

SEMINAR

THE CODE & PROTECTION OF THE RIGHTS OF VULNERABLE CONSUMERS IN DISABILITY SERVICES.

DUNEDIN, 16 MAY 2001.

The Health and Disability Commissioner, Ron Paterson, aware of the problems in protecting the rights of vulnerable consumers in disability services joined with the Donald Beasley Institute to hold a seminar examining key issues of concern. The focus of the seminar was on the possible gaps in the current operation of the law and the inaccessibility of complaints-based mechanisms for some consumers. The seminar, in Dunedin on 16 May 2001, aimed to:

- * Raise awareness of the vulnerability and rights of disabled people in disability services;
- * Remind disability service providers of their duties under the Code;
- * Identify strategies for more effective protection under the Health and Disability Commissioner Act and the Code;
- * Identify policy, service or monitoring strategies that may provide better protection;
- * Discuss possible legislative changes to provide additional protection.

Invitations were sent to key leaders of major provider and consumer groups, academic and legal leaders, policy advisers, and politicians to come together to share perspectives on the rights of disability consumers.

The format for the seminar included a variety of presentations and opportunities for group discussions and feedback to the seminar.

Conference papers

The Health and Disability Commissioner, Ron Paterson, started the seminar by posing the question "Does New Zealand have a Disability Commissioner?" He acknowledged the difficulty the Commissioner has in meeting the needs of disability consumers in the huge volume of complaints generated by health consumers. He outlined a strategy to improve the protection of disability consumers involving the targeted use of advocates, a wake-up call to providers and taking a test case to the Complaints Review Tribunal. Yes, the Commissioner assured us New Zealand does have a Disability Commissioner, Ron Paterson.

Professor Peter Skegg from the Faculty of Law at the University of Otago spoke on "The Legal Context of the Code - particularly in relation to Disability Services". The wide coverage of the Code and the very broad definitions in relation to "disability service providers" and "disability services consumers" in the Health and Disability Commissioner Act 1994 made these very powerful legislative measures in the protection of the rights of disability consumers. Their rights under the Code are the same rights as health consumers.

"Taking the Code seriously - for consumers who've never heard of it" was a thought provoking presentation by David Corner of IHC Self Advocacy Support and Anne Bray and Sue Gates of the Donald Beasley Institute. The presentation highlighted the very real vulnerability of disability consumers in knowing what their rights are and in exercising those rights. The lack of understanding of the Code in relation to disability consumers amongst health and disability providers and staff compounded the

difficulties of rights being met and added to the vulnerability of consumers. New Health and Disability Sector Standards offer some hope for improvement but this will need to be supported by contractual accountability and wide spread training of staff at all levels.

Tania Thomas, Director of Advocacy from the Health and Disability Commissioner's Office spoke on the role of advocates in supporting disability consumers under the title "I'm all right, Jack". Tania pointed out that those who are able to articulate and pursue their own complaints should not forget those who need help and support to ensure their rights are met. She recommended independent, empowerment advocacy as the mechanism for balancing outcomes for these two groups of people.

The final presentation was by Phil Grano, Co-ordinator of Villamanta Legal Services in Victoria Australia. Villamanta operates as a statewide community legal service for people who have a disability, in particular an intellectual disability. Phil gave an impassioned plea for a disability commissioner. Victoria does not have such a person and Phil gave examples of the many areas where he felt a Commissioner would be able to bring about improvements for disability consumers. Some of the problems Phil spoke about included a lack of funding for quality services, no affordable structure to investigate complaints and no legally enforceable principles governing the provision of services. Phil acknowledged that he was envious of the New Zealand situation where disability consumers have a Commissioner to oversee the standards of services and a Code of rights giving them legal protection when services are provided to them. He was in New Zealand to see if such a structure could work in Victoria.

Feedback from discussion groups

The broad topic for the first discussion was identifying which consumers are most vulnerable and why. To help focus the discussion it was suggested that groups answer four questions.

1. Which consumers are most likely to have their rights under the Code unmet, or poorly met?

In answering this question responses fell into five key areas. All groups identified aspects of disability and high levels of dependence as contributing to the likelihood of needs being unmet or poorly met; issues around access, the quality of provider and the effectiveness and availability of advocacy were other common themes.

Those with the following characteristics

Restricted ability to communicate because they:

- * Can not read or write
- * Have an intellectual disability, brain injury or dementia

Lack confidence:

- * Lacking energy and confidence because of health/life issues
- * Lack family support

- * History of institutional care and conditioned dependency
- * Do not know their rights

Age/Culture barriers:

- * Children/those over 65
- * Maori/Pacific Island consumers who find service culturally insensitive

People whom the community views negatively:

- * Those who offend society (ie: prisoners, drug addicts)
- * Those who are seen as difficult, non-compliant, demanding or a danger to themselves

Issues around access

- * Those awaiting reassessment
- * Those beginning to lose their independence
- * Those with no access to services have no rights under the Code
- * Those who use mainstream services
- * Those in their own home needing multiple services -access/co-ordination/rights especially for 65 plus age group
- * Maori and Pacific Island families where access to services is poor

Issues with providers

- * High level of dependence on one provider
- * No choice of provider
- * Providers under budget constraints
- * Staff not trained in Code
- * Providers with a strong business culture
- * Poor quality provider with poorly trained staff
- * Providers who see clients as "different" people with "different" needs rather than as employers with needs for respect and dignity

Effectiveness and availability of advocacy

- * Ineffective welfare guardian
- * Reliance on supporters who lack professionalism, knowledge (may be family)
- * Those without close and positive family involvement
- * Those with no independent advocate.

2. Why are they at risk?

In answering this question groups identified issues with providers, lack of other options, dependency and the difficulties of knowing how to complain and get improvements as placing disability consumers at risk.

Issues with providers

- * Lack of other options - no way of making a comparison
- * Lack of education of service providers
- * Inflexibility of service provision
- * Attitude of providers denying rights

Dependency

- * Not easy to complain or offer suggestions to people who you are dependent upon for survival

Not knowing how to complain

- * Lack of education Life experience doesn't include use of formal complaint mechanism
- * No advocacy or support
- * Process seen as negative and bureaucratic
- * Isolation

Past experiences

- * Will complaining change anything?
- * Not wanting to be labelled a 'trouble maker'

Risks in using the Code

High cost in terms of energy and risk of discrimination or retribution for minimal benefit. People need to pick their battles.

3 What current systems are supposed to protect the rights of these consumers?

This question was divided into two parts so that groups were asked to identify protective systems within and outside services. Aspects of service provision and consumer involvement were identified as currently providing protection within services while enforcement of standards, statutory rights and community involvement were outside systems seen as providing protection.

Within services

- * Aspects of service provision
- * Complaints procedures
- * Staff education both formal and informal
- * Lifestyle plans with expectations of service and standards
- * Vision and philosophy- audit, review, evaluation
- * Funding contracts
- * Information packs
- * Staff training
- * Money and reputation
- * Integrity of service

Consumer involvement

- * Consumer participation in management and service evaluation eg IHC Branch Committee

consumer involvement

Outside of services

Enforcement of standards

- * Service specifications
- * H&D service standards apply to all providers of disability services
- * Review and evaluation
- * Contracts including complaints mechanism
- * Accountability through independent quality assessors; quality accreditation audits eg MoH audits

Statutory rights

- * Code of Rights and Commissioner
- * HRC, PC
- * District Inspectors
- * PPPR Act

Community involvement

- * Advocacy DPA, People First, JAG, CABX, police, CYFS, lawyers, Family Court
- * MP's
- * Community integration
- * External friendships

What are the major weaknesses of these current mechanisms?

The major weakness from the providers' viewpoint were the complexity of the current statutory framework, lack of consequences for poor performance, balancing conflicting demands and unreal expectations.

From the providers' viewpoint?

Complexity of statutory framework

- * Statutory obligations not understood or complied with
- * Do not have core information or link to advocacy/complaints
- * Process often complex ;difficult to understand and can be aversive
- * Overload of HDC, HRC etc , and the courts

Lack of consequences for poor performance

- * Poor performers move from organisation to organisation - registration may help
- * Non compliance = low consequences

Competing demands and unreal expectations

- * Reviewing and policing is one part- motivation and inspiring staff is the other
- * Greater consumer involvement in standard setting and recruitment policies but need to avoid charge of tokenism
- * Inherent conflict of interest provider- staff, client- purchaser
- * Liability under OSH desensitised
- * Isolated staff with poor supervision both from peers and management
- * Complaints processes don't always lead to resolution
- * Training and quality systems treated as low priority and not funded
- * Unreal public expectations

From the advocates' viewpoint the complexity of the statutory framework and complaints processes, lack of external monitoring and skills and the negative consequences of complaining were the key weaknesses identified.

From the advocates' viewpoint?

Complexity of systems

- * Information not in easily readable form
- * Existing statutory protection at a very high level- enforcement is hard; resources lacking
- * Delays in investigation
- * The mechanisms to complain may be there but it is easy to be discouraged by a lack of response to your concerns - you then become an "education artefact" responsible for educating other advocates and service providers.
- * PPPR Act is often used against consumers rather than for them
- * Rights are seen as a commodity in legislation
- * NZ has no constitution. It is in fact spread over several pieces of legislation; Privacy Act, Human Rights Act, Disability Code; etc. The relationship between these Acts is not strong (silos). There is not one well-known or well-understood channel of complaint.
- * Freedom to make complaints and barriers to complaining (controlling consumers)
- * Ability to write to make complaints

Lack of external monitoring

- * Places people with disabilities in dangerous circumstances
- * No independent oversight
- * Evaluations are intermittent
- * Changes occur within service provision

Lack of skills

- * Those involved in disability sector are often volunteers; do they have the required skills?
- * Lack of information and power for staff

Negative consequences of complaining

- * Disabling viewpoints and models of "care"
- * Threat of being labelled as stirrers
- * Power imbalances between providers and consumers
- * "Residents" may not have the power to employ staff, yet people who have RIGHTS should have responsibilities
- * Reactive - requires a complaint

The second discussion focussed on identifying strategies and actions ." which could improve protection of the rights of vulnerable consumers. Participants were divided into groups of: service providers; advocates and advocacy organizations; and those involved in policy and law.

SERVICE PROVIDERS

The two groups representing service providers answered the discussion questions as follows:

What do service providers need to do to better protect and promote consumers' rights?

- * Service providers identified the need for all staff to be educated about their duties under the

Code of Health and Disability Services Consumers' Rights.

* Service providers noted the need to ensure that services embody an **orientation towards individuals**, which:

- * is designed around a client focus, rather than a service focus;
- * promotes participation of consumers in services;
- * provides accessible information on their rights to all consumers;
- * respects the rights and dignity of individuals;
- * ensures that choices are offered **and** clients are encouraged to make their own decisions;
- * ensures flexibility within services to meet individual needs and preferences;
- * Service providers challenged themselves to **monitor their own performance** and service models, even to the point of "laying complaints about themselves".

What are the barriers to achieving these changes, and how can these barriers be addressed ?

Service providers identified the major barrier to change as the failure of providers to take responsibility for driving change. There was also recognition that the inability of some consumers to communicate, placed responsibility on providers to ensure their rights were protected. They also identified the lack of funding for advocacy services to protect the rights of vulnerable consumers.

Possible strategies to address these barriers included:

- * providers taking a proactive approach to protecting consumers' rights;
- * when complaints are made, these should be addressed constructively and the process used to improve services;
- * increase the number and independence of advocacy groups and organizations;
- * the Health and Disability Commissioner's Office providing an "Advocacy information pack" for providers.

What needs to happen first?

* Service providers identified clear priorities for action. Firstly, providers must acknowledge the provisions of the Code and their legal duties under it. It was also noted that providers should also be aware of the Government's policy framework as set out in the Disability Strategy.

* Secondly, providers noted the urgent need to evaluate their own services with regard to how consumers' rights under the Code were being promoted. It was suggested that a consumer survey was one way of carrying out such an evaluation.

ADVOCATES AND ADVOCACY ORGANIZATIONS

The two groups representing an advocacy perspective also contributed extremely valuable directions for positive action.

What do advocates and advocacy organizations need to do to better protect and

promote consumers' rights?

Firstly, the groups identified the essential personal skills and characteristics needed in individual advocates:

- * the capacity to listen;
- * ability to learn quickly -often complex material such as legislation;
- * a clear understanding of the role of advocate and appropriate boundaries;
- * a passion and commitment to individual rights

Secondly, in order to improve current advocacy, advocates and advocacy organizations acknowledged that they needed to:

- * increase efforts to reach the most vulnerable consumers; train and upskill advocates;
- * provide professional development and supervision for self-advocates;
- * strengthen relationships and alliances; (> work with more service providers;
- * provide more community education and awareness training.

One group suggested that the Health and Disability Commissioner's Office should have a "high profile" TV promotion.

There was also acknowledgement that better information is needed on who currently provides advocacy services, to enable better coordination and use of each other's strengths.

One group suggested that the Health and Disability Commissioner Act should be amended by repealing Clause 3 (which refers to the provider having to show that it took "reasonable actions in the circumstances to give effect to the rights, and comply with the duties, in this Code).

What are the barriers to achieving these changes, and how can these barriers be addressed ?

The barriers identified all related to lack of resources:

- * financial;
- * trained and skilled advocates;
- * health professionals who understand the Code;

natural supports for vulnerable consumers (e.g. relatives- "-" friends).

In addition to more resources, other strategies to address barriers to improved advocacy were:

- * sharing of skills, information, successes;
- * early education in self and peer advocacy;
- * promoting the Code and associated advocacy of the rights in the Code as an accepted part of New Zealand culture.

What needs to happen first?

- * Advocates and advocacy representatives identified a number of urgent actions:
- * providing multi-level education about advocacy to increase understanding and avoid a stereotype of advocacy as adversarial;
- * strengthen the links and information sharing among advocates and advocacy organizations e.g. sharing of training and professional development;
- * work towards a change in the culture of advocacy work, towards a resolution of issues.

POLICY AND LEGISLATION

- * The two groups representing policy and the law added value at the broader level to the discussions by providers and advocates.

What are the policy and legislative gaps and limitations in protecting and promoting consumers' rights?

These two groups identified a number of gaps, including:

- * no public funding for advocacy, (apart from the Health and Disability Commissioner's office);
- * no legislation covering the rights of consumers to access services (the Code does not cover issues of access);
- * a lack of political and policy acceptance of the need for advocacy services;
- * no office of the Public Advocate/Public Guardian i.e. an independent source of legal advocates or welfare guardians.

There were also significant limitations perceived in a number of relevant areas, including:

- * insufficient attention to the interface between the application of the Protection of Personal and Property Rights Act 1988 and the Code;
- * inadequate monitoring of the services received by vulnerable consumers;
- * fragmented, ad hoc legislative solutions to protect individual rights;
- * insufficient education about current legislation;
- * insufficient focus on systemic advocacy and promoting change;
- * possible risks in the proposed assimilation or combination of various "rights" bodies.

What are the barriers to change and how can these be addressed? and what should happen first?

Broad barriers of community attitudes to people with disabilities and what they deserve were identified as ever present, with some suggestions that governmental attitudes should also be expressed in tangible ways e.g. resources, not only in "fine words".

The fragmented legislative framework for the protection of rights was also identified as a significant barrier to positive change. It was suggested that some legislative solution to the coordination of services may be needed.

Governmental recognition and funding of advocacy services was seen as essential.

One group suggested that some of the legislative gaps and fragmentation could usefully be the focus of

a project for the Law Commission.

There was some support for the idea that a mediation-focussed rather than a complaints/investigation approach may be worth pursuing, with greater targeting of the use of the Health and Disability Advocates.

The groups suggested only two initial goals:

- * ensuring an independent voice for the rights of people with disabilities; and
- * beginning from the "ground up", with small achievable goals. "

For the future

At the conclusion of the discussion group reports the Health and Disability Commissioner announced a nation-wide series of presentations by DPA and Advocacy Services targeted at disability consumers. The guidelines for advocacy are being changed to focus on the needs of disability consumers and the service will be targeted towards more vulnerable consumers. Education of providers and a reminder of their duties under the Code are also on the Commissioner's agenda. The ideas generated by the seminar will be used as a basis for these initiatives.