MJA INSIGHT OPINION PIECE:
Rethinking our response to eating disorders

Originally Published in *MJA Insight,* April 30, 2018

https://www.doctorportal.com.au/mjainsight/2018/16/rethinking-our-response-to-eating-disorders/

Author: Dr Sarah Maguire (BScPsych Hons, MA, DCP, PhD) is a clinical psychologist, researcher, educator and policy maker with who leads the InsideOut Institute for Eating Disorders at the Charles Perkins Centre, University of Sydney.

MJA INSIGHT OPINION PIECE
Rethinking our response to eating disorders

The InsideOut Institute for Eating Disorders has been launched at the Charles Perkins Centre, writes institute director, Sarah Maguire …

THE onset of a mental illness is often experienced as a personal, familial and social disaster of a kind. Like any disaster, the magnitude of its effects depends on two factors: the size or severity of the assault and the response brought to bear against it.

Eating disorders are not unique among mental illnesses, to the extent that they dramatically affect the lives of those who experience them and their families. However, according to just about every index of illness severity, they are among the most disabling. Eating disorders have an estimated prevalence between 4% and 8% (here and here). Anorexia nervosa has one of the highest (if not the highest) mortality rates of the mental illnesses and imposes a carer burden higher than for depression or schizophrenia. Together, eating disorders have a total social and economic burden greater than that estimated for anxiety and depression combined.

These are a set of facts that, still, most people are surprised to learn. Public perception of the illnesses has conflated with stigma and illness complexity rendering eating disorders neglected, relative to their impact, on the long list of human health priorities.

The consolidation of research findings around prevalence, mortality, carer, social and economic burden over the past 10 years, and the use of these facts by advocacy groups, has resulted in a shift in the public conversation about eating disorders. In a number of contexts, there has been a shift in policy too.

The most recent and powerful example being the recommendation from the federal Minister for Health Greg Hunt that eating disorders be included among populations requiring specific consideration in the Fifth National Mental Health and Suicide Prevention Plan released in 2017. Eating disorders have not made the inclusion list for any previous national mental health plans. Minister Hunt described eating disorders as a "personal priority" for future policy.

Shortly after he announced the National Agenda for Eating Disorders, he restated the government's commitment to deliver a Medicare response for people with eating disorders, for which a federal advisory group has been convened, reporting to the Medicare Review Tribunal.

This federal response comes in the wake of several such policy responses from state governments during the past 5–10 years. In New South Wales, South Australia and Western Australia, governments have announced significant policy and funding commitments to eating disorders, and the Queensland and Victorian governments both fund statewide coordination and service development centres for eating disorders.

Policy leadership in this field has certainly been needed. Eating disorders do not fall into the structural definition of "major mental illness" in many places throughout Australia, and as such, have not been eligible for treatment in many of the major hospital mental health

facilities. They suffer from the not unique position, but are perhaps the best example of, a mental illness existing alongside equally severe and life-threatening physical illness, posing a very real problem to our health system that divides neatly into medical and mental health structures. This has resulted in people with eating disorders often being considered ineligible for treatment – in a similar way people with co-occurring mental illness and substance abuse experienced before the advent of the "no wrong door" policy. Combine these systemic limitations with the symptomatic ambivalence about care that people with eating disorders can present with, and the stigma associated with mental illness, and there can be a powerful set of barriers to an adequate response to eating disorders both on a personal and community level.

In national surveys of mental wellbeing, eating disorders have previously not been included as a diagnosis for examination. So, estimates of their prevalence and impact do not register at this level, nor in the national strategy and policy that spills from them. As a result, eating disorders do not benefit from the analysis of level of impairment, impact on people and families, use of mental health services, unmet need, physical conditions, social impairment and suicide that the national survey undertakes on the other mental illnesses. The 2007 National Survey of Mental Health and Wellbeing explained the exclusion of "low prevalence" disorders such as schizophrenia, but their prevalence is accounted for in the publications and associated outputs from the survey. So, a rationale for the exclusion of eating disorders, with a prevalence of 4–8%, is unclear and unmentioned.

Historically, this type of structural exclusion has, unfortunately, not been uncommon for eating disorders. In many respects, eating disorders have been absent from the mechanisms of public health intervention and strategy; more often than not, they are simply not on the list and are now having to be retrospectively integrated.

For example, in NSW, eating disorders were not included in the protocols established for the statewide mental health assessment and referral phone line, launched only 5 years ago – the implications being significant, given the phone line is the front face of the mental health system in NSW and acts as the primary point of access to treatment in the public system. This exclusion, along with other system reforms, are currently being rectified by NSW Health as part of the broad system reform in eating disorders that they are undertaking – the NSW Service Plan for Eating Disorders 2013–2018. That such a broad process of reform addressing a single illness group has been required comes as no surprise to those with a lived experience of the illness or their treating clinicians.

The situation for parity in the research sector is no more encouraging. In Australia, government funding for research into eating disorders equates to approximately $1.10 per affected individual, which stands in marked contrast to research funding for other illnesses such as autism ($32.62 per affected individual) and schizophrenia ($67.36 per affected individual). The situation is similar in other large Western countries.

This is not to say that there is an absence of expertise or even endeavour in public health policy, intervention testing, academic thinking and research in eating disorders. There is a robust research, clinical and policy development community working Australia-wide to research and understand the illnesses and translate findings into clinical practice. Research outputs are obviously affected by available funding and structures to support research and innovation.

Eating disorders bear all the hallmarks of a devalued or stigmatised subgroup, among an already stigmatised group of mental illnesses, leaving them doubly disadvantaged. Research

indicates that people with eating disorders, more than other mental illnesses, are considered responsible for their own illness (here and here).

The unhelpful confusion of these mental illnesses with popular culture's thin ideal, resulting in the misunderstanding and minimisation of the illnesses, and a disconnect between the extreme physical imagery and the reality of the internal experience of illness for the person, has clearly not helped. Stigma is most commonly talked about in its personal or immediate social context, but stigma of illness affects not just personal and community response, but systemic response – health systems, government systems and research funding systems. Clinicians are community members too, as are researchers, directors of funding agencies, government employees, politicians, and peer review panel members. Stigma is a human phenomenon, and as such, we should expect it to affect every human being.

So, what is needed for an effective personal, community and national response to the personal, familial and social disaster of an eating disorder?

Leadership, without question.

The public and policy statements by federal and state government leaders have legitimised eating disorders as an illness group for the first time and established a national commitment to developing a better response to them.

Leadership within our own sector is essential; to partner with government, the health system, and research organisations and ensure that this clear mandate for an adequate response actually becomes one. As well as research teams across the country, there are service and policy development teams in a number of states that are working to bring change to the health system. These teams need ongoing support and resourcing.

To truly limit the impact of an eating disorder, early intervention for illness must become a national priority. More research is needed in this area, and the findings of research need structural supports to translate them into practice. Perceptions and practice are the ultimate targets for change, and they will be driven by good research leading to genuine innovation, hard-won changes to treatment pathways, the dispelling of myths and untruths, and the development of structural supports to ensure research findings are communicated effectively and translated into practice across the health system, education system and the wider community.

Dr Sarah Maguire is a clinical psychologist, researcher, educator and policy maker who leads the InsideOut Institute for Eating Disorders at the Charles Perkins Centre, University of Sydney. The Institute can be found on Twitter at @insideoutinst.