, employment support, etc.), there would be scope for NDIS to implement an accreditation system. In most cases for services to culturally deaf people, the critical skill is an ability to communicate in Auslan and to behave in a culturally sensitive manner. The Diploma of Auslan or demonstrated equivalent competence would be an appropriate benchmark for workers employed to deliver services to deaf and deafblind people, unless the services were of a nature that only required minimal communication (e.g. domestic services, transport services). Fluent communication skills and culturally sensitive interaction with deaf people are fundamental to quality service provision. Disability service provision for deaf clients **should not** be undertaken by people who are not able to communicate with their clients.

Auslan Interpreters – Skills Shortage

Auslan interpreting is perhaps the primary method by which Australia is able to meet its obligations to culturally deaf people under the CRPD. Auslan interpreting is, however, in a state of severe skills shortage. The importance of providing more regular training for new interpreters, developing Auslan interpreting as a profession, and taking measures to reduce attrition rates cannot be underestimated. This also applies to deaf relay interpreters who provide access for deafblind people.

Auslan interpreters have traditionally provided access for deaf people to medical appointments, legal appointments, education and training contexts and the workplace. As deaf people become more aware of their rights to access, and as the deaf population ages along with the rest of Australia, it is expected that this demand will increase. In addition, as deaf people access higher education and professional roles more and more, so Auslan interpreters require more and more specialised and complex skills.

At the same time that skills demands for the role of the Auslan interpreter are increasing, other factors make Auslan interpreting a less attractive profession than professions requiring comparable qualifications: poor working conditions, low pay, little job security, high incidence of Occupational Overuse Syndrome, risk of vicarious trauma, and a high level of responsibility in life-critical situations are just some of the reasons that Auslan interpreters leave the field. Although new interpreters are accredited each year, attrition rates are high because more attractive working conditions are available elsewhere. Those who stay do it for love not money, but this is not a solution to the looming problem of dire skills shortage. A study of the exit rate of interpreters from the profession found a very high attrition rate amongst interpreters in Victoria (NMIT 2006), and the same is true in our experience in NSW.

Currently – depending on the length of the work and the complexity of requirements – approximately two weeks' notice is required by most service providers in order to secure suitably qualified and experienced Auslan interpreters. The notice required is somewhat less for shorter appointments (such as medical appointments) and a great deal more for longer more demanding work (such as conferences, academic lectures, etc.). This is obviously a real problem for the productivity of deaf people. If an Auslan interpreter is not available for a job interview, then the deaf person can't attend the interview. If an Auslan interpreter is not available for a workplace training session, the deaf employee misses out.

It currently takes about 5 - 7 years to train an Auslan interpreter in NSW, but this is because almost all of the available training options in NSW are part-time or frequently unfunded, and training pathways are therefore haphazard. A student generally needs to complete Certificates II and III in Auslan with TAFE or a private provider and at least Certificate IV in Auslan (and ideally also the Diploma of Auslan) with a private provider before applying to undertake the Diploma of Interpreting (LOTE) through TAFE which leads to NAATI accreditation as a paraprofessional interpreter. There are often gaps of one semester or a year between each Certificate or Diploma. The Auslan courses provided by Deaf Education Network (the education division of the Deaf Society of NSW, the only private provider of

Auslan courses in NSW) are intensive, fast-tracked and highly effective, but are only occasionally funded and therefore students often pay full fees to access this training. NSW TAFEs typically take 2-4 times as long to provide Certificates II and III in Auslan, only rarely provide Certificate IV in Auslan, and do not provide the Diploma of Auslan at all. In Victoria more reliable full-time pathways are funded and training is completed more quickly.

These problems are solvable. In theory, it should be possible to train an Auslan interpreter in roughly the same time as it would take to train any other professional, i.e. about 3-4 years of full-time tertiary study. The courses and structures are in place, but need to be better funded so that pathways can be consistently available. There are also many accredited practitioners who could potentially be attracted back to the field if working conditions and job security were improved.

The NDIS would have a significant role in implementing these two solutions. Firstly, the body charged with administering the NDIS should also be charged with the responsibility for liaising with bodies in the vocational education and training sector in order to ensure that skills gaps are filled in a timely manner. Funding urgently needs to be set aside for Auslan courses, interpreting courses, and traineeships for Auslan interpreters, and the NDIS administrator should ensure that the national training system is able to put these measures in place. Secondly, the body which administers the NDIS should also be charged with responsibility for liaising with the Australian Sign Language Interpreters' Association (ASLIA) National to determine measures for improving the employment conditions for Auslan Interpreters and the recognition of Auslan Interpreting as a profession in order to attract already-accredited practitioners back to the field.

Some professional development for those already working in the sector should be funded through the scheme as part of a capacity building allocation, as outlined above.

Transition to the New Scheme

The difficulties of transition for the deaf community should not be underestimated. NABS was established in 2004 and it is only now – six years later – that the scheme is widely known and understood. Deaf Societies and consumer groups are still trying to educate the whole community about the EAF, which has been in existence for years. The voucher system for the purchase of TTY units was a failure because the community simply didn't know that vouchers were available or how to get them. Transition to the scheme would need to involve:

- Information *in Auslan* available on the internet on the relevant government department website
- Funding for extensive community consultation by consumer groups (especially in regional and remote areas)
- Ongoing support and referral services as outlined above under *Model of Funding*
- Avoidance of cost-shifting (as outlined below under *Avoiding Cost-Shifting*)

More/Better Services

To prevent a blow-out in costs, the principles of transparency and accountability for all registered providers should be in place as part of a quality management system under the NDIS. Services registered with the scheme should be obliged to submit their service fee structure and annual report to be posted on the NDIS website annually. That is, all registered providers, whether for-profit or not-for-profit, would be required to be accountable to the community. This would provide an incentive for service providers to operate efficiently, as well as a disincentive to for-profit companies taking advantage of the scheme.

The Deaf Society of NSW already has the organisational structures in place to allow for scaling up of service provision rather than a blow-out in costs for existing services. As a company limited by guarantee and a registered charity we also already operate on the basis of financial transparency and accountability to community and government. The not-for-profit governance model is a good one for accountability and transparency and we propose that governance requirements for registered service providers under the scheme be similar to the not-for-profit model.

Avoiding Cost-Shifting

As a general principle, the more service organisations there are, the more cost-shifting happens, and the more connected service providers are to their client base, the less they will shift costs. Therefore, we propose that the NDIS does not establish any new agencies other than the independent national statutory body, but uses existing infrastructure of (mostly) not-for-profit service providers with specific expertise and relationships to specific communities to deliver the scheme. The more specific the expertise of the organisation, and the more connected they are to their client base, the less likely they will shift costs onto other organisations.

In other words, the Deaf Society is “stuck” (albeit happily) with its client base – *we can’t shift costs, because most deaf people won’t be persuaded to go elsewhere.* We can communicate with them fluently (and cheaply, without interpreters), and we have an almost 100-year history of relationship with the community. We are very happy to be thus “stuck”, but it also makes us a prime target for cost-shifting by other organisations.

To give one example, our independent living skills program is constantly having to persuade other service providers that we are not funded to provide transport, social support, home-cleaning or personal care, even for deaf people, while the other organisations desperately try to shift the cost of these services onto us when they have a deaf client wanting those services – again, because we can communicate with the clients while the other organisations mostly cannot. (We would be happy to provide these services, of course, if there were funding available, but there isn’t, and our client and community services department makes a loss of about half a million dollars *every year* as it is.)

To give another example, providing one-to-one information about the scheme, support to access the scheme and referral to appropriate services are areas with a high risk of cost-shifting. As well-known, understood, and fully accessible points of contact for deaf people, Deaf Societies will be the ones asked by individuals for help to apply for the scheme, and to help find and access services. Whether we are funded for this purpose or not, the expectation from the deaf community will be that we will provide that assistance. We wish to avoid a situation in which some central organisation is funded to provide information, support and referral while deaf people and deafblind people continue to come to us because we can communicate with them.

To give yet another example, nursing homes frequently find themselves unable to provide for the communication needs of culturally deaf residents, and contact the Deaf Society to ask for support. We would be more than willing to provide support, but have no funding to do so. We do what we can as a charitable activity. Funding for this could be viewed as the responsibility of the nursing home or hostel, but usually they cannot afford to pay or do not wish to do so. As the deaf population ages along with the rest of Australia, this problem will become worse.

There are three **solutions to these cost-shifting problems**:

- Provide fully portable individualised funding that is not for any particular service, but for services they need – people should be able to come to the Deaf Society or other providers and ask for whatever they need, rather than having to fit in with what we

are funded to provide. This will allow organisations to provide services that are actually needed rather than shift costs around to other organisations.
- Provide a funding under the scheme to established community organisations which have relationships to the communities they serve in order for them to provide information about the scheme, support to access the scheme and referral to appropriate services. Because deaf people will come to us regardless, it makes sense for Deaf Societies to be funded to undertake the task of providing information, support to access the scheme and referral to services to the deaf community. The same is probably true for other specialist disability organisations.
- Allow people who acquired their disability before the age of 65 to access funding for disability services after they turn 65.

NDIS and Centrelink Payments

It is our view that income support and NDIS should remain separate and that Centrelink should not be involved in the administration of the NDIS. NDIS payments should not affect Centrelink payments to individuals. There should not, philosophically speaking, be any conflict between income and NDIS support, as they are for different purposes. One is to enable a person without the capacity to work to purchase the things that everyone needs (food, clothing, transport, shelter) and the other is for them to purchase those things that not everyone needs (interpreting, carers, casework, domestic services). These are fundamentally different functions and should not be seen to conflict.

Complaints

It makes sense for complaints about service providers to be handled by the independent statutory body with a disability ombudsman in place for complaints about the running of the scheme. An expanded role for the Human Rights Commission would be another avenue for government to explore in implementing the scheme.

Lessons from Existing State and National Arrangements

Lessons from existing NSW state and national arrangements are:

- **Lesson 1:** Failure to recognise the expertise of specialist disability services is inefficient, time-wasting and costly. Specialist service providers primarily relate to a specific client base, not to a service type or pre-determined set of government priorities. For example, we are funded to provide independent living skills programs, but some of our clients want social support. We can’t provide social support because we aren’t funded to do it (we do provide some social support as a charitable activity, and make a big loss, but we can’t meet all the need). HACC (under NSW ADHC) provides funding for social support, but only to service providers who cannot communicate with deaf people, or have to employ interpreters to communicate with deaf people. *We could do it for half the price and a tenth of the bother.*
    - **The solution:** fully portable individualised funding which can be spent at any registered disability service provider on any service that the person requests. This would allow service providers to respond to the actual needs of the clients they serve.
- **Lesson 2:** People with disability, on the whole, lack timely access to information and often lack the skills to negotiate complex systems. Even when funding is available, as in the case of the TTY voucher system, deaf people are the last to know, and tend not to access services unless they have the opportunity to find out about them from other deaf people. New organisations take years to develop relationships with deaf consumers.
    - **The solution:** There needs to be good community education/information programs, individual support for applications to the scheme, and referral services available through service providers who already have relationships

with the client base. In the case of the deaf community, the logical organisation to undertake this role is the Deaf Society in each state.

Unintended Consequences

Unintended consequences could include:

- Poorly conducted assessment leading to inappropriate allocation of funds. This has been the experience in some states which have some individualised funding – some clients don't need all their funds, and these are them given back to the scheme, while other clients are left without needed services. To avoid this problem:
  - the assessment procedures should proceed on the basis that the person with disability (with support as needed) is the person best able to determine the support needed
  - the assessment procedures should be carefully conducted
  - most funds should not be treated as income (except for a contingency payment as outlined above)
  - an expiry date for allocated funds should be set. If each person's allocation has an expiry date (say, 5 years after the allocation), then there is likely to be scope for more generous allocations – unneeded funds will simply revert to the scheme in due course if not used, thus providing a buffer for the scheme in case of cost increases.
- Slow uptake of the scheme is very likely in the deaf community, as we know from past experience with the TTY voucher scheme. This can be avoided by providing funding for community education.

Timeframe and implementation

As a rough guide, we have provided a table of some of the activities that could reasonably be undertaken in the first five years of the scheme in relation to the suggestions made above:

Year	**Activities**
1	o Identifying existing organisations with relationships to the client base and funding them to undertake community education on what the scheme will mean for their client base. o Liaison with appropriate bodies within the National Training System to have Auslan Interpreting recognised as a national skills shortage area. o Liaison with ASLIA National to determine strategies for attracting and retaining Auslan Interpreters back to the field. o Liaise with consumer representatives (specifically Deaf Australia) on the details of eligibility and assessment processes. o Choose an appropriate name for the scheme in consultation with consumer representatives.
2	o Identified organisations to continue community education program, and add individual support for applications to their responsibilities (increase in funding for this function). o Fully funded Certificate II in Auslan to Diploma of Auslan courses established in two more states (in addition to Victoria which already has one). o Begin to implement strategies for attraction and retention of Auslan interpreters. o Confirm and publish eligibility and assessment processes.
3	o First applications approved. o Identified organisations to continue community education program and individual support for applications, while adding referral services to their responsibilities (increase in funding for this function). o Continue to implement strategies for attraction and retention of Auslan interpreters.
4	o Identified organisations to continue community education program, individual support for applications, and referral services (maintain existing funding). o Evaluation of the first cohort of successful applicants.

	o Continue to implement strategies for attraction and retention of Auslan interpreters.
5	o Scheme fully operational. o Identified organisations continue community education program, individual support for applications and referral services (maintain existing funding). o Ongoing evaluation of the scheme. o Evaluate strategies for attraction and retention of Auslan interpreters.

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