

4<sup>th</sup> May 2011

Disability Care and Support Inquiry **Productivity Commission GPO Box 1428** Canberra City ACT 2601

# **Australian Government Productivity Commission** Inquiry into a National Disability Care & Support Scheme **Post Draft Report Submission**

Thank you for providing Northcott Disability Services with the opportunity to provide a submission for the inquiry into a national disability long-term care and support scheme. This submission is a follow-up to Northcott's submission made 16<sup>th</sup> August 2010 (submission number 376), and is made specifically in response to the Draft Report, which was released by the Commission on 28<sup>th</sup> February 2011.

Northcott welcomes the Productivity Commission's draft report in a national disability insurance scheme (NDIS) and sees it as an important step towards providing universal entitlement to all people with a disability, safeguarding people's rights to access services and supports relative to their needs. Northcott sees a *national* scheme as the means by which to ensure consistency and equity in funding and service provision for people with a disability. Northcott broadly supports the NDIS as proposed in the Productivity Commission's draft report and eagerly awaits the release of the final NDIS report.

Northcott would like to provide a response specifically in relation to the following issues from the Draft Report:

- 1. Individualised Funding
- 2. Intersection between NDIS and mainstream services
- 3. Support for children

### 1. Individualised Funding

Northcott welcomes the strong inclusion of individualised support packages, including selfdirected funding models, in the proposed NDIS. However, for these to be an effective, sustainable and workable model, sufficient resources and supports need to be put into training and education for people with a disability and their family and carers, so they are fully equipped to be active agents in planning, implementing and monitoring their support package. Service providers also need to have access to adequate resources in order to implement new financial and administrative systems required to support individualised funding models.

While welcoming of the widespread use of individualised funding models, Northcott also maintains that there are some functions of existing disability services providers which cannot be costed into individualised funding models and/or purchased by an individual service user; for example: research, community development and community capacity building etc. Therefore, Northcott also supports a NDIS which has additional capacity to resource these fundamental, but not individually funded, activities. This would also include resources to facilitate the development of innovative service models, interventions, technologies, equipment etc.

#### 2. Intersection between NDIS and mainstream services

Northcott believes that the boundaries and intersection of the NDIS with the various sectors and systems (including mental health, education, health systems etc.) are crucial transition points. Work in this area should build on and extend on initiatives already underway (such as the National Disability Strategy) and view disability from a 'whole of life' perspective. Northcott also supports that the relevant state based systems (e.g. education systems) be reviewed, and their operation and intersection within the NDIS framework be examined, to ensure they continue to provide appropriate and equitable support to people with a disability across the nation. Where relevant, this might include responsibilities and funding being transferred to the National Disability Insurance Agency (NDIA).

## 3. Support for children

Northcott welcomes that the Draft Report references the *UN Convention on the Rights of Persons with Disabilities* as a key framework from which to argue for, and demonstrate the importance of, a NDIS in Australia as a way of securing the human rights of people with a disability. However, acknowledging that children have specific needs, rights and protections, Northcott supports the inclusion of the *UN Convention on the Rights of the Child* as a specific reference point and guiding framework for the NDIS to address, support and strengthen the human rights of children with a disability.

Northcott has a long history providing a range of different services and supports to children with a disability and their families. Based on these experiences we would like to specially address the following issues in terms of support for children under an NDIS:

- a) Early Diagnosis Support
- b) Mainstream services

## a) Early Diagnosis Support

Northcott currently receives funding from NSW Ageing, Disability & Home Care (ADHC) to provide Early Diagnosis Support for families. This program provides information and referral, family support, and group work services to families with a child under six who has a developmental concern. This includes:

- Families who have a child with a disability which was diagnosed in the last six months;
- Families who have a child with an identified developmental delay and are in the process of obtaining a diagnosis;
- Families who have a concern about their child's development and are seeking support, even if they haven't been to see a doctor about it or had an assessment.

Where most disability services require a formal diagnosis to have been made before a child or their family is eligible to receive funded support, Northcott's Early Diagnosis Support Service doesn't have this requirement and families can refer themselves at the first sign of a concern with their child's development. Our experience working with families who have developmental concerns about their child, or who are going through the diagnosis process, is that this is a crucial point where families need support and information. The families Northcott works with have indicated that this can be a time of high stress, anxiety, isolation, and confusion; access to family support during this period is extremely valuable, not only in building family's resilience and capacity and helping them understand and navigate the service system, but also in facilitating early access to both disability specific and mainstream services and resources, which can help improve the long-term outcomes for the child and their family. While some families may be able to access generic family support services (through the community service system) during this period, Northcott's experience is that specialised disability early diagnosis support is required to support families, as it can provide the following expertise:

- Knowledge of child development and the indicators of developmental concern;
- Understanding of the impact of the disability on the child and the family;

- Information about the types of services and supports potentially available for the family;
- Advice and support in understanding and navigating the disability service system

Northcott is concerned that eligibility for the NDIS would require families to have participated in an assessment and diagnosis process *before* they are able to access any support. That is, in order for them to demonstrate their child has disability support needs which can be funded under the NDIS, they would have to proceed through the diagnosis process prior to having any specialist family support. Northcott's experience is that early support services, before and during diagnosis, is an essential support for families which helps improve family resilience and build the family's capacity to maintain their strength and ability to care for a child with a disability, at a time that is often fraught with confusion, isolation and anxiety.

Therefore, Northcott recommends that the NDIS also provide access to appropriate specialised early support services for families *prior* to diagnosis and their formal entry into the NDIS funding.

#### b) Mainstream services

Many children with a disability access a range of mainstream services and systems which, alongside disability specialist services, work to support the needs of the child in their everyday environment. For example, school children with a disability rely on additional supports provided through the relevant state based education department, in order to fully participate in their classroom, educational setting and school curriculum. Under the proposed NDIS, the responsibility for providing support for children with a disability in mainstream settings, such as schools, will remain the responsibility of the relevant state based system. This means that mainstream services will be operating outside the framework of the NDIS and support for children accessing these services may vary from state to state (as is currently the case). Therefore, Northcott supports that the relevant state based systems (e.g. health and education systems) be reviewed, and their operation and intersection within the NDIS framework be examined, to ensure they continue to provide appropriate and equitable support to children with a disability across the nation.

Given that a NDIS will see an increase in disability funding and support across the nation, Northcott is also concerned that the introduction of a NDIS may be a way in which mainstream services and systems could minimise their responsibilities to children with a disability, believing that the NDIS is providing all the necessary supports. Currently, education systems are not necessarily able to meet their existing responsibilities to support and ensure full and equal participation for students with a disability. Often citing insufficient resources to be able to make the necessary adjustments to support the full participation of a child with a disability, the introduction of a NDIS could see education systems further claiming inadequate resourcing as an issue in meeting the needs of students with a disability. Therefore, Northcott is concerned that mainstream systems may see the NDIS as a way of shifting their responsibilities in this manner, and further be a barrier to full participation and equal rights for children with a disability in these mainstream settings.

For these reasons, Northcott supports that a mechanism to safeguard children's rights to the support they require in mainstream settings and systems should be addressed in the final report, and potentially incorporated into the NDIS, so that children accessing mainstream services continue to receive the level of support they require from these systems.

This submission has been prepared by Liz Forsyth (Sector & Business Development Manager) and has been endorsed by Northcott's CEO Kerry Stubbs.