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Disability Care and Support Inquiry
Productivity Commission
GPO Box 1428
Canberra City ACT 2601

**Australian Government Productivity Commission
Inquiry into a National Disability Care & Support Scheme**

Thank you for providing Northcott Disability Services with the opportunity to provide a submission for the inquiry into a national disability long-term care and support scheme.

ABOUT NORTHCOTT

Northcott Disability Services was established as The NSW Society for Crippled Children in 1929 by the Rotary Club of Sydney. Northcott's purpose is to build an inclusive society. This is achieved by assisting people with disabilities to develop their skills and achieve their goals - including their potential for independence and ability to participate in their community. Northcott supports over 8,000 people with disabilities and their families across NSW and the ACT. Northcott employs over 400 staff state-wide, providing more than 80 services from more than 30 sites and offices across NSW and the ACT. Northcott provides services to people with a broad range of disabilities including physical, intellectual, sensory, acquired and degenerative disabilities, as well as challenging behaviours. Some of the services Northcott provides include accommodation, case management, individual and family support, early childhood support services, computer assistive technology, equipment, transition to work and community participation programs, employment, recreation, respite, therapy and specialist services.

INTRODUCTION

Northcott welcomes the Productivity Commission's inquiry into a national disability long term care and support scheme. As the Productivity Commission has already acknowledged in the *Issues Paper (May 2010)*, there is significant unmet need for people with a disability, and the current disability service system is inadequate to provide for the long-term future needs of people with a disability. As a disability service provider for over 80 years, Northcott has witnessed the changes in the disability service system over the years. Despite significant progress, improvements and initiatives to address issues in the system, there are still insufficient resources to meet needs and gaps in services; there also remains inequity in access to services, and people with a disability have limited control and choice in planning their own supports and having certainty about their future and how their needs will be met. Northcott hopes that a national disability care and support scheme, based on a social insurance approach, will begin to address these issues.

Northcott believes that a national disability insurance scheme would work to reduce the inequity in the system that results from varied, and at times arbitrary, eligibility criteria for services in the current system (including eligibility based on how a disability was acquired, disability type, age etc.), which changes across service types and states. Northcott also sees such a national scheme as a means to providing universal entitlement to all people with a disability, safeguarding people's rights to access services and supports relative to their need. Northcott also believes that a national disability insurance scheme will be able to generate more ongoing funding for disability services and supports, providing for a stable system to meet the long-term and future care and support needs of people with a disability.

There are many possible models for a national disability insurance scheme; some of the issues associated with the design of the system are further explored in this submission. However, regardless of the final design and funding model for a national disability scheme, Northcott advocates that the scheme must support and espouse the following principles:

- Access and equity
- Independence
- Informed choice
- Quality of life
- Social inclusion

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1. ELIGIBILITY

Northcott supports that all people with a disability (as defined under the *Disability Act 1993*) should be eligible for a national disability insurance scheme. This would allow for universal entitlement for all people with a disability. Once deemed 'eligible' people have life-long entitlement to the scheme and rights to receive the services and support relative to their need. However, access to services and supports varies across the life-span; entitlement to the scheme does not automatically equal continuous access to all services and supports. Assessment of need happens after overall eligibility is established, and relates to access to specific levels of funding and/or types of support. In this instance there are two issues of eligibility, one relates to access to the scheme

(scope) and the other relates to eligibility for different levels of funding or types of support (assessment of need) – both are further explored below.

1.1 Scope

Northcott supports a comprehensive scope for a national disability insurance scheme, enabling universal entitlement for all people with a disability. A scheme with a wide coverage would provide all people with a disability the rights to services and supports that are relative to their need. Broad base eligibility would allow for the potential for support and services for all people with at least a reasonable degree of need, but with support graduated to the level of need. Such a scheme would provide an equitable starting place for all people with a disability, and allow tailored support to all those who need some services.

The *Case Study* example from Northcott's Paediatric Spinal Outreach Service (attached in *Appendix 1*) highlights the current inequity in funding and outcomes for people with a disability in the Lifetime Care & Support Scheme versus those eligible for NSW Ageing Disability and Home Care (ADHC) funded services through the National Disability Agreement. The information provided in the Case Study highlights the fact that there are currently gaps in funding for services and resources for the majority of our clients. A minority of our clients are eligible to receive financial support and immediate access to specialist services and equipment because of the circumstances of their injury. The arbitrary criteria of *how* the person acquired their disability is the determining factor for entitlement for support under these different schemes, and highlights the need for a universal entitlement to *all* people with a disability as the eligibility criteria for a national disability insurance scheme.

Should such a scheme be implemented, it is only fair and equitable that all existing people with a disability be included, as well as new people. Currently services like the ADHC Community Participation program only accept new people who meet the eligibility criteria. Specifically, only people with a disability who are leaving school are eligible. As a result, a generation of people with disabilities were not eligible for a day program. In other cases people have remained on less funding as older day program models have not been brought into line with new programs that appear identical. In some cases the difference between being born in one year and not in the next meant that people didn't receive day programs funding for their entire adult life. With some eligible people receiving up to \$54,000 annually, this is a significant gap and creates enormous inequality between people with a disability.

Once eligible for the scheme, the person should be eligible all their life. The addition of an identity card which could be used by the person to access services may also be of benefit in providing "proof of disability" in some situations. Obviously privacy and confidentiality should be guarded at all times, and the information on the card only accessed with the permission of the card holder. If the information found on the card provided access to a central database outlining the person's medical history, this would prevent unnecessary paper work every time the person applies for different services or funding (see section 6. *Governance & Infrastructure* for more information).

Although eligibility for the scheme should be broad, the level of funding and support actually available to an individual should be heavily weighted towards those with the greatest need and towards early intervention (this is further explored below). This is the

notion of having defined boundaries to funding levels/services, based on having a clear and specific framework for assessing need (and appropriate mechanisms for appeals and reviews). Though some people with a disability will not be assessed as having the greatest need and they will inevitably protest that their level of funding is inadequate, we avoid the situation of people being completely excluded even though they may only just fall outside the required eligibility rating. This should also assist in mitigating budget blowouts and maintaining the stability of the scheme.

1.2 Assessment of Need

With a broad overall eligibility for the scheme, Northcott supports a more detailed criteria and process for eligibility for different levels of funding and/or types of support (that is, specific eligibility for funding levels and/or services based on a comprehensive assessment of need). Eligibility for the scheme should be established for a person, and then access to services and support should be assessed along the way, based on their changing needs throughout the life-span and changes in life circumstances. This will add a level of flexibility to the process, and allow a greater capacity for the scheme to meet the ongoing needs of a person as they change (which may mean adding or reducing the support being provided).

1.2.1 Defining support needs:

The criterion of 'severe to profound' can be useful for general understanding of disability diagnoses; however it does not map level of support needs. It is a way of *describing* diagnosis not the *impact* of diagnosis on a person's functioning capacity and life. An assessment of 'severe' or 'profound' disability, on its own, is not an appropriate measure of eligibility or support level requirements as it doesn't map an individual's needs or that of the carer's. Similarly, to categorise eligibility by specific disability type does not map or meet the person's needs. Using this to define support needs, a person's physical needs may be met, however it may not meet their holistic needs (for example: bridging gaps in cognition, socialisation, accessing the community, support to join social groups or maintain employment and continuing assistance to organise daily living requirements).

Northcott supports that eligibility for levels of funding/services under a national disability support scheme should be based on functional capacity rather than disability. In our experiences, the functional impact of the disability is the determinate factor of level of support needed, and is currently not taken into consideration fully when levels of funding are being determined. Functional capacity as a means of assessing and allocating funding is also consistent with person-centred practice, which looks at the individual in the context of their physical, social, emotional environment, rather than a level of severity according to a particular disability category or type. The World Health Organisation's International Classification of Functioning (ICF) would be a best practice framework for assessment and evaluation of functional improvements in a person's achievement of participation within the home, school and community environments.

Defining support needs also needs to happen across different environments. That is, assessment of need should not be based on the functional capacity of a person in *one* environment (for example, their school environment), but rather should include assessing this capacity across all environments in a person's life. Assessing need to determine eligibility for level of funding and/or service types in the scheme should also include consideration of a range of other facets of a person's life, including their age,

location, access to services, transport options, family dynamics etc., as these factors make the support needs of the person either higher or lower. Carers' needs and circumstances (including their ability to provide support and the impact their caring responsibilities has on their life) are also highly important when assessing levels of need, as carers may have their own support needs which may affect how (and how much) funding and supports should be provided.

Finally, but fundamentally, the wishes of the person with the disability should be central to defining their support needs and determining their eligibility for funding and services in a national disability scheme.

1.2.2 Assessment framework:

Northcott supports a holistic assessment framework that assesses a person's needs across environments. As such, Northcott proposes an assessment framework for funding level/services eligibility for such a scheme should take into account three factors, the first being need ('need' being defined based on those facets discussed above). This would take into consideration influences beyond the person's disability such as, access to informal and formal supports, as well as appropriate services and transport. This is vital if we are to create greater equality in our society, when a 'one size fits all' approach only perpetuates further inequality. For example, a person with a disability who has little informal support and lives in a regional area would require more funding in order to access services due to distance. They may also be required to employ more formal support due to a lack of informal support. This is not comparable to a person with the same disability who lives in the city and has a large network of family and friends who act as an informal support.

The second factor to be assessed should be the limitations to the person's functioning capacity (across different environments), and the supports required to overcome them. It is important to note that we shouldn't only measure how the person's disability affects core activities but also what level of support would be required for the person to fulfil these, and other, activities and live the life they want. This is an assessment approach that is being used in the United States with great success. The Supports Intensity Scale (SIS), by the American Association on Intellectual and Developmental Disabilities, is one such approach to assessment. The SIS is a planning tool that assesses the needs of a person (not their deficits) and measures the supports a person needs in order to complete a task they want to do, or achieve aspirations and life goals that they have set. For example, rather than simply assessing the general supports a person may need to participate in employment, this assessment framework asks what type of job the person wants and then looks at what specific supports the person needs to participate in their chosen job.

The third factor to consider should be that of the carer. This should include the carer's ability to not only support the person with a disability, but what impact this role has on the carer's ability to lead a 'normal' and fulfilling life. Once again, this is vital in creating a more equal society. Carers have been shown to be some of the most disadvantaged members of our community, yet receive little acknowledgement or support from the Government.

A person's eligibility for their level of support and funding in a national disability insurance scheme should be based on the collective results of these three factors. However, to ensure that assessments are fair and impartial, they should be conducted

by an independent agency not affiliated with providing direct services under the scheme – this is further explored in the following section. Northcott also supports that this assessment framework should be a nationally consistent tool.

1.2.3 Assessing and reviewing support needs:

Northcott has outlined an eligibility framework for a national disability insurance scheme that first establishes broad entitlement to access the scheme. Once this has been established, there should be a separate assessment of need, which determines eligibility for levels of funding and access to services and supports for the person with a disability.

Assessing eligibility and need should be a multi-discipline approach, determined by a range of health professionals in conjunction with self reporting. This should be finally reviewed by an independent person to unbiasedly gauge the individual's needs, both short term and long term. Northcott proposes that eligibility should be assessed (and funding allocation assigned) by an independent agency, or agencies, that are separate from direct service providers, both government and non-government. This will work to ensure that the eligibility processes are consistent, fair and transparent. This assessment process needs also to be accompanied by an easily navigated and transparent appeals system and process.

Northcott supports that there could be consistent national standards for independent assessment under the scheme, but that different local agencies (accredited to these standards) may be able to provide the assessment service in their local area. The crucial feature of who is accredited to be an assessment agency is that they are independent of service provision under the scheme; that is, they are not a provider of disability support services. It may well be useful to draw on existing government infrastructure for this assessment agency; using existing infrastructure, especially in small regional areas (for example by co-locating the national disability scheme assessment agency within the local Centrelink office), would work to reduce the costs of setting up this administrative bureaucracy. However, while the assessment agency could potentially be part of government, to maintain independence and avoid potential conflicts of interest it would have to be distinct area from any direct service provision under the scheme. As State governments provide direct services in the current disability system, it could be that the Federal government could set up an assessment agency that is co-located with other federal administrative services (eg. Centrelink, Medicare etc.). Alternatively, there could be many local agencies that are accredited as assessment agencies operating under national standards. Regardless of whether there is one or more assessment agencies, government or non-government, there is certainly a role for an Ombudsman in overseeing these independent agencies and the assessment process under the national disability insurance scheme.

Like everyone, people with a disability have changing needs, which may occur as a result of aging (many people with disabilities have been shown to experience the effects of aging in more profound ways than people without disabilities), types of disabilities that are degenerative (e.g. Muscular Dystrophy or Multiple Sclerosis), unplanned events (e.g. medical issues which occur), and changes in life circumstances and living environment (e.g. primary carer becoming unwell). As such, the eligibility and needs assessment process must have in-built ongoing reviews.

Northcott supports an assessment process that is flexible and has regular review periods, as this allows for greater capacity for the scheme to meet the ongoing needs of a person as they change. We propose that eligibility for funding levels/services is reviewed at key transition points (at times when the person's functional needs and/or life circumstances change), on application from the person with a disability, or by referral from their GP or service provider.

1.3 Ranking levels of need

Any assessment process needs to rank people's level of need and highlight priorities areas to target. A national disability insurance scheme should allocate more funding to those people with a disability who, through the comprehensive assessment process (described above), are found to have the highest needs (which will not necessarily be those with the highest 'severity' of disability). However, the groups having the highest needs should also be those people who have disabilities where early interventions are crucial and have a large benefit on their future functions. What also needs to be considered here is the opportunity for maximising people's quality of life, and how increased allocation of funding for people with a degenerative disability (for example, Muscular Dystrophy), might enhance their quality and end of life experience.

Therefore, aside from needs based allocation of funding, it is also important that a national disability scheme direct greater funding to early intervention. It has been shown that this approach yields significant long-term financial savings as well as greater long-term outcomes for people with a disability and their families. In practice, such a scheme may see an individual's funding reduce after an early-intervention period, though this may not be the case for those with the greatest need who require high levels of on-going support.

1.3.1 Priority areas:

The eligibility process and need assessment framework should also make priority those groups of people who are facing additional disadvantage. A national disability insurance scheme should target these specific groups of people and prioritise these groups when assessing need and determining eligibility for different levels of funding/services.

In Northcott's experience, there are many families who are not receiving services or are only receiving 'bare minimum' because they are not able to speak up for themselves and their families' needs. Depending on cultural background, English literacy skills, and/or self-advocacy skills of the carer, many don't tend to express the full level of support they require. The varying levels of resilience for carers also affect their ability to express their needs. A national disability insurance scheme should ensure that people who do not have a strong sense of entitlement are given the tools and mechanisms they require to help them articulate their needs and receive appropriate levels of support.

A national disability insurance scheme should also target those culturally and linguistically diverse communities, and Aboriginal and Torres Strait Island communities, who not only face additional disadvantages (socially and structurally), but who are also under-represented in the current disability system. Families with multiple children with a disability, and parents with a disability, are also a priority area and should be eligible for additional funding/levels of support in this scheme.

In Northcott's experience of providing support for adults with a physical disability there are no services or specialist supports to assist clients with dual diagnosis. These clients fall through the gaps, due to no single service having the skills or resources to provide the required support. People have their needs assessed and receive support based on their diagnosed primary disability, without consideration of their full mental and physical health issues. In these instances a person's physical needs may be supported, but they receive no or minimal support for mental health needs, emotional/social needs or living skills development. There can also be a "masking" effect whereby health professionals attribute mental health issues (like depression or anxiety) to a person's disability, and the person with a disability is not offered support for their underlying mental health issue. A national disability insurance scheme needs to prioritise people with dual diagnosis and ensure appropriate linkages with mental health services.

1.4 Natural Ageing

A national disability insurance scheme can address the issue of disability associated with natural ageing by funding and managing the provision of services for all sources of disability at *all ages*, with the exception of certain disabilities that are strongly related to ageing and that occur in people after middle age, or after what is considered the normative age for on-set. This would be an equitable and fair approach consistent with the broad basis of eligibility being all people with a disability, and supports the rights of people with a disability regardless of their age. However, Northcott only advocates this approach so long as the aged care system is able to provide people with an age related disability with the *same level of service* otherwise afforded under a national disability scheme. That is, people with a disability should not be disadvantaged in accessing the aged care system over a national disability insurance scheme. It could be that people with a disability associated with natural ageing (onset at the normative age) primarily receive funding under the aged care system; however, the national disability insurance scheme would also provide 'top-up' funding to ensure the person is not disadvantaged due to the age of onset of their disability. If the safeguard of providing comparable funding and support for people regardless of age of onset of disability is not included in a national disability scheme, then such a system could result in an inequitable two tiered level of support for people with a disability. In addition, a decision around what constitutes natural ageing and 'normative' age of onset needs to be considered in the context of structural issues and social and cultural circumstances; for example, the impact of lower life expectancy for people from Aboriginal and Torres Strait Islander communities.

1.5 Means/assets testing

Northcott is concerned that any eligibility framework that takes into account people's income or assets also needs to take account of the additional cost of living with a disability, and not structure a support system that further financially disadvantages people with a disability and their families, who are already active community members and making productive financial contributions to society. Northcott would support a system that may require co-contributions based on ability to pay; however, any means testing should take into account the additional costs of living with a disability. Such a system should also ensure that it does not create financial disincentives to economic participation in the workforce by people with a disability and their families. Northcott also supports a system that may make additional premiums available for those people who experience significant financial disadvantage and who have limited to no financial

capacity. This would work more like a safeguard for the very poor, rather than a system that assesses income to ration services. That is, everyone with the same level of assessed need should be eligible for the same level of basic funding, with some provisions available to provide extra support for those with additional financial disadvantage.

2. DECISION MAKING

Northcott supports that all services provided under a national disability insurance scheme should use a person centred approach, providing the person with a disability the power to change or personalise the support provided by the scheme. Northcott believes that a greater choice of support services gives power to the person with a disability. This allows the person to have a more fully informed choice as to what services and opportunities are available. Northcott advocates for individualised funding as a major way in which people with a disability, their families and carers, can have more control over their funding and choice of supports and services.

2.1 Independent agencies

Northcott proposes that decision-making about eligibility for levels of funding should be the responsibility of an independent agency, or agencies, that are separate from direct service providers, both government and non-government. As discussed in section 1. *Eligibility*, Northcott believes that assessments of need, and subsequent allocation of funding, should be undertaken through a comprehensive assessment process administered by an independent agency. This agency should also have responsibility for revised needs and funding review, and provide a transparent and easily navigated appeals system.

Northcott also proposes that the national disability insurance scheme must be supported by a coordination / case management (information, referral and brokerage) service, which could be the same agency as the funding assessment and allocation agency that determines eligibility. Alternatively, case management services could be provided by other agencies on a contract basis. This could operate similar to the Local Area Coordination (LAC) model used in Western Australia, whereby this independent agency assess need and level of funding, and works with the family to provide local information on how to meet needs with formal and informal supports, including making referrals and acting as a brokerage agent where necessary. This service would be provided to all people under a national disability scheme. Once assessed and assigned a level of funding, this agency would provide case planning and support coordination for the individual and their family, including providing information about available services and supports in their local area. For this reason it would work well to have localised offices/agencies to provide this service, as they are better connected to their local community and service systems. Specifically, this service would help the person develop a plan for meeting their needs using the funding available. This independent agency could also have a role in determining which people have the capability of making informed choices about their support plan and funding, and which people may need additional supports (and/or guardians and advocates) to make decisions on their behalf.

Due to the increased level of funding responsibility for person with a disability under an individualised funding model, independent advocacy/support services should also be created specifically for the purpose of assisting people to make beneficial decisions regarding their funding. This option would likely be useful in cases where people do not have family or friends whom they trust to assist them in their decision making. Having independent advocacy/support services, separate to an eligibility and case management service, is important to ensure people with a disability have a range of independent support options to empower them to be the decision makers in their lives.

2.2 Individualised funding

Northcott supports individualised funding under a national disability insurance scheme, and sees this as potentially taking several different forms. There could be individualised funding models that place all planning, purchasing, monitoring and accountability responsibilities with people with a disability and their families; there could be other models that allow individuals to hand over these responsibilities to service providers or government; and there are other models that may draw on any combination of these approaches. There are models that provide funding directly to individuals; models that enable individuals to access funding when purchasing specific services; models that provide funding direct to service providers but that is portable for the individual; models that exchange approved funding between government and services providers; models that provide funding in the form of payments for invoices; and/or any combination of these models and others. Northcott is comfortable with a range of individualised funding models, as long as there are a range of models available, which are flexible and adaptable to meet the needs of people with a disability. Northcott also recommends that there should be models of funding other than individualised funding packages available under the scheme, to enable people with a disability to choose the model that is most appropriate for them and would best meet their needs.

Northcott advocates that any models of individualised funding available under the scheme must adhere to the following principles:

- Informed choice
- Quality of life
- Access and equity
- Independence
- Social inclusion

Any individualised funding model must also provide people with a disability the right to access education, employment, accommodation, community participation, and social and recreational activities, which enable them to fulfil their personal aspirations and live the lives they want.

2.2.1 Guidelines:

In the interests of creating a fair and equitable scheme, all people with a disability should have the option to receive an individualised funding package, with the degree of coordination and administration they want.

Northcott does not support that funding under a national disability insurance scheme should only be considered as normal income, rather that there should be clear operational guidelines on the use of individualised funding. However, these guidelines should not be prescriptive on what a person can or cannot purchase with their funding.

Guidelines should be flexible and allow people with a disability to make decisions about their own funding package, provided there is a clear plan as to how this relates to and falls within the person's longer term care support needs. The independent assessment, allocation and case management agency should have responsibility for helping people develop a support plan and purchase the services or supports they need and that are in line with this plan. This includes purchasing mainstream and disability specific supports and services.

Northcott believes these guidelines should include a re-assessment of need (and therefore funding) on an appropriate basis, and/or with significant life-stage or functioning capacity change. In addition, Northcott supports that individualised funding under this scheme should be able to be saved and rolled over from year to year; however, individuals should not be able to borrow funding through the scheme, but they can apply to have a re-assessment of their needs and level of funding. There should also be easy, transparent mechanisms for appealing funding level decisions.

2.2.2 Monitoring and accountability:

Responsibility for monitoring individualised funding and meeting reporting requirements for accountability will depend on the model used. In some instances an individual or their family will maintain all levels of responsibility for this, while in other situations the person may choose to purchase this service from a disability service provider.

An individual's reporting requirements may also vary depending on the person's ability to use their funding appropriately. For example, should a person demonstrate they are meeting the accountability requirements for the funding, their reporting requirements may be reduced. On the other hand, reporting requirements may be maintained or increased should the funding be handled poorly. If the person with a disability disagrees with restrictions placed on the use of their funding, the independent advocacy/support service could also assist in appealing any decisions.

Northcott views the independent agency/ies responsible for eligibility, assessment of funding and case planning coordination as having responsibility for the overall monitoring framework for the individualised funding packages. As a national scheme, the Federal government should take ultimate responsibility for ensuring appropriate monitoring and accountability processes are in place to account for expenditure of public funding; this should fit within the National Disability Quality Framework (part of the National Disability Agreement). Some current government departments have structures that can be adapted to monitoring the use of the funding.

2.3 Regional and rural areas

For people living in regional and rural areas there is a lack of available services for people with a disability, especially centre based respite, therapy and specialist health support services. Where there are services available, they can often be considerable distances away; families can regularly travel a minimum of one hour through to six hours or more to access services (especially centre based respite services). In addition, there is often no appropriate transport available, and funding to cover the cost of travel is not provided under the current disability system.

There are also additional costs associated with providing services in regional and rural areas, including:

- Large areas for service coverage resulting in increased travel, accommodation and infrastructure costs for service delivery. This also impacts upon ability to meet service outputs as more time is spent on travel (indirect time) in order to deliver the same number of hours of service (outputs).
- Difficulty in recruitment of qualified staff – due to smaller pool of suitable workers and competition with government services (which pay at a higher rate). This can often mean employing less qualified staff who have additional training needs to meet the requirements of role.

Based on these factors, the issue of individualised funding models in regional and rural areas is more complex. Northcott supports that a national disability insurance scheme covers the costs of accessing a service, as well as the service itself. Therefore, individuals and families in regional or rural areas (where appropriate) should receive higher funding packages to cover the cost of travel to services.

Additionally, price setting for services under individualised funding models needs to include consideration of the additional cost of providing a service covering regional and rural areas (compared to the funding provided to the same service based in a metropolitan area). Under a national disability scheme, additional funding (in the form of higher unit costs) needs to be built into funding models for service delivery in regional and rural areas. There also needs to be greater flexibility built into regional and rural service models, to allow organisations to meet the needs of their local communities and be innovative and creative in providing services to people spread across large geographical areas. Resources and initiatives that assist not-for-profit organisations to deliver training in regional and rural areas should also be factored into a national disability scheme; as well as incentives for service providers to expand and increase services and programs in regional and rural areas.

2.4 Risks of individualised funding

Although Northcott strongly supports it, the advent of individualised funding under a national disability insurance scheme brings potential risks and could have negative impacts for people with a disability and service providers alike.

2.4.1 People with a disability:

Potential risks and impact for people with a disability and their families and carers may include:

- Lack of knowledge in the community of the services that are required to support their child's specific needs; for example, a family may just focus on Physiotherapy services as they don't have any knowledge of what an Occupational Therapist or a Speech Pathologist can provide.
- Lack of availability of resources for families to be able to make an informed decision on what services are required to meet their specific needs.
- People don't always know how to source the services that are available – they may feel it is more efficient to spend money on direct therapy (i.e. physiotherapy or occupational therapy), rather than indirect therapy i.e. social worker or case manager)
- Families overspending by choosing too many interventions and running out of money.
- Families being advised of inappropriate interventions by providers who are less ethical.

- For specialist services which have waiting lists (e.g. spinal services, cerebral palsy services) families may choose private (non-specialist) services for immediate service provision.
- The way families spend allocated funds may be influenced by advertising rather than being evidence-based. (i.e. may be influenced by a cheaper fee at the expense of a specialist service)
- Lack of time to make considered decisions by the individual leading to double-handling of tasks, lack of training/advice as to what they really need or the best way to go about tasks. This in turn could lead to wasted funds. This could be helped by having a service agreement in place outlining the specific roles involved within the relationship between service provider and the individual.
- Inappropriate use of funds by the individual or their family. This can be managed via a review and assessment panel that arbitrates in situation where the money is exceeding average use.
- Individualised funding may create a 'market' for disability services and competition for a person's funding. This means that service providers have to seek out and attract clients – which could mean that vulnerable people may be enticed into signing themselves into arrangement that are not able to be altered.
- Risk of unskilled therapists going into private practice who may not necessarily be skilled for the job.

Some of these risks could be managed by:

- Accreditation and/or registration for service providers – which includes continuous quality improvement framework
- Clear ethical framework for provision of service types
- Providing for competition in the market, and therefore choice, without encouraging exploitation of needs
- Community education and training
- Independent advocacy and support services
- Independent eligibility/assessment and coordination/case management agency
- Process for assessing and establishing validity and quality of new interventions

2.4.2 Service Providers:

Although individualised funding is being recommended and will create numerous benefits for the person with a disability, there are potential problems for service providers, which may include:

- Financial risk and service viability. Shifting to a market-based approach to disability service provision and the move to individualised funding has financial and cash-flow implications for organisations. With individualised funding packages, clients can move easily across programs and between services, which reduces income predictability.
- There are likely to be increased costs associated with reporting and accountability, including invoice and processing payments, reporting to individuals and governments, and monitoring of increased number or service agreements and cost centres etc.
- Another major financial risk that individualised funding poses is how fixed costs will be serviced – that is, how to maintain infrastructure and administrative functions within a demand-driven model?
- Block funding also provides flexibility to manage crisis and changing circumstances – how do organisations allow for crisis management, on an individual level, within individual packages and service plans?

- How can organisations access the funding required to continue to train staff, both in terms of core job skills and knowledge as well as offering opportunities for professional development.
- Portable, individualised funding could lead to sudden loss of people attending traditional services or specific organisations; some services may no longer be viable, thereby the amount of choices available to people with disabilities may actually be diminished.
- Lack of guaranteed funding for services will lead to difficulties in recruiting staff as people will not see their job as being secure, which will only perpetuate a problem that already exists within the industry.
- Another problem may be a reduction in innovation. As the industry will become more competitive, service providers will take fewer risks on research and developing new programs. Support options will become narrow and appear more basic.
- Further pressure will be placed upon reducing wages in order to stay competitive. In an industry where people are already poorly remunerated, this could be extremely detrimental.
- Will the shift to funding individuals (and not organisations), and the fact that this funding is generated from the general public (e.g. through the tax system), impact on public fundraising donations for organisations.
- If an increasing number of clients choose support from informal networks over formal staff there could be a de-professionalisation of the workforce supporting people with disabilities. This could result in skills sustainability issues and a causalisation of labour market conditions.

Some of these risks could be managed by:

- Prices need to be set that cover the full and reasonable cost of service delivery (including administrative costs), with appropriate indexation. Included in the determining of cost of services is not just wages and direct service costs, but also factor in costs for training and staff development, allowances for emergencies and contingencies, and contribution to organisational overheads, administrative systems and management structures.
- The Government provide minimum funding to providers to sustain a basic level of core support services. Funding could reduce and eventually cease as the service acquired funding from individuals. For example, a therapy service may receive funding to employ one Occupational Therapist and one Speech Pathologist to cover a particular area. However, as the service attracted consumers and became self sufficient, funding would reduce until it was no longer needed.
- Government should continue to fund new innovative programs and seek tenders from service providers. Once again as these programs became self sufficient, funding could be reduced or ceased.
- Providing funding for organisations to contribute towards the set up costs of establishing a new program or expanding into a new area.
- Arrangements need to be in place to manage 'bad debt' and develop contracts with clients that stipulate consideration of length of notice periods required for termination of services.

2.4.3 Other experiences:

Northcott is a panel provider for the FaHCSIA 'Helping Children with Autism' program. From this experience, we have found that:

- The service is not financially viable without some level of block funding (to cover administrative, travel, overhead, infrastructure, training costs etc. as the full costs of these cannot be sufficiently included fee structure for services)
- Some families (e.g. from culturally and linguistically diverse communities) do not access the funding package and available services is as too hard to negotiate the process and navigate the system.
- Because there is no case management included in the funding model, there is no one supporting families through the process to ensure informed decisions are made.
- There has been no evaluation or auditing of quality of service delivery in the program.

There is also much research from the UK on the impact of individualised funding, which saw small service providers closing due to viability issues from this new funding model. While some families accessed services well, other families with barriers to accessing services, such as literacy skills, did not access services. Another experience in the UK was that agencies were set up solely to manage people's funding and broker out to service providers – this resulted in client's losing some funds to these agencies for unnecessary administrative processes and fees. On the positive side, many unethical providers were not successful as families had the choice to move their funding to another provider.

2.5 Other forms of empowerment

Aside from individualised funding, there are other ways to empower people with disabilities and their families under a national disability scheme. Universal community access and a fully inclusive community is the best way to empower people with disabilities; this is a whole-of-government issue that includes accessible and available transport; access to venues, facilities and public spaces; fully accessible housing etc. Facilitating community access and creating a fully inclusive society also includes developing community awareness and understanding of people with a disability. Other ways to empower people with disabilities could be mechanisms to increase participation in workforce. This may include increasing employer awareness, providing better incentives, decreasing financial disincentives to work, increasing accessible transport etc.

3. NATURE OF SERVICES

Northcott supports a national disability insurance scheme that funds a broad range of services to meet the varied needs of people with a disability and their families and carers. As has been outlined in the previous sections, Northcott supports a model whereby people are assessed for their needs, a funding level is allocated, and a plan is developed. From this plan, Northcott envisages that people should then be able to receive funding, purchase disability supports / services, and/or purchase mainstream services and items.

3.1 Types of services

People with a disability require a range of different supports and services that change throughout their life-span. A national disability scheme requires well functioning

traditional service types, such as: accommodation, respite, therapy, personal care, community access and support, employment, advocacy, equipment, aids and appliances, transport, family support, case management and mentoring etc. However, there are other types of services that support people with a disability, and assist carers to maintain their caring role, which may not fall into these traditional formal service types. For example, accessing lawn mowing services might assist a carer to maintain their household and caring role, although it is not traditionally viewed as a support in a disability service system. Another example may be the use of funding to purchase an industrial washing machine to support a carer who looks after a person with a disability with severe incontinence. The purchase of whitegoods does not essentially fall into traditional types of services in a disability system; however, it does go to support the person with a disability and their carer. Accessing funding for non-traditional formal disability services should also be included in the scheme, so long as the support need relates to the care and support need of the person with a disability and/or their carer.

As such, Northcott proposes that any service that is addressing needs that do not relate to the person having a disability should not fall within the scope of the scheme. For example, the scheme should not fund general lifestyle needs (eg. food); however, the scheme should fund these needs if they would not have existed in the absence of a disability (eg. specialised food/formula required for a person who is PEG fed).

3.2 Priority Areas

There are many areas of need in the current disability service system (services that are non-existent or insufficiently funded and available) which highlights some key priority areas for services in a national disability scheme. As outlined in section 2. *Who makes the decisions*, Northcott advocates that any models of funding available under the scheme must adhere to the following principles:

- Informed choice
- Quality of life
- Access and equity
- Independence
- Social inclusion

Based on these principles, Northcott would like to highlight some priority areas of service for people with a disability.

3.2.1 Accommodation – the principle of ‘informed choice’ and ‘quality of life’:

Not only is there insufficient funding for accommodation in the current system, the models of accommodation support available are not diverse enough to meet the needs of people with a disability. For example, currently public housing, group home or nursing home accommodation are the only options available for most people with disabilities with high support needs, who want to (or need to) move from the family home. These models of housing are not suitable for all people with a disability, nor do they offer a truly person centred accommodation support service provided in the least intrusive, and most inclusive, way. A national disability insurance scheme must provide funding for innovative accommodation models that incorporate informal supports and regular living arrangements for people with a disability. This could include options for smaller ‘flatting’ accommodation for one or more people with disabilities sharing with people without a disability, or unpaid informal support through flatmate arrangements (whereby person without a disability gets accommodation provided in exchange for being an informal

support person for the person with a disability). Currently, some non-government organisations are already providing these types of accommodation models in response to the needs of their clients. A national disability scheme should allow people with a disability and their families to devise innovative and tailored accommodation support arrangements that are specific to their own needs, life circumstances and goals.

3.2.2 Case management and family support – the principle of ‘informed choice’:

In a disability scheme that incorporates individualised funding models, providing suitable case management and family support services is a priority. If people with a disability and their families and carers are to become purchasers of services under the scheme, responsible for coordinating their own care plans, managing their own funding and/or sourcing and employing services, access to support through case management and family support services is fundamental. In order to exercise their decision-making power and make informed decisions, individuals and families need access to information about the types of services available to them and the ways to navigate the system. They will also need support to manage the administrative and accountability responsibilities of being a recipient of an individualised funding package. Family support services that build capacity of individuals and families to self-advocate, to fully understand the system and make informed choices, is an important service in such a scheme.

3.2.3 Recreation Services – the principle of ‘quality of life’:

The inclusion of recreational services, and funding to access recreational support, should be a priority area in a national disability scheme. Often the types of supports funded in the disability system include those traditional formal services which although important, do not always facilitate real options for social engagement and fun recreational activities that are readily available to all people. These experiences are fundamental to a person’s development of friendships, self-esteem and quality of life. Funding for recreation support and services should be included in a national disability scheme, so that people with a disability have access to those same typical recreational and social opportunities as their peers.

3.2.4 Regional and rural services – the principle of ‘access and equity’:

Access to services in regional and remote Australia is a major barrier for people with a disability in these areas. Not only is there insufficient and at times non-existent services in the area to meet the needs of the people, the provision of services in these areas often costs more yet is funded at the same level as in metropolitan areas.

A national disability insurance scheme must include consideration of the additional funding required to provide services in regional and rural areas, and provide incentives for expansion of services in these areas. Northcott supports that the scheme would be flexible to allow local services to meet local needs, and to consider the additional transport and travel costs for some people to access the major medical and health services they require to manage their disability and enhance their quality of life.

3.2.5 Transport – the principle of ‘access and equity’ and ‘social inclusion’:

Many people with a disability are unable to access the services and support they need due to insufficient or non-existent transport options. In the current system, people may be eligible for a service, but unable to attend as the cost of transport cannot be factored into their funding arrangements. There needs to be more accessible transport available for people with a disability in all areas. Moreover, a national disability scheme needs to

include funding for transport and allow people greater levels of funding to cover additional transport costs to access services and the local community.

3.2.6 Transitional and living skills services – the principle of ‘independence’:

A national disability scheme should include an expansion of transitional services and services that focus on living skill development as a priority area. Northcott works a lot with adults with a disability who are anxious about what will happen when they become unable to look after themselves in their own homes, either as their condition deteriorates and/or as their primary carer ages. We also work with many children and families throughout their childhood and growth into adolescence and young adulthood; the experiences of many families is the anxiety about changes in the system at different ages, and the difficulty navigating the supports they require throughout their child's life-span. Planning for when a child leaves school and exploring the options available for their meaningful, independent future life (through further education, paid or voluntary work, or through other day and community participation programs) is an example of such a life transition. Currently, the process to start thinking about and planning for this transition does not happen early enough. A national disability insurance scheme needs to have services that anticipate and support key transition points throughout the life span. Provision for families to access transitional services for support at these times is fundamental. In addition, access to living skills development that supports people to move through transitions and develop independence should be a priority in this scheme; as should be access to funding for technology that makes this independence possible.

3.3 Facilitating Community Participation

To enable full participation in the community, and help increase the opportunities for labour market participation, a national disability scheme should structure services that provide people with a disability with the opportunity and support to:

Work: The person should be assessed on the basis of their skills, needs and wants, not their disability. The person with a disability should be able to access financial support to meet the cost of transport if the person is not able to access cheaper public transport such as trains and accessible buses. The person with a disability should also not be financially disadvantaged (through means tested access to disability income support and services) as a result of participating in the workforce.

The underlying principle here is that when a cost that the person with a disability pays directly because of their disability is significant and necessary, a national disability insurance scheme should step in to “level the playing field” and lift the financial burden for that person. This is so the person is not limited when living their ordinary day to day life, as a result of the financial cost of their disability.

Accessible accommodation: more accessible housing through public and community housing, and utilising different models of housing which are flexible enough to meet individual needs.

Social inclusion: Support to access the community as an individual or as part of a social network. This includes providing people with a disability the opportunities to develop living skills and the confidence to independently access the community. It also requires sufficient and appropriate accessible transport and community facilities and spaces.

3.4 Cost of services

An important consideration for the nature of services under a national disability insurance scheme is who sets the price of services, and what costs are included in determining the service price. In a market-based system, price mechanisms are based on supply and demand, and the question here is whether a national disability scheme should be modelled on the same. If price setting is left solely to the market, people with a disability who live in areas where there is only one service might be disadvantaged; if a service has a monopoly on service provision in an area, they could be free to charge whatever price they want. In such a market-based system, the needs of people with a disability could become a market commodity to be exploited for financial gain.

The other concern with determining the cost of services is how fixed costs (such as infrastructure, management and administrative functions) can be maintained in a demand-driven model. Prices and fees under this scheme need to be set so they cover the full and reasonable cost of service delivery, with appropriate indexation. Northcott also supports the concept that the determining of cost of services not just include wages and direct service costs (eg. office consumables), but also factor in costs for training and staff development, allowances for emergencies and contingencies, and contribution to organisational overheads, administrative systems and management structures. The additional cost of providing regional and rural services must also be considered in the scheme.

Northcott supports a national disability insurance scheme based on an equitable costing system that provides value for money and doesn't exploit the needs of people with a disability.

3.5 Linkages

Northcott supports a whole-of-government approach to people with a disability. A national disability insurance scheme must have strong linkages with mainstream services, such as the health, education and aged care systems. Northcott advocates that a national disability scheme should provide funding for more specialist transition services to support people's movement between systems, such as movement from a disability scheme to the aged care system, or to support the intersection between the education system and a disability scheme. Northcott also supports that people with a disability should not be disadvantaged when moving in between systems (for example, there should not be a change in the level of funding/support provided to a person with a disability if they move to access services through the aged care system).

Northcott's Spina Bifida Adult Resource Team is an example of such a specialist service that supports transition from children's services to adult services: Funded by NSW Health, this outreach service provides clinical consultation, education, support and preventative health strategies to adults with spina bifida, to support their transition from specialist spina bifida paediatric services to mainstream adult health services. This service not only provides people with spina bifida the information and support they need to understand and navigate through a new health and support system, but it also helps facilitate communication across paediatric and adult services, and mainstream health and disability service systems. Similar specialist services that provide targeted support at key points of transition (paediatric to adult and adult to aged care systems) would be beneficial for people with all disability types.

4. FUNDING & FINANCING:

A national disability insurance scheme will provide funding for the long-term care and support needs for people with a disability. Not only will this additional funding provide resources to address the current unmet need in the disability system, it should also work to provide ongoing funding for the future growing numbers, and increasing life-expectancy, of people with a disability.

There are many possible options for the funding model and financing options for a national disability scheme, each with their own strengths and weaknesses. Northcott is not going to advocate for a particular financing option or model over another; however, we do want to outline some broad points for consideration in the financing for a national disability scheme.

Northcott supports that the financing system for this scheme must be a national system, and not just a Council of Australian Governments (COAG) agreement or initiative. To contain costs and ensure sustainability, the scheme should have fixed parameters, and there should be periodical assessment as to changing needs and level of funding (as outlined in section 1. *Eligibility* – individuals should have regular assessment of their need and review of their level of funding if they wish to, at key life transition points, and/or if this is suggested by their GP or other service provider). Northcott also advocates that the introduction of new financing system to fund the national disability insurance scheme must have a gradual, and lengthy, lead time and sufficient resources to implement the scheme across the nation. During the implementation of the new financing system, the scheme should also provide appropriate mechanisms, resources and support for service providers to manage the financial risks associated with the changes to disability service funding (for example, the shift from receiving block funding to having to attract clients with individual funding packages).

Northcott believes that much about the strengths and weaknesses of the possible financing model for a national disability insurance scheme can be explored through examining similar social insurance funding models (for example, motor accident and workers compensation schemes) both nationally and internationally, and disability insurance schemes operating in other countries. Northcott also supports that a national disability insurance scheme would not replace the existing funding sources through which current disability services are funded. However, a national scheme should build on the existing funding generated through state based revenue systems and the National Disability Agreement. The additional funding in a national disability scheme might be generated through a pay-as-you-go system, through taxation, and/or could operate as something similar to the Medicare system and levy.

Regardless of the specific form of financing for the scheme, Northcott supports that the funding should be structured to create the maximum incentives for getting the best outcomes for people with disabilities and their families and in achieving early interventions. One way this could be supported is to structure a flexible funding system that provides universal entitlement, and allows access to funding at points in the life-span and/or where it is assessed as needed. That is, the system should allow all people with a disability an entitlement to funding under the scheme, but access to this funding would change throughout a person's life-span and in-line with changes in their life circumstances and care and support needs.

5. WORKFORCE ISSUES

A national disability scheme will provide additional long-term funding and services across the disability system, bringing with it an increased demand for skilled workers in the sector. Given the existing challenges organisations face recruiting the required workforce, and current experiences with skills shortages, workforce issues will be central to the implementation of a national disability scheme.

5.1 Recruitment & Retention

In order to recruit and retain workers in the disability service system, funding levels must be adequate enough for organisations to attract skilled workers. Currently in the disability system, state governments still provide some direct services; for example, in NSW ADHC provides centre based respite, case management, therapy, accommodation etc. However, non-government organisations are often funded at a lower rate than government (in this case, ADHC) services for providing the same service. As a result of this, staff working in non-government organisations received lower rates of pay than those working in government services for doing the same job. This can serve as a barrier to attracting skilled staff to the non-government sector. As such, Northcott supports consistency in levels of funding for government and non-government provided services under a national disability insurance scheme. In order to attract workers, the scheme should not only offer a fair, reasonable and comparable wage, but also provide appropriate on job training and career promotion opportunity to workers. Northcott also supports that the scheme develops and maintains an industry carrier path that is supported through tertiary institutions and subsidised in an apprenticeship style arrangement, so that workers are attracted from school. This could also be achieved by increasing the amount of FBT exemption that not-for-profit disability organisations are able to offer their employees to make their remuneration more attractive. The FBT allowance has remained at the same level for many years. Another possibility is that government agencies should move away from the direct provision of services in the disability field, except where it is obviously impractical or impossible for those services to be provided by the non government providers. This would reduce the unequal competition for staff.

Aside from remuneration issues, one of the most significant barriers to attracting staff is the community perceptions of working in the disability sector. In NSW, the *Care Careers* initiative (developed and delivered by National Disability Services through industry development funding from ADHC) has been successful in changing the community perceptions of working in the industry. This initiative, including advertising campaigns and website (offering jobs, forums, information and career advice for the care sector), has enabled the general public to see through the misconceptions and understand the benefits of working in the sector. A national disability scheme should support similar initiatives on a national level, to change broader community perceptions of the industry and work to attract a skilled workforce to the sector.

5.2 Skills, Training & Development

A national disability scheme requires a workforce with a range of different skills and roles. In order to ensure a nationally consistent system and workforce that provides comparable services across state based jurisdictions, the federal government should work with the sector to set minimum standards for roles/positions/service types.

5.2.1 Minimum standards:

Northcott supports that for services to be able to bill and/or access funding through the national disability insurance scheme, all workers should have a minimum level of training appropriate to their discipline and role. There should be clear, realistic, minimum standards criteria for service providers, and their workforce, to meet. These minimum standards would incorporate basic training requirements for workers in particular disciplines / roles. However, it will be a big challenge to roll out minimum standards across the nation. Northcott supports that to help this process there needs to be partnering between services, especially in regional and rural areas. The government also needs to provide technology and information systems infrastructure to enable access to minimum standards training through E-Learning models. Moreover, access to technology and online training should not just be available through service providers, but also available in the general community.

5.2.2 Skill shortages:

In Northcott's experience, the main workforce issue is the perception of working in industry rather than specific "skills bottlenecks". However, core skills in understanding privacy and boundaries, and building relationships, will continue to be important for the disability workforce, especially direct care workers.

A possible unintended consequence of a national disability insurance scheme is that it could potentially dilute the volunteer workforce available to the sector because people are already contributing to system through taxes, and may be therefore less inclined to also contribute through volunteering skills/time. Moreover, because the scheme should result in more funding available in the system, therefore more services and an increase in staff in disability services, people may expect to receive wages for work that once they may have undertaken in a voluntary capacity. A reduction in available volunteer workforce could be a potential skill shortage under a national disability scheme.

5.2.3 Training & Development:

Northcott supports that employing people in the role of direct care worker without any qualifications is often a good way to attract staff to the industry; however, minimum standards for this role should include appropriate induction and training prior to commencement, and ongoing on-the-job training requirements to enable staff to develop the required skill set. Northcott also supports that a Certificate 3 level qualification (in Disability or Community Services) as a requirement for all unqualified staff to commence within a certain timeframe, could be included in the minimum standards for direct care workers. Certificate 3 is an achievable training requirement; however, it needs more promotion in the sector and to be made more readily available, especially online. Additionally, staff should be able to start at Certificate 3 level and have a clear training path that can lead to a bachelor degree qualification.

To provide a quality service, staff in the sector must not only meet minimum standards for their role, they also need opportunities to participate in continuous professional development programs to update their knowledge and skills. Cheaper fees for individuals to gain additional qualifications through TAFEs, Universities and other tertiary institutions would encourage and enable staff to improve their skills. The workforce should also have increased access to accredited training.

5.3 Accreditation

Northcott supports national accreditation for services under a national disability scheme as a means of safeguarding the level of service provided to people with a disability, and ensuring a culture of continuous quality improvement. Accreditation should include national standards for the provision of quality services for people with a disability, plus minimum standards for the workforce (according to role/position/service type). This accreditation framework should build in the requirement for quality improvement through the renewal of training for staff where required (for example, requirements about first aid training renewal for direct care workers). Northcott also supports that the government provides the infrastructure required to audit the level and quality of service provided in accordance with the accreditation framework.

5.4 Managing Workforce levels

A potential issue with the introduction of individualised funding under a national disability insurance scheme is the ability of service providers to maintain appropriate workforce levels relative to demand for services. If clients become the purchaser of services, service providers need to be able to flexibly manage staff numbers in response to client demand. Service providers need to have enough staff to be able to demonstrate ability to provide quality service and respond to initial client need; that is, there must be sufficient staff levels so that when clients want to purchase a service they do not have to wait for the organisation to recruit appropriate staff. The flip side of this is that organisations may experience financial risks and viability issues if they have too many staff when client numbers fall. The ability of service providers to manage staffing levels with fluctuating levels of demand may see an increased use of a casualised workforce under a national disability insurance scheme.

5.5 Regional & rural workforce

There are additional workforce issues for disability service provision in regional and rural areas. Some of the issues these areas experience include:

- Staff and skill shortages, especially in terms of experienced qualified professionals such as allied health therapists.
- Recruitment is difficult due to a smaller pool of qualified staff being available.
- Increase cost of providing training due to often geographically dispersed workforce and/or limited access to appropriate training professionals and facilities.
- Communication and connectivity issues with information technology – limiting the wide-spread use of E-Learning training models.

As previously outlined, Northcott advocates for higher unit costs to be build into funding models for regional and rural services under a national disability scheme. This would assist with addressing the additional costs associated with regional and rural workforces. In addition to this, Northcott supports:

- Incentives and more promotion to bring qualified staff to regional and rural areas.
- Greater use of Therapy Aid positions.
- Subsidies for staff to travel to metropolitan areas to attend job related training and workshops.

6. GOVERNANCE & INFRASTRUCTURE

Given the significant changes that a national disability insurance scheme will bring (for governments, service providers, people with a disability and their families and carers), particular resources must be put into the governance arrangements and infrastructure to support the scheme and manage the change.

6.1 Implementation

Northcott advocates for a long lead time for the implementation of a national disability insurance scheme. Resources targeted to support the implementation process are also crucial. Service providers also need access to funding to support them to implement any new systems, especially new financial and administrative systems that may be required as a result of changes in the financing and funding models under a national disability scheme.

Northcott supports that there is grandfathering of existing benefits and levels of funding/service for people with a disability in the current system. This ensures that no one is disadvantaged by the introduction of a new scheme. However, those in the current system may be able to receive increased funding under a national disability insurance scheme if they are assessed as having needs that require higher funding than the current arrangements.

6.2 Information systems

As a national system, Northcott advocates for technological and administrative infrastructure that supports centralised information systems. One way this could be achieved is to introduce a national centralised database system, which could contain information about the person's disability diagnosis and medical history, assessments of their care and support needs, and the funding level allocated and plan developed to meet their needs. This system could draw on the existing infrastructure of the E-Health Strategy; similar to an E-health record, there could be a 'D-health' (disability-health) record that hangs off the E-health system. Drawing on the E-health system would reduce duplication in infrastructure and systems, and decrease the implementation costs associated with developing and maintaining a centralised database for the national disability insurance scheme. Part of the infrastructure could also include the introduction of an identity card which could be used by the person to access services, where the information on the card could enable access to a person's D-health record in the centralised database.

Obviously there are significant privacy and confidentiality issues with the introduction of such a system, and without sufficiently safeguarding people's right to privacy, such systems should not be implemented. However, enabling access to this information across services and states would stop the duplication of paperwork and reduce the frustration that many people with a disability experience in having to complete the same paperwork and answer the same questions every time they access different services. It would also help reduce the cost associated with setting up the administrative bureaucracy required to support a national disability scheme.

If a centralised database system is implemented as part of a national disability scheme, this database needs to be able to interface with service providers' existing internal

information technology and database systems. Information needs to flow both ways if the centralised database system is to be useful for the scheme; that is, service providers need to be able to view information in the database and also update and add information to the database. This would also enable accountability for funding and information about quality and level of service to be exchanged and monitored.

6.3 Financial Systems

If individualised funding is part of a national disability insurance scheme, Northcott sees financial systems as a crucial part of the infrastructure. If people with a disability become purchase of services, service providers will need adequate financial systems that have capability to do large volume of invoices and to monitor individual instances of service. Access to sufficient communication systems and technology (including systems to support mobile access to and exchange of information) will also be important for a national disability scheme.

6.4 Accreditation

Northcott supports that implementation of a national disability scheme must include a national accreditation system means of safeguarding the level of service provided to people with a disability, and ensuring a culture of continuous quality improvement. The National Quality Assurance system for disability services, part of the National Disability Quality Framework under the COAG National Disability Agreement, should provide the framework for accreditation of disability services. Northcott also supports that the government provides the infrastructure required to audit the level and quality of service provided in accordance with the accreditation framework.

CONCLUSION

Northcott supports a national disability insurance scheme to provide for the long-term care and support needs of people with a disability. The current system (with insufficient resources to meet needs, gaps in services, inequitable access, and limited choice and control for people with a disability) is not sustainable to meet the long-term and future needs of people in a fair, consistent and equitable manner. Northcott sees a national disability insurance scheme as a means to providing universal entitlement to all people with a disability, safeguarding people's rights to access services and supports relative to their need. Northcott also believes that a national disability insurance scheme will be able to generate more ongoing funding for disability services and supports, providing for a stable system to meet the long-term and future care and support needs of people with a disability. In this submission, Northcott has raised key issues and proposed particular approaches in relation to the design of such as scheme. What is fundamental when examining and deciding upon the final design and funding model for a national disability scheme is: whether it provides universal and equal access; whether it fosters and encourages independence for people with a disability across the life-span; whether it provides people with a disability and their families the knowledge and control to make informed choices; and whether it flexibly funds a range of services and supports to enable all people with a disability to live the life they want and be included as equal and valuable members of society.

APPENDIX 1 – CASE STUDY

Background information:

Northcott's Paediatric Spinal Outreach Service (PSOS) is a multidisciplinary outreach team that provides a specialised, family-centred, paediatric rehabilitation service for children and adolescents who have a spinal cord injury acquired through trauma or disease. Team members work with specialist medical clinics and other services to maximise reintegration into the home, school and the community. The majority of PSOS clients do not pay a fee for services provided. A small number of clients receive a case management service due to their injury being sustained as a result of a motor vehicle accident. The case manager works closely and liaises with insurance companies to support clients and families to receive the services that are required to help them return to home, school and their community following discharge from hospital. These clients are charged a fee for the services they receive.

In October 2006, The Lifetime Care and Support Authority (LTCS) Scheme was introduced to provide treatment, rehabilitation and attendant care services to children up to 16 years of age, severely injured in motor accidents in NSW, regardless of who was at fault in the accident. Once a child is accepted as a participant in the scheme, LTCS will pay for treatment, rehabilitation and care services that are reasonable and necessary to help them get back to their usual activities. Examples of treatment, rehabilitation or care that a child may receive include:

- Medical treatment such as doctor's appointments and hospital admissions
- Rehabilitation services such as physiotherapy, occupational and speech therapy
- Equipment such as wheelchairs, standing frames, orthotics
- Home and vehicle modifications such as a ramps or bathroom rails
- Services to provide personal and domestic assistance, and home nursing.

The level of severity of a child's spinal cord injury will determine the amount of treatment and services required. For example, a child with a cervical injury (quadriplegia) may require assistance with personal care such as showering and dressing at home, may require the use of a power wheelchair to mobilise, and may require teacher's aides or carers at school to participate in the school curriculum. A child with a lower level injury (paraplegia) may be able to use a manual wheelchair to mobilise, and may be able to attend to their own personal care at home.

Case study example – funding and outcome comparison of two PSOS clients with similar injuries:

Child one: sustained a spinal cord injury as a pedestrian hit by a motor vehicle. As a result of his injury he is a participant in the LTCS scheme. His case manager submits rehabilitation plans every 3 months which anticipate the services that will be needed to meet his rehabilitation goals during that period. He has paid carers at home, who provide assistance with personal hygiene, and rehabilitation exercises. He receives physiotherapy three times per week from a private physiotherapist; and has access to a private occupational therapist. All of the equipment that he uses (wheelchair, standing frame, splints, braces, and continence equipment) is paid for by LTCS. Any modifications required to allow access at home would be paid for by the scheme. To determine the most suitable home modifications to meet his needs, LTCS will select an

occupational therapist who has demonstrated specific expertise in prescribing major home modifications for people with severe disability.

Child two: sustained a spinal cord injury following spinal cord decompression surgery, secondary to scoliosis. Any assistance he requires with personal hygiene is attended by his family. If they wish to hire carers to assist, they can apply for funding to receive some respite care throughout the year. Any equipment he uses is funded mostly by his parents. Some equipment can be purchased through government bodies such as ENABLE or CAPS; however, applications must be completed, and eligibility assessed prior to the provision of any equipment. Local community therapy services are available to provide physiotherapy and occupational therapy. These services are often limited due to waiting lists, and therapists may lack the knowledge and experience specific to spinal cord injury. Finally, any home modifications that may be required would be partly funded through potential government assistance schemes; however the family would still be required to contribute funds towards the completion of modifications.

The information provided in the above case study highlights the fact that there are currently gaps in funding for services and resources for the majority of our clients. A minority of our clients are eligible to receive financial support and immediate access to specialist services and equipment because of the circumstances of their injury. The case study example also highlights the fact that an individual's needs are the same regardless of how the disability is acquired.

Should you require any clarification or further information on this submission please contact Liz Forsyth on (02) 9890 0153 or liz.forsyth@northcott.com.au

This submission has been prepared by Liz Forsyth (Manager, Service Development & Government Relations) and has been endorsed by Northcott's CEO Kerry Stubbs.