



Submission to the
New Zealand Government Mental Health Inquiry

June 2018

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Case studies

These two case studies are included to provide real life examples of the incredible difficult challenges that eating disorders create, not only for the patient but also for their families. These have not been edited in anyway.

Case study one

Our older daughter was treated for Anorexia Nervosa (AN) from 2011-2014. Her publically funded inpatient and outpatient care was excellent. We learnt an enormous amount about AN and Family Based Therapy (FBT) from experienced and well trained clinicians.

Our younger daughter was diagnosed with AN in mid-2017 and aspects our experience has been totally different.

I think our GP monitored our daughter too long and should have referred her into a private care provider months earlier. This was especially so since the public outpatient service took too long to see us and then turned us away as our daughter did not meet their criteria. This only gave the AN a stronger grip. Our daughter eventually was accepted but then told to wait for at least two weeks as a staff member was on holiday. Fortunately her paediatrician assessment came up and she was found to be physiologically unstable and was urgently admitted to public inpatient services where she stayed for three weeks.

At that first meeting with the outpatient service we were utterly horrified when our 16 year old was offered a choice between FBT and an unspecified individual therapy. Our daughter was at school and at home with parents very experienced with FBT. Our daughter even then was very aggressive, uncooperative and with no insight into her condition.

We knew that FBT was the only option for a child in our daughter's situation so we were furious that this choice was offered. Of course our daughter (controlled by the AN) chose the individual therapy as this was the least challenging to the AN.

In hospital our daughter rapidly gained weight and this continued at home due to our experience and competence with FBT.

However, the AN was very smart and knew that it could split us and the team by insisting on individual therapy which the outpatient service had inadvisably offered her. Tragically, the outpatient clinicians lacked the training and experience to recognise this as a ploy of the AN and continued leave the door open to individual therapy. This enabled the AN to become very powerful and, we believe, strengthened our daughter's violent and abusive behaviour.

We fought the outpatient service to support us to treat our daughter with FBT but they continued to undermine us. Because our daughter by this time was 17 they felt she legally had a choice. No one with AN has free choice and our daughter who was extremely violent, verbally abusive with no insight or buy in was an unsuitable candidate for anything other than FBT.

The outpatient clinicians confused theoretical consent with the urgent need for appropriate care. A more subtle understanding of FBT and a more intelligent and nuanced approach towards our daughter could have solved the problem. One particular clinician was lacking in empathy, hostile and at times very unprofessional in her dealings with us causing us almost unbearable stress.

There were moments when we felt trapped in a nightmare and at the mercy of people who just didn't know what they were doing and who were actually causing us and our daughter serious harm.

We totally lost confidence in the public outpatient service and are now receiving outstanding care in the private sector. Our daughter is in FBT with an excellent clinician and is finally making progress. Our big mistake was to stay in the public system so long.

There needs to be an urgent investigation into the public outpatient service by qualified experts in this field.

Case study two

Five years (2013) ago our 15 and a half year old daughter presented with eating disorder behaviours. Our GP was brilliant and understood eating disorders and realised she was struggling mentally with an eating disorder even though her BMI was still normal.

My husband, daughter and I saw an Art Therapist privately who was experienced in Eating Disorders. She introduced us to a style of treatment that was based on current evidence based treatment and the GP liaised with CAMHS.

As parents it was frightening to see our intelligent, high achieving, happy daughter descend quickly into tortured thinking and struggle with such overwhelming eating disorder thoughts playing over in her head. There is absolutely no logic to this illness but it has the power to control a mind and goes against basic survival instincts.

If our daughter didn't eat she would die and so we were trained to get her to eat. For us this meant life for her stopped i.e. no school etc. unless she ate. Suddenly our girl who used to eat normally was terrified of food and her anxiety levels around this were through the roof. Imagine trying to get someone you love to face their worst fear and to try and get them to walk through that extreme fear/terror at least six times a day.

Our daughter began self-harming unbeknown to us this had been occurring for three months prior to us knowing about the Eating Disorder and a school teacher who knew failed to report. (Systemic failings start at grass roots.) She became afraid to drink water as it might contain calories.

Our daughter who always erred on the side of caution and did the right thing would run away up the street on a dark cold winter night in pyjama pants, t shirt and bare feet with no

phone rather than face eating dinner. Many other irrational, extreme sometimes violent behaviours occurred based on a flight reaction to fear of food.

Unfortunately the GP went away for three months and left her practise nurse supervising things. The Practice nurse panicked and did an immediate referral to CHAMS. This was June and we waited until September to see someone. The CHAMS therapist made a promise to work with art therapist who was making headway and supporting us as a family. This promise did not happen. The CHAMS therapist often said to my daughter "I can't believe what terrible anxiety you have. I have never met anyone with such terrible anxiety about missing school and it's not normal. You should do star jumps to help your anxiety!" These are such unhelpful messages from a professional and only a sample of many inappropriate messages. She had clearly not read the GP referral which was evident in comments she addressed to me as a parent. This was not a positive start.

Daughter had started on low dose fluoxetine through GP on advice of CHAMS so when daughter met with CHAMS psychiatrist she said to daughter after a couple of consults she wasn't sure it was working so would double the dose and this would even help or blow daughter out of the water. Remember we are frightened parents watching our daughter suffering in the grips of this eating disorder and we trusted this trained professional's judgement.

Daughter began to get suicidal thoughts pretty soon after this and as parents who had never dealt with this it was terrifying. Daughter presented to the crisis team one evening extremely suicidal and then the next day we waited for a call from CHAMS that never came. We weren't sure what we were to do in terms of sending her to school etc. We phoned CHAMS and the therapist told us not to be anxious about it. She said send her to school and make a suicide plan with the school. Remember we had no experience of this ever and got no advice on how to do this! The psychiatrist was aggressive on the phone to my husband and basically said we told you this could happen with the medication change. They immediately stopped the fluoxetine and we later found out this cold turkey was inappropriate and caused daughters mental health to descend further and she had constant suicidal thoughts. She told the psychiatrist her feelings and rang crisis team a lot over this time.

Fortunately at this time we found support and resources through EDANZ and put in safety plans at home which meant constant vigilance, we already had knives razors etc. on lockdown due to self-harm and had removed daughter's access to money. We lived life on high alert and felt under stress. At no time did CAHAMs give us any advice on how to manage all of this. We had to discover this from other families who had been through these times.

Due to our vigilance we thwarted a plan where daughter would have ended her life. The next day finally the psychiatrist fronted up and apologised to our daughter that she hadn't listened to her about the suicidal thoughts and she said how concerned she was at our daughter's plan which would have been fatal. Daughter was then heavily medicated/sedated and we had to supervise 24/7 at home until a bed came up in an adolescent facility.

This treatment facility was amazing and so supportive of us as a family. It was a severely underfunded place so we took extra food for all residents as the food budget was low and the visiting rooms made us say if we won lotto we would donate for a revamp. These people understood adolescents and mental health.

Imagine the confusion and extreme worry and stress this put our family under and the impact on a sibling living in the house as well.

Fast forward 5 years and daughter still struggling with eating disorder. She has seriously self-harmed (requiring ED visits and stitches) over this time and overdosed three times all while under treatment in outpatient MH services. One overdose happened the day after she saw adult MH services and told them she was feeling suicidal, they just sent her home.

We believe some of the things that have really impeded her recovery are the fact that between CHAMS, ED Specialist unit and Adult Mental Health services she has been seen by eight different psychiatrists due to changes of staff, shortages of staff and being placed under registrars on six month contracts. Each one changed or added medications and added their own spin to what they thought were co-morbidities that sat alongside the eating disorder.

Imagine the confusion and disruption in treatment this would cause with this lack of continuity for our daughter and us.

Another difficulty for our daughter and us as a family in receiving evidence based specialist Eating Disorder treatment/therapy was we were not geographically located in the area where a specialist eating disorder service was available so could not access outpatient treatment. A year after seeing CHAMS (now 2014) the psychiatrist looked at daughter and said I don't think you will ever get better (she was now 16 and a half) and she referred to Eating Disorder specialist service for an assessment. They still could not see daughter as an outpatient but assessed her. Two inpatient admissions to Eating disorder clinic but still discharged back to general MH health service due to location.

In July 2016 daughter transitioned to general adult MH services. This treatment team highlighted the danger of professionals who do not have experience in treating eating disorders putting our daughter at serious physical risk. After six months of outpatient visits, the psychiatrist who did not know about eating disorders said we were not to supervise daughter's eating and this is when daughter had just got back to stable weight. The psychiatrist called this a transitional trial and at this point she had no clear Plan A and not a Plan B if plan A didn't work for this said trial. She also told daughter who had anorexic thoughts still she could lose 7 kilos and living at a lower weight might help her feel better.

We raised our concerns (daughter lived under our roof). This professional saw daughter weekly and weighed her and allowed her to drop 13 kilos in six weeks despite us calling after three weeks stating daughter was starving herself. Our family experience was completely invalidated and our voice was invalidated. The psychiatrist created triangulation. This professional underestimated the effect of the eating disorder difficulties on daughter's thinking and this imposed a huge risk to her physical health. The team failed to monitor the risk to our daughter's physical health adequately until her heart and kidneys were put at risk.

She had to cease work immediately and be on complete rest. This meant immediate dislocation from employment which had been positive for self-esteem and socialising.

We met with Supporting Families and had a What's working What's Not with MH service manager and never heard back from the manager! At this point I contacted Eating Disorder service and advocated for better treatment. Fortunately they have been very supportive ever since. We have learnt on this journey now to be advocates for best treatment but unfortunately all the delays and our daughter being ping ponged amongst professional in the public system have really impeded recovery.

Just at the end of last year (Oct 2017) daughter presented to us with a very low mood which was a result of being weight restored again. (Now we know!) She contacted MH services who she was under and they arranged no follow up with psychiatrist. Daughter then saw GP who assessed her with depression and anxiety and contacted the psychiatrist by email numerous times and got no response. GP medicated. Psychiatrist saw daughter in Feb 2018 and criticised GP decision to medicate daughter. Psychiatrist took daughter off GP medications right before she moved out of area to uni. MH services in new region were surprised at the psychiatrist's decision to stop the medication right when daughter was going into new situation that would create anxiety (which it did) so they put her back on the same meds GP prescribed!

We as a family have been placed under financial stress, our employment has been impacted, and our other child has been impacted in many ways. Our lives are no longer normal as we knew it. Without the support of EDANZ and other family's experiences we would probably have lost our daughter to suicide or starvation. We have learnt as much as we could about current research and treatment.

Eating Disorders need specialist treatment and not treatment from general MH services. Geographical location should not impede accessing public specialist services. Five years in and we are exhausted it is hard enough trying to support our daughter to fight this awful illness without having to navigate MH services that have not treated appropriately.

About EDANZ

The Eating Disorders Association of New Zealand (EDANZ) provides hope, information, support and resources to people supporting a loved one with an eating disorder.

EDANZ is a registered charity run by volunteers, who all have personal experience in the process of recovery from an eating disorder – either as parents, caregivers or recovered patients.

The focus is on improving the outcomes for people with eating disorders and their families. Alongside education and support work, EDANZ also advocates for social and governmental change. It is the only organisation of its kind in New Zealand and relies solely on donations and grants.

Goals

- Provide support, information, and resources for carers of people with eating disorders.
- Educate doctors, nurses and other medical professionals working with eating disorder patients
- Improve awareness and understanding of eating disorders in the community

EDANZ activity

EDANZ provides carers one-on-one support via 0800 line, email and group meetings. There is a team of seven people working on a roster, responding to phone calls and emails. The parents on the team have supported a child to recover from an eating disorder.

EDANZ provides information via its website <https://www.ed.org.nz>, brochures, and links to organisations and resources. It regularly participates in the training of health professionals working with eating disorder patients. Additionally it provides educational presentations to various other groups including parents, school staff, and community groups.

The charity was established in 2007, in response to a lack of services for people with eating disorders. EDANZ was involved in the advocacy that resulted in the Government publication of *The Future Directions for Eating Disorder Services in NZ in 2008*. <https://bit.ly/2xgQen1>

While EDANZ was delighted with the focus, and improvement in services this initiative provided, it is dismayed that since then, there has not any further investment in this area, yet there is a growing need for improved access to evidence based treatment.

EDANZ is unique in providing support for family members and other carers looking after a loved one with an eating disorder.

About Eating Disorders in New Zealand

Eating disorders are complex and difficult to treat. Eating disorders are serious biological brain disorders. They are associated with significant physical complications and increased mortality. The mortality rate for people with eating disorders is the highest of all psychiatric illnesses, and over 12 times higher than that for people without eating disorders.

Eating disorders affect both men and women, people of all ages, socio-economic groups, and from all cultural backgrounds. Eating disorders have devastating effects on those suffering as well as their families, friends, and the community.

Eating disorders cause a number of medical problems. No system of the body is immune to the effects of malnutrition.

Studies report varying death rates from eating disorders, but there are common findings. Collectively, eating disorders have the highest death rates among all mental illnesses. In most studies, anorexia nervosa has the highest mortality rate of the different eating disorders. In a recent study by Fichter and colleagues, individuals with anorexia nervosa experienced a standardized mortality rate of 5.0 – that is, they were five times more likely to have died over the study period than age-matched peers in the general population.

Individuals with bulimia nervosa and binge eating disorder had a standardized mortality rate of 1.5 (were 1.5 times more likely to die than peers without eating disorders).

A meta-analysis by Arcelus and colleagues found similar standardised mortality rates to Fichter's study: 5.86 for anorexia nervosa, 1.93 for bulimia nervosa, and 1.92 for eating disorder not otherwise specified (EDNOS). Research has demonstrated higher death rates for bulimia nervosa and EDNOS than these figures. According to one study, the mortality rate for anorexia nervosa patients aged 25 to 44 followed after hospital discharge was 14 times that of age-matched non-eating disordered peers. (That's 14 times!)

Suicide a common cause of death

Suicide and cardiovascular complications top the list of causes of death. Fichter and colleagues found that three-quarters of the deaths for patients with an anorexia nervosa diagnosis were due to cardiovascular complications related to low body weight. A study by Huas and colleagues found that there are two main predictors of death for individuals with bulimia nervosa: a history of prior suicide attempts and a lower minimum BMI.

Across a number of studies, suicide is a common cause of death, and an elevated suicide rate is found amongst all eating disorder diagnoses. Studies have shown that approximately 20% of the individuals with anorexia who had died had committed suicide, and 23% of the bulimia nervosa deaths were from suicide.

Prevalence

There are currently no figures available demonstrating the number of people affected by eating disorders in New Zealand, nor the social and economic impact of the disease on the population.

However, information gathered in other countries has relevance. For example, a 2014 investigation* in Australia found that 4% of the Australian population was suffering from an eating disorder. This is most likely to reflect the prevalence of the illness in New Zealand society.

*“Paying the Price -The Economic and Social Impact of Eating Disorders in Australia”
http://thebutterflyfoundation.org.au/wp-content/uploads/2012/12/Butterfly_Report.pdf

The foreword to the study from Professor Pat McGorry (Chair of the National Eating Disorders Collaboration Executive Director, Orygen Youth Health Research Centre Professor, Centre for Youth Mental Health, University of Melbourne) summarises the concerns and limitations in treatment that face eating disorder patients and their families.

The study “reinforces the prevalence and seriousness of these mental illnesses. I believe their debilitating effects are comparable to psychosis and schizophrenia. The suffering of the individual, their families and the community is greatly magnified by the difficulty many people face in accessing timely and appropriate treatment. Delays in diagnosis and access to care, exacerbate and prolong the illnesses, costing the community and affected individuals very dearly. The burden of these diseases is at least equal to those of anxiety and depression.”

EDANZ is the only organisation working in the area to support families and works with clinicians and others to mitigate the detrimental effects of these barriers to recovery.

Eating Disorder treatment in New Zealand

Eating Disorder treatment in New Zealand is provided through a Hub and Spoke Model.

DHBs are responsible for specialist eating disorder centres in Christchurch, Wellington and Auckland. These facilities offer inpatient (residential), partial inpatient (day programme), and outpatient services to people in their regions.

There is currently no data collected on the number of admissions, length or type of treatment being undertaken by these services. There is also no data about recovery rates, nor on relapse/readmission rates.

EDANZ believes access to this important data, along with an understanding of the numbers of people who may be undiagnosed or not accessing treatment will greatly improve treatment experience and outcomes for patients and their families.

Barriers to recovery

Eating disorders are notoriously difficult to treat for the reasons set out below.

1. Primary Health Care provider knowledge and experience

- Uneducated in eating disorder diagnosis and treatment
- Unaware that eating disorders are serious, potentially life threatening biological brain disorders
- Slow to diagnose
- Unaware of treatment pathway

2. Access to effective treatment

- Lack of diagnosis
- Not meeting criteria for acceptance to specialist services
- Geographical obstacles – rural & remote, or distant

3. Stigma

- Myths and beliefs about eating disorders
- Society's attitudes to mental health
- Society and media focus on "health", exercise and body size

4. Patient resistance and dropout

- Anosognosia (A person is unaware or "in denial" of their illness or symptoms of their disorder as a result of a brain-based illness (Prigatano & Schacter, 1991))
- Relapse
- Lack of family or community support

About EDANZ's submission

This submission is based on a combination of information gleaned from EDANZ's help line and other support work, in combination with results of a survey we sent to people on our email address list for the purposes of providing this submission. A summary of the research is attached to the email with this submission. Our mailing list consists of individuals who have accessed our support and information services, and subsequently asked to be on our database to receive ongoing information. Approximately 600 individuals received the survey, 23.5% or 141 responses were received.

Answers to the inquiry's questions

What's currently working well?

Summary

In Christchurch, Wellington, Hamilton and Auckland there are specialist eating disorder clinics managed by the relevant DHBs. These facilities offer partial inpatient (day programmes), and outpatient services to individuals living within their city, and have some spaces for people living in their wider regions. Additionally Christchurch, Wellington, and Auckland provide inpatient (residential) treatment to individuals over the age of 15 years. Limited beds are available, on a quota basis, in these facilities for individuals living outside the main centres. In the regions outside the main centres, Community Mental Health Services are supported by the main centre specialist centres to provide eating disorder treatment. While in principal there is a trained workforce with relevant training, or support nationally, in reality, the availability of clinicians skilled and experienced to provide evidence based eating disorder treatment is drastically below what is needed to meet the demand.

Survey results

- Approximately one third of respondents comment that once a specialist provider with experienced eating disorder services was found then the care for their loved one was a positive experience. Of that one third at least half of those providers were found in the private sector and not the public sector.
- Family Based Therapy was the treatment option that seemed to be the most preferred.
- Awareness, education and support from entities such as EDANZ, internet, etc. has been increased and improved in recent years.

- Many respondents commented that once they found a professional service provider that was specifically medically trained and understood Eating Disorders then treatment and the information they were provided with were excellent and in one case described as 'world class'. This comment was the case in both public but primarily private care providers.
- Seven respondents to our survey feel that nothing is working in the care of a loved one with an Eating Disorder.

NB While there are significant issues and so much more that needs to be improved in the treatment of eating disorders in New Zealand, EDANZ acknowledges the commitment and effort specialists and GPs are making to try and support these patients.

What isn't working well at the moment?

Summary

- Lack of training of GPs/primary health care professionals compromises their ability to recognise symptoms and diagnose eating disorders. Similarly they have limited or no knowledge of the treatment pathways available in NZ. Early detection and intervention is vital for the best outcomes.
- Limited knowledge, and education of clinicians in the community mental health services, means that, even within the specialist eating disorder clinics, a significant number of clinicians do not have training and experience necessary to provide treatment and support for individuals with these life threatening illnesses.
- Criteria - for admission to services, for discharge from services, for access to levels of care, are inappropriate. Individuals are missing out on vital specialist treatment due to not meeting admission criteria based on outdated knowledge of these illnesses. Patients are discharged from specialist services based on inappropriate criteria and relapse rates are high.
- Family involvement in treatment planning and delivery is restricted, prevented, or not considered. Latest knowledge is that in recovery from an eating disorder, family involvement, where possible, provides the best treatment outcomes.
- Transitions from one service to another, between levels of service, or discharge are shown to be times when communication and ongoing treatment plans are lacking, and relapse rates are high.
- People living in many rural and remote areas are experiencing inadequate or total lack of specialist eating disorder care.
- There are unrealistically long waiting times even in main centres. Early treatment is critical as these illnesses progress quickly.
- Statistics are non-existent – there is currently a lack of data on prevalence of eating disorders in NZ, the social and financial cost of these illnesses in NZ, and the efficacy of publicly funded services. It is difficult to address a problem in the absence of data.

Survey findings

GPs are unable to make a correct diagnosis

Nearly 60% of respondents answered that the ability of their GP to make a correct diagnosis was 'poor to fair'. Respondents were met with:

- a. an overwhelming lack of knowledge and understanding of Eating Disorders and how they should be treated. One respondent wrote “He asked me what the treatment plan was and why they needed all the blood tests. When she was released from hospital he asked me to find another GP as he felt out of his depth monitoring her medically and wouldn’t know where to start or what to watch out for”.
- b. a dismissive sentiment that they were not unwell at all.
- c. inference that they may be depressed or unnecessarily anxious
- d. a necessity to research the disorder as a patient so that they were equipped to inform, encourage or demand their GP provided a referral (This can be extremely difficult for adult patients when one of the symptoms of eating disorders is Anosognosia where - due to changes in brain chemistry from malnutrition - they lack the necessary insight into the seriousness of their illness.)

GPs knowledge of treatment

Approximately 60% of respondents had a ‘poor to fair’ understanding of the treatment processes and options available to them after visiting their GP.

- a) GPs did not have a confident understanding of the services available so patients resorted to researching options themselves through Internet, EDANZ etc. and provided this information to their GP in hope that they would get a required referral.
- b) GPs simply acknowledging they did not have enough knowledge and so referred them elsewhere...dietitians, mental health...very often to the wrong services.
- c) GPs did not know where to refer their clients simply because there were NO services in their local area

Wait to access specialist eating disorder services is too long

More than half of the respondents said the wait to be referred to a specialist service was ‘fair to poor’. Only 6% of respondents said it was excellent.

- a. “When your child is literally starving to death in front of your eyes, every day is a day too long”. The majority of the respondents who commented advised that they had to wait seven weeks to several months to get an appointment with a specialist provider in their DHB region.
- b. Four respondents said they were only provided any care when their child was taken to the emergency department in a critical state. One respondent wrote. “We were lucky in that my daughter was diagnosed severe and the wait was not too bad”.

- c. More often than not the respondents found that the delays between being correctly diagnosed by the GP and then being referred to the DHB specialist service was unacceptable. In many cases these delays were simply because either the GP did not have the correct pathway knowledge, or again sadly there were limited services in the region...e.g. families having to travel to another DHB region on a weekly basis to obtain care.
- d. In many instances respondents commented that the criteria for admission to services seemed to be misunderstood and in some cases totally lacking. Yet again both the Internet and EDANZ have been used extensively so that the carer is 'forcing' the GP to take action in diagnosing and providing the correct referral.
- e. Those recipients who chose to obtain care via a private provider almost always suggested that the length of time to wait for an appointment was acceptable.

PROMPT DIAGNOSIS & EVIDENCE BASED TREATMENT OF AN EATING DISORDER HAS A SIGNIFICANT IMPACT ON NOT ONLY THE LENGTH OF TIME TO RECOVERY BUT ALSO LONG TERM RECOVERY OUTCOMES. DELAY IN TREATMENT CAUSES INCREASED SERIOUSNESS OF SYMPTOMS IN A VERY SHORT TIME. WITH RISK OF DEATH DUE TO EFFECTS OF MALNOURISHMENT THROUGH RESTRICTING, BINGEING OR PURGING, OR DISTRESS OF PATIENT (SUICIDE) REGARDLESS OF WEIGHT OR PHYSICAL APPEARANCE OF THE PATIENT

Lack of information about treatment once in specialist services

Respondents suggested that because Eating Disorders are such a complex mental illness, the continuity of care between health professionals, and even within the same service, varied enormously.

A common theme in experience was that certain nurses or specialists understood the illness whilst others didn't. The level and consistency of treatment delivery was extremely varied. The ability to provide carers with relevant, consistent information about treatment was severely compromised.

Mixed levels of family involvement

A significant number of respondents were unable to be involved in their loved one's care as the Over 18 Years Old Privacy Act was implement.

- a. One respondent noted "The family was not allowed to have full involvement due to the Privacy Act. In my point of view, the patient cannot take proper decisions because of their starved mind and recommend family should be involved in the treatment regardless of patient's age.
- b. "As she was over 18 years the Privacy Act came in to play so I had to rely on how much she chose to tell me". (NB anosognosia means many patients are resistant to treatment)

- c. Almost 50% of respondents commented that when their loved one was being treated in a Specialist Eating Disorder facility and the family was totally involved (Family Based Therapy) the results were very good.

Lack of knowledge by health professionals

More than 60% of respondents felt that the knowledge of the health professionals looking after their loved ones was less than very good and only 15% of respondents suggested it was excellent.

- a. Confidence in treatment was increased again ONCE the family found the health professionals who had knowledge and understanding of Eating Disorders, however very often carers had to transition from one service to another without any continuity of care, and varied levels of care, understanding and consistent treatment within each treatment facility. One respondent wrote “some professionals had good knowledge. Some professionals we’ve encountered had very poor knowledge of Eating Disorders to the point of dangerous”.
- b. Respondents suggested the level of understanding of Eating Disorders among General Practitioners is generally appalling.
- c. Many respondents used EDANZ, the internet etc. to provide them with the knowledge to either battle through on their own or use their knowledge to push the health professionals to instigate the correct referrals and in some cases direct them to treatment options.
- d. A number of respondents found little flexibility was given by providers in exploring different treatment options.

High levels of inadequately treated co-morbidity

- Just under 60% of respondents reported that the patient had been diagnosed with a co-morbidity

Almost 50% of those with a loved one with a co-morbidity reported that treatment received was ‘poor to fair’. 5.2% answered ‘excellent’.

The overwhelming response among those who commented on this matter indicated that treatment, support, advice, continuity of care, discharge plans are not well provided for a loved one with a dual diagnosis.

Lack of cohesion transferring between services

Almost 70% of respondents had a “poor to good” experience when transitioning between services or on discharge. Only 5.8% had an excellent experience.

- a. Transitioning from one service to another is fraught with inconsistencies in levels of communication between the services or in many instances a total lack of relationship and understanding between services. One respondent who had been transferred from a psychologist to a psychiatrist and then back to a different psychologist commented “we have no support and our child is getting worse every day. We fear for her safety. She wants to die!”
- b. Within treatment facilities it appears there are varying degrees of level of care, with some respondents having an acceptable experience and others having a less than satisfactory experience, maybe therefore indicating some lack of continuity of treatment plans within the same facility.

Lack of information upon patient discharge

More than 50% of respondents felt level of information provided once their loved one was discharged was ‘poor to fair’.

- a. The majority of respondents’ comments regarding discharge identified that there is absolutely no consistency in the level of information provided to carers on discharge of their loved one and very often patients were discharged from a facility or treatment not only without relevant information for discharge but without receiving adequate care to keep them safe and well.
- b. Less than 10% of respondents felt they received adequate discharge plans.

Lack of relapse prevention

The survey found that:

- Only 34.38% of respondents had a discharge plan

Yet:

- 62.79% of respondents said having one was extremely important
- 20.93% of respondents said having one was very important

What could be done better?

EDANZ's work and survey has identified the following issues which need to be addressed:

- Educate primary health care professionals so they are qualified to detect symptoms, make diagnoses and refer patients to appropriate treatment. Early intervention and evidence-based treatment saves lives.
- Train and upskill community mental health clinicians to provide evidence based eating disorder treatment. These are often the first or only service that patients see for treatment. Currently in most places, their level of knowledge and experience is completely lacking or inadequate.
- Increase the number of specialist eating disorder clinics around the country. Increase the capacity of these clinics to reduce waiting times, and provide the necessary level of treatment required for each individual. Under resourced centres are resulting in long waiting times. Unqualified or under-qualified staff and premature discharge from service are resulting in increased severity and suffering, long duration of illness and relapse.
- Include people with lived experience in eating disorder treatment planning and delivery.
- The treatment pathway in NZ needs to affirm parents/families as key players in their loved one's treatment and recovery, at any stage of illness and any age of the patient.

Survey responses

Respondents firmly believed that there is a lack of education in relation to Eating Disorders being a biologically based mental illness and wanted better education to de-stigmatise this disease. It is firmly felt by respondents that they are isolated, ostracised and alone very often within their community.

Without question many respondents felt that they were 'shoved from pillar to post' when trying to get treatment for their loved one. This meant that the illness was given time to entrench itself further, thus general awareness of the symptoms of what an eating disorder may look like in your loved one is critical as early diagnosis makes a significant difference in the level of success in treatment..e.g. an education and awareness campaign is critical!

From your point of view, what sort of society would be best for the mental health of all our people?

Stigma, misperceptions and lack of knowledge about mental illness generally, and in particular with regard to eating disorders, presents a significant barrier to treatment seeking, accurate diagnosis and treatment outcomes. Individuals and their families suffer and experience greater social and financial disadvantage than that created by the illness, due to New Zealand society's lack of understanding.

We need a society in which a diagnosis of a mental illness is met with the same access to evidence based treatment, along with the sympathy, support and understanding, that an individual and their family receive upon news of a physical illness.

- a. Our survey showed that 47 of 71 respondents wanted a society that had more compassion and understanding of Eating Disorders. Due to the complexity of the disease and the social stigma the general knowledge of this disease is incredibly limited, as is an understanding of the number of people in our society that are affected by this disease. Thus respondents desperately wanted their loved one's illness treated with the same respect, level of care and concern as other illnesses. One respondent noted "broken minds are just like broken bones".
- b. Many of our respondents noted that social media heavily influenced 'negative body image thoughts' and self-esteem issues in our children. Respondents fiercely wanted to take action to re-address this part of our society, again wanting education and knowledge of Eating Disorders to be brought to the fore so that the stigmas were reduced/removed over time.

Anything else you want to tell us?

Eating disorders are treatable brain disorders, we need evidence based treatment available and accessible to all. Eating disorders do not discriminate – people of all ages, genders, races, nationalities and socio economic groups are affected by eating disorders. It is believed that up to 70% of individuals impacted by eating disorders will not receive treatment due to stigma, misperceptions, lack of education, diagnosis and access to care.

Survey response

One respondent said *“Eating disorders are a life threatening mental illness. More government funding is required immediately along with a task force to complete a study/overview on what is and what isn’t working. Our children are dying!”*

Recommendations

EDANZ provides the following recommendations in the six key areas identified by the inquiry.

Funding

For health professionals: Allocate funding to provide for the training of primary health carer providers, and community mental health services in diagnosis and evidence based treatment for eating disorders. Increase the capacity of specialist eating disorder services to allow access to evidenced based treatment to all New Zealanders, regardless of their location.

For carers and support in the community: Provide funding for EDANZ to continue to carry out our work of supporting carers and health care providers. We are the only organisation providing this service in NZ.

Governance and accountability

Require data collection so national statistics on eating disorder incidence and treatment outcomes are available

- at primary health care level – include in statistics those presenting to GP with disordered eating symptoms, whether diagnosed as eating disorder or not.
- Secondary services to measure and report on admissions, treatment, discharge, readmissions

Workforce planning

Absence of data, see below, has resulted in a deficit between the size and qualification levels of the current workforce providing evidence based treatment for eating disorders, and the need in NZ. With up to date, relevant data collection, we will have the ability to understand the size and nature of the workforce of trained clinicians and supports needed to provide adequate specialist eating disorder treatment to those in need.

Data collection

There is currently no data collected on the number of admissions, length or type of treatment being undertaken by the publicly funded services. There is also no data about recovery rates, nor relapse/readmission rates.

EDANZ believes collection of this data is vital. Additionally a record should be kept of the numbers of people who present to their GP with concerns about disordered eating - the GP

may diagnose someone as an eating disorder but not refer to specialist services, or may determine an individual does not meet the criteria for an eating disorder. These individuals should be captured in the data to be used for service planning, delivery and success measurement.

Design and delivery of services

Include people with lived experience as patients and as carers, in eating disorder treatment planning and delivery.

Include people with lived experience in multi-disciplinary treatment teams. This practice has been proven to improved treatment outcomes. It is being implemented with success around the world. Please refer to <http://www.ceed.org.au>

How to improve coordination between the health sector and other areas.

EDANZ would like to see more collaboration between people with lived experience and the specialist eating disorder services, as well as community mental health teams. Those with lived experience are being included in treatment design and delivery in many parts of the world with great success. As one local example please refer to <http://www.ceed.org.au>

Additionally we believe that there is a need for better co-ordination and communication between primary health care providers and the secondary mental health services to ensure those presenting with disordered eating symptoms are picked up and accepted into treatment in a timely manner. Also that they are transitioned out of secondary services, and picked up by their GP to sustain recovery and prevent relapse.

Appendix 1

High level survey results – attached to email accompanying this submission

Note that full results are available on request. (28 pages)