

Submission to McKeon Review
Professor Anne Kavanagh

This is a personal submission made by Professor Anne Kavanagh and addresses specifically issues related to the funding of disability-related research including research on the health of carers of people with disabilities.

Why is the health of people with disabilities and carers important?

The Centre for Women's Health, Gender and Society is currently preparing a research summary with VicHealth regarding the health of people with disabilities. On the basis of current data (which is sparse) the following observations can be made:

1. One in five Australians live with a disability. Disability cuts across many social categories including age, sex, race and class
2. The health of people with disabilities and their carers is among the worst of any population in Australia
3. With an ageing population the number of people with disabilities will increase and reliance will increasingly be made on aged carers who may also have a disability
4. People with disabilities and carers are among the most socially and economically disadvantaged groups in Australia (e.g. they are more likely to live in poverty and not participate in the workforce)
5. The social and economic disadvantage in which people with disabilities and carers live contributes to their poor health over and above the health effects of impairments
6. The level of disadvantage that people with disabilities and carers live is worse than observed in other OECD countries demonstrating that it is possible to improve the situation in Australia

What are the problems with current funding for research about people with disabilities and carers' health?

There is little attention to the health of people with disabilities and carers in NHMRC research-funded research. Potential reasons include:

1. Research in the field of disability has mostly been conducted in the disability-service sector and thus concentrates on the implementation and evaluation of various service models. A problem with this approach is that it marginalises disability as a mainstream health issue.
2. In public health, disability is usually conceptualised as an outcome (e.g. in the computation of disability adjusted life years) rather than as a determinant of health.
3. Unlike other disadvantaged groups such as indigenous Australians, people from culturally and diverse backgrounds and people living in rural areas, people with disabilities and carers'

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are not identified as a disadvantaged population group in need of substantial research investment

4. The collection of data from people with disabilities can be challenging, depending on the type and level of impairment, and requires flexibility in methods (e.g. visual methods, braille, proxy interviews). It is rare that these methods are utilised in research projects
5. Research with people with disabilities and carers' requires collaboration between communities, government, non-government organisations and advocacy groups, in order that priorities are identified, appropriate methods are used and research is translated into practice and policy. These collaborations require substantial investment of researcher time (usually unfunded) and is not recognised in the assessment of track records

Recommendations to improve current funding of research related to the health of people with disabilities and carers

1. Ask researchers submitting grant proposals whether people with disabilities are included in their research (e.g. as is currently done with regard to the inclusion of women and men). If researchers intend to exclude people with disabilities they should be asked to provide an explanation
2. People with disabilities and carers need to be identified as a priority population group. This can be done by:
 - a. Providing added incentives for research that includes people with disabilities and carers in scoring systems as is done in indigenous health research
 - b. Strategic funding (e.g. partnership centres, CRE, strategic grants or others) for research in the field of the health of people with disabilities and carers. This research should emphasise partnerships with key stakeholders and the evaluation of interventions (including policy interventions)
 - c. Scholarship and fellowship funding specifically for researchers with disabilities. People with disabilities may face challenges due to their disability (e.g. fatigue, mobility) which can reduce their research capacity and make it more difficult for them to compete with other researchers; however, people with disabilities are best placed to conduct research in this field.
 - d. Training for researchers on how to conduct research with people with disabilities
 - e. Expectation that researchers include routine questions about disability in their research as is routinely done for socio-economic position
 - f. Sufficient funding in grant schemes for complex methodologies to aid data collection from people with disabilities

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- g. Recognition of the importance of collaborative research and translation in track records (e.g. through improved metrics) as disability-related research needs to be conducted in close collaboration with the community so that research is relevant and unintended harm avoided
- 3. In developing funding initiatives that the NHMRC is mindful of other developments in policy and practice. For example, the recently released, National Disability Research and Development Agenda 2011 could be used in the development of funding priorities.