Scottish Eating Disorder Services Review

Summary Recommendations

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Scottish Government
Riaghaltas na h-Alba
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Table of Contents

"Being in lockdown has worsened my eating disorder." (Survey, Q33)

"Learning from those with lived experience and having their feedback [is] core to development." (Survey, Q21)

"..there's the stigma. And until that's sorted we won't get good treatment." (Workshop, person with lived experience)

"I had a certain friend who had to get down to a certain weight to get treatment. It's horrendous, it's dangerous." (Workshop, person with lived experience)

"Some of the Issues we have in Scotland are about scale and geography" (Workshop, healthcare professional)

Context of the Scottish Eating Disorder Services Review

On 2nd March 2020, Mental Health Minister, Clare Haughey announced that eating disorder services would be subject to a national review, designed to assess and improve support for people living with an eating disorder. This review follows on from the Mental Welfare Commission for Scotland's Themed Visit of the care, treatment and support for people with eating disorders in Scotland (1).

The Commission's report 'Hope for the future' was published in September 2020 and the current review was launched by the Minister on 16th October 2020. The review was led by three clinicians from different clinical and geographical backgrounds.

- Charlotte Oakley is Clinical Lead for the Connect-ed eating disorder service for children and young people in NHS Greater Glasgow and Clyde.
- Jacinta Tan is a Consultant Child & Adolescent Psychiatrist in Wales and led the Welsh Government's review of eating disorder services in 2018.
- Stephen Anderson is a Consultant Psychiatrist in Eating Disorders, now working in NHS Greater Glasgow and Clyde, but formerly in NHS Forth Valley.
- The review was supported throughout by Katie Hughes, an Assistant Psychologist in NHS Greater Glasgow and Clyde Adult Eating Disorder Service.

The remit of the review can be found at https://www.gov.scot/publications/national-review-of-eating-disorder-services-terms-of-reference/ (2) (Appendix 1) but in brief, was to:

- Provide a full picture of the current system of support for people with eating disorders and their families and carers across Scotland. The scope of the review includes support from primary care, through to specialist inpatient services and the third sector
- Provide detailed recommendations on how services and the wider support system should be constructed to ensure that the right treatment and support can be provided to those with an eating disorder, and their families

It is expected that this review will be a first step in a phased program, with a second phase of improvement work being guided by the review's findings and recommendations.

It should be noted that the review is running in parallel with the development of a Scottish Intercollegiate Guideline Network (SIGN) guideline on eating disorders which aims to publish later in 2021. The evidence base for treatment and interventions is being considered in detail by SIGN and will not be reviewed here.

In conducting this review, we engaged with key stakeholders, those with lived experience of eating disorders and their families, and with clinicians. We have met

with representatives of Health Boards/Integration Authorities. Separate surveys for clinicians and for people with lived experience were distributed in December 2020 and January 2021 with around 500 responses received. We held 7 virtual workshops from November 2020 to January 2021 via Zoom, with around 40 participants at each. We were keen to ensure representation from a wide variety of clinical backgrounds, and not just from specialist eating disorder services and are very grateful to everyone who took part. Further information about the groups, and clinical backgrounds of participants can be found in in the main report. Details of themes from these events and from surveys can be found in Appendix 2, 3 & 4.

This document contains brief information about the background to the review and also a summary of the main recommendations. Full detail of the recommendations is provided in the main report to be published separately. In addition to the summary and main reports, a number of appendices are available. as follows:

- Appendix 1   Service mapping and scoping exercise
- Appendix 2   Themes from public and clinician workshops
- Appendix 3   Data from lived experience and public survey
- Appendix 4   Data from clinicians' survey
- Appendix 5   Hospital admission data

The full report was submitted to the Minister on 17th March 2021.

Summary of background and context:

- Eating disorders are severe mental illnesses with the highest mortality of all mental disorders;
- There are 4 main eating disorders: anorexia nervosa, bulimia nervosa, binge eating disorder, and avoidant restrictive food intake disorder;
- They are common and costly;
- Evidence based treatment is available;
- Current service response in Scotland is geographically inequitable and underfunded;
- Current service response in Scotland is focused on the severely ill and mostly on anorexia nervosa to the detriment of other eating disorders;
- There needs to be provision of services across the spectrum of diagnoses, age and severity which is appropriate to each person;
- The experience of people with eating disorders and their families asking for help is variable across Scotland.

Reasons for current particular importance – the impact of the Covid-19 pandemic

Eating disorders thrive on isolation. Services across the country have seen increased numbers of referrals of people with eating disorders since the start of the pandemic, following a brief downturn in presentations during the initial lockdown. We are seeing people present later and significantly more physically unwell. A number of papers on the impact of the Covid-19 pandemic on eating disorders have been published (3,4).

Scottish Child and Adolescent Mental Health Services (CAMHS) eating disorder leads have reported an unprecedented increase in the number and severity of children and young people presenting with eating disorders. In the seven health boards able to present data there has been a combined 86% increase in referrals between 2019 and 2020 (range 33% - 280%). This increase is within the context of smaller year on year increases in referrals. In addition, all leads report an increase in severity, illustrated by the 220% increase in paediatric admissions reported by two of the regional adolescent in-patient units. This increase in number and severity has also resulted in an increase in adolescent psychiatric admissions. The two regional units able to provide data report a combined 161% increase in eating disorder admissions between 2019 and 2020.

It is not just NHS services that have seen increased numbers. The UK eating disorder charity Beat has seen calls to its helpline from Scotland increase by 162% between April and October 2020.

As with other services, eating disorder services are rapidly adapting to the use of technology – there is potential to use telehealth to provide equitable access to specialist care regardless of location, but this needs to be balanced against the particular need in eating disorders to undertake physical monitoring and maintain the medical safety of patients.

At the same time as increased numbers and severity of presentations, in-patient services are having increasing difficulty in managing safe transitions from specialist in-patient to community treatment because of the ongoing Covid-19 restrictions. This includes restrictions on time out of the ward to build up time out safely, and restrictions on visitors such as family members who are crucial to supporting safe discharge. This means that some patients could be discharged with less support than previously, or with less preparation for discharge such as home leave, which may prolong admissions. Other patients may have to wait longer for admission or remain in hospital longer than prior to Covid. This has an impact on the ability of services to be able to admit patients requiring this level of intensive care and managing more severely unwell people in the community.

Clinical Aspects of Eating Disorders

Eating disorders include anorexia nervosa (AN), bulimia nervosa (BN), avoidant restrictive food intake disorder (ARFID) and binge eating disorders (BED), and variants which are classified under other specified feeding or eating disorders OSFED), and feeding or eating disorders, unspecified (ICD-11 classification) (5). They are mental disorders with serious medical consequences as well as risks of suicide. Eating disorders have the highest mortality of all mental disorders.

There have been recent advances in treatments as well as changes and expansions of diagnostic categories for eating disorders. There is a trend towards inclusive services for treatment of all people with eating disorders, regardless of age and severity, with the development of all age services and early intervention approaches.

Eating disorders typically develop in early to mid-adolescence but can emerge at any age (6). There can be long periods of time before people seek or receive help and half of all first presentations are to adult (18 years and over) services. The prevalence of anorexia nervosa in the general population is approximately 1% among women and 0.5% among men. There has been a significant increase in the annual incidence in 10 to 14 year olds in the last 7 years. It is reported that half of those who meet diagnostic criteria in the community do not access treatment. Bulimia nervosa is reported to have prevalence of about 2%, and binge eating disorders up to 4%. The population prevalence of ARFID is not known, largely because it is a relatively new diagnosis and still not well known. The overall lifetime prevalence of eating disorders is estimated to be 8.6% for females and 4.07% for males. Changes in diagnostic categories and criteria affect estimates of prevalence rates but prevalence has been increasing over time. The overall one-year prevalence is estimated to be 1.66% (2.62% for females and 0.67% for males) (7–10).

Data from the 2019 NHS-England health survey reported that 16% of people over the age of 16 screened positive for a possible eating disorder (11). This is up by 277% over the preceding 12 years. This included 4% of people who reported that their feelings about food interfered with their ability to work, meet personal responsibilities or enjoy a social life. Eating disorders have significant impacts on functioning. These figures are likely to be an underestimate due to stigma and the fact that eating disorders can be seen by the person as part of themselves and not an illness so go unrecognised even by people themselves who have them. We do not have equivalent data from Scotland but there is no reason to believe that the data would be any different.

Experience of People with Eating Disorders and Their Loved Ones, and Clinicians

We were extremely grateful to people with lived experience and clinicians for meeting with us and completing our surveys. They provided valuable insight into the provision of good care, as well as highlighting issues in accessing and delivering care, treatment and support. They provided a wealth of suggestions about how eating disorder support could be improved. The themes that came up in the meetings and surveys are provided in detail in Appendix 3, 4 and 5. In brief,

People with lived experience of having an eating disorder, or caring for someone noted that

- Many services provide excellent care, however,
- It can take a long time to access care and
- People can experience barriers to accessing the right treatment
- They experience a postcode lottery with variability in services across the country
- They often experience the transition between child and adolescent services and adult services as very difficult
- There appears to be a focus on services for anorexia nervosa and people with other eating disorders may find it difficult to access appropriate treatment
- Carers do not always feel well informed or included in treatment, especially in adult services, even though they provide significant support

The public and clinicians were concerned about the variability responsibility for medical monitoring and management in different services.

Everyone believed that more training is needed to all healthcare professionals to enable earlier detection, prompt referral and appropriate treatment.

Current Service Response

The current situation in Scotland is highly variable as noted in the Mental Welfare Commission report '*Hope for the future*' (1,12). Both the public and clinicians tell us that there is inequity of access to services and an over emphasis on only treating the most severely ill, or those with anorexia nervosa. There is little evidence of early detection and intervention to prevent the development of more severe illness, and much less availability of interventions for other eating disorders.

Appendix 2 adds to the Mental Welfare Commission data with information collated during this review from meetings with services and representatives of NHS Boards or Health & Social Care Partnerships.

What does good look like?

The Vision for Eating Disorders in Scotland

Our vision for eating disorders includes the following principles:

- There is early identification of everyone with eating disorder symptoms and clear signposting to the right level of intervention to prevent disease progression.
- There is a whole system approach to treating and supporting those with eating disorders and their families and carers.
- There is an emphasis on self-management and peer support available to all.
- The physical, as well as mental, health aspects of care are seamlessly and robustly treated.
- Specialist treatment is equitably available across Scotland, is easy to access and is focused in the community. It should be of the highest quality based on best available current research evidence and fully equitable to all and not dependent on diagnosis, weight or other severity measures.
- All services work with people with eating disorders holistically, as individuals, maintaining hope irrespective of illness duration and other diagnoses.
- Families and carers are given a high level of support from the start of their loved ones eating disorder, and for as long as they need it.
- Services, including different specialties, work efficiently together to support comorbidities, putting the patient at the forefront of care.

Recommendations

The following 15 recommendations will ensure that Scotland meets the Vision, using the principles articulated above, within 10 years.

Short term recommendations are numbers: 1, Covid-19 response; 2, implementation planning; 4, lived experience panel; 6, self-help resources; and 13, families and carers.

Medium term recommendations are numbers: 3, co-ordination of national activity; 8, primary care; 9, medical care; and 12, education and training.

Longer term recommendations are numbers: 5, public health; 7, early intervention; 10, specialist care; 11, workforce planning; 14, in-patient care; and 15, research.

Recommendation 1: Covid-19 response

Emergency funding should be provided to rapidly meet the urgent needs of eating disorder patients and services as a direct result of an increase in the number and severity of eating disorder presentations related to the Covid-19 pandemic. Funding should prioritise physical health stability, risk reduction, support inpatient discharge and prevent admission to hospital.
Ownership: Scottish Government providing funding, individual health boards responsible to Scottish Government.

In Summary: This urgent funding is to enable rapid expansion of medical, nursing, dietetic and therapist time and additional support workers (including third sector) over the next 12 months.

Recommendation 2: Implementation planning

An Implementation Group should be set up by Scottish Government. This short-term group will be responsible for the implementation of these service review recommendations, planning for and setting the strategic direction, vision and ethos for improvement and service delivery over the next 10 years. This group should report directly to Scottish Government.
Ownership: Scottish Government, Scottish Government's appointed chair of Implementation Group

In Summary: Once the recommendations are accepted by the Scottish Government, the Implementation Group should take forward the task of planning the implementation of the recommendations with all stakeholders. This should be informed by the data provided in the Appendices. The Implementation Group should provide clear plans and timelines for developing quality standards in eating disorders for Scotland, a skills and competency framework, finalise the costing of the changes recommended and agree a national eating disorder dataset and plan for consistent data collection across Scotland.

Recommendation 3: Coordination of national activity and data collection

A National Eating Disorder Network should be established and funded by Scottish Government. This permanent Network will take over from the work of the Implementation Group to support the implementation of the recommendations on an ongoing basis. It will also be responsible for the coordination of national functions including training, national level service development, setting quality standards, and coordinating research and innovation networks for eating disorders.

Ownership: Scottish Government, Implementation Group with stakeholders, all Health Boards

In Summary: Responsibilities will include implementation, data collection and analysis, and supporting training at undergraduate and postgraduate as well as specialist levels. In addition, the National Network would host a national website as a focal point to provide and share information and support online training and awareness.

Recommendation 4: Lived Experienced Panel

There should be a lived experience panel set up who will advise the Implementation Group and work alongside the National Eating Disorders Network. The lived experience panel should include patients, families and loved ones, and third sector representatives and there should be diversity in the panel, for example, including all eating disorder diagnoses, men with eating disorders, LGBT representatives and people from ethnic minorities. The panel will advise on all eating disorder national changes.

Ownership: Implementation Group then National Eating Disorders Network, Scottish Government

Recommendation 5: Public health

The Scottish Government should fund and support development of a comprehensive public health strategy for Scotland that makes eating disorders prevention everyone's business.

Ownership: Scottish Government, National Eating Disorders Network and Public Health Scotland

In Summary: A comprehensive public health strategy should include working with parents, schools, higher education institutions, sport and fitness organisations, the food industry, the fashion industry, healthy eating programmes, mental health organisations, and other relevant organisations to promote and support a positive body image culture in Scotland. A further aim would be to reduce influences that lead to poor body esteem and poor body image, poor attitudes to food or dieting, and promote development or perpetuation of eating disorders. Public Health Scotland and the National Eating Disorders Network should work together to ensure clear strategies and consistent messaging in relation to obesity, fitness and eating disorders across the health, education and other ministries within Scotland.

Recommendation 6: Self-help resources available to all

Scottish Government should provide funding to the Third Sector to build platforms and a range of community services to enable the Scottish public to have free access to evidence-based self-help/management programmes and supports, including peer support networks.
Ownership: Scottish Government, the National Eating Disorder Group, Public Health Scotland and the Third Sector

In Summary: This will include third sector provision of evidence-based self-help packages, peer support networks, emotional and practical support to families and carers.

Recommendation 7: Early Intervention

Key Stakeholders and Healthcare professionals should be able to identify the signs and symptoms of all eating disorders including at early stages and know how to support and sign post people into treatment.
Ownership: Implementation Group, National Eating Disorders Network, Key stakeholder organisations, healthcare professional organisations.

Recommendation 8: Primary care

Awareness, detection and early, effective treatment of eating disorders at primary care is important. There should be an ongoing training programme for all primary care clinicians to ensure consistent high standards are maintained in identification and management of patients who may have eating disorders, and their families. There should be increased support from specialist services when primary care is asked to assist with physical monitoring or support, for instance when patients live far away from specialist teams.
Ownership: Implementation Group, healthcare professional organisations, Eating Disorder Education and Training Scotland **(**EEATS) and NHS Education Scotland (NES)

In Summary: There should be collaboration between specialist services and primary care to develop training and care standards for eating disorders. Professionals in primary care should not be required to hold medical responsibility for significant or severe eating disorders. There may be a role for primary care to provide some aspects of care in conjunction with specialist teams where this is appropriate (for example, in rural areas) but primary care must be adequately supported to do this.

Recommendation 9: Safe medical care

Medical aspects of care should be prioritized, with clear lines of responsibility and leadership from suitably trained medical experts. We recommend named eating disorder medical leads for every health board/region with oversight over the medical care of every patient with an eating disorder, who report data to the National Eating Disorder Network. This can be done in collaboration with General Practitioners, Acute Medicine and Paediatrics according to the local context of who has appropriate training in managing the medical aspects of eating disorders.
Ownership: National Eating Disorder Network, All health boards

Recommendation 10: Investment in specialist eating disorder services.

The Scottish Government should commission and fund equitable provision of high-quality accessible specialist community-based services for eating disorders across Scotland for all ages, which see all types of eating disorders across the range of severity.

Ownership: Scottish Government, Implementation Group, National Eating Disorder Network, All health boards

In Summary: Self-referral to specialist eating disorder teams should be available to all. Teams should take an 'all age' approach to treatment. The National Eating Disorders Network should lead in developing nationally agreed standards and SIGN concordant eating disorder care. Where needed to enable equitable delivery of care, the creation of regional specialist teams utilising telehealth may be appropriate.

Recommendation 11: Workforce

A comprehensive workforce plan will be developed that aims to build the workforce to be able it to meet the service standards over the next 10 years. This plan should emphasise staff retention and training within eating disorders services as well as recruitment.

Ownership: Scottish Government, Implementation Group, National Eating Disorders Network, All health boards.

Recommendation 12: Education and Training

A comprehensive training plan will be developed which will aim to equip the entire healthcare workforce which might see people with eating disorders and their families, to deliver high quality care for people with eating disorders in all settings ranging from early intervention to highly specialist care, and from community to inpatient. In addition, there should be appropriate education and awareness training for other relevant professionals, such as youth workers, counsellors, and sports coaches. Training should be appropriate to the role that each professional has with respect to prevention, identification, signposting, treatment and support of people with eating disorders.

Ownership: Scottish Government, National Eating Disorder Network, Eating Disorder Education and Training Scotland (EEATS) and NHS Education Scotland (NES)

In Summary: The development of a skills and competency framework and training strategy is needed to ensure that there is appropriate training for all professionals to the level they need based on their role with respect to people with eating disorders. There should be a particular focus on early intervention, medical aspects of care, and support; and training should range from undergraduate healthcare training to specialist training.

Recommendation 13: Families and carers

Families and carers should be given a high level of support from the start of their loved ones eating disorder, and for as long as they need it. Experts by experience (both patients and families) should be involved in service design and implementation as well as quality improvement.

Ownership: Specialist eating disorder teams, the National Eating Disorder Network and the Third Sector

Recommendation 14: Inpatient eating disorder services

Inpatient eating disorder provision is currently variable and inequitable across Scotland particularly for adult men. Inequitable access to inpatient care has significant impact on community services. Where there are inequalities, Health Boards should work together to ensure there are equitable access to services. We recommend a further, smaller review specifically of national inpatient provision across all ages in 5 years' time, after community service improvements have been implemented.
Ownership: The Scottish Government, Implementation Group and National Eating Disorder Network, all Health Boards

Recommendation 15: Eating disorders Research in Scotland.

Scottish Government should consider funding eating disorders research through NHS Research Scotland. Specific calls for eating disorder research should be made to support research which would fill gaps in knowledge and understanding of eating disorders in the Scottish population, and their treatment in Scotland. Particular note should be taken of gaps in the research base that SIGN identifies.

Ownership: Scottish Government, NHS Research Scotland, National Eating disorders Network, Health boards and eating disorder clinicians.

In Summary: We recommended co-production of funded research that would directly improve the treatment and welfare of people with eating disorders and their families. Developing a strong research culture in Scotland would ultimately improve standards across all services.

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