The Royal Children's
Hospital Melbourne

29 April 2011

Disability Care and Support
Response to the Productivity Commission Draft Report

The Royal Children's Hospital (RCH) welcomes the opportunity to provide a response to the Productivity Commission's Draft Report of its inquiry into a national long-term disability care and support scheme in Australia.

Our response has been developed with the collective input of staff across the RCH, in particular in the areas of Social Work and Development Medicine.

We would like to thank and acknowledge the efforts of government in developing what we believe is an excellent report which highlights the unmet needs of people with disabilities and makes very sound recommendations to improve their care and support. We believe that such widespread change will improve the day to day situation of people with disabilities and their carers and believe that implementation of these recommendations would do much to rectify the inequalities that currently exist.

Contextual numbers

The report cites the figure of 360,000 individuals needing this type of support. Whilst it is difficult to estimate a reliable figure, we suggest that the figures from the Australian Institute of Health and Welfare which estimate that 1.2 million Australians have a severe or profound core activity limitation[1] is a more realistic number. It is acknowledged that many of these will be old people that acquire disability late in life.

NDIS and NIIS

The report proposes two systems - NDIS and NIIS. We believe this will only perpetuate the current two tiered system, which disadvantages some children in our community. For example, in our experience patients who fall under the care of TAC are entitled to significant financial resources which children under Disability Services are not able to or find it very difficult to access.

Whilst the needs of patients from both NDIS and NIIS are the same, we can assume the greatest number of patients will qualify for service from the NDIS, resulting we can also assume in issues with resourcing and greater waiting times. If there are to be two schemes we believe it is imperative to ensure equity of service and access and ask for clarification on how this will be achieved.

Clarity will also be needed to determine which individuals might fall under the NDIS versus the NIIS. For example, catastrophic events can occur during labour or delivery, for example, an unanticipated maternal bleed or an abnormally small pelvis leading to an unexpected obstructed labour and subsequent perinatal asphyxia. It is questioned whether a child in such circumstances would be included in a NDIS or a NIIS.

The RCH is supportive of one system for all.

Indigenous/CALD and rural/remote communities

Clearly much more work and consultation with Indigenous groups needs to occur to ensure appropriate service provision. This is also true of other CALD groups and we recommend consultation with representatives from major ethnic groups resident in Australia as to their specific cultural requirements. There also needs to be more consideration and detail regarding service provision to rural and remote communities to ensure equity of access.

The assessment, funding and planning process

We would like to emphasise that, in the vast majority of situations, carers and people with disabilities themselves are the experts on what they need and so their views should form the basis of the assessment of the care required.

We note that the assessment of how much care a person is entitled to under the NDIS will be based on a number of factors including '*what would reasonably and willingly be provided by unpaid family carers and the community*'. Our experience is that the care that different families/communities can provide a child with a disability is not uniform. This part of the assessment needs to take into account factors such as the cumulative impact of the 'burden' of care over time - for example, the impact upon the family members' mental and physical health and relationships. An assessment of need therefore not only needs to be reviewed regularly as the capacity of the family members' to provide care will change over time, but also preventative services need to be provided to scaffold the family's capacity to care.

The level of care which can be expected to be provided by 'natural supports' is also heavily dependent upon and influenced by factors such as pre-existing mental and physical health issues and other vulnerabilities. For example, if a baseline measure is adopted such that a parent would be expected to provide overnight care to a dependent child five nights per week, then this needs to be a flexible measure if it is found that the parent has their own health issues to manage.

Gender and culture also need to be taken into account when assessing support which will be provided by 'natural supports'. In our experience in many two parent families it is the mother who takes on the vast majority of the care of the child with a disability, and in many cases fathers are effectively divorced from the caring role. In some cultural groups there may be norms around siblings or grandparents taking on the care of children with disabilities. In these cases we believe the assessment will need to be sophisticated enough to ascertain the real capacity of what the family can provide over the long term.

In addition we note that many respite providers are insufficiently trained to care for children with significant disabilities, so carers are often unable to leave the house when a respite carer is in attendance. In fact they participate in the respite by continuing to undertake essential care tasks. We believe this is a hidden burden upon carers.

We have some concerns about the proposal for funds to be ‘cashed out’, although we acknowledge that initially this would probably be for a minority of patients and the arrangements would be stringently monitored. However we feel it necessary to highlight that many children with whom we work, come from extremely vulnerable families where issues such as gambling, substance misuse, transience and cultural barriers would impact upon families’ ability to manage the financial resources in a way which would ensure best care for their children with disabilities. There must be clarification on what the proposed arrangements for ‘cashed out’ funding allocations are if the person then becomes hospitalised for a long period of time or dies.

The RCH also believes that the proposed ‘fixed contribution’ of $500 when claiming under the NDIS will be beyond the means of many families with whom we work - for example sole parents, parents with their own disabilities, parents on low incomes after leaving employment to care for their child with a disability.

Boundaries of the NDIS

It is noted that the responsibilities of education provision to people with disabilities fall outside the proposed boundaries of the NDIS. However we believe the arrangements are inadequate and require review. For example, children with tracheostomies are not eligible to access school bus services and we feel that it would be necessary to have advocacy from the NDIS on these and similar matters.

Similarly, with housing issues sitting within the responsibility of state government departments, access to safe, stable affordable housing is likely to remain a concern for people with disabilities and their carers.

Information requests

Chapter 4
High electricity costs do pose a significant burden on individuals with disabilities and their families. This matter might be best dealt with by having a universal discount on electricity costs for individuals meeting predefined criteria.

Taxis are in general not over used by individuals with disabilities. Some distinction may need to be drawn between taxis used to access work or education, versus taxis used for socialisation and recreational purposes.

Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance and the Child Disability Assistance Payment should fall outside of the NDIS. Families of children with disabilities are severely financially disadvantaged, one parent usually has to stay at home to be on call to collect the child from school and after school and holiday care is very problematic. These payments provide parents with some ready cash to meet the day to day requirements that may be necessary to support a child within a family - for example, to buy petrol or take them to the hospital or doctor on a regular basis. We believe that if the Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance and the Child Disability Assistance Payment come under the auspice of the NDIS, that this may restrict families' access to ready cash. In the proposal, there is insufficient information regarding the methods for distribution of such monies so we assume they may be subsumed into the wider care package arrangements and therefore not be available as cash payments. It also seems an unnecessary duplication for NDIS to arrange for distribution of cash payments on a broad scale.

Chapter 5

We welcome the recommendation of a "tool box" of assessment tools. There is no currently available perfect assessment tool but many assessments are available that could be trialled and considered for incorporation into the NDIS assessment process.

Reference

1. AIHW. Australia's health 2010. Canberra: AIHW; 2010 Contract No.: Document Number