

Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights (2009)

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Brief description of organisation/role:

President,
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Families speaking up for people with an intellectual disability

Our organisation was established in the 1980s as the *New Zealand Psychopaedic Hospital Parents' Federation* by parents of children with an intellectual disability who were worried about coping with de-institutionalisation. Since 1993 it has been known as Rescare New Zealand Inc. Originally our organisation was based on groups of parents and friends connected with the six psychopaedic institutions – Cherry Farm, Templeton, Braemar, Kimberley, Tokanui, and Mangere. Now that all those institutions have been disestablished, our organisation has reorganised itself around support groups which have formed in the geographic areas where former residents of the institutions are now living in community houses.

We are an independent body that receives no direct government funding. Our costs, covering payment for one part-time paid co-ordinator and modest administration, are met by subs from members and grants from such bodies as Lotteries and NZCT.

Nowadays more of our members are siblings, rather than parents, of people with an intellectual disability. And some, like myself, are friends or welfare guardians, rather than family members. However, we all have the same objective which is to ensure that our family members enjoy an improved quality of life in their new community homes. In this “watch dog” role we liaise with providers of residential and day services on matters of care. We also lobby government over such matters as assessment of needs, funding of services, provision of services, training of staff, and access to services.

It is the latter issue, **access to services**, which has motivated us to make this submission. Many of the people with an intellectual disability for whom we advocate have multiple disabilities which include paralysis of limbs, lack of speech, profound deafness, blindness, autism and various other challenging conditions. In order to achieve their “Right to services of an appropriate standard” under the Code many of them need assistance. When access to a service is denied, their right to complain appears to be unclear. (See our answer to Question 3)

We are happy for our details to be released under the Official Information Act 1982

Questions

Question 1 – Is it necessary to review the Act and Code every 3–5 years? Would 10-yearly reviews suffice?

No fixed view on this. Regular review may help to put pressure on Government when it is slow to respond.

Question 2 – What amendments to the Act or Code in relation to disability do you suggest and why?

We would like to see a designated Commissioner for Disability Issues

Question 3 – Should the Act and the Code be amended to include a right to access publicly funded services? If so, how would such a right be framed? YES

It was this question that motivated our submission to the review.

In the Kimberley Hospital residents had access to a permanent dentist on site who was able to carry out dental procedures under a general anaesthetic. When the Kimberley residents shifted into the community there was an expectation from the Ministry of Health that where possible deinstitutionalised residents would access dental care through a dentist in a community dental practice. Access to dental services through the hospital dental service should be only for people who could not be appropriately managed in a community dental practice.

Many of the ex-Kimberley residents, however, are very frail. As well as having an intellectual disability many of them have other disabilities which include paralysis of limbs, lack of speech, profound deafness, blindness, autism and various other challenging conditions. That is why historically their dental treatment had been carried out under a general anaesthetic.

In the Hawkes Bay area there were no problems about accessing dental services. Some people went to a local dentist and for those who needed more specialised care the DHB had a dentist on the staff who was able to provide the required standard of dental care. But in the Manawatu area things were very different. MidCentral Health DHB balked at providing a dental service for ex-Kimberley residents. In our view this was refusal was discrimination, but for MidCentral it was a funding problem. There followed long delays in getting dental care which resulted in serious health problems for some people.

For a while it was impossible even to get a dental check up, let alone dental care, for the people with an intellectual disability who were unable to cope with going to a dentist in the community. Our Horowhenua/Kapiti Support Group took up the case with the Ministry of Health, arguing that if the money was available for a specialised dental service when their family members were living in Kimberley, it should still be available when they were living in the community, but access continued to be denied.

When the local support group approached the Health & Disability Commissioner it was explained that his/her jurisdiction did not cover access and funding matters. However, the Commissioner did informally assist by passing on the concerns to the Ministry of Health and the relevant Ministers and by asking to be kept informed.

Eventually, after further discussion between the Ministry and the DHB the matter of access to dental services for those who needed them at secondary level was resolved, probably thanks to the H&DC intervention. However, we would like to see both the Act and the Code modified to make it clear that someone with a disability should not be denied a normal service simply because of their disability.

Question 4 – Should the Act and/or the Code be amended to include health information privacy? If so, what amendments do you suggest and why?

Having accepted that every consumer has “the right to have his or her privacy respected” many members of our organisation would possibly have a different view about putting too strong an emphasis on privacy of information. Many of them have experienced information being withheld from them on privacy grounds when it would have helped if someone had passed on the information. A family member, even when he or she does not have legal guardian status, can make a significant contribution when it comes to the care of a person with an intellectual disability. On the other hand we would definitely not want personal information to be abused.

Personally I agree with the preliminary report of the Law Commission (referred to in the H&DC review document) which states that the central issue for health information is “to achieve a proper balance between keeping personal health information confidential and getting the right information to the right person, at the time when it is needed” (page 23, para 76). The Commission noted that the delivery of health care raises complex questions about how to reconcile privacy and confidentiality with the need to share information for the benefit of the patient, or for the benefit of the wider society (page 204, para 8.78). While members of the health professions are under stern ethical duties of patient confidentiality to protect the information about the patient they have collected, they need to be able to communicate that information between themselves (page 205, para 8.79).

Over recent years it would appear that improvements to the Privacy Act seem to have achieved a reasonable balance, particularly with the introduction of the Health Information Privacy Code. However, if it would help to solve current privacy issues, we would support the suggestion to amend section 20(1)(c)(i) of the Act (and clause 4 of the Code) to delete the exclusion of information privacy, so that the right to have privacy respected in Right 1(2) would extend to privacy of information. This would allow for concurrent jurisdictions over complaints relating to health information privacy, and a referral power between HDC and the Privacy Commissioner in appropriate cases (as there is for discrimination with the Human Rights Commission).

Question 5 – Is the current contracting model for providing advocacy services appropriate? If not, which of the two alternative options identified do you support and why?

We prefer Option 2 with advocates as HDC employees. It is very difficult for the public to understand the current structure. The H&D Code is well publicised, yet when people approach the HDC to make a complaint, they are told they have to go elsewhere first. If advocates were directly employed by HDC there would be a one stop shop which people could be assisted to progress through. Much easier process.

However, we have another issue with the way that advocacy currently works. The H&D complaints service only works for consumers of services who are capable of making a complaint themselves or have a family member or friend who can access the advocacy services on their behalf. There is a need for advocacy to be available for people with disabilities who do not have family or friends to advocate for them. The Select Committee Inquiry into the quality of care and service provision for people with disabilities recommended that Government “Introduce legislative change to strengthen and expand the scope of Government-funded advocacy and complaints services for people with disabilities.”(18). The new Government’s response to the Select Committee report which was published last week recognised this problem in 21c and indicated a willingness to investigate whether less formal types of advocacy might be supported.

Rescare would like to see an advocacy service where advocates could play a proactive role in checking on the quality of disability services.

Question 6 – Do you suggest any amendment to the Act in relation to appeal rights or naming decisions?

We agree there should be more clarity on this matter.

Question 7 – Do you suggest any change to the definitions in the Act relating to health services? NO

Question 8 – Are the definitions in the Act relating to disability services appropriate? If not, what changes do you suggest?

No left to answer this one!

Question 9 – Do you agree that the Office of the Health and Disability Commissioner should be renamed the “Health and Disability Commission”?

YES

Question 10 – Do you support clarifying the status of Deputy Commissioners pending possible reappointment?

YES

Question 11 – Are the functions of the Commissioner appropriate? If not, what amendments do you suggest and why?

No time left for this one.

Question 12 – Do you think that the Act should be amended to require HDC to refer all complaints about registered health practitioners to the relevant registration authority?

Yes, so long as this does not preclude HDC from taking action.

Question 13 – Should section 38 of the Act be revised to better reflect its purpose?

No time for this one

Question 14 – Do you consider it is necessary or desirable to amend the provisions of the Act governing the Commissioner’s investigations? For example, by giving complainants the opportunity to comment on the Commissioner’s provisional opinion even if it contains adverse comment about the provider(s), or by setting prescribed timeframes?

Natural justice is important here. Timeframes would be helpful.

Question 15 – Do you suggest any amendment to the Act in relation to the Commissioner naming providers found in breach of the Code?

Clarity needed here.

Question 16 – Do you agree that the fine for an offence under the Act should be increased? If so, do you agree that the maximum fine should be \$10,000?

We agree that there should be consistency with other relevant acts.

Question 17 – Do you consider that ethics committees should be under the oversight of HDC?

Have a conflict of interest here as I am on the Health Research Council. Anyway this is

too big an issue for this review. It would need a comprehensive review of its own!

Question 18 – Do you consider that the Act should be amended to provide independent expert advisors contracted by HDC with the same degree of immunity enjoyed by “members, office holders or employees” under the Crown Entities Act?

YES

Question 19 – Should the Act be amended to allow information obtained during an investigation to be withheld, while the investigation is ongoing?

YES

Question 20 – Do you think any of the above Code rights should be amended?

Would like access to standard care clarified

Question 21 – Do you agree that section 47 should be amended to clarify that the Director of Proceedings may take action only upon referral from the Commissioner?

Question 22 – Should the Director of Proceedings have the same powers as the Commissioner under section 62 until a decision has been made pursuant to section 49 to issue proceedings?

Question 23 – Should the Director of Proceedings have to make a decision to issue Human Rights Review Tribunal proceedings within a certain timeframe, after which point the Director might be deemed to have “failed” to bring proceedings?

Question 24 – Should an aggrieved person be able to bring proceedings where the Director of Proceedings has decided to withdraw a claim, or reverses an initial decision to issue proceedings?

Question 25 – Should the Act be amended to state that any limitation period under the Limitation Act should start to run from the date on which the Commissioner finds a breach of the Code? If so, how long should the Director of Proceedings or

individual person have to bring a claim once the Commissioner has found a breach?

Question 26 – Should the term “aggrieved person” be defined? Should it be limited to health or disability services consumers?

Question 27 – Do you suggest any amendment of the Act in relation to the Commissioner’s jurisdiction over disability services?

Question 28 – Do you think a Disability Commissioner with a dedicated focus on disability issues and services should be created within HDC?

YES