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Mr Tom Duncan
Clerk
ACT Legislative Assembly
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Dear Mr ~~Duncan~~ ^{Tom}

Thank you for your letter of 31 July 2018 to the Minister for Health and Wellbeing, Ms Meegan Fitzharris MLA regarding petition 7-18 lodged by Mr Pettersson MLA about Eating Disorder Health Care Services in the ACT. As this matter falls under my portfolio as Minister for Mental Health, I am responding on behalf of Minister Fitzharris.

The enclosed *ACT Eating Disorders Position Statement* is the Government Response to petition 7-18 Eating Disorder Health Care Services in the ACT. This Position Statement has been developed to communicate the guiding principles that outline the ACT Government's approach to the development of eating disorders services in the ACT.

The Position Statement sets out a clear ACT Government commitment to develop services for the treatment and management of eating disorders. It describes a number of the short-term initiatives underway as well as longer term projects that could be pursued, depending on future budgets and more detailed work.

Thank you for raising this matter. I trust this information is of assistance.

Yours sincerely

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ACT
Government
Health

ACT Eating Disorders Position Statement

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1. Foreword

Eating disorders are serious illnesses that cause high levels of psychological distress for people who experience them. A person with eating disorders has increased risks of developing long term mental and physical illnesses, an increased risk of premature death due to medical complications and an increased risk of suicide. Eating disorders can occur at any stage of life, although the incidence peaks nationally between the ages of 12-25.

A 2012 report commissioned by the Butterfly Foundation, *Paying the Price: the economic and social impact of eating disorders in Australia* (Paying the Price), suggests that around 4% of the Australian population is affected by eating disorders at a clinical level¹.

The treatment and care of people with eating disorders usually involves multi-disciplinary input from a range of health practitioners and services. The resulting complexity can create complications that impact timely access to, and engagement with, treatment. Gaps in the system and difficulties navigating it may result in disjointed care for people and delays in accessing care.

The ACT Government is committed to improving eating disorder services in the ACT across the full spectrum of care, so that we can provide the best treatment and care for people with eating disorders when they need it, where they need it. This Position Statement outlines the guiding principles for the ACT Government's commitment to strengthening the eating disorders services system and provides an overview of the ways that the ACT Government is currently working towards this. The Position Statement lists a number of current initiatives that are underway to improve services and concludes with an outline of future projects that could be pursued to continue development. ACT Health is currently in the process of identifying how best to proceed with these future options.

While all eating disorders are relevant to this Position Statement, its focus, and the priorities for service development are the four most common diagnoses, as detailed below².

- **Anorexia Nervosa (AN):**

A person with Anorexia Nervosa places severe restriction on the amount and type of food they consume, leading to a body weight that is lower than the minimum expected for their age, gender and general health. Even when people with Anorexia Nervosa are underweight they will still possess an intense fear of gaining weight, and will engage in behaviours to avoid weight gain.

¹ Butterfly Foundation, 2012. *Paying the price: the economic and social impact of eating disorders in Australia*, Butterfly Foundation, Melbourne.

² The National Eating Disorders Collaboration. (2013) *Eating Disorders in Australia Fact Sheet*: Available at: <https://www.nedc.com.au/assets/Fact-Sheets/Eating-Disorders-in-Australia-ENG.pdf>

- **Bulimia Nervosa (BN):**

A person with Bulimia Nervosa engages in repeated episodes of binge eating, which are followed by behaviours to compensate for these episodes (e.g. self-inducing vomiting, extreme exercise, laxative abuse) as a way of controlling weight. These compensatory behaviours can include vomiting, fasting, drugs or medications. These behaviours are often concealed and people with Bulimia Nervosa can go to great lengths to keep their binge eating and compensatory behaviours secret. Many people with Bulimia Nervosa experience weight fluctuations; they can be in the normal weight range, be slightly underweight or be in the overweight range.

- **Binge Eating Disorder:**

A person with Binge Eating Disorder will repeatedly engage in binge eating episodes where they eat a large amount of food in a short period of time. During these episodes they will feel a loss of control over their eating and may not be able to stop even if they want to. People with Binge Eating Disorder often feel guilty or ashamed about the amount and the way they eat during an episode. Binge eating often occurs at times of stress, anger, boredom or other forms of emotional distress.

- **Other Specific Feeding and Eating Disorders (OSFED):**

A person may present with many of the symptoms of other eating disorders, but not meet the full criteria for that diagnosis. In these cases, the disorder may be classified as atypical or low frequency/limited duration under the overall heading of an OSFED. This does not mean that the person has a less serious eating disorder. All disorders in this category are serious mental illnesses that cause significant distress and psychological impairment.

2. Reasons for an Eating Disorders Position Statement

THE IMPACTS AND BURDENS OF EATING DISORDERS

Eating disorders are a group of mental illnesses that can have significant impacts on the physical, psychological and social wellbeing of individuals and families affected. Children and adolescents with eating disorders can experience interrupted physical, educational and social development and are at a long-term risk of significant medical complications³ and mental health issues.

The mortality rate for people with eating disorders is significantly higher than that of the average population and among the highest for all mental illnesses. Eating disorders also have very high rates of comorbidity, including higher rates of anxiety disorders, cardiovascular disease, chronic fatigue, depressive disorders and suicide attempts³.

³ National Eating Disorder Collaboration, 2012. *National Eating Disorders Framework: an integrated response to complexity*, NEDC, Sydney.

These diseases cause distress, anxiety and burden to sufferers, their family, carers, partners and friends. The *Paying the Price* report summarises the personal costs of eating disorders to individuals, their families and support networks. In addition to the large personal costs, the report also highlights significant lost productivity incurred through premature death and an impaired ability to work.

MISCONCEPTIONS ABOUT EATING DISORDERS

Eating disorders are often poorly understood and underestimated. This can include beliefs that eating disorders are the results of vanity, dieting attempts gone wrong, a cry for attention or a 'phase'⁴. Eating disorders are also commonly seen as only affecting adolescent girls, although they can develop at any age and affect a person of any gender. Contrary to these beliefs, population studies suggest that up to a quarter of people suffering with AN and BN are male, although this is expected to be under-representative of the true number because of the negative stigma associated with eating disorders in males⁵.

These misconceptions are not limited to the general public but can also affect the responses and explanations that people with eating disorders receive when they present for help from general practitioners and health care professionals. This can lead to a failure to detect and treat eating disorders, as well as causing great distress and withdrawal for individuals who need help.

NAVIGATING THE SYSTEM AND GAPS IN SERVICES

Across Australia and overseas, there are gaps in the range of services for people with eating disorders and regional differences in access to and delivery of services, particularly between urban and regional/rural areas and between patients accessing private versus public services.

Furthermore, the needs of children and adolescents differ from those of adults and transition of care between age sectors is a period of high risk. The integration of medical, mental health and allied health interventions also remains underdeveloped. A lack of clarity about which clinical system should be primarily responsible can lead to a lack of clinical leadership, poorly developed care pathways and inadequate coordination of care⁶.

COMPLEXITY CALLS FOR A DEDICATED FOCUS

People with eating disorders often present with symptoms that can vary in severity, acuity, complexity and risk. As a result, managing eating disorders can be extremely complex.

⁴ headspace, 2014. *MythBuster: eating disorders*. Available at: <https://headspace.org.au/assets/Uploads/OR19863-Mythbuster-EatingDisorder-2017WEB.pdf>

⁵ National Eating Disorder Collaboration, *Who is affected?* Available at: <https://www.nedc.com.au/eating-disorders/eating-disorders-explained/something/who-is-affected/>

⁶ NSW Ministry of Health, (2013). *NSW Service Plan for People with Eating Disorders 2013-2018*. Available at: <http://www.health.nsw.gov.au/mentalhealth/publications/Publications/service-plan-eating-disorders-2013-2018.pdf>

This complexity is reflected by the average length of hospital stays for people with eating disorders, which is 19.5 days. This figure is more than 6.5 times the average national patient stay². The *Paying the Price* report calculated that the overall per person hospital inpatient cost for eating disorders is \$13,123. The report also estimates that, based on 2008-09 Australian Institute of Health Welfare data that has been adjusted for inflation, the cost of eating disorders to the health system may have been close to \$100 million, with the resulting impact on productivity being as high as \$15 billion.

RECOVERY IS POSSIBLE

Despite the complexity of eating disorders, there are evidence-based models of care that are available to help people recover from an eating disorder. Evidence and expert consensus support a multidisciplinary approach to ensure that the individual receives access to the medical, dietetic and psychological interventions that are required to maximise the chances of a full recovery.

The majority of people with an eating disorder who receive such treatment, delivered in a timely manner and with personal commitment, can make a full recovery. However, this process can be challenging and may require prolonged treatment and engagement. The provision of care over extended periods is required for recovery, can maintain physical and psychosocial functioning or minimise its deterioration, contain escalation and moderate demand on non-specialist parts of the health system.

Evidence shows that the sooner treatment for an eating disorder is started, the shorter the recovery process will be. Seeking help at the first warning sign is much more effective than waiting until the illness is established⁷. Delays in diagnosis and access to care can exacerbate and prolong the illness. It is well established that early identification and prompt responses to eating disorders must be a priority to reduce the duration of illness and optimise chances of recovery.

PRACTITIONER KNOWLEDGE AND COMPETENCE

The effectiveness of treatment and early identification of eating disorders is reliant on the knowledge and skill of the health workforce. During the care of people with eating disorders there are common assumptions that patient management is the domain of experts in some other service. This can lead to, potentially unnecessary, referrals of patients with mild illness to specialist tertiary services by health practitioners who have limited experience with the management of eating disorders⁸.

⁷ Victoria Department of Health, 2014. *Victorian Eating Disorders Strategy*, Victoria Department of Health, Melbourne.

⁸ NSW Ministry of Health, (2013). *NSW Service Plan for People with Eating Disorders 2013-2018*. Available at: <http://www.health.nsw.gov.au/mentalhealth/publications/Publications/service-plan-eating-disorders-2013-2018.pdf>

The workforce needs to be adequately supported to understand the best models of care for eating disorders and to identify and respond safely to the needs of people with eating disorders. Without this, it can be difficult for teams to maintain their skills or be familiar with referral pathways if only a limited number of people with eating disorders are seen.

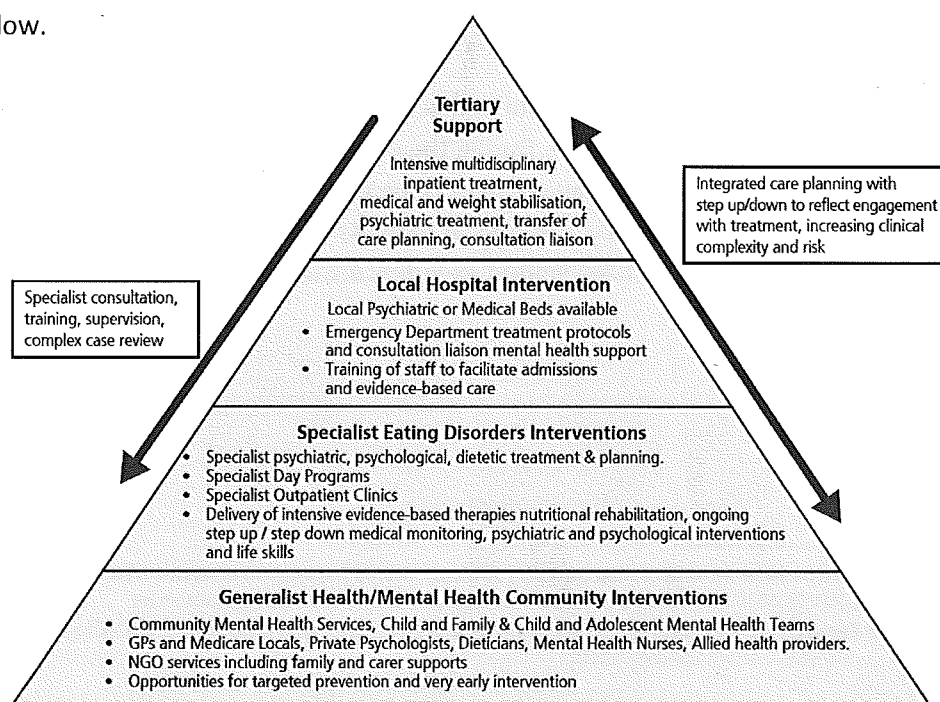
3. Service Spectrum

Eating disorders are complex and multi-causal disorders that necessitate flexible, individualised care solutions that can be provided across a range of settings and in a coordinated way that reflects best available evidence. However, due to funding, resource and time constraints the eating disorders sector has been a fragmented, albeit committed, sector.

To address this, a number of policy documents have been developed to guide action on eating disorders, including service plans and strategies from New South Wales and Victoria and a National Framework for eating disorders developed by the National Eating Disorders Collaboration. Each of these documents describe the key principles and domains which are required to appropriately manage eating disorders and have informed the development of this Position Statement for the ACT.

These plans outline the need for eating disorder services that are developmentally appropriate and flexible across the entire continuum of care from early engagement to ongoing treatment and addressing fluctuations in risk and condition. As a result, there are four clear pillars that are needed across a stepped-care model for the effective management of eating disorders in a health system. These pillars include community-based interventions, specialist outpatient treatment, hospital-based interventions and tertiary specialist inpatient treatment.

These four pillars are represented in the figure below, adapted from the NSW Service Plan⁸, and defined below.



GENERALIST HEALTH/MENTAL HEALTH COMMUNITY INTERVENTIONS

Generalist mental health community interventions include general practitioners (GPs) in primary care and community mental health and Non-Government Organisations (NGOs). In particular, GPs have key roles in the early identification, response to and management of eating disorders as they are often the first point contact for health concerns. Consequently, GPs and other frontline health professionals should be properly supported to identify and manage eating disorders within a primary care setting.

Community-based organisations and NGOs are also vital components of the eating disorders sector. These organisations play key roles in providing advocacy, information and support for people with eating disorders and can be a key point for referrals.

While primary care services and community organisations can provide services for people with mild to moderate symptoms, it is also important to have established networks and referral pathways from these generalist interventions to more specialist treatment for people with higher clinical needs.

SPECIALIST EATING DISORDERS INTERVENTIONS

Specialist eating disorder interventions include a range of outpatient clinics and services. Examples include day programs, which offer early intervention and sub-acute alternatives to hospital care, and outpatient therapy and case management provided by multidisciplinary community teams.

Outpatient services can be delivered as part of a hospital or community-based treatment program or through an NGO-support service. Outpatient services are less restrictive than inpatient programs or admissions and are an important component of the eating disorder system. For many people with an eating disorder, outpatient care may be sufficient⁸.

LOCAL HOSPITAL INTERVENTIONS

People with eating disorders can present to Emergency Departments, and these departments have a key responsibility in facilitating patient entry into treatment. Health practitioners working in Emergency Departments need continued and up to date training in the triage, risk identification and medical management of people with eating disorders. As such, clinically informed assessment is essential and procedures to ensure locally supported treatment and referral pathways need to be established.

In general, inpatient services can be provided on general medical wards, mental health units or specialist eating disorders units. The effective management of a patient with an eating disorder requires collaborative multidisciplinary care. Where a specialist unit is not available, inpatient care should include input from psychiatrists, physicians and dieticians. Consultation liaison and telemedicine support from specialist services can help to ensure evidence-based treatment plans for patients and linkages to appropriate referral pathways.

TERTIARY SUPPORT

There will always be a proportion of patients, with complex needs, who will require specialist inpatient care in units that specialise in eating disorders. Staff in these specialist inpatient services need ongoing education and supervision in order to provide such specialised care and continue to develop their skills. An important element of enabling health professionals to maintain these skills is the constant throughput of cases for people with eating disorders. As a result, people around Australia may not be able to receive such comprehensive care at local sites. This is true of the ACT, where there is currently no specific inpatient unit for eating disorders. Currently, people living in the ACT who require admission to a specialist eating disorders unit will attend services that are interstate.

4. Current ACT Context

Currently, eating disorder services in the ACT include:

GENERALIST HEALTH/MENTAL HEALTH COMMUNITY INTERVENTIONS

Primary Health Care

- GPs can be accessed for eating disorders and can refer to other eating disorder services. GPs will also have access to professional development opportunities that will help general practices in working with clients to manage eating disorders.
- There are Eating Disorders Health Pathways established by Capital Health Network. These Pathways will continue to be updated to reflect development and improvements to the service system made as a result of this Position Statement.
- Private practitioners, such as psychologists or dieticians in private practice are available in Canberra. However, seeing these practitioners can be expensive, which limits the accessibility of these services.
- Referral to psychological therapies are available through the CHN's Next Step Psychological Services or through a GP Mental Health Plan.

Community Programs and Education

- Mental Illness Education ACT (MIEACT) deliver the Any Body's Cool program in high schools to explore stigma about body size and shape. The program is currently offered to girls in years 7 and 8, teaching staff and school support staff.
- MIEACT are currently examining options for the development of a body image program for boys in years 7 and 8.
- The Butterfly Foundation have also been engaged by schools in the ACT to provide workshops, presentations and resources for young people to address the factors influencing eating disorders and their management.

SPECIALIST EATING DISORDERS INTERVENTIONS

Outpatient ACT Health services

- The ACT Mental Health Justice Health Alcohol and Drugs Service (MHJHADS) Eating Disorder Program is a specialist tertiary service which provides free, public, specialist eating disorders therapy to residents of the ACT. The Eating Disorder Program provides services within an evidence based practice, including family based therapy for adolescents and cognitive behavioural therapy for people aged 18 and over.
- The Women, Youth and Children Nutrition Service has expertise in the area of eating disorders and can provide counselling and advice regarding disordered eating to young people under 25 and all women during pregnancy and up to two years after birth.

LOCAL HOSPITAL INTERVENTIONS

Inpatient Services

- ACT Health inpatient weight stabilisation is available at Canberra Hospital and Calvary Hospital. For people aged 16 years or under, inpatient management is in the Paediatric ward. For people over 16, inpatient management at Canberra Hospital is in the Adult General Medicine Ward.
- If medically stable, patients can be admitted to Calvary Public Hospital Mental Health Ward 2N or the Adult Mental Health Unit at Canberra Hospital. This is mainly for treatment of acute psychiatric and suicidality risk, rather than access to an eating disorder specific program.

TERTIARY SUPPORT

- Multidisciplinary models of care for support into the Emergency Department and General Medical beds are being developed.
- There are no Private Hospital based eating disorder inpatient units in the ACT.
- Patients can be transferred to NSW, or other jurisdictions, to access eating disorders inpatient services through private hospitals.

5. Data and Modelling projections

Modelling resources used by the Commonwealth Department of Health to support regional planning and resource allocation estimate that, based on average national demand, the ACT would require an average of three inpatient eating disorders beds at any time to meet demand. A three bed service would not support the multidisciplinary therapy program required for a continuous and effective eating disorders inpatient unit in the ACT.

Analysis of ACT inpatient data for admissions with a primary diagnosis of eating disorders to Canberra and Calvary Hospitals revealed that admissions were seen at inconsistent rates throughout the year, with a range of between two and four admissions at any one time, over the last five years. This observation is consistent with the above national data modelling. However there are reports from the community that there are significantly more people requiring access to these services, who are instead travelling to Sydney or elsewhere interstate for inpatient admission. This indicates more work is required to properly capture access data in Emergency Departments and gain a picture of interstate admissions. This would enable more accurate analysis of access demand in the ACT.

Together, this data suggests that there would not be necessary demand to justify the establishment, or allow for the safe operation, of a specialist in-patient unit for eating disorders in the ACT. As a result, this Position Statement investigates and proposes a range of enhancements and interventions across the whole stepped care model of care for eating disorders. These strategies might better support people with eating disorders across their spectrum of needs, inclusive of practical improvements to experiences of general medical admissions, rather than a focus on solely providing more inpatient beds as the primary solution to current community demands.

It is important to consider that service demand and admissions trends will continue to evolve as services for eating disorders are implemented and improved. As a result, ACT Health will continue to monitor hospital admissions and eating disorders service contacts to guide future developments.

6. Opportunities for intervention

Across each of the four pillars there needs to be flexible patient flows supported by collaborative care planning and appropriate step-up and step-down services. The most complex and severe presentations of eating disorders will require treatment by the most specialised services, while less severe presentations are, where possible, best managed locally in community and outpatient services.

The ideal care model would allow for a seamless treatment and support journey along the continuum of eating disorders management. This would include appropriate referral pathways across symptoms and services with clear roles and mechanisms for consultation collaboration and review. To maximise support for people with eating disorders, their family and carers, this model aims to outline opportunities to engage and link people with relevant non-government agencies to provide recovery support.

Achieving this ideal model requires action across the spectrum of eating disorder services. Because of the linkages required, any actions cannot be considered in isolation as changes will affect the wider service environment. For example, if referral pathways are improved and General Practitioners (GPs) increase referrals to outpatient services without requisite improvements to these services, there will be bottlenecks and harmful impacts. As a result, proper staging of service reforms will be essential.

While sometimes new services may be necessary, improving capacity within each level of the service spectrum does not necessarily require the development of wholly new services. Much can be achieved through workforce development and capacity building within existing services to provide the requisite levels of expertise and knowledge of evidence based treatments to address eating disorders when they present.

7. Immediate Actions

The ACT Government will take a number of short term actions to strengthen the eating disorders service system. These projects include:

- a. Increasing knowledge of eating disorders amongst GP's by promoting access to General Practitioner Training and Resources, in partnership with the Capital Health Network;
- b. Establishing a Specialty Network listing of health professionals with an interest and passion in eating disorders, which can be shared between community organisations;
- c. Exploring interstate clinical specialist partnerships;
- d. Increasing community access to existing specialist e-Therapy programs and services;
- e. Inpatient mapping, modelling, data analysis and coding for future health services planning;
- f. Incorporating eating disorders literacy training for general mental health workforce;
- g. Working with our established health and mental health service providers to raise awareness and service offerings for eating disorders;
- h. Community health promotion campaigns; and
- i. Ensuring better linkage of services across private services, Calvary, ACT Health and primary care.

8. Future Options

ACT Health also understands that further service developments will be required in the future and that these developments will need to be system-wide, rather than intently focused on acute services.

A number of options that ACT Health has identified are listed below. ACT Health is currently in the process of identifying how to best proceed with the implementation of these options. The decision to pursue any of these options will depend on the outcomes and evaluations of current service developments.

- a. Developing local coordination capacity and leadership through the establishment of clinical excellence hubs;
- b. Specialist eating disorder consult liaison;
- c. Opportunities for partnership with NGOs and community organisations. This can include step-up step-down transition support, community based counselling, advocacy, education, and case management;
- d. Further development and implementation of contemporary Clinical Guidelines and Referral Pathways;
- e. Promoting and enabling better discharge planning and transition;
- f. Support for families and carers.

9. Conclusion

By developing this Position Statement the ACT Government is looking to build on the existing eating disorder services in the ACT to provide better outcomes for people with emerging and current eating disorders. As outlined in this Position Statement, actions need to be considered across the wider context of the continuum of care for eating disorders. As a result, the Position Statement proposes system-wide options that can interface with each other, rather than emphasising an acute services focused solution.

The initiatives outlined in this Position Statement will be a great starting point for improving our service system, particularly in primary and community settings, and the ACT Government is committed to continuing to examine the options for future improvements right across the continuum of care.

The complexity of eating disorders requires multiple services, settings and agencies to coordinate their efforts and work together. This level of change will take time and require a staged approach. However, this ACT Position Statement for Eating Disorders represents a significant first step towards making positive change for the management, treatment and care for people with eating disorders in the ACT.