

**DISABILITY CARE AND SUPPORT,
DRAFT INQUIRY REPORT**

**RESPONSE FROM THE CENTRE FOR CEREBRAL
PALSY, WESTERN AUSTRALIA**



EXECUTIVE SUMMARY

The Centre for Cerebral Palsy strongly supports the Commission's recommendation to establish a National Disability Insurance Scheme (NDIS) to provide funded support to individuals with profound and severe disabilities. It is incumbent upon all stakeholders, including the Commission, to maintain the pressure on all governments and their oppositions to make this recommendation a reality in a manner that assists the lives of people with disabilities and the services that are available to them.

To ensure that the NDIS achieves optimal outcomes for people with disabilities, the Commission needs to further investigate aspects of the implementation processes, prior to drafting its final report. The Centre strongly urges the Commission to ensure that no client who now receives funded support is left worse off as a result of the NDIS.

The Centre agrees that complementary services such as education services, employment, health, housing, income support and public transport should not be included in the NDIS. This is particularly important to ensure that agencies responsible for these areas not only provide appropriate services to their clients with disabilities, but also lift their game in this regard.

The Centre welcomes the establishment of a timeline to commence the Scheme's implementation, the trials in 2014, followed by its rollout throughout Australia in 2015. However, since all Australian jurisdictions have unique features and characteristics The Centre strongly recommends that trials to be conducted in an identified region in all Australian jurisdictions.

The Centre questions the need to have two distinct schemes to cater to the needs of people with disabilities. The Centre believes strongly that no differentiation in entitlement to the NDIS should be made on the basis of how a person acquired a disability and recommends the integration of both schemes.

The Centre assumes that the Commission's estimate that about 360,000 people will receive funded support through NDIS is a conservative one. The Centre is concerned that there is no assurance in the report that people who now receive funded support will continue to do so under the NDIS. The purpose of establishing the NDIS would be defeated if fewer people receive disability funding than do so now.

The Centre strongly recommends that disability acquired through catastrophic injury be included in the eligibility criteria for the NDIS in line with The Centre's recommendation that the NDIS and NIIS be integrated into one system.

The Centre welcomes the acknowledgement by the Commission that more funding than is currently available will be required to fund the NDIS. The Centre strongly supports funding through consolidated revenue. To ensure that the additional funding to the NDIS is adequate and is a sustainable certainty, The Centre supports the option of making a share of consolidated general revenue available for this purpose through a legislated formula.

The Centre supports the Commission's suggestions that there should be no means or assets testing for getting NDIS funded services. The Centre's preferred position is that the notion of an upfront fee be abandoned altogether. The Centre does not

support co-payments as they are likely to result in forcing many individuals and their families to opt not to have services.

The Centre strongly supports people with disabilities having more power and being able to choose their service providers and where they opt to cash out their support packages and manage it themselves. While strongly supporting individualised options and management of funds by an individual, the organisation urges a step-by-step approach, particularly in the implementation of the latter.

The Centre is concerned about service delivery viability in rural and remote Western Australia. Due to the limited availability of services in rural and remote Western Australia, clients in these areas will have limited opportunity to choose services, unless a concerted effort is made through the NDIS to expand available services.

The situation related to Indigenous clients needs to be addressed urgently. It is particularly important for the Commission to encourage the establishment of Aboriginal specific services in rural and remote areas so that Aboriginal people with disabilities residing in those areas are able to receive services in their own environment. The Centre supports the Commission's recommendation that block funding to specific providers continue, at least in the short term for the provision of services to Indigenous clients.

The Centre strongly recommends that the NDIS be managed as a federated model, which has an overarching national framework including national standards, benchmarks, expected outcomes, accountability measures and governance within which implementation is managed locally. State disability authorities have a good understanding of local features, characteristics and factors and have organisational structures that suit the needs of local circumstances. Western Australia has a very effective and inclusive approach to the development and provision of disability services. Jurisdictions are best placed to manage the scheme's implementation within the national framework and their involvement needs to be retained within the NDIS. An inter-governmental agreement between the Federal Government and State/Territory governments can be the basis of the federated model. It is the Centre's view that the federated model which the Commission proposes for the NDIS would work well for the NDIS.

The Centre strongly supports the Commission's recommendation to enable people with disabilities in the NDIS to remain in the sector upon reaching the pension age if they wished to do so.

It is imperative that the assessment tools being developed be trialled extensively to ensure that they have the capacity to be objective and meet individual needs. The Centre strongly recommends that they be trialled across jurisdictions and across varying types of disabilities.

The Centre strongly believes that assessors need to have a good understanding of specific disabilities, particularly those disabilities which are at the higher end of the disability scale where clients usually have a multiplicity of needs. Towards achieving the best outcome for clients through assessments, the Centre strongly recommends that they be undertaken by multidisciplinary teams.

The needs of many clients, particularly those with a multiplicity of needs, cannot be assessed in a short space of time. Their needs become known through continuous

assessment over a longer period of time. Equally, their situations can change quickly, sometimes even overnight, requiring different supports. The Centre is unclear about how the NDIS will deal with these situations and urges careful consideration to be given to this issue.

For the assessment and planning processes to be meaningfully applied to clients, families and carers strong strategies need to be developed to increase their capacity to participate fully in these processes and to get the best possible outcomes from the new scheme.

The Centre welcomes the establishment of a complaints office so that people with disabilities and service providers could complain or contest the decisions of the NDIA. The credibility of the complaints office would be boosted with clients and service providers alike if it was located outside the NDIA, and is entirely independent of Government.

Providing support to many clients can be complex, but this may not be immediately apparent to the brokering agencies, unless individuals playing this role were highly knowledgeable about specific conditions. The Centre urges that there be an easy process, that does not include penalties, for clients to change service providers if the initial service they opted for does not meet their needs.

The Centre envisages the implementation to be perfected through trial and error over a considerable period of time. It is likely that varying lessons will be learnt through its implementation in the different jurisdictions. It is therefore necessary that officials who have foremost responsibility for implementing the scheme be prepared to have an open mind, be flexible, and perceive the first few of years of implementation as a period of learning and adjustment.

Introduction

The Centre for Cerebral Palsy (The Centre) recognises the enormity of the work undertaken by the Productivity Commission towards putting together the Draft Report and wishes to congratulate it for many of its major recommendations. In particular, it congratulates it for recommending the establishment of a National Disability Insurance Scheme (NDIS) which would provide insurance cover for all Australians with a significant disability. The Draft Report recognises that the current system is fragmented and unfair and is incapable of providing effective care, based on choice for all people with disability and their families. The Commission's major recommendation of establishing a NDIS marks a turning point in the provision of disability services. The Centre endorses the recommendation of establishing an NDIS and the principles upon which it will be founded. It is incumbent upon all stakeholders to make these recommendations a reality in a manner that assists the lives of people with disabilities and the services that are available to them.

By recommending the overhaul of the current system rather than merely tinkering with it, the Commission has provided the opportunity for Governments to meet its obligations under the United Nations Convention on the Rights of Persons with Disabilities which the Federal Government ratified in 2008.

The Centre is reassured by the support the draft report has received from the Federal Government and the opposition, service organisations and the media. While the scheme will directly benefit people with disability, an additional bonus of the scheme should be that family members of people with disabilities who have often carried the economic burden of providing support to their loved ones would have the opportunity to be productive members of a tight labour market.

While supporting many of the Commission's major recommendations, and providing unequivocal support to its foremost recommendation, the establishment of an NDIS, The Centre is aware that even such a progressive concept as the NDIS can have dire consequences for some clients if its implementation is not well thought out and managed sensitively. To ensure that the NDIS achieves optimal outcomes for people with disabilities, the Commission **needs to further investigate aspects of the implementation processes, prior to drafting its final report.** The Centre strongly urges the Commission to ensure that no client who now receives funded support is left worse off as a result of the NDIS.

The Centre's specific comments relating to individual recommendations are provided below.

National Disability Insurance Scheme – Tier 3

The Centre's Board, Management and client families unequivocally support the establishment of the NDIS which is intended to publicly fund individualised support packages to people with significant disabilities. The Centre notes the range of disability supports that will be covered which include:

- Aids & appliances;
- Home & vehicle modification;
- Community access supports;
- Respite

- Specialist accommodation support;
- Domestic assistance;
- Transport assistance;
- Specialist employment services;
- Therapies
- Case management;
- Crisis/emergency support;
- Guide and assistance dogs.

The Centre agrees that complementary services such as education services, employment, health, housing, income support and public transport should not be included in the NDIS. This is particularly important to ensure that agencies responsible for these areas not only provide appropriate services to their clients with disabilities, but also lift their game in this regard. There is a tendency among mainstream agencies to relegate these responsibilities to those agencies that are perceived to have primary responsibility for special needs clients. However, it is important that the NDIS work closely with these departments to enable individuals with disabilities to receive a better coordinated and a more holistic service to address individual need.

The Commission recommends that the NDIS cover provision of specialised accommodation services such as group houses. Although there are many benefits to this recommendation, it may also trigger a negative reaction from community based housing authorities and other agencies such as Lotteries Commissions who currently make sizeable contributions of funds and technical expertise to this area. It would be important for the Commission to weigh the pros and cons of including the specialised accommodation services in the NDIS more thoroughly prior to its inclusion.

The Centre welcomes the establishment of a timeline to commence the Scheme's implementation, the trials in 2014, followed by its rollout throughout Australia in 2015. Although these timelines have not been accepted by Government as yet, recommending timelines makes the Scheme more real for clients and can make it harder for Government to drag out its implementation. However, since all Australian jurisdictions have unique features, a trial conducted in one jurisdiction may provide a biased picture regarding the scheme's potential and likely implications for other jurisdictions. The Centre urges trials to be conducted in an identified region in all Australian jurisdictions to ensure that the NDIS recognises and acknowledges the unique characteristics and features of all jurisdictions and operates to benefit people with disabilities in all Australian jurisdictions. In addition, there are many special features that are built into local systems in the different jurisdictions from which the NDIS can learn and benefit.

The Centre does not expect the implementation process to be flawless straightaway, rather it envisages the implementation be perfected through trial and error over a considerable period of time. It is likely that varying lessons will be learnt through its implementation in the different jurisdictions. It is therefore necessary that officials who have foremost responsibility for implementing the scheme be prepared to have an open mind, be flexible, and perceive the first few of years of implementation as a period of learning and adjustment.

The need for two distinct schemes

The Commission's draft report recommends that the National Disability Insurance Scheme (NDIS) provide insurance cover for all Australian with a significant disability, and a no fault National Injury Insurance Scheme (NIIS) provide fully funded care and support for all cases of catastrophic injury.

The Centre questions the need to have two distinct schemes to cater to the needs of people with disabilities. The Centre believes strongly that no differentiation in entitlement to the NDIS should be made on the basis of how a person acquired a disability. The crux of both schemes should be the extent of the disability rather than how it was acquired. The Centre urges the schemes to be integrated and for all people with a profound or severe disability to be provided with funded support under the proposed NDIS. An integrated system will also remove the disparities inherent in the many systems available throughout Australia.

National Disability Insurance Scheme – Tiers 1 & 2

The Commission acknowledges that while some people with disability will not seek funded support provided through an NDIS, they would require other types of support to enable them to participate in the community, and to lead lives to their fullest potential. The less intensive support is covered under Tier 1 and 2. Tier 1 relates to promoting opportunities for people with disabilities, increasing community awareness about disability, and engaging with other agencies to improve public health and safety. Tier 2 relates primarily to the provision of information and the establishment of a referral service relating to services not funded by the NDIS.

The need for functions included in Tiers 1 and 2 are acknowledged by The Centre because they play important roles for people with disabilities and their families. Despite the good work undertaken by many people, organisations and governments, people with disabilities continue to be discriminated against in many aspects of everyday life. While there appears to be a greater understanding about people with disabilities compared to a few years ago, there is much scope for improvement in this area. The Centre proudly acknowledges that people with disabilities are living fuller and longer lives and acknowledges the need for more research to be undertaken to improve these aspects further.

It is also the case that many people with disabilities do not access available community services due to limited or lack of knowledge of options and services available in the community. A better coordinated information and referral service is therefore welcome.

However, The Centre questions whether these services need to be part of the functions of the new agency responsible for the NDIS. People with disabilities, like other vulnerable groups in society, engage with services more willingly and enthusiastically when this engagement is built on already established relationships. Therefore, while on the one hand, a central information repository would enable easy access, it may cause some concern to clients if they have to rely on a 'faceless' agency for information. Western Australia's clients, service organisations and even government agencies are well aware of the limited knowledge people outside Western Australia have of this State's unique features. The organisational structure

through which Tier 1 and 2 are managed and implemented would need to be carefully considered prior to providing the central agency with these roles. The draft report states that the potential 'customers' for these roles would be high while the overall costs would be low. As there are many organisations within Australia's states/territories already undertaking these roles, The Centre urges the Commission to give more consideration to whether Tiers 1 and 2 would be most efficiently and effectively imparted by the central agency or by agencies that currently provide these services but with a sharper focus.

Eligibility

Everyone is eligible to access Tier 1. Tier 2 may be accessed by anyone with a disability.

To be eligible for support from the NDIS a person needs to have a long term disability and have one or more of the following conditions; significant limitations in communication, mobility or self care; an intellectual disability; or participation in an early intervention group.

The Centre notes that the Commission has estimated that about 360,000 people will receive funded support through NDIS. The Centre assumes that this is a conservative estimate.

In its initial submission, The Centre advocated that all people with disabilities have an automatic entitlement to disability support, similar to the entitlement relating to unemployment benefits. However it understands the Commission's restriction of eligibility to ensure the scheme's economic viability.

Unlike The Centre, the Disability Investment Group advocated for similar eligibility criteria to those proposed by the Commission. This group estimated that of the 1.2 million with a profound or severe disability in Australia about 50 per cent were under 65 years old. Many of those over 50 years could have acquired their disability before they reached 65 years which means that in the future a proportion of people currently over 65 would be eligible for NDIS. Of the 405,500 people with disabilities in Western Australia, 115,800 have profound or severe core activity limitation, a majority of whom would be eligible for funded support. Western Australia usually represents about 10 per cent of the nationwide population. The Centre believes that Western Australia has one of the more equitable systems in the disability sector and the NDIS would benefit from including some of these features. The Centre would be concerned if individuals currently receiving funded support were to be ineligible for similar or better support through the NDIS. The disparity in the figures presented above is of considerable concern and The Centre hopes that people currently getting funded support do not lose this support under the NDIS.

The Centre is reassured by the Commission's statement that the population estimates are merely indicative and have been used for general statistical purposes rather than as a precise guide for eligibility, and that the NDIS would fund all people who met the criteria for Tier 3 funding.

The Commission states that because the NDIS would have broader criteria for providing funded services than existing state and territory arrangements, most people currently getting disability services would receive more support under the

NDIS. Without knowing what these criteria are, it is difficult to assess the validity of this statement. The Centre is concerned that there is no assurance in the report that people who now receive funded support will definitely continue to do so under the NDIS. The purpose of establishing the NDIS would be defeated if fewer people than now receive disability funding do so under the NDIS. This would mean that rather than reducing the under-met and unmet demand the NDIS would have added to it.

The Centre strongly recommends that disability acquired through catastrophic injury be included in the eligibility criteria for the NDIS in keeping with The Centre's recommendation that the NDIS and NIS be integrated into one system.

Funding the National Disability Insurance Scheme

The Centre welcomes the acknowledgement by the Commission that more funding than is currently available will be required to fund the NDIS. The Commission's estimate is that an additional \$6.3 billion per annum would be required to fund the scheme. The Centre notes that the Commission has not made a recommendation on how best to fund the Scheme, although it favours the Australian Government making direct payments from consolidated revenue into a 'National Disability Insurance Premium Fund'. The Commission also sees a tax levy as a possible option although it perceives it as the less favourable option.

The Centre strongly supports funding through consolidated revenue. At a time when there appears to be major public concern over the flood levy and the carbon tax, any hint of the introduction of another tax is unlikely to receive public support. Disability is a matter that concerns the whole society, because every person can have a disability at some point in their lives. Yet, despite much work undertaken by many stakeholders, people with disabilities encounter discriminatory behaviour towards them on a daily basis from members of the general public. The introduction of a tax to fund the scheme has the potential to generate a backlash against people with disabilities. To ensure that funding to the NDIS is adequate and is a sustainable certainty, The Centre supports the option of making a share of consolidated general revenue available for this purpose through a legislated formula. There will then be less scope for political machinations of individual governments to play an intervening role in the amount of funds allocated to it.

The Centre supports the Commission's suggestions that there should be no means or assets testing for getting NDIS funded services. It also supports the waiver of any upfront initial contribution like an excess, for families assessed as already having contributed significantly towards the costs of support through unpaid care. The Centre urges the Commission to approach the suggestion of payment of an upfront fee for other families cautiously. It needs to be recognised that during the lifetime of people with disabilities, their families usually contribute significantly more than monetary support. Research demonstrates the many hardships families endure and the sacrifices they are forced to make. In addition a majority of families with a member with disabilities struggle financially, and are estimated to be in the poorest two fifths of all households. For all these reasons, The Centre's preferred position is that the notion of an upfront fee be abandoned altogether.

Co-payments are charges made each time a person uses a service. Co-payments are usually charged to offset costs and to eliminate wastes by ensuring that individuals

will only access essential services. The Centre does not support co-payments. Co-payments are likely to result in forcing many individuals and their families to opt not to have services.

The Centre does not support including carer payments in an individual's support packages. Carer payments are made to informal carers in recognition of the enormity of the task they undertake in supporting and caring for people with disabilities. This payment should be distinct from support packages even when the individual or the family opts for managing the budgets for funded supports themselves.

Giving people with disabilities power and choice

The Centre strongly supports people with disabilities having more power and being able to choose their service providers and where they opt to cash out their support packages and manage it themselves. The policy of providing individualised options has been government policy for a few years and most service providers are making adjustments to the way they conduct business to enable the policy to be implemented.

While The Centre strongly supports individualised options and management of funds by an individual, the organisation urges a step-by-step approach, particularly in the implementation of the latter. In Western Australia many service providers are exploring their capacity to implement different service models to empower clients. These models include:

- Private rentals
- Co-residency models
- Shared management.

Families interviewed for this submission indicated their uncertainty about how the option for cashing out funded support packages would work. While some families would welcome individualised funding, they felt many will not be equipped to make choices and that some may even misuse the funding. To cater to the different needs and circumstances of individual families, they advocated strongly for flexibility in any adopted system. It is important that good, easy to understand information be available to individuals and families in a variety of formats, including formats that are appropriate for Indigenous people and people from Culturally and Linguistically Diverse backgrounds. In addition training may need to be provided to clients and families prior to making the cashing out option available.

Many of The Centre's clients have complex communication and cognitive skills with severe restriction on mobility. With the model being proposed, some families may be tempted to move away from The Centre's services, to services perceived to be more modern and state of the art. Providing support to many of The Centre's clients is complex, but this may not be immediately apparent to the brokering agencies, unless individuals playing this role were highly knowledgeable about cerebral palsy and similar conditions. The Centre urges that there be an easy process that does not include penalties, for clients to change service providers if the initial service they opted for was not meeting their needs.

Services in rural and remote locations including services to Indigenous clients

The Centre is concerned about service delivery viability in rural and remote Western Australia. Due to the limited availability of services in rural and remote Western Australia, clients in these areas will have limited opportunity to choose services, unless a concerted effort is made through the NDIS to expand available services. Whilst all clients in rural and remote areas of Western Australia will have limited opportunity to opt for individualised options, the situation for Indigenous clients has been recognised over a long period of time as being totally unacceptable.

A majority of Western Australia's Indigenous population live in rural and remote Australia. The Centre is very aware of the limited services available to them. The incidence of disability in the Indigenous community of Western Australia is consistently higher than for the non-Indigenous population. Despite Indigenous people comprising 3.8 per cent of the State's population, Aboriginal children made up 8.4 per cent of children born with cerebral palsy between 1980 and 1999. It is also suggested that Aboriginal people were twice as likely as their non-Indigenous counterparts to require assistance with a core activity.

For a variety of reasons Aboriginal people are often unwilling and distrustful to approach and engage with non-Aboriginal service providers. Due to the inadequacy of services in rural and remote areas, often Aboriginal people with disabilities have either had to put up with available services even when they do not realistically fulfil their need, or be referred to an urban centre with which they have little familiarity. Their situation in terms of these referrals is compounded by their inability to communicate effectively in English and the lack of understanding of this inability by mainstream service providers. In an environment of competition which an NDIS is likely to create, there will be greater scope for Aboriginal individuals and families to have choice relating to services. It is also likely to prompt mainstream service providers to appreciate more the need to be sensitive to the cultural needs of Aboriginal clients. The Centre supports the Commission's recommendation that block funding to specific providers continue, at least in the short term, for the provision of services to Indigenous clients.

As part of any future long term care and support scheme, it is particularly important for the Commission to encourage the establishment of Aboriginal specific services in rural and remote areas so that Aboriginal people with disabilities residing in those areas are able to receive services in their own environment.

The National Disability Insurance Agency

The Centre acknowledges the need for streamlining the disability bureaucracy to make this aspect easier for people with disability and their families. The Centre notes the recommendation to establish a National Disability Insurance Agency (NDIA) to manage the NDIS and to be responsible for managing the roles and tasks associated with Tier 2 and Tier 3.

The Commission suggests that the State/Territory governments either transfer the revenue they now direct to disability services to the Federal government or reduce their taxes by that amount to enable the Federal Government to fund the NDIS scheme. To date State/Territory governments have played a major role in providing funded support in the disability sector. They also have a strong commitment to

people with disability which is reflected in the contributions they make annually to disability services. While acknowledging all the problems associated with the current system, it is highly unlikely that State/Territory governments would want to relinquish their roles without compelling arguments for them to do so.

The Centre understands that the agency would be established through legislation drafted through consultation with States/Territories and that the appointment of the Agency's Board will be overseen by all Australian Governments. State governments' experiences over many years have demonstrated that the notion of equal partners counts for little when State perspectives clash with the Federal perspective. With the NDIA being a federal agency the most likely scenario in the event of a clash of perspectives is that the Federal perspective will hold sway. Since State/Territory perspectives are usually formulated on the basis of state interests, such clashes can have negative consequences for clients and services of individual States/Territories.

Over many decades State/Territory governments have invested in considerable infrastructure and human capital in the disability sector and the success of the new directions would depend greatly on their support. The Commission Report states that State/Territory Governments can decide whether they want to retain a role in directly providing services and supports to people with disability. Since State government agencies have gradually delegated the provision of services to funded agencies, a role reversal may not be in the best interest of the many disability service providers who themselves have developed considerable infrastructure and human capital over many years. In any case for governments to become direct service providers would run counter to most governments' policies.

If the report's recommendations are implemented many service delivery organisations would be forced into making many changes – it is important that implementation of the new system happens with the least amount of disruption to organisations which have provided the best possible services to clients over a long period of time.

For the reasons listed above, together with the need to protect the unique circumstances, features and characteristics of each jurisdiction, **The Centre strongly recommends that the NDIS be managed as a federated model**, which has an overarching national framework including national standards, benchmarks, expected outcomes, accountability measures and governance within which implementation is managed locally. It is critical that local circumstances and unique features are fully recognised and addressed in the scheme. State disability authorities have been designed with local factors in mind and would be best placed to manage the scheme's implementation. An inter-governmental agreement between the Federal Government and State/Territory governments can be the basis of the federated model. It is The Centre's view that the federated model which the Commission proposes for the NDIS would work well for the NDIS.

Aged Care as a parallel system

The Centre notes that the NDIS will only apply to people who get a disability before 65 years. In an ideal world everyone with a disability should be entitled to access the NDIS. However given the cost associated with the NDIS, The Centre understands the need to restrict access to the NDIS and to continue providing support to people who get a disability after 65 years through the age care system.

In its initial submission The Centre requested the adoption of strong measures to improve the interface between the disability and aged care systems. Neither system is well equipped to deal with the needs of clients of the other sector. People with disabilities can experience conditions arising from premature ageing despite not reaching the traditional age upon which ageing is said to commence. For them transferring to the aged care system has caused many concerns. For example although the base rates for Disability Support Pension (DSP) and Age Pension (AP) is the same, clients transferring from DSP to AP at times lost some entitlements such as the mobility allowance and incentive allowance leaving them less well off and struggling to cope. Some have also been placed in aged care accommodation facilities which are unsuitable for their needs.

The Centre strongly supports the Commission's recommendation to enable people with disabilities in the NDIS to remain in the sector upon reaching the pension age if they wished to do so.

The Commission notes that people with disabilities opting for either sector will be subjected to the co-contribution arrangements recommended in the aged care report. However, it is highly unlikely that a person with profound disabilities over a long period of time would have acquired enough assets or income to allow them to make this co-contribution.

Assessments

Families of The Centre's clients have been sceptical about current eligibility assessment mechanisms due to the inequities that exist and the inability to make long terms plans. One of the major issues they confronted was the need to reach crisis point before support was provided. They felt that current assessment processes force them to portray the worst case scenario regarding their family member to ensure funded support continued. The process disallows dignity for persons with disabilities and prevented celebration of their achievements, a goal that families, service providers and funding bodies are working to achieve.

Families strongly advocated for simple, fair and flexible assessment tools that can be portable across the system. The Commission states that its intent is to avoid the uncertainty, chronic under-funding and unmet demand that has beset the current system. While supporting the Commission's pledge to develop such assessment tools, The Centre is concerned that the NDIS will commence prior to fair and equitable assessments tools being developed. It is imperative that these tools be developed urgently to prevent recurrence of current inequities. The new assessment tools would need to be trialled extensively across jurisdictions and across different types of disabilities to ensure that they have the capacity to be objective and meet individual needs.

To ensure objective assessments, the Commission recommends that the people making assessments be independent from the clients, unlike treating GPs, be properly trained in the use of assessment tools and be appointed by the NDIA solely for the purpose of assessments. While acknowledging the need for the independent assessors to be well trained in the assessment tools, The Centre strongly believes that assessors need to have a good understanding of specific disabilities, particularly those disabilities which are at the more profound end of the spectrum

and have the potential to include a multiplicity of needs. For assessments to achieve the most equitable outcome for clients The Centre strongly recommends that they be undertaken by multidisciplinary teams rather than by individual assessors.

The Commission states that assessments would not be automatically rubber stamped, and that benchmarks would be established to determine consistency in assessment. The Centre agrees that benchmarks can be useful where the individual need of one person replicates that of another person. However, if individual need is to be the basis of the NDIS, the use of benchmarks to harden or soften assessments should be used cautiously.

The Centre notes and understands that assessments would concentrate on the reasonable and necessary supports people require. However, it is concerned that current client packages would be used as the gauge of reasonable expectations. This can result in the discrepancies of the current system being replicated in the new system. Under the current system, although some people have been successful in getting more support than is needed, many others have received much less than is needed. Individual need rather than any expectation people might have should form the focal point of assessments. For the scheme's assessment and planning processes to be meaningfully applied to clients/families and carers, strong strategies would need to be developed to increase their capacity to enable them to engage with and participate fully in these processes and to get the best possible outcomes from them.

As stated before, The Centre's clients have complex communication and cognitive issues. Often their needs, particularly for therapy services, are not overt and cannot be assessed in a short space of time. In the case of many of The Centre's clients, their needs become known through continuous assessment over a longer period of time. Equally, their situations can change quickly, sometimes even overnight, requiring different supports. The Centre is unclear about how the NDIS will deal with these situations and urges careful consideration to be given to this issue. The Commission states that the NDIS would periodically reassess people's need for funded support as their circumstances changed, especially at key transition points like leaving school, getting a job, moving out of home or losing a natural support. For many of The Centre's adult clients, these transition points are irrelevant. Their situations can change rapidly and often without warning with support needing to change immediately. To ensure the health and well-being of many of The Centre's clients a process that can respond to these changes without delay, needs to be built into the assessment process.

A short upfront assessment module would be used to establish whether an individual would receive NDIS funded, individualised support. The Centre welcomes the acknowledgement by the Commission that assessment would be waived for individuals who unambiguously experience significant limitations in mobility, self care or communication. However, The Centre's concerns relate to those who may not be perceived to have unambiguous limitation, but nevertheless require on-going support.

The Centre agrees that exaggerated claims and vague or generous use of assessment tools can '...risk diluting resourcing, be unfair, undermine community acceptance of adequate public funding and threaten scheme sustainability...' and that there should be safeguards to prevent sustainability of the scheme being derailed. However, it is equally important to ensure that there are ample safeguards

to protect individuals against an all powerful bureaucracy, particularly one that has a strong commercial leaning, despite being a government body.

Complaints mechanism

The Centre welcomes the establishment of a complaints office so that people with disabilities and service providers could complain or contest the decisions of the NDIA. However it questions the wisdom of locating it within the NDIS, even with the assurance of the office being headed by an independent statutory officer. In government relations, even independent statutory officers can be vulnerable to the directions and wishes of government. Usually, the strength of character of the individual holding office determines such an office's success. The disability sector needs a system or an office which will put clients' needs over all else. The credibility of the complaints office would be boosted with clients and service providers alike if it was located outside the NDIA, and is entirely independent of Government.

Service Delivery

The Commission recommends the establishment of Disability Support Organisations whose role it would be to offer people with disabilities:

- (a) brokering services such as information about service providers and arranging support on their behalf;
- (b) initial information about the scheme, the assessment process and their rights and responsibilities (funded by the NDIS);
- (c) personal planning;
- (d) the skills and confidence to practically exercise choice;
- (e) advocacy services;
- (f) management services (such as dealing with the administrative aspects of self-directed funding, were a person to go down that route).

Under the current system there are many service delivery agencies, which like State/Territory governments have over the years made considerable investment in infrastructure and human capital. Most of them provide a variety of services through block funding from State/Territory funding agencies. More recently they have made several adjustments to their operations to keep abreast of changing policy perspectives. It is likely that they would need to make further adjustments once the new scheme is implemented.

The Commission states that service delivery agencies can undertake roles (b) to (f) above but not role (a) to ensure independence and avoid bias. It must not be assumed that bias will automatically be avoided merely because disability service organisations have the brokering role. It is important for the NDIA to have formal mechanisms to regularly review decisions made by brokering services to ensure that they are working in the best interests of the client rather than working in the best interest of specific service organisations.

The Commission's intent is to make the sector work like a market economy where competition amongst service providers is essential to ensuring that the best services are available to clients. The major issue regarding this model is that it may lead to increases in service pricing which can have adverse consequences for clients.

Under the new scheme service delivery agencies would also not be responsible for a major role they now have, namely assessment. For reasons outlined under the section on assessment, The Centre is concerned about how the new assessment process would work for many of its clients. It is vital that any new scheme of assessments have built in safeguards to ensure that the needs of the most vulnerable and highly complex clients are assessed properly. It would be a mistake to believe that a single yardstick of measurement, whether in relation to assessment or satisfaction would be applicable across the board. If a single yardstick is utilised, the chances are that the needs of the most vulnerable clients would not be well looked after.

The Draft report refers to many accountability measures for service delivery agencies such as national standards, the development of a quality framework, independent audits and consumer surveys. These measures are already utilised by funding agencies such as the Disability Services Commission in Western Australia to increase the accountability of service organisations. While service organisations are familiar with many of them, The Centre strongly opposes the use of surveys to get feedback from clients with complex cognitive and communication skills. While surveys are the most frequently used methodology and likely to be the most economical, particularly with advances in technology, more innovative methods of feedback need to be developed if funded agencies are serious about getting feedback from the diversity of clients in the sector.

The Centre acknowledges the possibility for service organisations to expand services and create innovative services as a result of the extra funding proposed for the NDIS. It also recognises that the scope for disability support staff such as personal support workers would expand, increasing the likelihood of wage increases over time, a factor which is urgently required in the sector. However, The Centre is concerned that many services may have an overcapacity of skilled and professional staff when the new system is proposed because they would forgo some functions they now do. The Commission should investigate the possibility of some of this overcapacity being transferred directly to the NDIS, if staff were agreeable to do so.

Conclusion

The Centre supports the establishment of the NDIS. Nevertheless, it believes that many issues have to be resolved prior to the Commission's final report being drafted. The NDIS is expected to address the sizeable unmet and under-met demand that currently exists and make the funded support system more equitable and portable across Australia. In the establishment of a new system there is always a danger of having winners and losers and to some extent this may be inevitable. A cautious and systematic approach is strongly recommended to enable the outstanding issues of the current system to be addressed without disruption to the lives of people who are, and have been dependent on funded support to reach their potential. Such an approach should also build on the achievements within jurisdictions such as Western Australia and retain their involvement rather than establishing a centralised bureaucracy.