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Nic Aagard  
Acting Principal Policy Analyst  
Senior advisor  
Ethics  
Quality Assurance and Safety  
Protection, Regulation and Assurance  
Ministry of Health  
Wellington

**IHC National Office**

Level 15, 57 Willis Street  
PO Box 4155  
Wellington 6140  
Tel: 04 472 2247  
Fax: 04 472 0429  
[www.ihc.org.nz](http://www.ihc.org.nz)

Dear Nic

**Draft National Ethical Standards for Health and Disability Research**

IHC welcomes the opportunity to give feedback on the draft National Ethical Standards. Our comments in this letter are further to those made at the consultation discussion meeting organised by Ezekiel Robson on 17 September.

IHC strongly supports the Draft Standard's principles of Te Ara Tika, references to inequality and inequity, rejection of stereotypes and recognition of different population groups. We like the mention of the ethical principles and standards being applied not only to research but to other relevant areas of practice.

People with intellectual disability have some of the poorest health, social and economic outcomes of any population group in New Zealand. They experience inequities in access to and quality of healthcare and health promotion activities. Despite this they are often positioned as 'other' or too difficult to include and thus excluded from participating in and contributing to research. The Draft Standards provide a framework to increase the participation and contributions of people with intellectual disability in research.

To further help we suggest that what is meant by health and disability research is made clearer by distinguishing between

- Participating in general population research on health and wellbeing or as members of particular population groups such as Maori, Pacific, women, children, in a regional area.
- Participating in research about and with people with an intellectual disability such as on health or wellbeing for this population group.

Incorporating supported decision making (8.15) and supported consent (9.15) as has been done in the Draft Standards is a positive step in both aligning with New Zealand's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and giving practical ways to support and safeguard people's rights, consent and participation in research.

Other work to consider is

- The Health and Disability 2017 consultation on Right 7(4) of the Code of Health and Disability Services Consumers' Rights (informed consent to health and disability research) and their recommendations.

- Office of Disability Issues, Ministry of Social Development coordinated work with government and community and disability organisations on UNCRPD Article 12: Equal recognition before the law. Being able to exercise legal capacity and supports and safeguards for decision-making are central to this work.

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 flourish extending to the right.

Trish Grant  
Director of Advocacy