

## **NZORD submission to the Mental Health Inquiry 2018**

### **Question 1: What's currently working well?**

*We know there are concerns with how we view mental health and addictions, promote mental wellbeing, and provide support and services to those who need it. We also know there are some good things already happening that could be supported and expanded. We want to hear about the good things currently happening.*

*What do you think is currently working well? Why do you think it is working well? Who is it working well for?*

When acute care is required and access is not an issue the care provided by key services is excellent. There are great teams of staff doing the best they can with the resources they have in place.

It appears to be targeted at the most severe cases with potential dual diagnosis of mental health and/or addiction issues.

### **Question 2: What isn't working well at the moment?**

*We know that some things are not working so well at the moment. We want to hear what you think isn't working well, and where there might be gaps or problems — such as the underlying causes of the problems, unmet needs, the way services and support are delivered, the links between services, and the availability of services and resources.*

*What mental health and addiction needs are not currently being met? Who isn't receiving the support they need and why? What is not being done now that should be?*

Mental health is a major issue for people with rare disorders, and the people who care for them. 50% of patients with rare disorders are children and 30% of those children will die before they are five years old. Many rare disorders are life-limiting and difficult to manage. In a survey undertaken by EURORDIS-Rare Diseases Europe, it was found that patients and carers are three times more likely to suffer depression than the general population. NZORD believes the figures would be similar in New Zealand due to the current barriers in our health system for rare disorder patients.

The complex nature of rare disorders creates a cobweb of challenges:

#### 1) Stigma and discrimination

Diagnosis is one of the most important issues affecting the health and wellbeing of people with rare disorders. From our work with patients and carers, we know people suffer stress gaining a diagnosis, being misdiagnosed or disregarded, often being told it's all in one's head and not being taken seriously. It's hard to get doctors to listen. The attitude of clinicians and lack of understanding is a major hurdle for these patients.

“Not only do we have to put up with years of being treated like it's all in our head, or dismissed, or shoved from one doctor to another, we are also missing out on possible treatments and clinical trials which could give us a much better quality of life.” Allyson

## 2) Access to treatment

*The issue of providing access for suitable treatments to patients living with a rare disorder is a challenge for many health systems around the world. Rare diseases, by their nature, do not naturally fit within public health benefit equations because patient numbers are low and typically, treatment costs per patient are high. There are very good reasons to adopt an equitable approach that spreads medicine funding across as many areas of health need as possible.*

The current system of funding medicines through PHARMAC means these patients are missing out on potentially lifesaving, or life-extending, medicines that are more freely available in other countries.

“SMA is going to cause Heath’s body to slowly get weaker until he is completely reliant on machines to live. There is one treatment currently available for SMA. This treatment - Spinraza - is not available here in New Zealand. At \$125,000 per injection (\$750,000 for the first year) it is well out of our reach. Through conversations with members of parliament, Medsafe and PHARMAC, we have been told because it's a rare disease Spinraza is not worth their investment.” Anna

## 3) Work/education

Rare disorders affect social determinates of health including financial impacts. Having a rare condition or caring for someone who does can make it difficult to continue employment, and many carers are surviving on single incomes or government assistance.

Education options may also be limited as complex physical and behavioural issues are barriers to accessing school or higher education. Many parents have to fight to get adequate, specific support for their child.

“He finds school really hard, with the noise and chaos that goes on. As well as the bullying and lack of friends. Then he thinks he is stupid because he cannot do as well as his peers. He has no funding for extra help.” Terri

## 4) Carer stress

Carer stress is a major component of mental health impact within the rare disorder community and this aspect is often overlooked. Many individuals with severe disability and complex care require lifelong support from parents and other family members. Many patients with disabilities are not

identified as having a rare condition, although the majority will have a genetic or lysosomal basis to their disorder.

While other parents can step back from their responsibilities over time, parents of children with complex needs are forever committed to caring for their loved ones.

“One thing that saddens me though is the fight you have to go through to get them that very support the geneticist spoke of in her letter.” Kirstine

#### 5) Social/community

Being diagnosed with a condition that is so rare most people have never heard of it leads to unique obstacles. Humans have a deep need for connection and for those with physical, often invisible, symptoms that prevent them engaging with their community the mental health implications are obvious. Isolation and despair are factors that combine to rob many patients with rare diseases of hope.

"I grew up a normal kid so it is very frustrating for me now because I can compare things and contemplate all I'm missing out on." Doug

#### **Question 3: What could be done better?**

*What are your ideas about what could be done better or differently to improve mental health and wellbeing in New Zealand? What could be done better or differently to prevent addiction from occurring? What could be done better or differently to prevent people taking their own lives and support those affected by suicide? How could support be better provided to those who need it?*

The rare disease community needs better access to mental health support to help them with their unique challenges. Having increased ability to access mental health support with a genuine person who has some awareness of the needs and challenges involved.

Having a centre or community hub which can offer supports for people who wish to talk through their concerns, fears and challenges may offer a preventative approach.

Suicide prevention is about having opportunities to share deeper and darker emotions, online and with real people. Having more media coverage of suicide and its impact on others, more awareness of supports, more sensitivity within the medical model of health and referrals onwards for people when risks are identified in a responsive and helpful way. Being able to feel of value at a time of deep depression can prevent suicide.

For the rare community, having a central organisation like NZORD is of immense value and expanding on support available for open dialogue about emotions with a trained person available as a resource would be fantastic - especially if this was a regular 'slot' online for people to access (Facebook live or Zoom meetings across NZ). Currently there is no MH support offered for this sector many of whom are carers of extremely sick children who have a bleak outlook for their future.

**Question 4: From your point of view, what sort of society would be best for the mental health of all our people?**

*We want to hear what your ideal, healthy New Zealand would look like. What would be the foundations, principles or values that would support positive mental wellbeing for all New Zealanders, and how we might best assist those who need help.*

*Envision how you could refresh how the system in Aotearoa promotes positive mental wellbeing, and prevents, identifies and responds to mental health and addiction challenges, including suicide.*

*What would a refreshed system look like, how would it be different from what we have today, where would you start, and where would you focus your efforts?*

This would encompass all people under mental distress and offer early, simple access to talking therapies/a real person who can make a real connection and not just provide a one off call centre response with a time limited factor. Some follow up is required (if agreed to) so the person feels acknowledged. A community-linked service or hub made available in easy to reach ways. For the rare disease community, in particular, the stress is often hidden and there is a reluctance to reach out for help. This service could be based at local community centres or a marae. GP practices could all have access to counsellors with barriers (cost, respite care etc) being addressed.

A genuine input at the early stages of mental distress can alleviate and prevent further illness and is worth funding.

If someone is to present at hospital there would actually be a person from Crisis Assessment Teams (or trained psychologist/counsellor) available and responsive. This does not occur at present and an extremely reluctant response from an unenthusiastic staff member has been the outcome of such requests from MH needs in ED. This is a vital part of people feeling valued and of worth.

The system would also have a collaborative basis with clear communication between community and hospital input to prevent a dismissive approach with lost awareness of risk. This may involve discharge planning documents or at least communication occurring at the professional level to maintain a flow and continuum of care. This would increase the quality of mental health services.

Submitted by the New Zealand Organisation for Rare Disorders

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