



Working for People with Intellectual & Other Developmental Disabilities

Developmental Disability Council of Western Australia

Submission to the Draft Report of the Inquiry into Long-Term Disability Care and Support Scheme

1. Introduction

The Developmental Disability Council of Western Australia (DDC) is a systemic advocacy organisation representing the interests of people with intellectual and other developmental disabilities and their families. Our membership includes people with developmental disabilities and their families, a number of the support organisations that work closely with them, and several specialist disability service providers that provide formal funded support services.

DDC has actively campaigned for a secure and sustainable solution to the unmet need for critical specialist disability support services for more than twenty years, with a focus on those people with severe and profound levels of intellectual disability. Our numerous campaigns, both local and national, have been driven by the eternal question asked by parents: "What will happen to my son or daughter when I'm gone." To support our efforts, we developed the Politician Adoption Scheme, to raise awareness amongst our State and Federal politicians of the real impact that unmet need for these important services has on quality of life for people with disabilities and their families.

While there have been several successes in achieving periodic increases to State and Federal funding for specialist disability support services, never before have we seen a response that addresses the fundamental issue of providing a secure and sustainable solution to this national issue and the very personal impacts of unmet need.

DDC commends the Productivity Commission on producing for reflection and discussion a National Disability Insurance Scheme (NDIS) model that addresses the fundamental issue of secure and sustainable revenue. The report makes clear that disability is an event which, unlike ageing and many preventable health conditions, the community cannot reasonably expect individual Australians to plan for. Neither are there appropriate commercial products available if they did. Therefore this is not something that our community and economy can expect individuals and families to take responsibility for alone by subjecting them to such a rationed and crisis driven system in which they have no assurances about if and when they will be able to access the supports they need. Unless and until Governments provide a secure and sustainable response to fund these services, our economy and society will continue to pay for the missed opportunity costs of outcomes such as lower participation rates by individuals and family carers and poor physical and mental health outcomes. And it is individuals and families who will continue to pay the price in their day to day lives.

From this position, we recognise that an insurance scheme provides a reasonable framework for spreading the 'risk' of disability across the community in a more equitable way and addressing future need in a secure and sustainable fashion based on evidence based planning and sound financial management. While we support an insurance model in principle, in this submission we will highlight a number of safeguarding issues which we would like to see more explicitly addressed in the final recommendations.

We also commend the Productivity Commission for its examination of the framework for administering and delivering future investment into specialist disability support services to ensure that future investment has the best possible impact. In light of the variation between jurisdictions across the country, we recognise that this was and will continue to be a considerable challenge, particularly in the implementation of any national scheme. The disability sector in each individual jurisdiction is a product of its own unique history and development and we wish to ensure that in delivering national consistency we also ensure that we make the best advantage of local knowledge and relationships to support the desired outcomes of the NDIS.

People with disabilities and their families must have trust and confidence in the NDIS. Many people with disabilities and their families have had very negative experiences in their interaction with the administrative and delivery arms of human services systems. There are many practical lessons that can be learned from the administration and delivery of human services around the country by both the Commonwealth and State Governments. In this submission we will provide feedback on what we think are some of the key administrative and delivery priorities, including greater clarity on the role of existing State Government infrastructure.

2. Insurance – Delivering Equity of Risk and Safeguarding Vulnerable People

As indicated in the introduction, DDC recognises that an insurance scheme provides a reasonable framework for spreading the 'risk' of disability across the community and over time in a more equitable way and addressing future need in a secure and sustainable fashion based on evidence based planning and sound financial management.

The DDC strongly endorses the recommendation to fund a NDIS through Federal direct revenue based on a legislated formula which is evidence based and which can be adjusted if the evidence indicates this is necessary. The success of an NDIS is reliant on secure and sustainable resourcing. The recommendation, if implemented, would not only clearly state that this is a national issue and priority. It would also put a clear end to the history of disputes between Commonwealth and State Governments over questions of resourcing. By enshrining the funding in legislation, the NDIS would ensure that it is protected and is therefore secure from the vagaries of Budget processes and competing political priorities.

We understand that the revenue would go into a National Disability Insurance Premium Fund which would then be invested to in turn generate further income to fund the NDIS sustainably. We also understand that models such as the Traffic Accident Commission in Victoria have provided successful, sustainable examples of such an approach.

Safeguards

Sound financial management will be critical to the ongoing sustainability of the Scheme. However, we are concerned that the inherent driver within an insurance model to maximise efficiencies could have a detrimental impact on some people with disabilities, particularly those people who are highly vulnerable and who because of their vulnerability often require very unique interventions and support. As an insurance scheme, the NDIS must ensure sufficient flexibility. Some have expressed this concern as a fear that an insurance scheme will drive service delivery towards the “lowest common denominator” in the drive to minimise costs.

DDC would like to see more specific detail in the final report on safeguards in the NDIS for people with very high or very complex needs who might require very high amounts of formal support. Within our current system in Western Australia, we know that there are a number of people who are funded at very high levels because they require very intensive support due to the nature of their disability. This is sometimes due to very high levels of medical care or complex behavioural issues.

Two particular groups of people who are at very high risk in the existing systems, and who will continue to be at high risk in any future system, are those people who have very complex behaviour issues and those people who have no family members or others in their life to look out for their wellbeing other than service providers. To safeguard the needs of these people, the NDIS must include within its menu of services specialised positive behaviour support and potentially specialist mental health services for people with intellectual disabilities who may exhibit challenging behaviours. We believe the NDIS should also have a clear interface with bodies such as the Public Advocate to ensure that highly vulnerable people have someone independent of their service provider who can advocate on their behalf. This should include more specific attention and resources for individual advocacy.

Finally, the transition to any new system must not disadvantage those people currently receiving funded specialist disability support services, particularly those receiving very high levels of support. The final report should explicitly address safeguards for people currently receiving support as this is a potential cause of considerable angst and fear.

Advocacy & Support

Advocacy has historically been the “poor cousin” of the disability sector. In our current crisis driven system, the fundamentals of accommodation and day support services have naturally taken much higher priority. Advocacy is a critical safeguard for people who are vulnerable and disenfranchised both at the individual and systemic levels. Strong and independent individual and systemic advocacy is absolutely essential to ensure that as a community we keep our systems accountable for their outcomes.

The final report must articulate far more specifically where both individual and systemic advocacy will fit within a National Disability Insurance Scheme.

Individual and systemic advocacy **must not** be funded out of individual support packages. Advocacy and other capacity building supports such as coordination, planning, referral and information are an **essential, independent infrastructure** which must exist if the NDIS is to be effective at the individual level. People are unlikely to use their valuable support package funding for ‘advocacy’, even if it is something they feel they need, because it will dilute the value of their ‘direct support dollar’. Furthermore, processes like individual planning vary considerably between individuals and to set an arbitrary amount of funding out of package that should be dedicated to this purpose is not realistic and again will dilute the individuals funding for direct support.

The Productivity Commission articulated very clearly that an objective of the NDIS as it has proposed will be to put power and control over their services into the hands of people with disabilities and their families. Advocacy and capacity building support is critical to the NDIS fulfilling this objective. While many people with disabilities and their families are well placed in this regard already, many others will need support and advocacy to realise the full potential of the NDIS to improve their lives. Families who are vulnerable, people with moderate disabilities who live in the community with no informal networks of support, and people with severe and profound levels of disability who have no people in their lives other than support workers are in particular need of this support and advocacy.

DDC recommends that advocacy and capacity building support services be funded on a block grant basis and not out of independent individual support packages. Within the NDIS, these services should also be administered so as to ensure no perceived conflict

of interest between them and their funder so that they can provide frank and fearless advice and support.

Price

In the development of new systems such as this, there is very often an imperative to set a 'price' for services. It is well understood that many of the efficiencies of service delivery in more centralised locations with higher densities of populations are not achievable in other locations. This contributes to cost variances in service delivery across the country, particularly between metropolitan, regional, rural and remote locations. Higher workforce costs in different locations can also contribute to cost variances.

While we recognise the need for cost benchmarks, the NDIS must provide adequate scope for these variances in order to safeguard quality services

3. Administration & Delivery

In deliberating on its response to issues of administration and delivery, DDC would like to distinguish between three components of the National Disability Insurance Scheme as proposed:

- Delivering a secure and sustainable revenue source – the financing of the scheme;
- Delivering national consistency and equity – standardised eligibility criteria, assessment frameworks, and quality benchmarks; and
- Driving systemic change – shaping social, community, business and government responses for people with disabilities.

The Productivity Commission's recommendations on the financing of the Scheme have in large part been addressed in the previous section. The Productivity Commission has made a very clear argument which draws together both economic and social arguments as to why this is in the national interest. At its core it is fundamentally a political question as to whether the Federal Government will support hypothecated revenue, and what States and Territories might give up in the way of taxation.

DDC will focus its comments in this section on the issue of national consistency and equity, and in driving systemic change. DDC acknowledges that there has been a significant investment in infrastructure, experience, knowledge and relationships within the WA disability sector by our State Government and we would like to see the final report define a clearer role for that investment by the States in the implementation of a National Disability Insurance Scheme, particularly in the two identified areas.

We recognise that the Productivity Commission has highlighted the need for the NDIS to have a strong local presence. However, we would ask the Productivity Commission to consider whether or not local offices of the recommended National Disability Insurance Agency are necessarily the best way to leverage this localised knowledge in implementation in every state. Rather, we would ask that the Productivity Commission consider that existing state government infrastructure could also perform some of these functions. Some have referred to this as a “federated” approach to the NDIS. Under a federated approach, States and Territories would be responsible for the administration of the NDIS rather than state offices of the NDIA.

However, under a federated approach there must be clear accountability mechanisms to hold States accountable for outcomes under the NDIS and to continue to drive better practice. There has been some confusion about what future role the Productivity Commission recommends for State government under a NDIS, and we believe that the final report must make this much clearer.

National Consistency & Equity

The NDIS provides a powerful opportunity to deliver national consistency in eligibility, assessment and quality. The eligibility framework as set out in the report is fairly straightforward and we will not comment on this. Our focus will be on assessment and quality. DDC believes that national consistency and equity are highly dependent on getting the right balance between accountability and flexibility, and taking the best possible advantage of local knowledge, networks and relationships to maximise good outcomes for individuals and families.

Our comments in this area are in large part informed by our knowledge of two existing national human service delivery systems: Centrelink and the Disability Employment Services network.

Many people with disabilities and their families have very low levels of trust and confidence in administration and service delivery frameworks. Most often, this lack of trust and confidence is a direct result of quite negative experiences where processes are driven by administrative imperatives to deliver consistency but where the experience and outcome for individuals is very poor.

Centrelink and reforms to the delivery of specialist disability employment services are often cited by people with disabilities and families as an example of this. Both of these systems are driven by national administrative imperatives to deliver consistency. But people often have very negative experiences and there is little evidence that they have made a substantive impact on the broader outcomes they are meant to achieve. It is difficult to get feedback back through the system where things aren't working, and to change processes accordingly, as decision makers are highly removed from the operations and impacts.

Assessment of support and funding is the 'holy grail' of disability. The fundamental challenge appears to be balancing qualitative and quantitative measures. A person's support needs are highly unique. They depend not only on their particular disability and how it affects them, but also on a whole range of personal circumstances, reflecting the social rather than medical model of disability. Administrative drivers for consistency and transparency often create very complex and burdensome assessment models that ultimately fail in their objective of creating a useful picture of what it is that someone needs. The assessment process must provide plenty of scope for information from people who know the person and their family to have input into the assessment process. It must also be able to recognise the cost variations, as indicated in the earlier discussion of price.

Ensuring consistent quality of services will be critical, particularly at a time when we are likely to see the emergence of new and innovative service delivery organisations to respond to emerging demand. While some of the "market" forces which the NDIS will potentially unleash will drive quality by empowering people with disabilities and their families to exercise greater choice and control, there will of course be the need for ongoing monitoring and sector development. Effective sector development requires not only high level data on gaps in supply, but also local content knowledge and relationships that add qualitative value to that data. Effective sector development requires good local knowledge and relationships about where emerging demand is, what local contextual factors are informing that demand, the capacity of existing

services to meet that demand, or the need for new and emerging services to develop. In the Western Australian experience good relationships between State government (as funder) and the disability sector has been important to the creation and development of new services, and the redevelopment or transformation of existing services.

Driving Systemic Change

DDC congratulates the Productivity Commission for recognising that national reform to the delivery of specialist disability support services cannot happen in isolation. For any such reform to have substantial and lasting impacts, attention must also be given to the broader social, economic and government context. We therefore support the Productivity Commission's inclusion of broader systemic change through shaping social, community, business and government responses to people with disabilities within the scope of the NDIS.

DDC believes that sustainable systemic change is best achieved through combined efforts in three areas:

- The development of policy and legislative agendas for change;
- Grass roots action to support demand from citizens for better services and outcomes; and
- Community development to create more responsive and inclusive environments for people with disabilities and their families.

Each of these areas of work requires strong local knowledge, relationships and networks.

Due to the nature of Australia's Federal system of Government, most mainstream community and social services systems that people with disabilities interact with are highly localised. They are delivered by either State/Territory or local government. Here in Western Australia, the State Government has played a lead role in developing frameworks and supporting action to drive policy and legislative change in mainstream areas such as the development of initiatives such as Disability Access & Inclusion Plans, and more recently *Count Me In – Disability Future Directions* – a State wide strategy.

DDC believes that the NDIS/NDIA will certainly have significant leverage support the drive for change, such as in the example of employment and potential employers provided in the draft report. However, due to the highly localised nature of this work and the existing investment, infrastructure and skills DDC believes that this body of work is best undertaken at the State government level. It is the experience of DDC that local office representation of federal government agencies has not delivered this kind of influence or change at the local level which the report suggests local NDIA offices might have.

Having said that, DDC does believe there must be much stronger mechanisms for holding State governments accountable for their outcomes for people with disabilities and their families. For this reason there must be a very close relationship between the NDIS and the National Disability Strategy.

We also believe that disability support and advocacy organisations such as DDC also have a significant role to play in these areas. Sustainable change cannot be driven by government alone. As indicated earlier, DDC believes that disability support and advocacy organisations, as distinct from service providers, have been historically undervalued and under-funded. And yet they have incredible potential as change agents, particularly where they have very close connections to people with disabilities and their families. These organisations can be highly mobile, innovative and responsive. But most importantly people with disabilities and their families very often have a very high degree of trust and confidence in these organisations.

4. Conclusion

While the National Disability Insurance Scheme has only recently come to public attention, people with disabilities and their families have been campaigning for this kind of transformative change for many years.

As long time campaigners on this issue, DDC firmly support a National Disability Insurance Scheme as a secure and sustainable response to this issue. The focus of our attention is on the key issues of implementation of the NDIS to ensure that it has the best possible outcomes for people with disabilities and their families. Our input is based

on extensive experience of observing the implementation of national and state based human services systems and their impacts on individual outcomes.

DDC recognises that a national reform of this scope requires a review of administrative arrangements of the disability sector between the Commonwealth and the State. We endorse the Productivity Commission's recommendation that the Commonwealth be given sole responsibility for the funding of specialist disability support services and consistency and equity across the country. We do not however support a system that would give sole responsibility for day to day administration to a national organisation, even with a local presence.

We have two clear reasons for this position. The first reason is that in our experience this kind of national structure does not provide the local feedback, responsiveness and relationships that are essential to human service systems which are successful in the outcomes which they deliver to individuals. The second reason is that while the disability system in Western Australia is far from perfect there has been a significant investment by the State Government in infrastructure and relationships which DDC believes must be leveraged in the NDIS.

Finally, the NDIS must recognise the unique and critical role that advocacy and capacity building support services have to play within the disability support system.