

**24 March 2017**

Dear Commissioners

**Submission to the National Disability Insurance Scheme (NDIS) Costs study  
Productivity Commission**

This submission is made by Professor Anne Kavanagh on behalf of the **Centre of Research Excellence in Disability and Health (CRE-DH)** funded by the National Health and Medical Research Council.

*About the Centre of Research Excellence in Disability and Health*

The first centre of its kind internationally, the CRE-DH will generate the evidence needed to guide social and health policy reform with the explicit intent of improving the health of working-age Australians with disabilities. The aim is to identify policy reforms that will improve the health of people with disabilities and reduce the avoidable (inequitable) health and wellbeing disparities between Australians with and without disability.

The Lead Investigator on the CRE-DH is Professor Anne Kavanagh (University of Melbourne) and Co-Directors are Kavanagh and Professor Gwynnyth Llewellyn (University of Sydney). The CRE-DH includes Chief Investigators from the University of Melbourne, University of Sydney, Monash University, UNSW and RMIT with multidisciplinary skills in epidemiology, health economics, health and social policy, psychology, psychiatry, public administration and public health. The CRE-DH will further develop the future research leaders in disability and health. (Appendix A has a list of the Chief and Associate Investigators associated with the project).

The CRE-DH has four work programs:

1. Mapping inequities in social and economic and health inequities between people without disabilities and developing a monitoring framework
2. Identification of the social determinants of health of people with disabilities
3. Health economic modelling of health and social policies

#### 4. Policy research to identify the key emerging issues in health and social policy related to people with disabilities

We are working in collaboration with key stakeholders in the sector including Department of Social Services, ABS, AIHW and peak bodies in the disability advocacy and service sector. The program of work will produce new knowledge about the social and economic factors that drive the health and wellbeing of Australians with disability. The CRE-DH has a strong emphasis on the use of large, administrative data sets to identify the key drivers of health and wellbeing for people with a disability.

##### *This submission*

We note the wide scope of the current Study being conducted by the Productivity Commission much of which lies outside of the scope of the CRE-DH. CRE-DH Investigators are making submissions in other relevant areas. This submission focusses on the importance of high quality data for monitoring, evaluation and public accountability. Access to such data is not only critical to help answer those questions posed in the CRE-DH but also critical to help answer many of the questions posed in the current Productivity Commission issues paper.

The success and sustainability of the NDIS rests on making the best use of the available resources to improve the long-term social and economic outcomes as well as the health and wellbeing of people with disabilities and their families and carers. As the National Disability Insurance Scheme moves to full rollout there will be a comprehensive data base on all components of the scheme and user experiences such as service provision, service use, costs, and social, economic and health outcomes of the people with disabilities. It is critical to use this data to evaluate the outcomes of the Scheme and to identify how it can be improved. Careful analysis and reporting of this data is critical to ensure accountability to people with disabilities and their families and the Australian community.

Importantly the NDIA data will be longitudinal and will enable the tracking of outcomes within and between individuals over time. Currently the NDIA produces quarterly and annual reports that provide cross-sectional information against a

broad set of performance indicators and, as far as we are aware, the analyses of longitudinal data have not yet been reported. While the NDIA intends to make use of this data for its own evaluation purposes we believe that it is important that this rich data is made available to external researchers from a broad range of disciplines (e.g. business and economics, epidemiology, statistics, social sciences, public policy) who can provide independent evaluation of outcomes. This data should be de-identified unit record data and should be available only to credentialed researchers subject to data security and approved governance arrangements. This would significantly improve research capacity. The Agency has relatively limited internal capacity to conduct the broad range of research questions that need to be answered. This recommendation is in line with the Productivity Commission's recent Inquiry into Data Availability and Use.

We also propose that the Commission consider the importance of linking NDIA data to other administrative and survey data sets (e.g. Census, Department of Social Services, Australian Tax Office). A model for this is the Multi-Agency Integrated Data Project (MADIP) being conducted by the Australian Bureau of Statistics as part of their data transformation activities:

<http://www.abs.gov.au/ausSTATS/abs@.nsf/be4aa82cd8cf7f07ca2570d60018da27/5eaa695de4bc61d1ca257f4c00170b7f!OpenDocument>

Linking NDIA data to the public survey and administrative data will significantly enhance capacity to examine the impact of the Scheme on a broad range of social, health and economic outcomes. A model for this is the Statistics New Zealand Integrated Data Infrastructure [http://www.stats.govt.nz/browse\\_for\\_stats/snapshots-of-nz/integrated-data-infrastructure.aspx](http://www.stats.govt.nz/browse_for_stats/snapshots-of-nz/integrated-data-infrastructure.aspx) which has been successfully made available to approved researchers under agreed privacy arrangements. Like Statistics New Zealand we recommend that linked NDIA data is made available to external researchers.

In sum, the CRE-DH recommends that the Commission consider:

1. Access to de-identified unit record NDIA data be made available to approved external researchers
2. Linking NDIA data to ABS and other routine public data sets and making integrated data available to approved external researchers.

The CRE-DH strongly believe that implementation of these recommendations would significantly improve monitoring, evaluation, transparency, fairness and public accountability of the Scheme and would produce the evidence-base needed to improve the efficiency and impact of the Scheme and related mainstream services used by people with disability.

Yours sincerely

A handwritten signature in black ink, appearing to be 'Anne Kavanagh', written in a cursive style.

Professor Anne Kavanagh on behalf of NHMRC Centre of Research Excellence in Disability and Health

## **Appendix A      Chief and Associate Investigators, Centre of Research Excellence in Disability and Health (CRE-DH)**

### **Chief Investigators**

Professor Anne Kavanagh, University of Melbourne

Professor Gwynnyth Llewellyn, University of Sydney

Professor Eric Emerson, University of Sydney and Lancaster University

A/Professor Dennis Petrie, Monash University

A/Professor Helen Dickinson, UNSW

Dr Hannah Badland, RMIT

Dr Gemma Carey, UNSW

Professor Peter Butterworth, University of Melbourne

Professor Stewart Einfeld, University of Sydney

Professor Roger Stancliffe, University of Sydney

### **Associate Investigators**

Dr John Gilroy, University of Sydney

A/Professor Julie Simpson, University of Melbourne

Professor Luis Salvador-Carulla, University of Sydney

A/Professor Rebecca Bentley, University of Melbourne

Dr Melanie Davern, RMIT

Professor Gloria Krahn, Oregon State University

Professor Karl Atkin, University of York

Professor Maria Alarcos Cieza, World Health Organisation

Dr Tom Shakespeare, University of East Anglia

Dr Jennifer Smith-Merry, University of Sydney