EDCS
Eating Disorders Carer Support
(New Zealand)

Eating Disorders
Carer Support

national charitable not-for-profit
organisation for all carers and supports.

Act and Code Review – Eating Disorder Carer Support Submission

12th August 2024

The Health and Disabilities Commissioner is reviewing the Code of Health and Disability Service Consumers’ Rights (the Code) and the Health and Disability Commissioner Act (the Act).

Eating Disorders Carer Support NZ (EDCS) has utilised the notes taken by ourselves and which have been provided to us by the HDC review team during a ‘TEAMS’ virtual meeting held 12/08/2024 as the basis of this submission. Some comments here are more of a ‘think tank’ style, as a reflection of this.

Attendees Sarah Rowland (Co-Founder & Co-Chair) ; Donald Irvine (Chairperson); Emma Worsfold (executive member)

Review team present: Ikimoke Tamaki-Takarei; Kylie Te Arihi; Catherine McCullough, Jane Carpenter.

Catherine provided an overview of HDC, the Code of Rights and the review.

- HDC covers all health providers and all disability services
- HDC protects people’s rights as set out in the Code of Rights
- The HDC Act sets out our function to promote rights and resolve complaints when people believe those rights have been breached. Includes a requirement to regularly review the Act and the Code.

The HDC are focussing on four topics in the review, plus minor and technical amendments:

- Supporting better and equitable complaint resolution
- Making the Act and the Code effective for, and responsive to, the needs of Māori
- Making the Act and Code work better for tāngata whaikaha | disabled people
- Considering options for a right to appeal HDC decisions.

Discussion - points are themed rather than in chronological order.

Power difference as a barrier to complaints resolution

In Australia the complaints process is more of a mediation. Report by Productivity Commission in Australia Inquiry report - Mental Health - Productivity Commission (pc.gov.au) says the mental health system is not functioning well and identified what gaps and barriers needed to be addressed. One such gap detailed on page 8 of the report identified “*Supports that are below best practice — in part due to a lack of measurement and evaluation of what works, and in part due to a culture of superiority that places clinicians and clinical interventions above other service providers, consumers and their families and carers”.*

EDCS NZ members would agree that their experiences of the complaints system also mirrors this gap of superiority displayed by workforce and of people in authority/services and at higher executive levels, imbalances in the positions of power between clinicians and consumers, failing to measure what’s not working, and not looking to improve.

People who are in charge have all the power and authority and dismiss complaints and say, “that’s my clinical opinion,” or get really defensive. Seems adversarial instead of looking at what is the issue. Focus should be on how we can do things differently. Ensuring people can really be heard.

A person can be on the edge of death and carers are trying to put their case forward to go to hospital following the appropriate MEEDS guidelines and for it to be passed off as a mental health issue, and not a medically acute or emergency or issue. In some cases when the support person or loved one presents evidence, then clinicians have gone on the attack, and in some cases taken punitive action in making reports to child protection services Oranga Tamariki. Then when other carers in similar circumstances make a complaint clinicians threaten taking a similar action.

Power and authority.

The system tends to believe the unwell person and in a lack of nuance in eating disorders and the damage/effects upon cognition, views the parent as an 'overbearing' or 'difficult' person. So when a parent goes to a complaints body it is very easy for providers to have things explained away as a clinician's decision in mental health.

There is no efficient restorative process or mediation service. The Advocacy service hasn't worked effectively in acting as a mediator.

Barriers to accessing complaints as a parent when they don't have the support of the person receiving services

With mental health complaints and with eating disorders where malnutrition is involved, there are people so mentally unwell, they may not want to be involved in complaints, or able to agree to treatment.

Clinicians don't have all the answers; carers and communities have a lot of valuable information to add in support of their loved ones.

Listen to the families and involve them. Their anxiety and stress levels may be off the charts so need support to get the gold.

Age 18 is the cut off - so clinicians usually don't hear from parents and then they can't access or receive appropriate treatment from the treatment team or GP in family-based and/or therapy and treatment models.

Common themes being reported by EDCS members include, but are not limited to:

- the inability to have support to make a complaint and in feeling too overwhelmed to do so.
  Fear of repercussions to the person/consumer and to the carer is a driving factor
- Failure of primary providers/including HIPs to follow clear health pathways and apply the medical guidelines is a key concern as a key area of early intervention.
- Lack of knowledgeable workforce to carry out those health pathways and awareness / training to apply primary/emergency assessment guidelines when people are presenting with restrictive eating and eating disorders or accompanying mental health issues including anxiety, depression, self harm and suicide ideation.

    - Lack of training in awareness or misinterpretation, or coercive use of the MH Act
    - Lack of training, awareness or misinterpretation of the Privacy Act even when there are immediate and grave medical or psychological safety concerns for the person and their whanau supporting them.
    - Once young people are reaching 18 years old parents do not have a voice, even when there are highly concerning safety issues to the person and their whanau.
    - It must be safe for parents to hand over concerns about a child’s service, without causing additional harm including fracturing relationships with the family and the child/consumer.

Anosognosia (a lack of awareness in the illness and/or its severity) is one of the defining symptoms of eating disorders. Triangulation is a behaviour used to split/separate the child/person from the clinician or team. This is also used to split the parent from the child though this is often poorly recognised because of the lack of training/awareness by clinicians/services.

Allegations or perceptions of abuse. It is a common and noted scenario where community support services and in both primary and secondary specialist services where health professionals, clinicians will believe the child is raising an issue of parent’s abuse when instead there is an clinical reason why the child might react in this way to resist treatment, and often to parents who are following the Family Based Treatment (FBT) at recommendations of services.

Concerns about poor adherence to best practice guidance for eating disorders

Eating disorders are the poor cousin of mental health and addictions and with almost zero awareness in public health services. Across society there is an extremely poor understanding of eating disorders. Lack of professional training and opinion-based treatment – clear breaches of the Health and Disability Consumer Code of Rights are commonly experienced as normal, being reported by carers.

Research identifies that less than 6% of people present as medically underweight who have an eating disorder - there is poor knowledge of this vital information during assessments in acute situations, which happen at any size/weight.

Chronic, Severe and Enduring Eating Disorder (SEED), Severe and Enduring Anorexia Nervosa (SE-AN) and Terminal Anorexia Nervosa (T-AN) are terms being used created as a direct result of poor access and adherence to treatment models. EDCS members report that even teenagers are being labelled thus despite these terms not being recognised as official clinical diagnosis or in the DSM V. The impacts of these terms are causing unimaginable harm to people and their whanau.

The MH Act can be vital and highly supportive as a route to access lifesaving treatment for people with eating disorders if used with a nuance in workforce training and with compassion. Decision-making capacity is also affected by psychiatric comorbidities and severity of state of malnutrition.

Eating disorders have the problem in the withholding by clinicians/psychiatrists of the use of Compulsory/Community Treatment Orders rather than the overuse because services do not have the training in appropriate treatment management or capacity or facilities to use the Mental Health Act.

“the Mental Health Review Tribunal ('MHRT') held that a person with anorexia can be a 'mentally ill' person and involuntarily treated under the MHA”

An example in the use of the MH Act is in New South Wales - “A person with anorexia can be involuntarily admitted to a mental health facility if their circumstances meet the statutory criteria of a mentally ill or mentally disordered person in MHA ss 12–14.” The Chief Magistrate of the Mental Health Review Tribunal in NSW specifically identified anorexia nervosa as falling within the current definition of a mental illness.
“There are statutory obligations to share information about the person with carers, including keeping them advised of medications prescribed, consulting with them at the point of discharge and providing advice of care options after discharge (ss 73-79 MHA).”

When parents say to services that the Code or the Mental Health Act is not being met, we find they are dismissed. We also commonly hear from carers about clinicians encouraging independence of the young person (at times from below the age of 18) from parents, which is contrary to treatment management guidelines.

One experience shared was of a child being removed from a parent's legal guardianship on several occasions because of advocating for her child to receive appropriate clinical care in line with management guidelines. Multiple failures of services, Oranga Tamariki and Family Court.

Some of these experiences and system failures have been reviewed by the Director of Mental Health John Crawshaw following an investigation by a District Inspector across the Southern and Canterbury Specialist Services. This is not an uncommon story. Years of ongoing additional mental and physical illness including addictions have been created as a consequence. No-one is held to account.

There is not enough accountability in New Zealand with the inability to sue - a supportive option which was removed for carers.
There are no requirements or frameworks for specialist eating disorder training or qualifications.
There are no senior clinicians with specific eating disorder qualifications for example.

There are clinical management guidelines – AED and RANZCP and Workforce Core Competency frameworks, guidelines and training which have been developed by the Australia & New Zealand Academy of Eating Disorders (ANZAED) , the joint professional body. These have been implemented only in Australia.

There are primary and emergency assessment and management guidelines *MEEDS (Medical Emergency in Eating Disorders) in which there is low awareness and are rarely followed by primary care staff, GPs, hospital emergency staff, general psychiatrists.

Seeing common themes of parents and young people where being told that their young people and families are just hard work / the most complex, when actually they're not applying guidelines and appropriate clinical care or management including patient-centric and individualised planning.
The South Island is a particular hotspot but these themes are common themes across New Zealand.

Services often discourage support people and discourage recordings of meetings.

Issues of not being able to access notes in a timely way, even when parents have permission from a consumer – One member has made complaints to the Ombudsman, and there are still delays.

Multi-disciplinary failures. There is enormous cost to the system which could be reduced with effective use of available management resources, treatment models adherence and frameworks of accountability by workforce and multicultural competencies training including for workforce entering the workforce and differences in cultural perceptions including diet and in body types.

Protection against retaliation, and group complaint mechanisms

With eating disorder services, there's no alternative. Parents want to make complaints but have had bad experiences. First because it takes a long time and because it is adversarial.

Fear of treatment being affected or witheld prevents complaints.
When people/carers or consumers do handover feedback to providers, it is immediately handed over to the young person, causing more harm. This low number should be assessed as to why? Whether bad or good.

Services report seeing a very low number of complaints - this is because of fear by parents/carers/consumers. Because they hear that only the consumer can make a complaint (?) families can feel like they are left out in the cold.

Support group complaints.
EDCS has been exploring making supporting carers in making a joint or group complaint because of the common themes, though put off because of the difficulty of the carers/parents in making one.

Whenever a complaint is lodged, carers report it gets sent to the other party to respond to, and they are recognised as having authority. Services need to get better at getting people better and working out what needs to change. If you don't measure what you are trying to do, then you won't succeed.

Carers need support and protection against retaliation, but how would it be enforced?

Restorative processes and quality improvement

Need a system culture of immediate and continuous improvement.

Indicators KPIs for correct treatment and journey towards recovery. Record journey. Open and accountable. Measure good performance. If getting someone falling off the recovery curve, see what else is available.

Culture shift for workforce so complaints are an opportunity to do things differently

Refusing to meet face to face, with advocates, or only with legal representation

Having clear guidelines for the complaints process would be helpful. A restorative process would be the first port of call, where mana is upheld. Feels one-sided at the moment. Would want independent facilitators.

Provider and HDC complaint processes

If complaints are to be assessed and investigated then needs an **independent** specialist eating disorder expert to provide advice and guidance and without conflicts of interest. Having someone within a service or working within or connected to the small pool of public services clinicians investigating their colleagues is not good enough.

Free legal representation is important and acceptance of support people in meetings. Make people feel like they are being heard and comfortable in the process

Next steps

HDC committed to share what has been raised with the Deputy Commissioner within HDC with the responsibility for mental health, addictions and prisons. As the watchdog of the health and disability sector, we can consider your stories and decide whether to look further into the concerns you have raised.

EDCS offered for HDC to reach out if there are any other resources or information needed.

Contact for this submission:

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Facebook: https://ww.facebook.com/EDCSNZ/

About
EDCS is a registered charitable trust which represents and supports parents and carers of people who have eating disorders. Our Aim is to provide Lived Experience Peer support, educational materials, awareness and education at all levels for ongoing system improvements.
Charity Reg No. CC60989

References -
*MEEDS Guidelines - Medical Emergencies in Eating Disorders:
NSW Mental Health Review Tribunal ruling -
https://www.mhrt.nsw.gov.au/files/mhrt/pdf/TreatmentOptionsForAnorexiaUnderTheMentalHealthAndGuardianshipActs.pdf