



**Welsh Government
Eating Disorder Service
Review 2018**

NOVEMBER 2018

Executive Summary:

There have been recent advances in treatments, changes and expansions of diagnostic categories for eating disorders, and new NICE guidelines and quality standards (2017) which all require a more inclusive service for treatment of all people with eating disorders, regardless of age and severity.

The implementation of the 2009 Welsh Framework for Eating Disorders represented a significant investment with major reconfiguration of services to develop specialist eating disorder teams across Wales for adults with eating disorders. The 2009 Framework and its associated funding has led to the development of a small but dedicated group of eating disorder clinicians; however, resources have been severely limited from the start and change in the service structure is now needed. Nearly ten years on, we are a much more mobile and digitally connected society. There have been expansion and changes in the diagnostic categories. There is increasing specialisation of both adult and CAMHS eating disorder services, and an increasing range of evidence-based treatments. There now needs to be another major reconfiguration to move to align the service with the new emphasis on working seamlessly across agencies across Wales in the interests of promoting wellbeing and emphasising timely and effective early intervention. This is also to align with recommendations and directives in the NICE guidelines for eating disorders (2017), the Wellbeing of Future Generations (Wales) Act 2015 as well as multiple documents emanating from the Welsh Government in related arenas.

There is a compelling case for change in the Welsh NHS eating disorder service. This Service Review report presents findings regarding the current NHS eating disorder service, the state of the art, and most importantly the voice of the people who suffer from eating disorders and their families. Eating disorders have exacted too high a price in terms of suffering, debility and even loss of life in Wales. We have developed considerable expertise in the treatment of eating disorders since 2009 in Wales, particularly in Tier 3 adult services and some more specialist CAMHS teams. It is now important that the Welsh eating disorder services move from 'back foot' delivery of healthcare to ill patients, to 'front foot' pro-active investment in prevention and assertive early intervention with identification and prompt treatment of people with eating disorders before they get severely ill. We now also need increased expertise and increased equity of access balanced by closer integration of healthcare with other agencies to support the health and wellbeing of people with eating disorders and their families.

These are the principles that have been clearly articulated by the public, which will underpin all recommendations:

Underlying Principles

1. **Early Detection and Intervention:** Helping people like teachers and parents to identify people who might have an eating disorder and providing support to access help.
2. **Inclusivity:** Never turning people away – anyone in distress who thinks they or a loved one might have an eating disorder deserves a response. An eating disorder specialist service isn't always the right source of help but we will always try to help people get help and support.
3. **Person-Centred:** Prompt expert help for those who have eating disorders, giving people what they need and trying as far as possible to deliver it to them where they are and to co-work with services around them to ensure person-centred, holistic care for the person and whole family. Shared decision making with all decisions made together with patients and families taking into account their views, values and preferences.

4. **Relationship-Based:** Seamless care with strong trusting relationships with named clinicians rather than patients and families being expected to make transitions between different levels and types of treatment and care.
5. **Recovery-Focused:** Helping those with severe eating disorders to recover and return to living their normal lives in close partnership with Third Sector agencies, with emphasis on living in the community and maintaining independence with appropriate support.
6. **Trauma-Informed:** Eating disorders often arise as a coping mechanism, and in common with other mental disorders there may be underlying trauma, especially in childhood. The approach will go beyond trying to fix a disorder to helping people address and resolve past hurts or underlying issues as appropriate, in order to support and free people to lead happy, healthy and productive lives. The recent Adverse Childhood Experiences (ACE) study in Wales produced compelling evidence that childhood adverse experiences is an underlying mental health issue which must be addressed both in prevention and in treatment of young people and adults who have developed mental health problems (See section on Early Intervention and Prevention).

Recommendations:

Eating disorder services in Wales are significantly under-resourced. The public and clinicians are very aware of this, and very often it is only the severe cases that can receive appropriate eating disorder services.

1. **Even taking into account the work taking place and generic services, the current Welsh eating disorder services are severely under-resourced with respect to recommendations for services. There is a strong case for significant investment to eating disorder services in Wales.**
2. **We recommend a major reorganisation of, and investment in, the eating disorder services across Wales to align it with a clear set of principles. Any recommended eating disorder service model must take a whole nation, whole system approach in order to deliver equitable, accessible and world class eating disorder service to all people in Wales who need it. It must be pro-active in co-working with other agencies to promote the welfare of both people who have eating disorders but also to help prevent eating disorders by working in partnership with other agencies to build resilience, and by collaborating with other agencies to support those with disordered eating.**

There are currently no recommendations for staffing levels for the eating disorder services in Wales. Therefore, health boards can choose to allocate funding as they please, which can produce an unfair distribution of funds to match the need for certain services, particularly for eating disorders.

3. **The Health Boards should be held to their previous agreements to match fund Welsh Government contributions to specialist eating disorder services.**

The level of education and knowledge of eating disorders in primary care is reported to be very limited. For general practitioners, who are an essential part of assessing and treating eating disorder patients are in desperate need for more support and training.

4. **Detection and early, effective care of eating disorders at primary care are important. There should be general practitioners or primary care specialist practitioners funded to work in**

the national eating disorder service with a particular remit to help to build relationships between eating disorder services and general practice. These general practitioners will contribute to the medical assessment, monitoring and treatment of people with eating disorders, as well as contributing to eating disorder policy and improve training, support and access for general practitioners and other primary care practitioners who have concerns about their patients.

- 5. We recommend discussions between the eating disorder service and the Royal College of General Practitioners in Wales to find a mutual way forward to improve the recognition, assessment and treatment of eating disorders in primary care.**

It is reported by the public that trying to access eating disorder services in Wales is very difficult. For example, certain services that act as ‘gatekeepers’ to specialist services, can be a barrier to care when they are unable to refer, or do not know how or where to refer to.

- 6. There should be a single point of access for all referrals to reduce the barriers to seeking help. The eating disorder service should accept referrals from all sources, including self-referral, without removing the involvement of general practitioners.**

There is a large amount of literature supporting the many benefits of early intervention for eating disorders (see section 7). This is also supported by the public and their stories about their personal experiences, who argue that an early intervention approach would have made all the difference in their eating disorder treatment and recovery.

- 7. The SPEED early intervention model should be implemented and offered across Wales for all young people with eating disorders. There should be a corresponding early intervention model for adults, such as FREED; or in line with the extension of family-based treatments to young adults, SPEED could also be trialled with young adults.**

The prevention of eating disorders in schools and universities is considered a key step to improving the services in Wales. However, it needs to be a broad integrated approach.

- 8. Welsh eating disorder services should work with Welsh Government and other agencies to develop and deliver the Whole School Approach with the aim of preventing eating disorders through promotion of emotional resilience and dealing with precursors of eating disorder such as body image issues.**

There are current waiting list targets for CAMHS but not for adult services in Wales. In England, there are new waiting list targets for eating disorder CAMHS services which are recommended by NICE guidelines but no uniform targets for adult services. These inequalities should be rectified, particularly because there is great urgency in assessing and treating people with eating disorders, in the small window of opportunity before they become severely ill or the grip of the disorders strengthens and they lose motivation to seek help.

- 9. The Welsh Government generic targets should be kept and exceeded for all people with eating disorders, with specific additional standards in line with the NICE Quality Statement and NHS England Access and Waiting Time Standard for Children and Young People with an**

Eating Disorder. This waiting time of 1 week from referral to treatment for urgent cases and 4 weeks from referral to treatment should be applied to all ages and types of eating disorders to achieve parity of access.

From the public perspective, specialist expertise is considered absolutely essential for working with eating disorders, in that all staff working in an eating disorder service should be appropriately trained and supported.

- 10. The new NICE guidelines require that the eating disorder service staff are fully trained and able to identify and assess eating disorders as well as to deliver a range of NICE-concordant therapies to children, young people and adults. In addition, eating disorder clinical staff should be trained in treating common co-morbid mental health problems. Ensuring clinical staff are fully trained in these and other therapies should be a priority for the eating disorder service, and a recurring training budget is required to ensure that ongoing training programme is supported to develop and maintain the skills of all staff working in the eating disorder service.**

Eating disorders are both a physical and a mental health disorder. The current interface between medical and mental health services has produced gaps and misunderstandings, such as the medical responsibility of the patient and professional roles within the service.

- 11. There should be prioritisation of the medical needs of people with eating disorders. There should be specific funding for consultant eating disorder psychiatrists, paediatricians, physicians and general practitioners to be integral members of eating disorder teams and support the safe medical care of people with eating disorders.**

The public feel that all eating disorders should be recognised and prioritised in the same way, without any fixed criteria determined by weight or BMI measurements.

- 12. The Welsh eating disorder service should expand its remit in line with NICE guidelines to include the treatment of binge eating disorders. The Welsh Government's Obesity Strategy should take into account how people with comorbid binge eating disorder and obesity should be detected and helped to receive treatment. The eating disorder service should work together with weight management services in each Health Board to develop relationships and pathways to detect and treat people with binge eating disorder.**

There is an abundance of literature supporting the use of telehealth for mental health, child psychiatry and eating disorders (see section 9).

- 13. The eating disorder service should be one of the early adopters on a national basis of extensive and integrated use of telehealth for communication and for delivery of treatment which complements and augments traditional face to face approaches. There should be prioritisation of investment of effort to ensure the infrastructure is in place for telehealth to operate well (for instance, the Welsh Government ensuring delivery of their undertaking for high quality internet access to be available across all areas of Wales, and NHS clinical bases and hospitals should have WIFI).**

The NHS are not the only profession who can provide specialist care and support for eating disorders. There are many other sectors and services available who can help provide an excellent service alongside the NHS.

- 14. The Third Sector should be invited to be more actively involved across Wales in supporting patients and families seen in NHS services and should be commissioned to provide and deliver advocacy and specific support (for example, through provision of intensively supported housing and support workers integrated into NHS teams) to patients and families.**

There is growing evidence of the greatly raised risks of dual disorders, such as type 1 diabetes and an eating disorder or autism and an eating disorder, and now services such as paediatric diabetes are beginning to recognise that an integrated approach between these services is needed.

- 15. The Welsh eating disorder and diabetes teams for both children and young people and for adults must develop national protocols to co-work with each other for patients who have both eating disorders and diabetes. There should be national leads in both eating disorders and diabetes services who can cooperate to develop training and awareness amongst staff in both systems, and to work particularly to identify and manage patients with diabetes who have disordered eating or early signs of eating disorders. Given the major diabetes-specific challenges and high medical risks involved in managing patients who have diabetes and eating disorders we recommend a national multidisciplinary subspecialist team within the national eating disorder service which has dual expertise in diabetes and eating disorders.**

- 16. The Welsh Government should ensure that NICE guidelines for diabetes should be adhered to and that diabetes teams should have psychology input for their patients, who are skilled in identifying and managing disordered eating.**

- 17. The Welsh eating disorder and neurodevelopmental teams for both children and young people and adults should develop national protocols to co-work with each other for patients who have both eating disorders and autism and their families. There should be national leads in both eating disorders and autism/neurodevelopmental services who can cooperate to develop training and awareness amongst staff in both systems, and to work particularly to identify and manage patients with autism who have disordered eating or early signs of eating disorders. Given the rapidly evolving evidence for autism and eating disorders and the highly specialised diagnosis of autism, we recommend a national multidisciplinary subspecialist team within the national eating disorder service which has dual expertise in autism and eating disorders.**

The role of the families in the current eating disorder service is under-utilised. With better support and funding, families can be an integral part of the eating disorder service.

- 18. The needs and perspectives of families of both children and young people and adults with eating disorders should be considered in the eating disorder service for Wales. Family members should be consulted and involved in treatment, and their perspective should be considered in service delivery, quality improvement, policy, and research. We recommend two Lay Representative leads for Wales, who can lead on patient and family perspectives**

respectively. There should be funding for a trained ‘carer consultant’ for each regional centre to work alongside families to coach them.

- 19. Addressing equality and diversity issues and ensuring parity of esteem is crucial. There should be a national lay representative lead who will take a central role in ensuring advocacy for any potentially disadvantaged groups of people or individuals, along with partner Third Sector charities such as Beat, FEAST, Men Get Eating Disorders Too (MGEDT) and Gofal. There should be national leads and teams for males and for Welsh speakers, so that these people can receive treatment in an environment they prefer which is conducive to engagement with treatment, formation of strong therapeutic relationships and promoting recovery.**

The current eating disorder service is very divided and split up with variability of services across Wales and patchy provision of different treatments. The public felt that this results in a very diluted service of expertise and care.

- 20. For patients of all ages, it is crucial that eating disorder clinicians develop and maintain strong links and working relationships with other specialist and local generic services, so as to collaborate to meet the complex needs that arise from comorbid mental health issues. Eating disorder clinicians should have appropriate training to develop skills to manage most common co-morbid mental health issues that arise in the patient group with eating disorders. It is also important that they develop and maintain strong working relationships with both national and local statutory and Third Sector agencies who are crucial in supporting all patients with eating disorders and their families. The presence of comorbidities increases the complexity and need for support in order to address all needs and achieve recovery.**

The public fear that ‘no matter how slick the design of an eating disorder service is’, if it is watered down, it just won’t work. Every service needs to evolve and change to continually improve itself and stay responsive to need.

- 21. There should be a national eating disorder quality improvement lead, overseeing a national system of data collection, with an associated national eating disorder research lead who can research issues that arise. There should be adequate provision of administrative and analyst support to measure and monitor outcomes and service performance, as well as to support audit. There should also be national eating disorder lay representative leads to work with the quality improvement and research leads to develop the arenas of outcome measurements of shared decision-making, patient satisfaction and goals.**
- 22. We recommend a further, smaller, service review after the new service has fully established and stable indications of the inpatient demand levels has been achieved, at 5 years (according to when inpatient demand stabilises). This review will revisit and reconsider the need for an adult inpatient unit in Wales, once the impact of the Whole School Approach, better relationships with primary care and other agencies, early intervention and outreach have been achieved.**