



UNITINGCARE NETWORK RESPONSE

to the

PRODUCTIVITY COMMISSION
DRAFT REPORT INTO
LONG TERM DISABILITY CARE AND SUPPORT

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INTRODUCTION

UnitingCare Australia believes the Productivity Commission has provided a potentially transformative framework for the funding and administration of support and care for people living with disability in Australia. Along with other organisations that work and advocate with people living with a disability and their families and carers, we support the proposals made in the draft report regarding:

- The establishment of a nationally funded disability care and support entitlement based scheme that is adequate and sustainable, and will ensure consistency and transportability throughout Australia.
- The focus on person-centered approaches, and decision making by individuals and their families about what services will be used and how services are delivered.
- An emphasis on inclusion in community life and local solutions.

We also acknowledge that there is significant difference between States and Territories in their level of experience with self-directed care, and that while it is imperative that there is more flexibility and scope for innovation for consumers and suppliers of disability services there are risks associated with moving to a more market-oriented system.

To achieve fundamental reform, and meet the aspirations of people with disabilities, their carers and families, Australia needs to reconceptualise what disability services look like; to eliminate the tiers, duplication and gaps in services and supports and to transform disability into a mainstream issue, not just the concern of the disability sector. This requires, where possible, that services and facilities provided for all Australians are available, accessible and relevant to people with a disability. This needs to occur in all spheres of activity - education, health, housing, transport, access to facilities, provision of goods and services - and in both the public and private sectors.

In order for the scheme to be sustainable, there also needs to be a strong focus on prevention of disability, and early and effective planning to limit costs in the longer term. A benefit of having one, insurance based scheme is that it will make strong economic sense for the agency to invest in prevention and planning. The current maze of funding and service provision does not incentivise these activities.

However, any service system response needs to be situated within the broader framework of enabling people with disabilities to have full citizenship within our community, being fully included in community life and having access to a lifestyle that all other citizens of this country expect. The design of a new system should begin with this end in mind. A key to this is the right for all people to be able to access mainstream community resources and facilities, and be guaranteed the right to the additional supports that are needed to live well with their disability. This needs to be explicitly articulated in any new scheme.

Better long term care and support will be more possible if there is a strong foundation of inclusion that ensures broader social and economic systems include and enable people living with disability to live a decent life, to participate and belong in their community.

Through the current process to develop a National Disability Support Scheme we have the opportunity to create a sustainable service system to support a broader goal of equal citizenship, by enabling people to have control and choice over where they live and how their supports are provided. The scheme should focus not just on supporting individuals but on structural and systemic change to ensure that all people in the community are able to access what they need regardless of their level of impairment.

The process for design, implementation and monitoring of the new system needs a tri-partite taskforce, involving representatives from the Commonwealth Government, and

State/Territory Governments, and Non Government Organisations (NGOs). This model is being successfully used for the design, implementation and monitoring of the National Framework for the Protection of Australia's Children, and would ensure that all parties that can contribute to the success of the scheme are engaged and actively involved in policy and process. NGO representation should include consumer, carer, service provider and research groups.

CORE PRINCIPLES FOR REFORM

The core principle of control being vested in the individual needs to be enshrined in a new model of funding and services. We are concerned that implementation decisions could undermine control being vested with the individual – for example prescriptive guidelines for expenditure of consumer's entitlements could limit consumer control. Our preference is for robust accountability rather than prescriptive. A key aspect of increased control and choice is allowing funding arrangements to support establishing and maintaining informal, reciprocal relationships as well as formal care services. There will be a fine line that needs to be found between balancing protection from risk against consumer choice.

From a broader perspective, inclusion needs to be a foundation principle that encourages and ensures that the broader social and economic system enables people living with disability to live a decent life, to participate and belong in their community. The interface between the disability service system and mainstream services – education, housing and health – is therefore a key area. How does the NDIS facilitate access to mainstream services?

Reforms in these other areas – income support, mental health and housing reforms, aged care reform and employment opportunities – need to encapsulate similar philosophies and priorities.

ISSUES FOR FURTHER ATTENTION IN THE FINAL RECOMMENDATIONS

We would be interested to see more commentary in the final report on how the NDIS will contribute to:

- Improved access to mainstream services.
- Better supporting life course transitions
- Adequacy of and interactions between income support and support packages
- access to support for people with a mild disability who often end up in criminal justice system, mental health and homelessness services
- Improving access to high quality support for people with complex needs who experience disability
- Carer recognition and support
- Addressing workforce skills gaps and shortages especially as proposed timeframe for implementing changes is short
- Support for community service organisations to move into a new system and adopt new approaches

ISSUES FOR CONSIDERATION AS IMPLEMENTATION PLANNING COMMENCES

How could the expertise of service providers, consumers and carers be incorporated into design, prioritising and monitoring of outcomes of reform?

How could current cross-jurisdictional decision-making forums (eg CDSMC) incorporate non-government service provision and advocacy expertise?

How will consumers be safeguarded in a more open service market – quality of workforce, consumer confidence that skill sets are relevant to different services purchased, accountability and monitoring that is light touch and focuses on fraud/exploitation.

How will the NDIS ensure that funding arrangements enable reciprocal relationships between people with disabilities and people in community able to provide support, while also safeguarding employee entitlements and ensuring consumer safety?

How will the system deal with locations and groups for whom the market fails? There will be a role for the NDIA to monitor this, but also ongoing need for advocacy. NDIS funding and guidelines will need to be flexible and regularly reviewed to ensure services are funded at a sustainable level, and to adopt new/improved service approaches and including sustainable remuneration for the workforce. There will need to be a loading on funding to account for places or people for whom service delivery is more expensive.

UnitingCare Australia detailed commentary on the draft recommendations

Outlined below are the more detailed comments UnitingCare Australia would like to make about the draft recommendations in the report. Our more detailed comments and suggestions follow the major headings in the recommendations chapter of the draft report.

Chapter 3 Who is the NDIS for?

UnitingCare Australia supports the general principles articulated by the Commission regarding “who the NDIS is for”. However, there are a number of issues that we believe are not examined in enough detail in the report.

There are a number of groups who appear to be ineligible for support under the NDIS, but who would significantly benefit from assistance and support, and for whom support will often significantly reduce personal and social costs in the future:

- people with a mild disability often end up in the criminal justice system, and with mental health and homelessness services, and these areas are often ill-equipped to understand or support these people’s needs
- numbers of people currently receive low levels of HACC funding that enables them to continue to live in the community without further support

UnitingCare Australia believes that there needs to be mechanisms by which these people can access earlier and more sustained support.

UnitingCare agrees that people with a disability should access services unrelated to their disability through mainstream services (eg housing, education, employment services, health services, transport etc), but that these people regularly “slip between the cracks”. There is an underlying assumption within the report that mainstream services are capable of providing appropriate services and supports to people with complex needs or needing disability support, but that effective protocols and MOUs need to be put in place to clarify who is responsible for service provision in certain instances to ensure these people do not “fall through the cracks”. UnitingCare Australia would question this, believing that there is a need for significant skills development and culture change in many of these services to become inclusive, supportive environments and effective service providers, able to adequately support people living with disability and other complex personal and social issues.

Chapter 4 What individualised supports will the NDIS fund?

UnitingCare Australia generally supports the recommendations regarding what supports should be funded through the NDIS. However, UnitingCare would like to see more discussion around recommendation 4.6, regarding the Disability Support Pension remaining separate from the NDIS. In our experience it is difficult to separate these income support payments from specific disability support, as for many people their disability affects their daily needs, and income support adequacy is interrelated with adequacy of support packages. For example, income support may be used to top up transport assistance for those who can’t access public transport.

Chapter 5 Assessing care and support needs

UnitingCare Australia agrees in principle with the proposed assessment framework, specifically that it will be person centered, strengths based and forward looking and consider the supports that would allow a person to achieve their potential in social and economic participation, rather than only respond to what an individual cannot do.

We expect the framework will:

- Draw on multiple information sources,
- Assess the nature, frequency and intensity of an individual's support needs.
- Determine what supports outside the NDIS people should be referred to
- Consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports'), and the "costs" of providing these services (eg shared housing)
- Translate the reasonable needs determined by the assessment process into an individualised support package funded by the NDIS, after taking account of natural supports
- Provide efficiently collected data for program planning, high level reporting, monitoring and judging the efficacy of interventions.

We also appreciate the emphasis on periodic reassessment of need as people's circumstances change, especially at key transition points in the lifecycle or in the social context.

UnitingCare Queensland, in their response to the draft report, raised a number of issues they felt needed further focus or detail, including: independence of assessments; timeliness of assessments; quick approvals for client-proposed changes; sharing assessments with mainstream agencies; specific assessment tools; dual and multiple diagnoses and assessing intellectual disability.

In addition to these points, UnitingCare Australia would like to emphasise that we believe that *the process of assessment is as important as the assessment tool itself*.

While we acknowledge the importance of independent assessment, we believe that in order to obtain accurate outcomes from an assessment there needs to be a process to enable the development of trust and open communication between the assessor and the client, especially with people who have complex needs and/or multiple disadvantage. From our experience the more disadvantaged the client, the more important it is to have an existing, and continuing, relationship based on trust in order to obtain accurate and relevant information.

Partnership between the NDIS assessor and a local organisation

As outlined in the draft report, we believe it is important that an individual has access to a local advocate to assist them in their meeting with the assessor. While this advocate could be an individual's "circle of support", or a worker from a local disability support organisation, we believe that it would be important that this person had knowledge not only about the person's skills and challenges, but also about the process, in order to be in the position to advocate effectively. The model mentions a "case manager". It is not clear whether this person is working with a local organisation or with the NDIS, and what relationship and role this person would have with the person seeking support, and their family/carers.

Skills needed in the assessor

The assessors would need to be highly trained and highly skilled, experienced both with working with people with multiple disadvantage and familiar with the provision of services, in order to understand the practical implications and possibilities regarding service delivery. UnitingCare Australia would like to ensure that the framework is flexible enough to ensure that individual's specific needs can be met within the framework

The tool

When designing a tool to identify individuals care and support needs, there is a difficult balance to achieve between being too detailed and being too superficial. In our experience, the skill of the assessor is as or more important as the tool itself, and if assessors are skilled, then the most effective tool identifies broad categories, and enables the assessor to evaluate strengths, social assets, core needs, and the issues that might impact on need (for example what challenging behaviours may impact on the ability of an individual to be transported on a bus with others). In order to ensure consistency and rigour within broader assessments, it is then important to include other checks such as peer reviews and good practice case studies to ensure that assessors are providing similar outcomes.

Information collection

The model states that the outcome of assessment will be an agreed package of supports and an informed individual. It is important to remember that the level of data that needs to be collected is different at this point to the data needs of service providers, who need more specific data in order to tailor their services appropriately.

Link between assessment and support package

Currently, once an assessment is made, it is sent to the NDIA for checking and the determination of the assessment package. There is the possibility that this process will be very time consuming, and it is at this point that flexibility and tailoring may be lost, especially where individuals have complex needs or challenging behaviours. It may be important for the sustainability for the scheme, and for accountability, that there is separation between the assessment process and the allocation of resources. However, it is important that this separation does not negatively impact on the adequacy and/or scope of an individual's support packages.

Chapter 6 Who has the decision-making power?

UnitingCare Australia fully endorses the draft report's philosophy that people should be given greater flexibility and control over their lives, utilising a consumer choice model with individual budgets for self directed funding.

Core principles need to be enshrined in the new model. The key principle is for control by individuals, and independence of key parts of the system (entitlement setting process, regulation, complaints and quality, assessment and allocation) but there are aspects of the proposed NDIA and NDIS that could undermine individual control. We believe these risks of undermining individual control can be addressed by ensuring systems focus on robust accountability of expenditure with a focus on demonstrating achievement of positive outcomes, not prescriptive guidelines for expenditure of consumer allocated funds. The critical issue here is to correctly balance consumer protection, protection of public interest in expenditure of funding and genuine flexible consumer choice.

Chapter 7 Governance of the NDIS

The process for design, implementation and monitoring of the new system needs a tri-partite taskforce, involving representatives from the Commonwealth Government, and State/Territory Governments, and Non Government Organisations (NGOs). This model is being successfully used for the design, implementation and monitoring of the National Framework for the Protection of Australia's Children, and would ensure that all parties that can contribute to the success of the scheme are engaged and actively involved in policy and process. NGO representation should include consumer, carer, service provider and research groups.

Chapter 8 Delivering disability services

Ensuring that appropriate and high quality services are available, adequately resourced, and are delivered by a skilled workforce is essential to the success of the new schemes.

The Commission is not explicit or detailed in its discussion about the supply of disability services, though the Commission implies that an NDIS model of disability service provision is likely to introduce competitive pressures – lower prices, the entry of new suppliers, improved quality of service and creation of new products to meet needs. These changes should be to the benefit of those accessing services.

While supporting in principle the move to make the market more responsive to demand, UnitingCare Australia is concerned that there is limited evidence that a liberalised market for disability services can, on its own, ensure that appropriate and quality care is available, even when people have the resources to buy such services. We hold significant concerns regarding both demand and supply.

There is significant research describing market failure relating to demand, with key areas of failure including: information asymmetries, unfair trade practices, unfair standard contract terms, high search and switching costs, and imperfect decision-making processes. We are most concerned with the latter two areas, given that many consumers of disability services have limited capacity to 'shop' for services and adopt market practices. Such characteristics include difficulty in responding to changes, a tendency not to make change, limited cognitive and decision making capacity, limited income, hospital discharge pressures and crisis driven decision making being a norm.

Regarding supply, UnitingCare Australia is concerned that the lack of surety of funding will lead to a distorted growth in the market, with disadvantaged groups and locations not able to attract investment. UnitingCare would like to see more detail in the final report regarding contingencies to mitigate market failure which could be to the detriment of consumers, specifically:

- In rural and remote areas of the state – particularly for Aboriginal and Torres Strait Islander people
- For other particular needs groups e.g. people with disability in forensic systems; people with complex and high support needs including those with challenging behaviours.

Supporting locations and groups for whom the market fails will be an important aspect of the work done by the NDIA, and there will be the need for ongoing advocacy around this issue.

We would like to see the final report demonstrate that a liberalised market has, in other circumstances, ensured the provision of essential services such as disability services. We would like to see the detailed analysis of the structures and regulations that would be required to ensure the supply of these essential services to especially vulnerable and disadvantaged groups. Funding arrangements will need to accommodate higher costs associated with providing services to these groups

Consideration will also need to be taken regarding regulation of the industry as the mix of providers changes – traditionally govt and not-for-profit organisations have provided the majority of services, and these agencies have a business model that prioritises wellbeing outcomes. The for-profit sector is likely to increase its involvement under this model, and this may require a different regulatory framework. There will need to be a balance that ensures consumer safeguards in a more open service market – quality of workforce, consumer confidence that skill sets are relevant to different services purchased, accountability and monitoring that is light touch and focuses on fraud/exploitation - while enabling the system to be responsive and flexible.

NDIS funding and guidelines will need to be regularly reviewed to ensure services are funded at a sustainable level, and to adopt new/improved service approaches and more sustainable remuneration for the workforce.