Productivity Commission
Canberra ACT

1 April 2011

Long Term Disability Care and Support draft report submission

I make a submission regarding the draft report published by the Productivity Commission in February 2011 regarding a disability care and support scheme. I set out below my submission, with accompanying personal information to illustrate the issues. I reiterate my comments in my submission dated 30 June 2010 to your inquiry on this topic (see submission 74 on the Commission's website).

Overview

I applaud the work of the Productivity Commission as displayed in its draft report and I endorse the recommendations in that report subject to the comments in this submission. My suggestions for improvement of the draft report reflect my experience as a mother and primary carer of a child with severe disabilities, including decision-making disabilities. My submissions address the following topics:

1. Enshrine in new legislation setting up the proposed national disability insurance scheme ("NDIS") carer rights to act on behalf of people with disabilities (PWD's) who have decision-making disabilities;

2. Clarify uncertainties regarding determination of what are reasonable and necessary aids and additional everyday costs related to disability under the proposed NDIS;

3. Limit your proposal to forbid PWD's and their families from taking decisions that unreasonably increase NDIS costs in order to leave people free to make important personal decisions about choice of carers, employment and other issues;

4. Integrate the NDIS and mental health sectors to an appropriate degree having regard to the special vulnerability of some NDIS clients;

5. Add PWD's living inappropriately in respite centres as a priority group for early implementation of the NDIS;

6. Waive annual upfront contribution for PWD's requiring greatest support;

7. Pay family carers; and

8. Increase paid care costs for PWD's with very high support needs in models of proposed costs of NDIS.

Enshrine Carer Rights to Monitor and Complain on behalf of Vulnerable PWD’s in NDIS Legislation

The draft report (page 68 Overview) seeks feedback on monitoring instruments that could potentially be used to assist oversight of the disability sector. Specific safeguards are required to monitor the quality of disability services provided to vulnerable PWD’s whose disability undermines their ability to monitor and complain about quality, for example due to intellectual or communication limitations. It is expected that this group will comprise a very large section of the heaviest users of the NDIS. The NDIS differs from accident insurance schemes in that the NDIS is likely to have a larger proportion of users whose intellectual disability precludes them from effectively complaining (or independently engaging in the many actions that the NDIS will require of them). Carers and family members of vulnerable PWD’s should be used as a monitoring instrument to oversee the disability sector and need legal support in NDIS legislation to do so.

The single most effective method of monitoring quality for vulnerable PWD’s is to empower an Advocate (usually the primary carer in the family) with legal rights to monitor and complain about services. Family carers are people who love the PWD and may be with them daily or weekly and are in a position to see the real, everyday aspects of disability services. The unacceptable institutional care offered in the 20th century was paired with an expectation of zero family involvement in the life of the PWD. The more active modern role for carers with PWD’s, including those in supported accommodation who are most vulnerable, is a fundamental shift that can drive quality control in disability services. This important cultural change needs to be supported by a tailored legal framework in the NDIS.

I refer to the article headed “Fearful Mother ‘mentally ill’” on the front page of the Sydney Morning Herald dated 30 September 2010 regarding action taken by NSW Ageing Disability and Home Care (“ADHC”) to have the mother of a PWD declared mentally unfit to act for her daughter so that ADHC could appoint a compliant guardian. The mother had been critical of the quality of care her daughter had been receiving in supported accommodation and the service provider had supported ADHC’s failed action to appoint a guardian. The service provider had implemented a behaviour support plan with very intrusive elements despite the mother’s refusal of consent.

In that case the mother was successful, however only after a cumbersome legal process. Carers have been scared off and discouraged from standing up to ADHC and disability service providers for a lifetime. In addition, workers in disability bureaucracy and service providers have enjoyed too much power over PWD’s and carers. The mindset of many individuals in disability services needs significant adjustment to give full effect to the rights of PWD’s.

In that article Andrew Constance MP is quoted as saying “Families such as this have lost all confidence in dealing with the current NSW Government because of the ‘us versus them’ mentality that is part of the existing culture.” This ‘us and them’ culture also exists between disability service providers and carers who criticise disability services. In the absence of very clear and strong legal rights for an Advocate to act on behalf of vulnerable PWD’s, family members will be unable to enforce protections necessary for the NDIS.

It is my experience as a carer that disability service providers are happy to fully recognise the carer's role when they are giving the carer work to do or using the carer to obtain information supporting tasks that the service provider wants. However, when the carer seeks information on behalf of the PWD or wants to complain or assert rights that are inconvenient for the service provider, the service provider is much more concerned about strict legal requirements of privacy and other laws.

Carers' rights to act for vulnerable PWD's are not clear enough. In general, these rights are easier to enforce while the PWD is under-age, but even in that case I have encountered resistance from disability service providers. Once the PWD reaches adulthood, the carer's ability to support the PWD is very difficult in the absence of clear laws that are easily and widely understood by all.

Page 6.17 of the draft report observes that there are "strong grounds for guardians (such as a parent or partner) familiar with the person with disability to act as their proxy under self-directed funding." I submit that this does not go far enough. The current process of appointing a guardian for a PWD with a decision-making disability applies on an exception basis, is not tailored to the needs of a new NDIS and focuses on informal negotiation of issues as a precursor. The current guardianship laws are not sufficient for use by the NDIS for the following reasons:

1. Special vulnerability of a large number of NDIS clients;

2. the very powerful and intrusive actions that can be taken by a disability service provider in respect of a PWD; and

3. the need to change a culture of paternalistic disability service providers and disempowered carers.

The NDIS will require that carers' rights to act on behalf of vulnerable PWD's be clear, easy and universal. The Advocate should have all rights to act as if they are the PWD including:

1. unfettered right of unannounced access to the PWD and their home (similar to a Community Visitor);

2. exception from privacy laws so that they may stand in the shoes of the PWD to call for, copy and review all relevant information and documents regarding the PWD; and

3. the ability to assert all the PWD's rights under the NDIS including to choose service providers, talk privately with service provider employees, inspect operational documents of service providers and to complain about quality of service.

The NDIS will need a formally appointed Advocate for vulnerable PWD’s merely to undertake its administrative functions, as well as to gain the collaborative involvement suggested throughout the draft report (see for example page 5.20). It will also be more efficient for the NDIA and service providers to have a single appointed Advocate with whom to deal, rather than potentially differing views taken by, for example, divorced parents of a child with disability. My proposal is a logical extension of that role to ensure effective monitoring of quality. I consider that the failure to propose a formal role for an appointed Advocate for vulnerable PWD’s in the draft report’s discussion of complaints (see page 7.39 and following) to be a serious deficiency in the draft report.

I refer you to discussion of appointing an Advocate in my previous submission to the Commission’s inquiry on the NDIS.

Clarify Costs NDIS will Cover

The draft report is unclear as to the extent to which is it proposed that the NDIS should meet costs related to disability. The general rule proposed of providing funding to cover costs of items that are ‘reasonable and necessary’ is very general. It is difficult to determine objectively what specialised equipment and additional costs of living one needs as a result of a disability.

Section 4.2 of the draft report discusses certain specialist disability supports that will be met without providing sufficient detailed rules regarding the extent of those costs. In particular I am not clear on the definition of aids and appliances that fall within the NDIS, nor the extent to which it is proposed that the NDIS should cover the additional costs of everyday living due to disability.

Pages 4.9-4.11 of the draft report discuss additional costs of everyday living and suggests that the NDIS should consider covering two examples (additional electricity costs and PEG feeding) without stating a proposed general rule to be applied to additional costs of living. Why does the draft report only ask for feedback on the NDIS treatment of electricity costs (see page 67 Overview) and not about the huge number of other additional costs that arise due to disability?

I have incurred numerous additional costs related to my son’s disability as follows:

1. Specialised clothing (that is not removable by the wearer due to behavioural issues and/or has incontinence features);
2. Specialised toothbrushes ($12 each sold by the Westmead Hospital dental clinic) for use with/by people with disabilities;
3. Specialised plates and eating utensils;
4. Specialised toys with occupational therapy properties;
5. home modifications to enhance safety and security such as closed circuit infra-red camera, blackout shutters, internal window bars and locks;
6. a modern ‘straitjacket’ for car restraint (cost $650).

None of these items have been certified by a medical professional as medically required but I consider they are necessary for everyday living with a PWD in our circumstances. How would the NDIS determine the need for specialised everyday equipment? Would certification by a doctor or therapist be required? How would that be determined?

I would request that the final report of the Commission consider setting rules regarding the determination of ‘aids and appliances’ and ‘additional costs of everyday living’ to include in the NDIS as this will be an important factor in cost estimates for the NDIS. Leaving uncertainty on these matters will give rise to significant argument as to what is ‘reasonable and necessary’.

Limit Prohibition of PWD or Carer Action that may Increase NDIS Costs

Draft recommendation 7.11 includes an obligation for PWD’s and their carers to avoid decisions that unreasonably impose costs on the NDIS scheme. This is a very wide obligation and the draft report gives insufficient discussion of the proposed limits of this requirement.

The draft report makes clear on page 7.44 that this rule is proposed to address the facts of the Witten-Evans case to impose a requirement that PWD’s who require home modifications not move to a house that is very costly to modify. This broad rule could also disallow the following decisions by a PWD or carer if the administrators of the NDIS considered it unreasonable:

1. moving to a remote area;
2. moving house too often, for example, is it unreasonable to move three times in ten years, after making home modifications?;
3. moving out of a modified house too soon (say one year?) after modifications were made;
4. PWD’s mother/primary carer chooses to undertake paid employment. Query any different decision on reasonableness if the employment requires very long hours of work?;
5. PWD’s mother/primary carer chooses to take an annual holiday without their children. Query any different decision on reasonableness if the holiday lasts for one week or four weeks? Query any different decision on reasonableness if the child is five or fifteen or thirty years old? Query any different decision on reasonableness if the child requires constant care and has behavioural problems?
6. PWD chooses not to be provided with (free) care by their family;
7. PWD’s mother argues with her mother-in-law (who was providing a lot of free care for the PWD) and refuses to allow her to care for the vulnerable PWD because the mother considers that the mother-in-law is not acting appropriately toward the PWD and is causing him to have behaviour problems;
8. PWD requiring 24-hour paid care chooses to live in their own home instead of a group home.

This proposed rule has the potential to intrude into a huge area of the PWD’s and carers’ private decisions and is too broad. Constant uncertainty would exist as to what is a reasonable decision. A better method of addressing the concerns about cost restrictions would list the nature of decisions that the NDIS would prohibit, for example, it could limit the cost contribution toward home modifications to a fixed percentage above a fixed/average cost based on other NDIS users or it could limit the frequency of this type of contribution.

In many ways the rule in draft recommendation 7.11 could conflict with the general rule in draft recommendation 5.2 that carers would only be expected to provide care to the extent they are willing (see examples 4 and 5 above). The Commission should make it clear that the rule in draft recommendation 5.2 regarding willingness to provide care takes precedence over the rule in draft recommendation 7.11 regarding avoiding increasing NDIS costs.

Boundaries between NDIS and Mental Health sector

The draft report (page 67 Overview) seeks feedback on where the boundaries between the mental health sector and NDIS might lie, in particular how the NDIS would practically integrate any role in ongoing non-acute services with the wider mental health sector. I imagine some services provided to NDIS clients might overlap with services for mental health clients, for example, case management, respite and supported accommodation.

I would like to make a suggestion to be kept in mind regarding any overlap or integration of services. The clients of these two groups may have similar needs but they are drawn from different backgrounds. NDIS clients usually should be kept physically separate from mental health clients, because NDIS clients are likely to be much more vulnerable than mental health clients. Some NDIS clients with intellectual disabilities like my son may act permanently like a three-year-old child with no understanding of the world and be easily led. Some mental health clients may come from a world-weary background as a drug addict and their potential to affect adversely NDIS clients should be recognised.

Prioritise People Living in Respite Centres for Implementation of NDIS

On page 17.10 of the draft report you refer to PWD’s in nursing homes as a priority group for introduction of the NDIS. I would submit that PWD’s living in various inappropriate settings including respite centres, should be included for priority action as well.

Waive annual upfront contribution for PWD’s requiring greatest support

Annual upfront contributions add an administrative burden that should be kept to a minimum. The draft report asks for suggestions on the point at which family care should be considered sufficient to earn a waiver of an annual excess. This could be unwieldy to manage. A simpler approach would be to waive the excess for all NDIS users who live with a family member and have high support needs, for example, those who require assistance with a core activity more than six times per day. If the excess exemption used a simple test that will be determined for other purposes of the NDIS anyway, then administration costs will be minimised.

Pay Family Carers

Draft recommendation 6.5 suggests a trial of paying family carers. I submit that family members should be paid for providing care on a permanent, not trial, basis. This would provide family carers with a more realistic choice of providing care or undertaking paid employment elsewhere. The failure to pay family carers actively discourages family care and this is not desirable due to the higher quality care provided by families. Failure to pay families will exacerbate a serious risk of a collapse in the amount of family care provided once the NDIS starts and a paid care alternative exists (particularly in circumstances like mine where families care for a person with very high support needs and have been overburdened for too long).

Increase Paid Care Costing for PWD’s requiring High Support

I am concerned by the costings included in chapter 14 of the draft report as they seem insufficient to cover care and support for PWD’s requiring constant care. On page 14.14 of the draft report the highest cost category for clients requiring care and support receives an average of 8 hours per day of paid support. This applies to PWD’s needing help with core activities more than 6 times per day who are 15 - 64 years old.

This average could be achieved in various ways which I discuss in turn:

1. the number of PWD’s requiring more than 8 hours paid care per day are balanced out by a larger number of PWD’s requiring less than 8 hours paid care per day (eg each person requiring 24 hours of paid care per day is offset by 2 people requiring zero paid care everyday within the group who need assistance with core activities more than 6 times a day);

2. a single paid worker is provided to care simultaneously for multiple PWD’s fulfilling these criteria; or

3. paid care is provided at less than the rate needed and families are expected to fill the shortfall.

PWD’s requiring more than 8 hours paid care per day are balanced out by a larger number of PWD’s requiring less than 8 hours paid care per day

The most needy group I am primarily concerned with are people like my eldest son Jack. He has autism, ADHD and intellectual disability for life. He requires constant care at a one-on-one level for approximately 14 hours per day every day. I am very concerned that your average of 8 hours of paid care per day underestimates the number of people like my Jack who need the support of the NDIS.

Surely before the time a PWD with very high support needs reaches 64 years old the NDIS would recognise that most, if not all, PWD’s like my son will require 24 hour paid support (or at least 16 hours per day on average to cover normal waking hours)? In the absence of details in the draft report, I have assumed so.

In order for the modelled average paid work per day to be correct a large portion of PWD’s requiring help with core activities more than 6 times per day must nevertheless have relatively low paid support needs. This seems unlikely to be correct. Accordingly, the planned average of 8 hours of paid care per day may be unsustainable as it would require an unexpectedly large portion of the most needy group to require zero hours of paid assistance per day to balance.

I would have expected that Table 14.6 should include a separate group requiring at least 16 hours of paid care per day on average, with the subgroup requiring active individual care during sleep periods balanced out by a similar sized subgroup who need between 8 and 16 hours of paid care per day. This would include PWD's currently out of family care and expected increases in this group over time, assuming aggregated care for most people during sleep times. Even this assumption of aggregated care at sleep times for PWD's not living with their family seems difficult as it assumes all of this group will live in group homes. However the NDIS includes laudable flexibility in housing solutions that make it more likely that PWD's with very high support needs will live in their own home (not a group home).

A single paid worker is provided to care simultaneously for multiple PWD's

A single paid worker can care for multiple PWD's with very high support needs when they are sleeping in a group home and do not need 24-hour medical intervention.

However, in waking hours this solution would require aggregation of groups of PWD's with high support needs, which seems to run counter to government policy of de-institutionalisation and seems difficult to achieve in a self-directed funding model of support. The only way this could be achieved for many people like my son Jack would be by using sedation and physical confinement. His quality of life would be severely curtailed.

I have grave fears about aggregation of PWD's as I have seen the effect of this in current NSW education policy with insufficient resourcing. I see the very low quality of education my son receives simply due to the absence of the fulltime one-on-one carer he (and many others) require but cannot obtain public funding to support. I would be concerned if this was an expected part of the NDIS you propose.

I submit the draft report should be expanded to provide some information on the calculation of paid carer hours so that it is clear that those who need a one-on-one carer will receive it. In addition, some clarification should be provided in your report as to how the need for individual care will be determined. You will appreciate carer community skepticism on this question as we have been told for years by successive governments that the current disability support system provides for needs, but in reality it is rationed to whatever the insufficient budget will cover.

See further discussion of this issue in my original submission to the Commission last year.

Paid care is provided at less than the rate needed and families are expected to fill the shortfall

Under your proposed NDIS, who is going to provide the other 16 hours of support per day for average 64-year-old PWD's requiring assistance with core activities more than 6 times per day? Their 90-year-old mother? Their 60-year-old sister? This seems unrealistic and will lead to unexpected costs in the NDIS. The major reason for introducing the NDIS seems to be to control the drain on the public purse from collapsing carers who are given an unreasonable burden of care, yet your NDIS proposal seems to make unrealistic assumptions about what family carers are willing and able to provide.

Your modeling in Table 14.6 does not even increase the expected average hours of paid care from 8 hours per day over the 50-year period during which the PWD is 14-years-old to 64-years-old. It should be recognised that a large proportion of PWD’s with very high support needs (often due to severe intellectual disability) will never marry so there is no prospect for this group to transfer from parental support to spousal support.

The average age of new mothers is currently around 30-years-old. Accordingly, your modeling expects average mothers (usual primary carer) of a child with severe congenital disability to provide 16 hours of care per day (hoping that the child sleeps approximately 8 hours per night so it is only 8 waking hours) every day for the period over which she is 44-years-old until she is 94-years-old. There are no weekends or holidays of rest for these mothers. This is in addition to her child’s first 14 years of life, during which there was less paid care.

No doubt it is hoped that this indefatigable average mother in your model will accumulate others around her such as healthy mainstream children and community volunteers to help (and we know that this group of women has a very high rate of divorce so many (most?) will not have a partner to assist in care or paid work).

Your model seems unsustainable. The average hours of paid care should increase as the PWD ages, with a view to family care ceasing for waking hours for many people with very high support needs when the mother of the PWD is 60-years-old. For me to provide the bulk of care for my son Jack until I am 60 would require a large increase in public support (quicker than the proposed NDIS) plus herculean effort from us. As this is unlikely to happen I expect to renounce the care of my eldest son before I am 50 (by the usual method in NSW of abandoning him at a respite centre when I collapse). By that point I will need my husband to care for me, so we will not be able to continue to provide care for Jack. As there is no hope for my family, the milestone I am trying to reach before this occurs is merely that my younger son (who is currently 9-years-old) reaches adulthood before this catastrophe hits our family.

My single greatest fear as the mother of two children, one of whom has severe disabilities and requires constant care, is that my younger son’s life will be sacrificed by an uncaring community to provide the constant care his older brother needs. I accept the sacrifice of my life to my older son’s needs and I, at least, had a full, normal life for the 30 years before my eldest son was born. My younger son has lived in a household ruled by his brother’s extreme needs for his whole life to date. It is immoral for our community to expect him to provide care for his brother once I cannot. Surely all fair-minded people would agree that my younger son has the right to try to get a job and start his own family?

Accordingly, I have been teaching my younger son all his life that he is not to provide personal care for his beloved brother as that is not his responsibility. My younger son is being trained to assume an Advocate role for his brother for the rest of his life. Close to 100% of PWD’s with very high support needs will not have a sibling who is willing to take over the job of primary carer from their parents and governments are going to have to cover this cost as growing numbers of PWD’s requiring constant care are abandoned by their families. For families like us, the NDIS is merely an orderly system to provide this support and minimise public costs by stretching family care as far as possible.

The draft report underestimates costs of the NDIS but that is not a reason to abandon the NDIS because the government will face those costs (and more) even without the NDIS.