Butterfly
Foundation for Eating Disorders

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Commissioners Angela MacRae and Richard Spencer
Productivity Commission
GPO Box 1428
BARTON AUSTRALIAN CAPITAL TERRITORY 2600
Submitted via upload to: http://www.pc.gov.au/inquiries/current/ndis-costs/make-submission

Dear Commissioners

NATIONAL DISABILITY INSURANCE SCHEME & EATING DISORDERS

Butterfly Foundation is the national peak organization for those with a lived experience of eating disorders. Eating disorders, including Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and atypical presentations, are complex neuropsychiatric disorders with a high mortality rate.

All eating disorders need a multidisciplinary approach but particularly for those with complex, chronic presentations there is a critical need for integrated services and supports. To date, a number of people with such presentations have been included in the Partners in Recovery and Personal Helpers and Mentors Services programs.

Butterfly would like to provide the following response to the Productivity Commission's issues paper on National Disability Insurance Scheme Costs with a particular focus on the psychosocial disability that results from suffering a long term chronic eating disorder.

EATING DISORDERS IN AUSTRALIA - 2017

Butterfly is committed to working collaboratively with the National Eating Disorders Collaboration, the Australian and New Zealand Academy of Eating Disorders, and other stakeholders to develop the knowledge base of eating disorders and how they are most comprehensively treated with a focus on recovery oriented approaches. The National Eating Disorders Collaboration coordinated by Butterfly has over 2,000 members drawn predominantly from health and allied health disciplines.

As noted above, eating disorders are complex and serious neuropsychiatric illnesses which, through the disordered eating and exercise behaviours engaged in by sufferers, result in significant physical complications and increased mortality. This group of psychiatric illnesses includes Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and 'Other Specified Feeding and Eating Disorders.'

Eating disorders are frequently comorbid with other psychological and physical disorders including depression, anxiety disorders, substance abuse and personality disorders.

The reality of eating disorders in 2017 includes:

- 1 million Australians currently experience eating disorders, however less than 25% are seeking and / or receiving treatment
- Lifetime prevalence rates are 10% across the Australian population, with an increase to 15% for females
- There are increasing rates of males experiencing eating disorders with current estimates of 25% of those with Anorexia Nervosa and Bulimia Nervosa and 50% of those with Binge Eating Disorder
- Eating disorders represent the third most common chronic illness for adolescent females
- Mortality rates are the highest for any psychiatric illness and over 12 times that seen in people without eating disorders, including elevated rates of suicide
- Total socio economic costs (as estimated in 2012) of $70B, with over $16 billion representing productivity costs. The highest component of cost is that calculated as the Burden of Disease at $52 billion, impacted by current low recovery rates (<50%), duration of illness and high mortality rate.

There are known psychological, biological and environmental risk factors with recent evidence showing that genetic vulnerability is a key risk factor.

In 2012 and 2014 Butterfly commissioned Deloitte Access Economics to better understand the impact of eating disorders in Australia. These reports; *'Paying the Price' and 'Investing in Need',* confirm that the current situation for those living with eating disorders in our country is desperate. Support and advocacy work continues to remain a priority for Butterfly, as does our prevention and early intervention education work in the community.

Copies of these reports are provided with this submission. *'Paying the Price'* addresses the economic and social impact of eating disorders in Australia, underpinned by the prevalence rates, the very low engagement in treatment services and the high mortality rate. *'Investing in Need*' details the benefit to cost ratio of investing in accessible evidence base treatment services which are provided as early as possible in illness and in episode, reducing the duration and cost of an eating disorder. This ratio is 5:1 – for every dollar invested there would be a $5 benefit.

We share these reports to inform the Commission's work on understanding the cost drivers for people with eating disorders including: access, scope, volume, price and delivery.

Since these reports Butterfly has continued to engage with consumers and carers and in a survey undertaken in 2016 they reiterated the reality of the challenges experienced by those with eating disorders and their families, including:

- Missed or inaccurate diagnosis
- Severely unwell people unable to access treatment

- No treatment pathways for people with mild to moderate binge eating disorder and bulimia nervosa
- Short treatment duration with no support for recovery and relapse prevention
- Lack of access to psychological therapy in medical care and vice versa
- High costs of treatment and lack of public health services
- Very high strain on family resources, mental health and relationships
- Lack of access to treatment for people in rural areas.

THE OPPORTUNITY OF THE NDIS FOR AUSTRALIANS WITH SEVERE AND ENDURING EATING DISORDERS

Concern has been expressed, by a number of key organisations in the mental health sector, consumers and carers that the NDIS may not delivered on promised benefits for Australians living with complex mental illnesses, such as eating disorders. There is a fundamental tension between the NDIS' aim to support those with permanent and incapacitating conditions, and the belief that recovery from mental illness is possible.

Eating disorders directly straddle mental and physical illnesses. As neuropsychiatric disorders they require intensive psychotherapy. However, as they manifest in highly disordered eating and exercise behaviours they also cause significant physical impairment requiring parallel medical treatment. Physical complications can include cardiac distress, potassium level imbalances, damage to the gastrointestinal system, osteoporosis, and organ failure.

While it is possible to recover from an eating disorder, the lack of accessible treatment for the majority of Australians means that current recovery rates are, on average, less than 50%. The impact includes a significant number for whom the eating disorder becomes severe and enduring and the experience substantially reduces their functional capacity and/or psychosocial functioning,

The overarching approach of the NDIS, namely that it is a person-centred model of care and support and funding being determined by an assessment of individual needs, is highly appropriate for people living with severe and enduring eating disorders.

Investment in eating disorders is fundamentally inadequate. Butterfly is leading the eating disorders sector in developing the first National Agenda for Eating Disorders which sits alongside the Fifth National Mental Health Plan. The Agenda's purpose is to develop a minimum, baseline effective level of evidence based care that is accessible for all Australians who are affected by eating disorders. Establishing a baseline of evidence based care for people with eating disorders in Australia is critical and urgent. In 2017 it is a struggle for all and for too many an impossibility to gain access to effective evidence based treatment delivered in sufficient dosage and for sufficient duration to treat these illnesses and support sustained recovery. The high rate of mortality is resulting in unnecessary deaths.

Essential systemic changes identified in the National Eating Disorders Agenda include:

- Eating disorders being core business for all mental health services and in all related policy and initiatives. This needs to include access to the NDIS for those suffering complex and chronic eating disorders;
- Implementation of national standards for eating disorders;
- Workforce development to ensure a workforce that is knowledgeable and skilled to identify eating disorders and deliver eating disorders treatment and support;
- Targeted service development to address gaps in the continuum of care; and,
- Accountability measures to ensure that service planning and development at all levels continues to prioritise the development of evidence based responses to eating disorders.

Development of safe, effective responses to eating disorders will require collaborative effort between states and territories, between public and private health, between medical and mental health services and between diverse professional groups. Butterfly understands from our engagement with consumers, carers and state based eating disorder services that the transition to the NDIS has created great uncertainty for many who access services which may be transitioned to the NDIS. It is critical that the transition to the NDIS does not inadvertently create additional gaps in the continuum of care. While in other areas of health care there has been concern about potential duplication of services across national, state and territory funded initiatives, the reality for those living with eating disorders is that there are too few services to meet demand.

The Productivity Commission is particularly interested in the scope of the supports provided to individuals under the NDIS. We understand that the Joint Standing Committee on the NDIS is also considering the transition to the NDIS of all current long and short term mental health Commonwealth Government funded services, including the Personal Helpers and Mentors services (PHaMs) and Partners in Recovery (PIR) programs, and in particular; whether these services will continue to be provided for people deemed ineligible for the NDIS. Butterfly is aware of consumers who are currently within these programs. As the criteria for the NDIS requires a permanency to the disability that is not a current requirement of PiR or PHAMS, it is imperative that the NDIS not be seen as a replacement for these current programs. If this was to happen, it could render people with significant eating disorders without access to important services that enhance their quality of life. If anything, these services need to be expanded to reach even more Australians living with eating disorders who require significant support to support and maintain recovery.

CONCLUSION

While recovery from an eating disorder is not only possible, but sustainable, this will only be achieved with coordinated national and state activity to develop integrated continuums of care supported by professional expertise in health and allied health. Due to the significant under investment in eating disorders services to date, there is an unacceptably high number of Australians who are living with an eating disorder than has become severe and enduring. These Australians require access to the NDIS to ensure ongoing services and support that will enhance their quality of life and reduce their risk of mortality.

It is important that resources are allocated to ensuring that planning processes adequately take into account the unique circumstances of those living with these complex neuropsychiatric illnesses. As the peak body for those with an eating disorder and their loved ones, Butterfly would welcome the opportunity to work with the NDIS to ensure that the voices of those with an eating disorder are heard.

Thank you again for the opportunity to provide a response to the Productivity Commission's Issues Paper on National Disability Insurance Scheme Costs. I would be pleased to make myself available to speak with you about the issues raised in our submission.

Yours sincerely

Christine Morgan
Chief Executive Officer

THE BUTTERFLY FOUNDATION
103 Alexander Street Crows Nest NSW 2065
Phone: +61 2 9412 4499 Fax: +61 2 8090 8196 Email: info@thebutterflyfoundation.org.au www.thebutterflyfoundation.org.au
ABN: 42 102 193 582