



IHC Submission to the Human Rights Commission

Draft Chapter for Discussion: The Right to Health

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1. About IHC

Mission Statement:

IHC will advocate for the rights, inclusion and welfare of all people with an intellectual disability and support them to lead satisfying lives in the community.

IHC New Zealand Incorporated (IHC) is a community-based organisation providing support and advocacy for people with an intellectual disability and their families. Through our service arm, IDEA Services, IHC works with approximately 3000 families with children who have an intellectual disability and provides support to more than 4000 people with disabilities to live in IHC homes and flats. IHC's other service provider, Timata Hou, provides services for about 70 people with intellectual disability with challenging behaviour, of which a significant number are subject to the IDCCR Act.

IHC also advocates for the rights of more than 50,000 people with an intellectual disability in New Zealand.

IHC has a long history of political and systemic advocacy and is committed to non-government funded programmes of work related to individual and systemic advocacy, empowerment of individuals and families and inclusion of people with intellectual disability in society. IHC has a particular interest and expertise in human rights and social justice issues affecting people with intellectual and other disabilities.

IHC endorses the New Zealand Disability Strategy (NZDS) and the United Nations Convention on the Right of People with Disabilities (UNCRPD) as strong frameworks for guiding Government policy, practices and decision-making.

2. Introduction

IHC appreciates the opportunity to comment on the Human Rights Commission's draft for discussion: *The right to health*. We note that this draft chapter is one of a number of chapters that the Commission is completing for its report on the status of human rights in New Zealand which is due to be released in December 2010. The updated Status Report will provide the basis for the Commission's priorities for action for the next five years.

3. Overall Response

IHC believes unequivocally that health is a human right. This is clearly articulated in the UNCRPD.

IHC is pleased to see the ICESCR referenced in this draft chapter. Of particular interest are the following specific clauses of Article 12:

1. *States Parties recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.*
2. *The steps to be taken by States Parties to achieve the full realisation of this right shall include those necessary for:*
 - (a) *The provision for the healthy development of the child;*
 - (b) *The creation of conditions which would assure to all medical service and medical attention in the event of sickness.*

IHC wishes to bring to the Commission's attention the issues regarding the health of children, young people and adults with intellectual disabilities.

People with intellectual disabilities experience poor health outcomes and high morbidity due to very low social, economic and political determinants, which are impacting negatively on the well-being of this vulnerable group.

Inequalities in health care access impact on the health outcomes of people with intellectual disabilities. They experience lower life expectancy and greater prevalence of health problems compared to the general population. However, often these health conditions, including mental health concerns, are either under recognised or inadequately managed. People with intellectual disability do not have access to the same levels of preventative health care and health promotion programmes as others in the community.

3.1 *An Ordinary Life*

In 2001, the National Health Committee produced a report, *An Ordinary Life*, which highlighted the issues:

- poor health and high levels of medication are part of having an intellectual disability
- the provision of appropriate primary, secondary and tertiary health care is a health issue, not a disability support responsibility
- ensuring that adults with an intellectual disability have adequate income for health care, is an income support issue
- the role of disability support services is to assist adults to access services, including health services. This should include:
 - ensuring regular health checks occur
 - assisting communication with health professionals

- enabling the person with an intellectual disability to apply for appropriate income to meet the cost of health care

The Committee made several recommendations:

- That the systemic neglect of the health of adults with an intellectual disability be urgently addressed
- That the Minister of Health and the Minister for Disability Issues directs the Ministry of Health to ensure that:
 - i. primary health care providers are aware of the health needs of adults with an intellectual disability and have:
 - clearly developed policies for access to services
 - comprehensive health assessment tools for people with an intellectual disability
 - appropriate staff education programmes, including peer review processes
 - ii. health promotion material is produced that is directed towards and accessible by this population
 - iii. prescribing practices for this population are consistent with current best practice guidelines
 - iv. District Health Boards examine access to their secondary and tertiary services for people with an intellectual disability, identify barriers and take active steps to minimise or remove them.

To date, nine years later, there has been no substantive or sustained response from successive Governments. The Ministry of Health has consistently failed to offer any solutions or initiatives to address these systemic issues. The needs of people with intellectual disabilities continue to be over looked in the health sector.

3.2 Annual Health Assessments

In Australia, Lennox (2007) has demonstrated in a randomised controlled trial that annual health assessments led to increased:

- detection of vision impairment
- hearing testing
- immunization rates
- women's health screens
- detection of previously undiagnosed disease

Since the *An Ordinary Life* report, IHC has persistently lobbied governments and held discussions with the Ministry of Health, regarding the introduction of universal annual health checks. No commitment to this initiative has been forthcoming. The Government has instead chosen to work on identifying how the Primary Healthcare strategy can be more responsive to need.

3.3 Disabled Children

UNCROC, UNCRPD and ICESCR all refer specifically to the right of disabled children to good health and well-being. However, through its current Children's Rights seminar series *Startstrong*, IHC has found that children

Children with intellectual disabilities are over-represented in the following statistics:

- 12% of all children in New Zealand between the ages of zero and nine have a disability
- 52% of these children have their disability from birth
- 26% have a disability due to disease or illness
- 16% of children with a disability have a health need that is not being met
- 25% of children with a disability live in house that depends on a benefit payment
- 28% live in homes with only one parent in them
- 18% of children with a disability live in families with an income of less than \$30,000 per year
- 43% of caregivers that needed respite did not get the help when they needed it
- 523 disabled children are currently (2010) under the care of Child Youth and Family

(source: Statistics NZ, Disability Survey 2006)

3.4 Aging Population

Reflective of society in general, people with intellectual disabilities are an aging population group, which is characteristically experiencing age-related health conditions. Currently 27% of residents living in IHC homes are 50 or older. As with aging populations globally, this demographic phenomenon will pose significant challenges in the near future to service providers and the governments which fund them.

Substantial international research has indicated the increased morbidity relative to age in people with intellectual disabilities, for example:

- Earlier onset menopause (Carr et al 1995, Schupf et al 1999)
- Sensory impairments
 - High risk of hearing impairment (Meuwese-Jongejeugd et al. 2006)
 - <50 yrs = 38%; >50 = 62%
- Increasing vision impairment and blindness (van Splunder et al 2006)
 - ~1/3 vision impairment < 50 years
 - ~2/3 vision impairment > 50 years
 - Blindness ~2.6% <50 cf 7% >50 years
- Osteoporosis (Centre et al 1998, Angelopolou et al 1999)
- Osteoarthritis (Hresko et al. 1993)

3.5 Institutional living

IHC was a driving force behind the closure of New Zealand's many psychopedic institutions which held large numbers of intellectually disabled children and adults. As this group of people transitioned into communities to live in residential services, their quality of life improved and consequently their life-expectancy was extended.

Inappropriate prescribing practices occurred at times in institutions to deal with such things as challenging behaviour. Incorrect prescribing or over-medication has caused long-term health problems for some former residents of institutions.

3.6 Living options

Around 10 years ago, the Ministry of Health introduced a new supported accommodation model (Supported Living) to the range of service options available for people with intellectual disability. This model was intended to give more autonomy, self determination and thereby be more aligned with a Human Rights framework. However, anecdotal evidence suggests this model is delivering poorer health outcomes to the people who choose to take up this option. Their living circumstances, social isolation and poverty are contributing inevitably to poorer health. It is increasingly obvious that their health is significantly lower than those living in community residential (group home) situations. Yet to date no formal evaluation of the service model has been conducted.

3.7 Mental Health

It is not unusual for intellectually disabled people to develop mental illness, such as depression and chronic conditions like Schizophrenia and Bipolar Disorder. People with an intellectual disability can often face difficulties in both accessing and receiving mental health assessment and treatment. Mental health services have been known to decline assistance because the primary diagnosis is intellectual disability and therefore not in their scope of expertise. And conversely, intellectual disability services declining requests for support due to lack of capacity to deal with mental health conditions.

A dual diagnosis can also have various related health complications.

It is a well researched reality that people with Down Syndrome present with early onset Dementia on average earlier (average age of onset is 50-55 years) in the life span than the general population. In addition to premature mortality, the dementia of Alzheimer's disease is associated with high rates of morbidity including functional decline, increased dependency as well as increasing morbidity including behavioural and psychological symptoms of dementia, seizures, mobility impairments, feeding and swallowing difficulties and aspiration pneumonia, often recurrent. With increasing life-expectancy, this is becoming a serious concern for this sub-group of intellectually disabled people, for their families and for service providers, who do not have the capacity to provide the appropriate level of specialised care.

3.8 Access

Some people with an intellectual disability have experienced barriers to accessing allied health services needed for proactive interventions that keep them healthy and prevent enduring problems. For example, people who have difficulty swallowing due to their condition, may choke on their food, yet have not been seen by a speech language therapist for swallowing assessment and help to remediate; people with physical disabilities not receiving a physiotherapy assessment and help with strengthening muscles.

People with an intellectual disability do not access preventative healthcare and health promotion programmes to the same extent as others in the community.

3.9 *Death by Indifference*

In 2007, MENCAP, the leading disability advocacy organization in the UK, published an alarming report resulting from an investigation into the avoidable deaths of intellectually disabled people within the public health service. The report brought to light the following issues:

- little concern amongst professionals regarding equity
- the knowledge and input of parents was ignored
- health professionals had limited knowledge and understanding of disability
- poor inter-agency relationships and communication
- the prevalence of discrimination, abuse and neglect
- people with disabilities are invisible – especially in Primary Care
- poor monitoring and recording of data
- inadequate appropriate training of the health sector workforce

Over the past three years in New Zealand, the Health and Disability Commission has investigated two deaths of disabled people which were the result of systemic failure within the public health services. The Commissioner identified similar issues in these cases, to those listed above.

4. Omissions:

IHC acknowledges the Draft Chapter's identification of continued poor health outcomes for Maori, Pacific Island and for people with mental health disorders.

However, IHC is concerned that the Draft Chapter is silent on the fundamental lack of monitoring and evaluation of the impact of continued poor health outcomes on people with disabilities and more specifically people with Intellectual disability.

For example:

- there has been no evaluation of the IDCCR Act to ascertain if it has achieved desired outcomes for people affected by the Act.

- almost all new initiatives to improve general population health, such as the initiatives in primary health, have not collected data/information related to people with disabilities, e.g: the evaluation of Care Plus.
- there is little or no research being currently being carried out in NZ on people with Intellectual disability and their health. Even basic data collection is not occurring.
- lack of accurate information about the current experiences and future needs of people with disabilities, makes it impossible to adequately forecast service requirements and funding levels.

The principle legislation intended to protect the right to health is the Public Health and Disability Act. Of particular relevance to people with intellectual disabilities is its objective of achieving the best care and support for those in need of services, to be able to be independent and participate in society. IHC notes that this Draft Chapter has omitted to identify the systemic failure that exists despite this legislation, which has led to significant disparity in health outcomes for people with intellectual disabilities.

5. Priorities for Action

IHC endorses identification of the following as possible priorities for action to progress the right to health for people with intellectual disabilities in New Zealand:

Monitoring

Ensuring the right to health is monitored across the treaty body reporting framework.

Social, economic and cultural rights

Extending the BORA to include social, economic and cultural rights to provide a more complete, substantive set of rights to better address the needs of all New Zealanders.

Inequalities

Tackling entrenched inequalities via a systematic, comprehensive, long term, whole of government approach with explicit targets and timelines and clear indicators to monitor the impact.

6. Conclusion

IHC supports the Human Rights Commission's review of the Action Plan for Human Rights and appreciates the opportunity to give feedback on omissions, identify incorrect information and make suggestions for additions.

New Zealand's ratification of the United Nations Convention on the Rights of Disabled Persons has provided a wider lens to reconsider the rights of intellectually disabled people. IHC is keen to see the new rights related to improved health outcomes reflected in the revised Action Plan for Human Rights.

We believe that there is some distance to go in responding to the human rights of one of the most vulnerable population groups in New Zealand society, those with intellectual disability. It is clear from our consultation with people with intellectual disability that there are persistent and enduring barriers to people with intellectual disability being able to exercise and enjoy their human rights in most spheres of their everyday life.

We believe that the Human Rights Commission has a responsibility to ensure that the progress established is now expanded to reflect New Zealand's compliance with the UNCRDP. We look forward to ongoing dialogue with the Commission to ensure that the points raised within the IHC submission are considered and taken account of.

7. Recommendation

That the Commission's revised Action Plan for Human Rights contains the following prioritises for action:

- To remind the government that by its obligations under ICESCR, Article 12, it is required to prioritise action to address the unacceptably poor health outcomes for people with intellectual disability

We are happy to provide any further information or clarification about these matters.

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