21st June 2011.

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

RE: *Disability Care and Support* draft report

Following our response to the *Disability Care and Support* draft report, The Royal Children's Hospital (RCH) would like to take this opportunity to provide an outline of our expertise in the area of research and data collection. This response has been developed by Development Medicine, in conjunction with Solve! At the RCH.

Developmental Medicine at the RCH is involved in the assessment and management of children with disabilities, particularly cerebral palsy, spina bifida, the autism spectrum disorders and intellectual disability. We look after the most complex children who often have multiple comorbidities, aiming to provide wholistic care and family support to optimise the potential of each individual and the quality of life of the family unit. In addition, we take responsibility for teaching a large number of professional groups in the area of childhood disability.

Over the past 20 years, Developmental Medicine, in conjunction with the RCH campus partner, the Murdoch Childrens Research Institute, has established a substantial research program with the objectives of furthering knowledge about the causes of disability and determining optimal treatments. To date the department has over 110 publications in refereed journals and has secured over $4,650,705 in research grants.

In 2004, we took a further step by establishing a research and fundraising arm of the department, known as Solve! At the RCH. A strategic plan was developed with the key objective of creating a Professorial Chair in Developmental Medicine. Funds were secured and Professor Katrina Williams was appointed in 2010. This is the first chair in Developmental Medicine in Australia and will further increase our capacity to undertake high quality research in the area.

As part of our long standing research program, a major initiative has been the development of the Victorian Cerebral Palsy Register. This Register records information about the birth history of the individual, the type and severity of the motor disorder and the associated comorbidities. Information is also collected about major interventions, for example, gastrostomy placement and insertion of intrathecal baclofen pumps. Currently the dataset contains information about 4,670 individuals with cerebral palsy born since 1970 and is the largest such dataset both nationally and internationally. Data is also provided to the recently established Australian Cerebral Palsy Register.

The major advantage of this large dataset is the ability to monitor trends in the occurrence of cerebral palsy over time, to monitor the nature and extent of the disability, and to extract cohorts for further studies. To date, 42 publications in refereed journals have resulted from studies undertaken using the Victorian Cerebral Palsy Register. It is therefore a powerful tool for furthering our understanding of this large cohort of individuals. For example, studies from the Register have enabled us to determine:

- The spectrum of brain magnetic resonance imaging (MRI) abnormalities in children with cerebral palsy as a step towards deepening our understanding of causes
- The frequency and nature of hearing impairment
- The association between assisted reproductive technologies and cerebral palsy
- The frequency with which children with cerebral palsy should have hip Xrays to detect hip displacement

In addition, with the help of the parents of children with cerebral palsy, assessment tools have been developed which are now used nationally and internationally. Examples include:

- The Melbourne Assessment of Unilateral Upper Limb Function
- The Quality of Life Questionnaire for Children with Cerebral Palsy

The Victorian Cerebral Palsy Register, and all research programs undertaken in Developmental Medicine, are governed by the strict guidelines of the RCH Research Ethics Committee to whom we provide regular reports. In addition, the collocation of the RCH campus partners, the Murdoch Childrens Research Institute and The University of Melbourne, means there is ready access to valuable resources including the Clinical Epidemiology and Biostatistics Unit, sophisticated brain imaging and state of the art genetics services.

As you are aware, there will be many areas in which research will be important for the National Disability Insurance Agency. In addition to the development of assessment tools to determine eligibility, studies to evaluate outcomes for children and their families that will utilise the new scheme, will be essential.

The RCH, through its department of Developmental Medicine, would be pleased to offer our assistance with collecting data and undertaking high quality research, in partnership with the National Disability Insurance Agency. Over the years we have collaborated with a number of Universities and non-Government agencies and have built strong experience in the area of data collection and program evaluation. We are committed to ensuring that both our data collection and our research studies are of the highest standard and are based on our substantial clinical knowledge of these children and their families.

Thank you for considering this submission. We would be very willing to provide any further details that would be helpful.

Yours sincerely

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