

16 October 2018

Dr Alexandra Boyle
Policy Analyst
Health Research Council of New Zealand
Te Kaunihera Rangahau Hauora o Aotearoa
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Dear Dr Boyle

Re: New Zealand Health Research Strategy- discussion paper on setting New Zealand's health research priorities

IHC welcomes the opportunity to give feedback on the proposed Strategic Investment Area framework and contribute suggestions for specific priorities.

We strongly support the strategic focus on health and wellbeing in children and youth and sustaining this through adulthood alongside promoting equity and strengthening pathways for translating research findings into policy and practice.

People with intellectual disability experience some of the greatest inequities and poorest health, social and economic outcomes of any population group in New Zealand. In health this is recognised with the inclusion of improving health outcomes for people with intellectual disability in the 2014-2018 Disability Action Plan (Priority 11c) and the 2016 New Zealand Health Strategy Roadmap of actions (Action 4d).

Despite this situation there have been longstanding problems with getting funding for impairment specific research with and about people with intellectual disability and within the disabled population. Further to this there is a lack of research that includes people with intellectual disability as participants in general population studies or as members of particular population groups such as with Maori, Pacific, women, children or in a regional area.

IHC makes the following recommendations for inclusion in the Strategic Investment Framework and revision of the health research priorities

- People with intellectual disability are recognised as a priority group by the Health Research Council
- A disability fund is established similar to the Health Research Council's 2005-2010 disability placement programme. We note the success of the fund in enabling research on areas that were identified as important by people with disabilities and their communities. The programme also provided funding for mentoring that was of benefit for research centres and collegiality among researchers. Such a fund should extend to post-doctoral funding to help build a critical mass of disability related research.
- Disability advisors and representation should be included in all levels of the Health Research Council's work.

- Mentoring support should be available for all Health Research Council funded research to encourage the inclusion of people with disabilities in general population research and to develop partnerships with disability researchers.
- Make reference to people with intellectual disability in the framework and priorities wherever promoting equity and reducing disparities occur.

Our contact details and responses to questions 11-18 (off line submission) are attached on the following page.

Please do not hesitate to contact us if you if there anything further we can help with.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Trish Grant', with a stylized, cursive script.

Trish Grant
Director of Advocacy

IHC responses to questions 11-18 (off line submission)

Question 11: Name

Trish Grant

Question 12: Contact details

trish.grant@ihc.org.nz

Question 13: Organisation

IHC New Zealand Incorporated (IHC)

Question 14: Position

Director of Advocacy

Question 15:

IHC is a community-based organisation that has provided advocacy and support for people with an intellectual disability and their families for 65 years. IHC raises awareness and advocates for the rights of over 65,000 people with intellectual disability at both a national and an international level. IHC's service arm IDEA is New Zealand's largest provider of residential, supported living and vocational services for people with intellectual disabilities providing support for around 4,500 people. IHC's wholly owned subsidiary Accessible Properties is a registered community housing provider and manages one of New Zealand's largest non-government social housing portfolios. IHC's charitable arm includes an extensive advocacy programme, a one to one volunteer programme and the country's largest specialist intellectual disability library. Nationally we work with many disability, community and government organisations and contribute internationally through our membership of Inclusion International.

Question 16:

- Organisation based in New Zealand .

Question 17:

Which interest group do you best represent?

- Non-governmental organisation

Note – IHC does commission and fund some research

Question 18:

We intend to publish the submissions from this consultation, but we will only publish your submission if you give permission. We will remove personal details such as contact details and the names of individuals.

- You may publish this submission