Introduction / Overview

Yooralla appreciates the opportunity to review and respond to the Productivity Commission Draft Report on Disability Care and Support ("the Report").

The Productivity Commission is to be commended and congratulated on an excellent and comprehensive report, one that encompasses very challenging issues and which provides a blueprint for the future funding and structuring of disability services, nation-wide.

The proposal for a National Disability Insurance Scheme (NDIS) which for the first time would bring equity and fairness into the publicly funded supports for people with disability and their families across the nation, is wholeheartedly supported as being one of the most important social and economic initiatives of our time.

This submission does not seek to respond to each of the recommendations in the Draft Report. Rather, Yooralla believes there are a small number of areas where the Productivity Commission could further develop or strengthen the Report, and offers suggestions in each of those areas.

Suggestions for further development

1. Nature of supports to be funded by the NDIS

Yooralla acknowledges the challenges facing the Commission in developing a list of what is "in" and what is "out" of the NDIS, and endorses the approach which proposes that the person with disability (with or without support as required and chosen by them) selects both the way their supports are funded, and selects a package of services from the "menu" of services on offer from a wide range of providers.

However, in places the Report seems heavily focused upon a "personal care service", not an emphasis on "the person". Specifically, the "will be funded" list should include supports for people with disability which are not just about functional and personal care types of service. To live a full and enriched life and achieve personal desires and ambitions, people need to be supported in real social settings with a focus on community participation. This is not about "having a goal oriented plan", but about actually living out the actions and activities that everyone aspires to; be they be by conscious design or spontaneous.

For example, Yooralla seeks to provide active support for people with cognitive disability, where it is not just about taking the person to the gym or pool and then the worker having interactions with other gym users; but the worker encouraging and supporting the person with disability to make social connections with other gym / pool users. This extends the notion of "community access supports" that are listed as NDIS funded activities; as they go beyond simply facilitating the activity and, potentially, can lead to informal supports replacing formal support structures—which are good for the individual and the Scheme. This could be provided in conjunction with one of the listed supports, as an important "service/support" in itself or through a type of 'potentiality' allowance within the total funding package.

Yooralla also suggests that a greater emphasis should be made to recognise that a personal care / attendant care model needs to be modified for people with intellectual disability. Provision for people with a cognitive impairment is more complex, drawing in their inner circle of family and friends, and should be focused on "person centred active support" to facilitate engagement in everyday life and social participation. In some cases, for example, for people with behaviours of concern the complexity extends to the need for a stable and trained team of staff supported by specialist staff who are part of an organisational cultural approach of positive outcomes for the client.

In these instances – which are by no means uncommon – the issue is not about an episode of support, a lone worker and their qualifications. It is about the holistic planning for and delivery of support organised around a 24 hour period, 7 days a week. Staff are required to facilitate independence and not simply provide care as directed by the person.

Yooralla would also encourage the Commission to further review who makes the decisions in regard to the purchase of Assistive Technology (AT) services and aids. Yooralla's experience, as a state-wide specialist provider of AT, is that currently there is a substantial under use of AT, and that this can stem from many reasons including funds; lack of knowledge of assessors, care planners and brokers as to the type of AT available and the benefits it could have; and lack of access to AT specialist services.

Yooralla would like to see much clearer statements and pathways to information, access and provision of AT services, including an understanding of new mainstream technologies (the iPad is a recent example given its adaptive characteristics) and the needs for AT to be supplemented by specialist therapy assessment, fitting, supports and reviews. Without this, the potential benefits of AT can be missed or substantially reduced. This is critical as not only can appropriate AT add great life enjoyment, independence and dignity for a person with disability; it can also significantly reduce the costs associated with personal care.

Yooralla would also like to see a much clearer indication of the support which will be provided to individuals and families where there is more than one person with a disability, where the individual needs are low but the collective needs are significant. For example, in a situation where there are two children with mild disability, each might be ineligible but together the children and family should be included in Tier 3 of the NDIS, because of their combined needs.

Finally, people who have previously received a lump sum pay out as injury compensation or do so in the future represent a complex eligibility issue. The principle should be 'no double-dipping' and so a means test or other mechanisms should be applied, including refunding any payments from the NDIS which were made pending a successful claim.

2. Separation of brokerage and service provision

Yooralla understands the concerns that the Commission has heard in regard to the potential conflict when the person assisting with the purchase of services is also part of a service provider organisation. Yooralla agrees that this can create a perception of "referring to oneself", which in turn can be seen as having the potential to not represent the best interests of the client.

However, Yooralla requires its staff to put the client first and so brokerage staff are very focused on ensuring that the best of advice and information is provided to the client – regardless of whether this could be seen as being in the short term interests of the company or not.

The Report notes that DSP organisations can provide five out of the 6 roles to be offered by DSO except for brokerage services. So, looking at this from a client perspective, all direct service needs may be met by one organisation, except brokerage. But the system is still going to require an individual to go to another separate organisation for brokerage, if they do not manage their own funds. For people who are time poor, this is an added complexity, especially when they trust the service provider.

Therefore, would it be possible to consider a trial of DSPs offering brokerage services, where the services being sought through a broker are small, say less than 20 per cent of a total package, just as the Commission has suggested a trial of employing family members?

3. Cost of the Scheme

The report notes the additional net costs of the NDIS will be $6.3 billion. In order for a more complete presentation of the "costs" of the NDIS, Yooralla would suggest a fuller analysis, encompassing two aspects of this of this key question.

First, given that costs of disability services are rising at around 8 per cent per annum, it is clear that the point of comparison for costs is not zero. More specifically, there is a high cost to Australia and Australians of ***not*** having an NDIS and this should be quantified financially and socially.

Second, the suggestion that the $6.3 billion referred to in the Report represents an additional net cost is not accurate. These are additional **gross** costs. The net cost will be $6.3 billion **less** important second round effects which include:

- Reduction in costs applied to acute and emergency health, mental health and crisis accommodation services through lack of adequate supports for people with disability
- Reduction in Disability Support Pensions (DSP) as people with disability are better supported to enter and remain in the workforce
- Reduction in carer payment as family carers of people with disability are able to return in full or part time work due to increased funded supports

While acknowledging that the accurate costing of such factors is challenging, a range of estimates would be a fairer reflection of the true net costs of the Scheme, especially considering that these second round effects are one of the primary benefits of the insurance approach..

4. Employment and Education

Whilst the list of supports proposed to be provided the by the NDIS includes "specialist employment services", it is not clear whether this includes an ability to purchase employment services from an Australian Disability Enterprise (ADE). Yooralla suggests that the final report should be clear that this is an included support. ADE's provide a very important employment option for some people with disability. In some cases they are the only employment type which provides the level of support necessary for a person to stay in employment; in other cases they offer a great entry level and pathway to open employment.

Even if the bulk of ADE's were to continue to be funded by FaHCSIA in the current manner, allowing the purchase of these services via an NDIS package effectively uncaps the program. The current capping has been one of the greatest criticisms and drawbacks of the ADE service. Studies show that governments spend roughly twice as much to keep a person with disability in day programs, as it does to fund them in an ADE place. In addition, the DSP is reduced when a person is earning a wage in an ADE – hence the public, as well as the personal, economic benefits are much greater through increased access to ADE employment options.

We also submit that the same purchasing ability should be clear in the report as applying to education programs, especially those which lead towards employment pathways. At present, access to funded or subsidised education is often linked to DEEWR funded Disability Employment Services, or as part of day programs. Giving the person with disability the control to choose to spend some of their NDIS package on education which both enriches their life enjoyment and increases their chances for independence and employment would be a very positive step. We urge the Commission to make these points clear in the final report.

Controls to help place some protection around quality of training could be placed for example by ensuring that training was provided by a Registered Training Organisation (RTO). It may also be that such training is required to be clearly linked to a recreation / community engagement or employment pathway or personal plan for the individual, in order to avoid conflict with education programs funded in other manners.

5. Workforce issues

We note the proposals within the report to not “over qualify” where certain levels of qualification are not required for the job at hand. We support this proposal and suggest that the Commission note as part of implementation that this may require some negotiation with other bodies including professional associations, which often lead the demand for qualifications and regulation of staff. There may be other areas such as legislations and insurances relating to the administration of medication in the community, in order to allow ‘unqualified’ but suitably supported staff to administer medications that a lay family member can administer.

Without such changes, people with disability will be forced to pay for nursing staff (at a great cost to their package) where a well trained support worker, with appropriate supervision and monitoring mechanisms in place, would be adequate and safe. Yooralla, for example, has a specialist support unit made up of therapists and nurse educators who provide intensive, hands on training, for support workers who provide assistance to take medication, deliver PEG nutrition, monitor blood glucose levels, monitor ventilation support etc. We have established a Complex Health Support Committee to oversee the quality of training and support delivered in this area by direct support staff.

Yooralla also encourages the Commission to consider being more clear in the Final Report in regard to whether or not there would be a requirement for family members or other people directly engaged by individuals (not through an organisation) to comply with regulations facing organisations, including police checks and working with children checks. The rules which ensure minimum standards of quality/safety should be the same for all participants in the disability sector.

There is also an important issue of the Federal Industrial Relations laws which may be out of step with personalised service approaches. Modern Awards are very prescriptive around minimum hours of service; time / spread of hours of service; location, etc – with potentially great loss of purchasing power to individuals who choose to live independently. We suggest that the Final Report should note these contradictions and identify any necessary changes to labour market regulations which would better balance the needs of care workers for minimum standards of employment and suitable flexibility for individuals.

6. Trial of the Scheme

The proposal by the Commission for a single trial seems to be based on the need to establish reliable financial benchmark data.

This is vital, but of equal importance is that the trial should provide a guide to the optimal transition path from the current system to the NDIS. As the disability systems have developed differently in each jurisdiction, it is strongly suggested that there should be a trial in each State, and possibly, Territory, in order to identify the optimal ways forward.

These trials would also give important insights into priorities in the implementation/roll out phase and the likely timeframes for full implementation, which may vary between States and Territories depending on both the potentially different areas of most critical need and how ‘NDIS ready’ each jurisdiction is at the time of the Scheme’s introduction.

7. Health / Disability Boundary

Yooralla supports the concept that people with health conditions should be supported by the Health system.

However, there are some circumstances where people have a health condition, for example, Huntington’s and Motor Neurone Disease, which leads to life long ‘disabling’ conditions. Another group supported by Yooralla is those who had polio and are living with very high levels of disability for the remainder of their lives. The cause of the disability is the health condition, and in these circumstances people usually require long term health supports within their own homes and communities that is much higher than the normal usage by the disability population as a whole.

A specific example that helps to illustrate the complexity of the health/disability boundary is Yooralla’s support for a group of people who are ventilator dependent. The model was developed initially in close consultation with the acute health system, which funded the capital costs of land purchase, building and fit out. At that time the clients were ‘living’ in an acute ward at the Austin Hospital as their needs were too high and specific to be supported in the community. However, technically they were not ‘sick’. On a day to day basis their ‘health condition’ was stable, but they required ongoing monitoring and support by health professionals. At that time funding of all supports was provided by the health system.

There are now four houses in the community, each with five beds, which provide support to people now living in their own homes and respite in the community rather than in hospital. Day to day support is provided by highly trained disability support workers. There is a nurse rostered within the support service 24 hours per day to immediately respond to health related issues. Therapy resources are available within the budget and are purchased on an as needed basis.

The funding level for the Ventilator Support Service was established by the Acute Sector (Department of Health) and included 24 hour nursing, therapy and medical consumable items that are not usually made available through funding of accommodation and respite services in the disability sector. Once finalised, responsibility for funding and overseeing the service was transferred to the disability sector.

While the funding is classified as shared supported accommodation it is at a rate of $4.1 million per annum, which is significantly higher than that made available to other groups, including younger people coming out of nursing homes and people with other conditions such as Huntington’s Disease.

While the people living in Yooralla’s ventilator support service houses (and those who come in for respite) have a reasonable and necessary level of support through the disability budget, it could be argued that the nursing component should be funded from health and that in cases of Huntington’s and Motor Neurone Disease this is not funded by either disability or health and should be funded by the health system.