Report of the Health Committee

Petition of Rebecca Toms: Urgent expert care and subsidy assistance for young people with eating disorders

March 2022

Contents

Dr Liz Craig
Chairperson

Petition of Rebecca Toms

Recommendation

The Health Committee has considered the petition of Rebecca Toms—Urgent expert care and subsidy assistance for young people with eating disorders—and recommends that the House take note of its report.

Request for support for young people with eating disorders

The petition was presented to the House on 3 June 2021. It requests:

> That the House of Representatives urge the Government to provide more expert care and subsidy assistance for young people with eating disorders.

The petitioner explained that she submitted this petition because she was astonished to discover and experience the "gaping hole" in society for those battling this life-threatening illness. We heard that her daughter was "pushed around" the health system since she was diagnosed with an eating disorder. The petitioner has also been told that specialist units were full and that her daughter's disorder was not severe enough.

According to the petitioner, the public health system is so underfunded and under resourced that it is struggling to effectively help. As a result, she was left to find her own way. The petitioner said she has spoken with parents nationwide in the same situation, who shared similar experiences of being lost in the system.

Comments from the petitioner and EDANZ

In July 2021, the Eating Disorders Association of NZ (EDANZ) made a written submission on behalf of the petitioner. EDANZ submits that it is the only NGO providing support for families who have a loved one with an eating disorder. It also provides education for health professionals, medical students, school staff, and others in the community.

EDANZ is "extremely" concerned about the shortage of specialist evidence-based treatment for eating disorders and the consequent suffering of individuals and their families. In its view, access to treatment for eating disorders has been "inadequate" for years. EDANZ maintains that there has been a shortage of trained and supported clinicians. Now, the anxiety and stress created by COVID-19 has exacerbated resource constraints for an already stretched service.

About eating disorders

EDANZ referred to a 2019 US study that found that eating disorders affect about 9 percent of the population.[1] EDANZ believes these figures are also applicable to New Zealand. Eating disorders affect people of all ages, genders, socio-economic groups, and nationalities. Although they have the highest death rate of all mental illnesses, eating disorders are

[1] Report: Economic Costs of Eating Disorders. Retrieved from: https://www.hsph.harvard.edu/striped/report-economic-costs-of-eating-disorders/.

treatable and full recovery is possible. When patients have access to prompt and timely treatment, they and their whānau can return to full health, living their lives productively. EDANZ added that people can get better in their own homes if the right treatment and support for them and their whānau is provided promptly.

EDANZ noted that the cost of supporting an individual with an eating disorder places a great strain on families. It highlighted an Otago University study that found that annual income for family carers reduced by an average of 27 percent.[2] The petitioner also shared her experience of the costs of accessing private care and said that some parents had given up work to look after their loved ones.

Increase in the number of people suffering from eating disorders

EDANZ explained that, since March 2020, New Zealand has experienced a surge in the number of people suffering from eating disorders. This surge aligns with an increase in cases internationally. EDANZ told us that the number of people contacting its support lines had more than doubled since March 2020.

EDANZ observed that it is difficult to accurately detail the increase in cases due to inconsistency in data collection and reporting. However, it highlighted data obtained through an Official Information Act 1982 request that shows that waiting times for community services have increased "dramatically" over the past six years. EDANZ submits that hospital admissions have grown exponentially over the same period. It maintains that this is due to a lack of timely access to treatment.

Difficulty accessing specialist services

According to EDANZ, individuals and their families are having great difficulty accessing specialist treatment. It attributed this to a lack of education and support for GPs and other primary health providers, resulting in delayed or no diagnosis for many individuals. Other factors are long wait times to access specialist community mental health services, as well as these services not having enough trained clinicians to meet demand.

We were told that people's conditions are significantly worsening as a result of the delays. Further, many are becoming so medically compromised that they require hospitalisation. EDANZ said that readmission rates are high and it is seeing unnecessary, unacceptable suffering, multiple relapses, hospitalisations, and, in some cases, death.

Independent review of current eating disorder treatment

EDANZ noted that the provision of treatment for eating disorders was last reviewed 14 years ago. This resulted in the publication of *Future Directions for Eating Disorders*, as well as a one-off investment in training in evidence-based treatment for clinicians. EDANZ considers that the service that was established at that time is not adequate and is not working. It said that the provision of treatment across the country is inconsistent, which it believes is due to a lack of training and support for clinicians.

[2] The Cost of Eating Disorders in New Zealand: a Health Economics Analysis. Retrieved from: https://www.otago.ac.nz/christchurch/research/researchoffice/studentships/otago828485.pdf.

EDANZ requests an urgent independent review of the current provision of eating disorder services. It would then like a plan for urgent action to provide treatment resources commensurate with the need established in the review.

EDANZ considers that it is vital that a review includes the voices of those with lived experience. It said that, of particular note, it is hearing from the following people, both within and outside specialist services:

- GPs who are seeking knowledge and support.
- Schools and other organisations that need information, resources, and support.
- Families who are "in limbo" with their loved one deteriorating rapidly due to a range of factors. They include a lack of diagnosis or not being deemed sick enough for admission to treatment. Other factors include being too unwell for admission to the specialist eating disorder service or being discharged from services before being fully recovered.

EDANZ's proposed solutions

EDANZ recognises that increasing the capacity of the workforce cannot be a "quick fix". However, it considers that their capability can be increased in the short term. EDANZ noted that it provides a tutorial for fifth-year medical students at the University of Otago Medical School, Wellington. It said that this is the only education in eating disorders that any medical students in New Zealand receive at present. EDANZ would like training to be provided to medical students, GPs at the front line, and community health clinicians. The training should be based on the latest evidence and knowledge. The petitioner also emphasised the importance of training and education to be able to identify the signs of an eating disorder early. She highlighted the vital role that school nurses can play in doing this.

EDANZ would like an NGO to be funded to provide support, education programmes, and guidance to people affected by eating disorders. As well as individuals and their families, the NGO would provide support to health professionals. We heard that EDANZ is currently undertaking a lot of this work. However, it could do a lot more if it had funding that enabled it to employ staff.

EDANZ also requests that community eating disorders services be adequately resourced to provide evidence-based treatments that are commensurate with need. It would like patients to receive early diagnosis and evidence-based treatment, and to be discharged from service only upon full recovery.

Establishment of an external advisory group

The petitioner said she appreciates that an external advisory group has been set up, which will talk to representatives in the community. The group is a partnership between the Ministry of Health and Whāraurau.[3] She told us that she looks forward to hearing the outcomes of the process.

We asked what the petitioner believes the working group needs to deliver. The petitioner told us that she has received feedback that information is lacking once a person has received a

[3] Whāraurau is a national centre for Infant, Child and Adolescent Mental Health at the University of Auckland. It provides training and workforce development.

diagnosis. This includes information about where to go, experts who are trained in eating disorders, and available resources. She said she had to search for care for her daughter and this was “stumbled across” rather than being easily accessible.

EDANZ said it is also pleased that the advisory group has been established. However, it is concerned about what it described as some “significant shortcomings” of the initiative. EDANZ considers that there are gaps in the representation and diversity of the group. For example, the group does not have representatives for primary health care, school counsellors, specialist paediatricians, psychiatrists, inpatients, or the private sector. EDANZ also believes the composition of the group is “unbalanced”, with a high number of representatives from the four leads of current services and the ministry.

EDANZ observed that the project description for the group specifically refers to children and young people. It is concerned that the adult population is being ignored, particularly given the exponential increase in hospitalisations for adults.

We heard that the importance of whānau and parents in treatment and recovery is another area that EDANZ would like the advisory group to address. It proposed that a goal of the advisory group should be to support, inform, include, and empower whānau.

We asked EDANZ what it considers are some tangible outcomes that it would like the advisory group to provide within a 6- to 24-month time frame. EDANZ said it would like to see training proactively provided to GPs and primary health care providers, including school counsellors and nurses. It would also like to see the service that EDANZ provides to families acknowledged, and empowered to improve what it can currently offer.

We are interested in who EDANZ considers should be responsible for this education. EDANZ told us that it is willing and able to continue to train people, but would require resourcing, involvement, and acknowledgement to do so.

Comments from the Ministry of Health

Overview of eating disorders services

New Zealand has four Regional Eating Disorders Services, based in Auckland, Waikato, Hutt Valley, and Canterbury. They provide specialist services to their local area and support other district health board (DHB) areas across their wider region.

In most DHBs outside the main cities, primary health care organisations and DHB general community mental health services provide treatment for people who experience eating disorders. The eating disorders liaison role connected to the Regional Eating Disorders Services provides support and clinical advice to the services outside the main cities.

Young people who experience eating disorders generally receive outpatient treatment and follow-up by DHB Infant, Child, and Adolescent Mental Health Services (ICAMHS). For people who experience severe eating disorders, inpatient care is provided in Auckland, Wellington, and Christchurch. There are 27 inpatient beds nationally.

When a young person needs to be hospitalised, there are clinical pathways between eating disorders services and medical and paediatric teams. People requiring medical admissions for stabilisation receive this through their local DHB medical wards.

Increase in demand for eating disorders services

The ministry acknowledged the pressure that eating disorders services are facing. It noted that demand for specialist eating disorders services has substantially increased over the past 10 years. This includes an increase in the number of children, young people, and males accessing services.

The ministry told us that it collects data about the provision of specialist eating disorders services nationally. However, it does not hold data about support for eating disorders provided through general mental health and addiction services, primary care, general practice, or private treatment. Also, the ministry does not have up-to-date information about the population prevalence of eating disorders. It is therefore unaware of the unmet needs of people who may have an eating disorder but have not sought treatment.

The ministry observed that ICAMHS has also experienced increased demand, which affects wait times. To manage the increased demand, ICAMHS prioritises access so those with the highest need are seen first. We heard that young people need to reach a high threshold of severity before they can access ICAMHS services. As a result, the ability for ICAMHS to provide early intervention and treatment is limited and some people with less immediate needs may have to wait longer for services.

We were told that the number of presentations to general hospitals for the medical implications of eating disorders has also substantially increased. We heard that DHB services have reported that the numbers have accelerated in the COVID-19 environment.

The ministry said its data shows that wait times for people accessing specialist eating disorders services have increased. It acknowledged that the data collected has limitations and the reasons for the increase are unclear. For example, clients may have more complex needs and are engaged with services for longer or the number of referrals may have increased.

We also note a 2021 University of Auckland study, which assessed demand for eating disorder services in the Waikato district in relation to the COVID-19 pandemic.[4] The study assessed clinical records to calculate rates of hospital admissions and outpatient referrals for eating disorders during 2019 and 2020. It found significant increases in hospital admissions, particularly for adults. Greater proportions of children and adults also had a first-ever admission due to an eating disorder. For outpatient services, young people were referred more frequently during the pandemic and were more physically unwell when referred. The study confirmed increased demand for eating disorder services in the Waikato region as a result of the pandemic, which was consistent with findings reported internationally.

Funding for eating disorders services

Specialist eating disorders services are funded from within DHBs' mental health and addiction "ring-fence". The ring-fence is a certain amount of DHB funding set aside for mental health and addiction services. The ministry said that the ring-fence expectations

[4] Hansen, S. J., Stephan, A., & Menkes, D. B. 2021. The impact of COVID-19 on eating disorder referrals and admissions in Waikato, New Zealand.

mean that DHBs cannot spend less than this amount on mental health services, but they can spend more.

We heard that ring-fenced mental health funding is increased annually to adjust for cost increases and demographic pressures. This enables DHBs to maintain existing service levels. The ministry noted that funding for specialist eating disorders services has increased from $7.2 million in 2008/09 to $15.5 million in 2020/21.

We understand that in 2020/21 the number of people being treated for eating disorders was 7.5 people per 10,000. This compares with a rate of about 3 per 10,000 in 2016/17. Some of us expressed concern that funding for specialist services did not increase accordingly over this time period.

The ministry emphasised that it has invested in community services and is working on how it trains the workforce. It is also broadening the range of approaches across the health system so it can intervene early and try to avoid people needing secondary services. We discuss some of this work in our next section.

The ministry pointed out that, at present, the 20 DHBs each decide where funding is allocated and their own priorities. The ministry said it hopes that, under the reform of the health system, a national entity (Health New Zealand) will determine where investment is needed, based on need.

Work to address demand for eating disorders services

The ministry said that work is under way to help address the pressure on specialist mental health and addiction services, including eating disorders services. It is also working to better respond to the needs of people who access these services.

Increasing workforce development and training

The ministry agreed that workforce capacity and capability are challenges for providing timely advice and support for eating disorders. It pointed out that prevention also includes early detection to ensure that people get the right treatment at an early stage. This requires supporting the development of a skilled workforce that can identify and respond to eating disorders. Early detection also requires health professionals to be supported to access training in evidence-based treatments. As well, the ministry recognised the need for upskilling primary health care workers, the mental health workforce, and general medicine staff.

The ministry acknowledged that the current structure of the health system largely focuses on people who require hospital and more intensive treatment for eating disorders. It told us that, as well as supporting the current system, its approach involves identifying how it can intervene earlier. We heard that the ministry has started some tangible interventions that could enable it do to so. For example, training is under way for family-based treatment. The Goodfellow Unit, which delivers continuing professional development for primary healthcare professionals, is also providing online sessions. The ministry acknowledged that this does not reach schools or school-based nurses, but considers it is “a start”.

We heard that the ministry is proposing to make information more available to primary care providers, using HealthPathways as a mechanism.[5] It said it is also improving the information available on its website and other places where providers seek information.

We observed that it can be a challenge for GPs to find relevant information given the number of conditions, services, and support groups across the country. We suggested that the ministry could take a lead by creating an online repository where a GP can find information about eating disorders, along with the pathway for referrals. The ministry told us that providing this information should, theoretically, be easier under the reforms of the health system. This is because it will no longer be working with 20 DHBs. It said it is having discussions with the transition unit in the Department of the Prime Minister and Cabinet about what this work would involve.

Work to promote prevention and early intervention

Budget 2019 provided funding of $455 million to expand access to, and choice of, primary mental health and addiction support nationally. The Access and Choice programme aims to ensure that people can access free and immediate support that meets their needs, where and when they need it. Support through the programme is available in a range of community settings. A person does not need to be referred to these services and there are no entry requirements. The services are available to people experiencing an eating disorder.

The ministry considers that these services could prevent needs from escalating to the point of needing specialist services. It said it has been ensuring that health coaches, health improvement practitioners, and mental health professionals with knowledge and understanding of eating disorders are in general practices across the country.

The ministry explained that it is considering how young people consume media, particularly social media, given the messages that they receive about body image from these sources. It told us that it is very interested in a University of South Australia trial of a programme called Media Smart. The programme seeks to help young people make critical choices about the media that they consume and the messages that they see in the media. We heard that trials of Media Smart are also under way at intermediate schools in Canterbury and Nelson.

Review of eating disorders services and service planning

The ministry noted that a significant review of the mental health and addiction system was undertaken in 2018, *He Ara Oranga*. It said it is now working to implement the recommendations from the review. The ministry has also published *Kia Manawanui Aotearoa*, the 10-year pathway to reform and change the mental health and addiction system and focus on mental wellbeing.

The ministry explained that it published *Future Directions for Eating Disorders Services in New Zealand* in 2008 to guide future investment by government and DHBs. We heard that the document was intended to build and broaden the availability and effectiveness of services for people and whānau affected by eating disorders.

[5] HealthPathways is an online manual used by clinicians to help make assessment, management, and specialist request decisions for a number of conditions.

In its written submission, the ministry told us that it was developing a National Mental and Addiction System and Service Framework. The framework will identify the main components of a mental health and addiction system, including expectations of what is provided locally, regionally, and nationally. It will provide guidance on how mental health and alcohol and other drug services, including eating disorders services, are configured in the future.

Eating disorders advisory group

The ministry explained that the eating disorders advisory group was established to provide national oversight and direction to improve eating disorders services. It acknowledged that it may not have got the group "quite right" as yet. The ministry pointed out that establishing a group that includes paediatricians, psychiatrists, and GPs can be challenging due to their other competing commitments. It said it is exploring how it could bring their views into the group.

The ministry told us that the purpose of the group is to provide advice to Whāraurau about its workforce development programme for eating disorders. The ministry said that the programme focuses on increasing access to family-based treatment and improving the knowledge of GPs and school guidance counsellors. The other purpose of the group is to provide advice to the ministry about issues relating to eating disorders. We heard that the group has deliberately focused primarily on young people because they provide the biggest opportunity for early intervention and prevention.

Our response to the petition

We thank the petitioner for highlighting this important matter, and commend her for her advocacy on behalf of families who have loved ones experiencing an eating disorder. We were pleased to hear that her daughter is in strong recovery from her eating disorder. We would also like to acknowledge EDANZ for its work supporting families and providing education to a range of individuals and groups.

We note that both the ministry and EDANZ have acknowledged that the demand for specialist eating disorder services has increased in recent years and that further work is needed to reduce the pressure on specialist mental health services and support the development of a skilled workforce, which will enable early identification, diagnosis, and treatment.

We were pleased to hear the ministry talking about initiatives to upskill primary healthcare professionals, including training in family-based treatment and the online continuing professional development sessions being offered by the Goodfellow Unit. We would encourage the ministry to consider how such training might be expanded to include a wider range of primary healthcare professionals—for example, school based nurses and health improvement practitioners working in primary healthcare settings.

We also note that the ministry is proposing to make information about eating disorders more available to primary care providers using HealthPathways, as well as improving the information available on its website and other places where providers seek information. We encourage the ministry to explore the possibility of an online repository where primary healthcare professionals could find information about eating disorders, along with pathways for referral.

We also note the petitioner's comments that from a family's point of view, once a person has been diagnosed with an eating disorder, it is not always clear where to go for further help, or what resources are available. If such an online repository were to be developed, we encourage the ministry to also consider how it might assist those with eating disorders and their families, to learn more about the services and supports available.

We were also pleased to hear the ministry has established an eating disorders advisory group to provide national oversight and direction to improve eating disorders services. However, we also note EDANZ's concerns that the group may not sufficiently represent the views of a range of groups, including primary care, school counsellors, specialist paediatricians and psychiatrists. We note the ministry is currently exploring how it could bring such views into the group, and will await the outcome of this work with interest.

New Zealand National Party differing view

The National Party supports EDANZ's request for an urgent independent review of the current provision of eating disorders services. National believes the best way to achieve this is through a Health Select Committee inquiry.

Appendix

Committee procedure

The petition was referred to us by the Petitions Committee on 9 September 2021. We met between 22 September 2021 and 2 March 2022 to consider it. We received written submissions from EDANZ and the Ministry of Health and heard oral evidence from the petitioner, EDANZ, and the Ministry of Health.

Committee members

Dr Liz Craig (Chairperson)
Matt Doocey
Dr Elizabeth Kerekere
Dr Anae Neru Leavasa
Dr Tracey McLellan
Debbie Ngarewa-Packer
Sarah Pallett
Dr Shane Reti
Dr Gaurav Sharma
Tangi Utikere
Brooke van Velden

Evidence received

The documents we received as evidence in relation to this petition are available on the Parliament website, www.parliament.nz.