The Welsh Eating Disorder Service Review: 3 years on

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Executive summary

The purpose of this report is to assess the progress that has been made in the last three years towards achieving the vision set out by the Welsh Eating Disorder Service Review 2018; and to make recommendations for the Welsh Government and the NHS in Wales.

The findings of this report are based on an online survey of health and care professionals and volunteers, and Freedom of Information (FOI) requests.

The Welsh Eating Disorder Service Review 2018

In spring 2018 the Welsh Government commissioned an independent review of eating disorder services. That review, submitted to the Government in late 2018, found a system geared towards providing care for those that have already become severely ill, rather than early intervention. It found significant variation in the availability and quality of eating disorder treatment across Wales, gaps between services rather than integrated care, and that often families were not being informed, supported and empowered. The review set out an ambitious vision of a 'world class' service focused on prevention and early intervention – identifying and providing quality treatment before people become severely ill, in every part of Wales.

Progress made toward the vision set out by the Welsh Eating Disorder Service Review 2018

While some progress has been made in expanding and improving eating disorder services in the last three years this has been very uneven, continuing the inequity documented by the eating disorder service review.

Access to treatment

The service review called for treatment to be accessible at an early stage, with the removal of referral or eligibility criteria.

In some areas, new specialist teams based in Child and Adolescent Mental Health Services (CAMHS) have been established. Some health boards have developed or expanded tier 2 adult community eating disorder services - designed to broaden access to specialist treatment. However, in some areas access to specialist treatment is still restricted to those who have already become severely ill and is not available for those with certain types of eating disorder such as binge-eating disorder (BED) or Avoidant Restrictive Food Intake Disorder (ARFID). There are major differences between health boards in the size of their eating disorder caseloads (the number of patients treated).

Waiting times

The service review highlighted the importance of minimising delays between referral and the start of eating disorder treatment.

There were significant gaps in the data that health boards were able to provide on waiting times. There does not appear to be a standardised system in place across Wales to

consistently measure and report the full waiting time from initial referral to the start of specialist treatment. Several clinicians that responded to our survey told us that waiting times at their team/service have increased significantly since the start of the COVID-19 pandemic, as demand for treatment has risen. They expressed concerns about people deteriorating as they wait for treatment, and the impacts on families and other carers.

Integrated care

The service review explained that early intervention and evidence-based treatment require an integrated approach, with good communication and collaboration between services. In particular it focused on the need for strong working relationships between eating disorder services and primary care, weight management services, diabetes services, autism/neurodevelopmental services, other mental health services and the voluntary and community sector.

Some of the clinicians that responded to our survey said that there was good communication and collaboration between health and care services in their area, although slightly more reported that this was not the case. The National Clinical Lead for Eating Disorders has led important work to develop communication and collaboration between eating disorder teams/services and other health services in Wales. The response to our survey questions on this subject show the need to build on these efforts, so that patients with eating disorders in every part of Wales can experience integrated care.

Supporting and empowering families and other carers

The vision set out by the service review recognised that families and other carers can play a vital role in recovery if they are properly informed, supported, and empowered, and that families and carers should be consulted and involved in treatment. Our survey asked health and care professionals and volunteers about support for families and carers in their area. There was a mix of answers, with a bigger share reporting insufficient information and support.

The service review also said that the perspectives of families and other carers should be accounted for in the design of services, research and policy. While the National Clinical Lead for Eating Disorders has consulted significantly with families and other carers on the design of services, there is not yet a formal process in place to ensure that they are fully involved in the development of all eating disorder services in Wales.

Factors that have impacted progress

Delayed response from the Welsh Government to the review report

Although the eating disorder service review was submitted to the Welsh Government in late 2018, there was no formal response to this report until September 2019. In its response the Government pledged to recruit a ‘central resource’ to support health boards to plan improvements to services. It took 15 months before the National Clinical Lead for Eating Disorders was recruited and able to start work. Since the national lead started work in January 2021, she has demonstrated the value that this role can provide.

Although the Welsh Government's terms of reference for the eating disorder service review stated an intention to publish a "*new framework*" in Spring 2019, this has not happened.

Limited and variable investment

There has been some additional investment in eating disorder services since 2018/19. However, eating disorder services received just 7% of the total 'Service Improvement Funding' allocated to health boards in 2020/21, and their spend on specialist tier 3 adult community eating disorder services increased by just 1% in real terms from 2018/19 to 2020/21. Health boards have been given a high degree of autonomy over how much they choose to invest in eating disorder services, and investment has varied widely between them.

Insufficient staff and poor staff wellbeing

Although there has been an increase in the number of staff working in CAMHS eating disorder teams/services, most of this took place at one health board. In some areas new staff have been recruited to provide treatment for adults with less severe presentations. The service review highlighted particularly concerning shortages of staff from certain disciplines. The number of psychiatrists, paediatricians and other medical staff working in eating disorder services is still very small and may be lower than at the time of the service review. There has been a small increase in the number of dieticians and occupational therapists used specifically for the treatment of eating disorders. Some health boards reported that they have sought to recruit additional staff but have found it difficult to attract eligible applicants.

Responses to our survey show that many health and care professionals and volunteers are very concerned about staff wellbeing and burnout, driven by services being ill-equipped to keep up with demand.

The impact of the COVID-19 pandemic

The COVID-19 pandemic has led to a significant increase in demand on eating disorder services, with increased referrals and levels of acuity. This is continuing and makes achieving significant and equitable progress toward the vision set out by the eating disorder service review even more urgent.

Recommendations

In order to support further progress in improving eating disorder services and doing so in a more equitable way across all of Wales, we recommend that:

- **The Welsh Government should publish a new framework or model for eating disorder services that contains timelines for the achievement of each milestone. This should focus on:**
    - **Early intervention and prevention**
    - **Integrated care**
    - **Support for families and other carers**

    - **Investment in the workforce, including support for staff wellbeing**

- **The Welsh Government should set a minimum spend on eating disorders from the Service improvement funding that it allocates to health boards and it should hold health boards to account over their investment in eating disorders.**

- **The Welsh Government should make the position of 'National Clinical Lead for Eating Disorders' a permanent post.**

- **The Welsh Government and NHS Wales should ensure that people with lived experience of eating disorders, including families and other carers are formally incorporated into the monitoring, development and evaluation of eating disorder services in Wales, both at the national and local levels.**

- **The Welsh Government should fund an eating disorders clinical audit, as part of efforts to ensure that all health boards collect and report a standard and comprehensive set of high quality data.**

Introduction

Eating disorders are serious mental illnesses[1]. At least 60,000 people in Wales have an eating disorder[2]. Types of eating disorders include binge eating disorder, bulimia, anorexia, other specified feeding or eating disorder (OSFED) and avoidant/restrictive food intake disorder (ARFID). They can affect people of any age, gender, ethnicity or background[3-7].

Anorexia has the highest mortality rate of any mental illness, and the mortality rates of the other eating disorders are also high[8;9]. People with eating disorders often develop severe physical health problems and overall quality of life has been estimated to be as low as in symptomatic coronary heart disease or severe depression; many become unable to participate in education or employment[1].

However, recovery is possible. Access to the right treatment and support is life-changing, and early intervention provides the best chance for recovery[10]. Delays prolong the suffering of the individual and those who care for them, as well as significantly increasing the costs to the NHS, as hospital admission becomes more likely[11]. When properly supported and empowered, families and other carers can play an important role in recovery[12].

The Welsh Eating Disorder Service Review 2018

In late 2018 an independent review of eating disorder services in Wales[13], commissioned by the Welsh Government, set out an ambitious vision to create a 'world class' service focused on prevention and early intervention – identifying and treating people before they become severely ill, wherever they live in Wales. It explained that significant extra resources would need to be invested to enable such a transformation.

> "*Eating disorders have exacted too high a price in terms of suffering, debility and even loss of life in Wales*" (Welsh eating disorder service review, 2018, p.5)[13]

This report assesses progress made toward the vision set out by the Welsh eating disorder service review 2018.

The service review found a system geared towards providing care for people that have already become severely ill, rather than prevention and early intervention. It described major variation in the availability and quality of treatment, gaps at the interfaces between services rather than integrated care, and families often not properly informed, supported and empowered[13].

The review team carried out significant engagement with people that have personal experience of an eating disorder, including families and other carers. They reported a set of underlying principles that people with lived experience in Wales want services to adhere to. These are reproduced in figure 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.

- **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.

- **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.

- **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.

- **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.

- **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.

Figure 1. Underlying principles articulated by people with lived experience of eating disorders to the Welsh eating disorder service review team (see pages 5-6 of the review report[13]).

Based on these principles the review[13] made a series of recommendations and put forward an ambitious vision for Wales to become world-leading in its response to eating disorders. This vision was based around a shift towards prevention and early intervention and ensuring equitable access to evidence-based treatment and support across the whole of Wales. These themes align with the ambitions of 'A Healthier Wales'[14] (the Welsh Government's plan for health and social care), and the Wellbeing of Future Generations (Wales) Act 2015[15].

Responding to the review report in 2019, the then Minister for Health and Social Services, Vaughan Gething MS said in a written statement that:

> "*I want to ensure that patients who need treatment are able to access that treatment at the appropriate time, and that thresholds for treatment do not push services into missing the opportunity to intervene at an early stage.*"[16]

And in a letter to NHS Wales health board Chief Executives on the subject of the review he stated that:

> *"Given the significant and valuable input from those with lived experience of eating disorders I am committed to ensuring that the independent review is able to shape future eating disorder services in Wales."*[17]

The research conducted for this report

Beat carried out an anonymous online survey of health and care professionals and volunteers and submitted Freedom of Information (FOI) requests to all seven NHS Wales health boards, Digital Health and Care Wales (DHCW), and the Welsh Health Specialised Services Committee (WHSSC) (see Appendix).

Both the survey and the FOI requests asked questions about the demand for eating disorder treatment in Wales over the last three years, and the capacity of services to meet this demand. Data and information was also collected on investment in eating disorder services in the last three years, and the improvements and plans that health boards have made in response to the service review.

Progress made toward the vision set out by the Welsh Eating Disorder Service Review 2018

Access to treatment

The Welsh eating disorder service review[13] found that certain services designed to act as 'gatekeepers' to specialist treatment can be a barrier to care, and that despite the importance of early intervention, "*very often it is only the severe cases that can receive appropriate eating disorder services.*" (p.6). It raised particular concerns about access to treatment for people with Avoidant Restrictive Food Intake Disorder (ARFID) or binge-eating disorder (BED). It recommended significant investment in eating disorder services that would enable referrals to be accepted from all sources (including self-referral), and treatment to be accessible for all patients, whatever the severity of their illness, or their diagnosis.

Responses to our survey of health and care professionals and volunteers illustrated how generally the mental health system in Wales is not designed and resourced to facilitate early access to evidence-based treatment for people with eating disorders, echoing the main finding of the eating disorder service review[13]. Some of these responses are shown below:

> "*There is little facility for treating eating disorders at an early stage; patients are deemed not 'unwell enough' or their weight isn't 'low enough' for specialist input. If we treat hypertension to prevent a stroke, we should treat someone in distress before they are grossly undernourished.*" (Primary care clinician: #9)
>
> "*Non specialist services tend to rely exclusively on BMI in assessment of severity. I have seen significant damage done to ED* [eating disorder] *sufferers by the lack of understanding and evidence-based treatment, particularly encouraging a weight loss diet or food restriction, and emphasising BMI as a gateway to treatment.*" (Voluntary and community sector/third sector staff or volunteer: #5)
>
> "*Lots of hoops to jump through to access tertiary eating disorder team*" (Adult community mental health service clinician: #8).

Responses from health boards to our Freedom of Information (FOI) request indicated that in some areas, there are referral/eligibility criteria in place that can restrict access to specialist eating disorder treatment to those that are already severely ill. For example one health board said that access to specialist treatment for adults was only available to those who present with either a Body Mass Index (BMI) lower than a specific threshold; rapid weight loss; high levels of bingeing and purging behaviours; pregnancy; or certain comorbidities. At another health board adult patients with a BMI above a specific number could only access eating disorder treatment at secondary care level if they had an 'unstable' presentation (e.g., rapid weight loss or presence of blood abnormalities).

The FOI data also shows that there are major differences between health boards in the number of people receiving eating disorder treatment (the size of their eating disorder

caseloads). This suggests[i] that it is much easier to access specialist eating disorder treatment in some health boards than others.

Only two health boards were able to report the number of children and adolescents (under 18s) on their Child and Adolescent Mental Health Services (CAMHS) eating disorder caseload at the dates requested. Figure 2 shows that on 31 March 2021 there was a five-fold difference between the size of the CAMHS eating disorder caseloads at these two health boards, after taking into account differences in the size of the populations they serve[18].

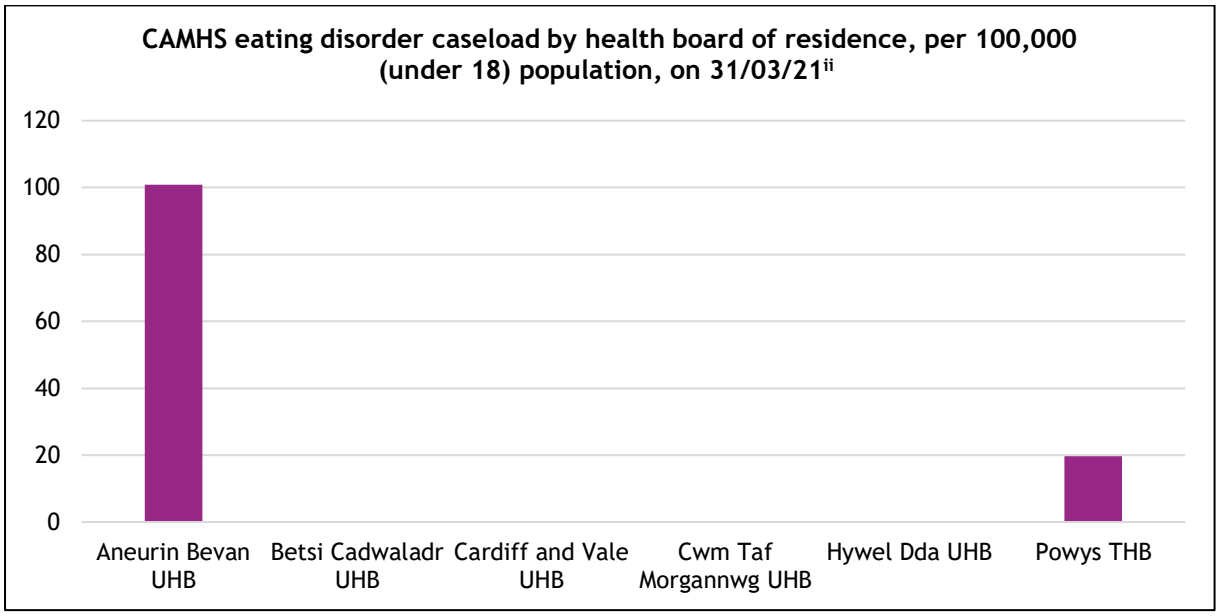

Figure 2. Note UHB = University Health Board; THB = Teaching Health Board.

For adults, almost no data was available on the size of eating disorder caseloads at primary-care (tier 1) or general secondary care mental health services (tier 2)[iii]. Four health boards provided data on the size of eating disorder caseloads at their tier 3 adult community eating disorder services on 31 March 2021 (see figure 3). On 31 March 2021 there was more than a three-fold difference between the size of these caseloads, after taking into account differences in the size of the populations they serve[18].

[i] Although it should be noted that other data would provide further important context including on the frequency of appointments, and the nature and duration of the treatment provided.
[ii] Note: Cwm Taf Morgannwg University Health Board (UHB) provides CAMHS services to Swansea Bay UHB. Those health boards with a value of zero were not able to provide the data requested.
[iii] Adult mental health care for people with eating disorders in Wales is generally arranged through separate tiers as recommended by the Eating Disorder Framework for Wales 2009[19]. Through this framework tier 1 services provide primary-care based mental health support; tier 2 denotes more specialist treatment generally provided by staff based in Community Mental Health Teams (CMHTs); tier 3 denotes specialist adult community eating disorder services; and tier 4 refers to inpatient mental health units.

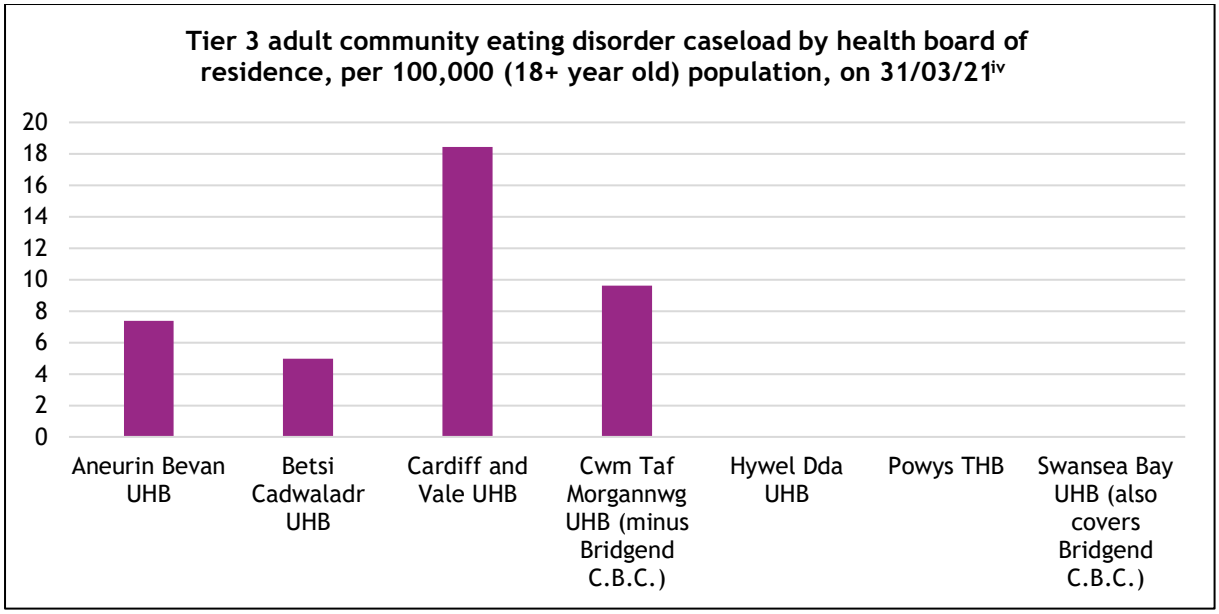

Figure 3. C.B.C. = County Borough Council.

There has recently been some important progress in creating and expanding services to facilitate early intervention. Some health boards have established or are in the process of developing new eating disorder teams within their CAMHS or tier 2 adult mental health services, enabling access to assessment and treatment at an earlier stage. Powys Teaching Health Board (THB) is planning to develop an all-age community eating disorder service. At least one CAMHS service has broadened its referral/eligibility criteria to enable earlier access to eating disorder treatment. This was reported by some clinicians that responded to our survey, including the comment below:

> "*We originally assessed and treated moderate to severe ED* [eating disorder] *but now we are assessing any level of ED* [eating disorder] *concern*" (Community CAMHS clinician: #14).

Responses to our FOI request suggested that there is still limited provision of specific treatment for Avoidant Restrictive Food Intake Disorder (ARFID). Some positive initiatives were reported, with services undertaking relevant training, and one health board having recruited two additional staff to provide treatment for ARFID within their CAMHS eating disorder service, after a successful funding bid. The National Clinical Lead for Eating Disorders organised a free virtual conference in October 2021 to highlight best practice in the identification and treatment of ARFID, and to raise awareness of the need to fill gaps in current service provision.

A separate Beat FOI request[20], submitted in Autumn 2020, found that only three health boards provided specific treatment for binge-eating disorder for under 18s, and that just five of the seven health boards provided binge-eating disorder treatment for adults. Only three health boards reported that their weight management service/s screened for binge-eating disorder.

[iv] Note: Hywel Dda UHB and Swansea Bay UHB were unable to disaggregate caseloads between tier 2 and tier 3 adult community eating disorder services. This figure could not be calculated for Powys THB.

Although overall access to treatment appears to have improved, progress in this area has varied widely between areas. This perpetuates the inequity in service provision across Wales highlighted by the service review[13].

> "*It's still a postcode lottery as to what is available and what criteria you have to meet*" (Voluntary and Community Sector/Third sector staff or volunteer: #3)

Waiting times

The eating disorder service review identified long waiting times to access specialist eating disorder treatment as a key concern and recommended the introduction of waiting time targets in line with those currently in place for children and young people in England[13]. These targets would set an expectation that patients in Wales – of all ages - should wait no longer than one week from referral to start of eating disorder treatment in urgent cases, and no longer than four weeks in all other cases.

Our FOI requested data from health boards on the median (average) waiting times from referral to the start of treatment at CAMHS and at each 'tier' of adult community mental health/eating disorder service. Due to shortcomings in data collection, waiting times data could only be provided for a minority of the relevant mental health and eating disorder services in Wales. (This is despite the then Minister for Health and Social Services, Vaughan Gething MS, having asked health boards to conduct a baseline review of waiting times for eating disorder treatment in 2019, to inform their response to the review report[16]).

Only two health boards were able to provide data on waiting times for children and adolescents (under 18s), but the very short nature of these reported median waiting times (one week in one case and around three weeks in the other) suggest that the data provided may actually refer to the wait between referral and the date of assessment (for which there is already an NHS Wales target in place across CAMHS for all conditions[21]).

Most health boards reported either that there was "*no waiting list*" or waits of between one and four weeks to access their adult community eating disorder team/s or service/s. However, in some cases the wording used suggested that in calculating this they may also have been defining waiting times solely in terms of the gap between referral and assessment. For example:

> "*as a tier 3 service we do not typically have a waiting list all individuals who meet our referral criteria are offered an assessment within a week*"

To the best of our knowledge there is no standardised system in place in Wales to collect and report the full length of waiting times from the point that an adult is first referred, to the date that they start treatment at a specialist eating disorder team/service. The number of steps and delays that can occur following an initial referral are illustrated in the quote below:

> "*referral to ED* [eating disorder] *specific teams is via the CMHT* [Community Mental Health Team]- *a secondary mental health team. This means the client is referred to primary care via a GP, they are assessed and then placed on a waiting*

list in primary care. This list may be 3-4 months long. The client is seen by ourselves, and if not appropriate referred to CMHT, where they are assessed again and referred to the ED [eating disorder] *team where they are inevitably assessed again. Although the therapy is available, the pathway to it is often difficult.*" (Primary care-based adult mental health clinician: #3).

Many respondents to our survey highlighted that waiting times have increased since the start of the COVID-19 pandemic as shown in figures 4 and 5, and in the quotes that follow.

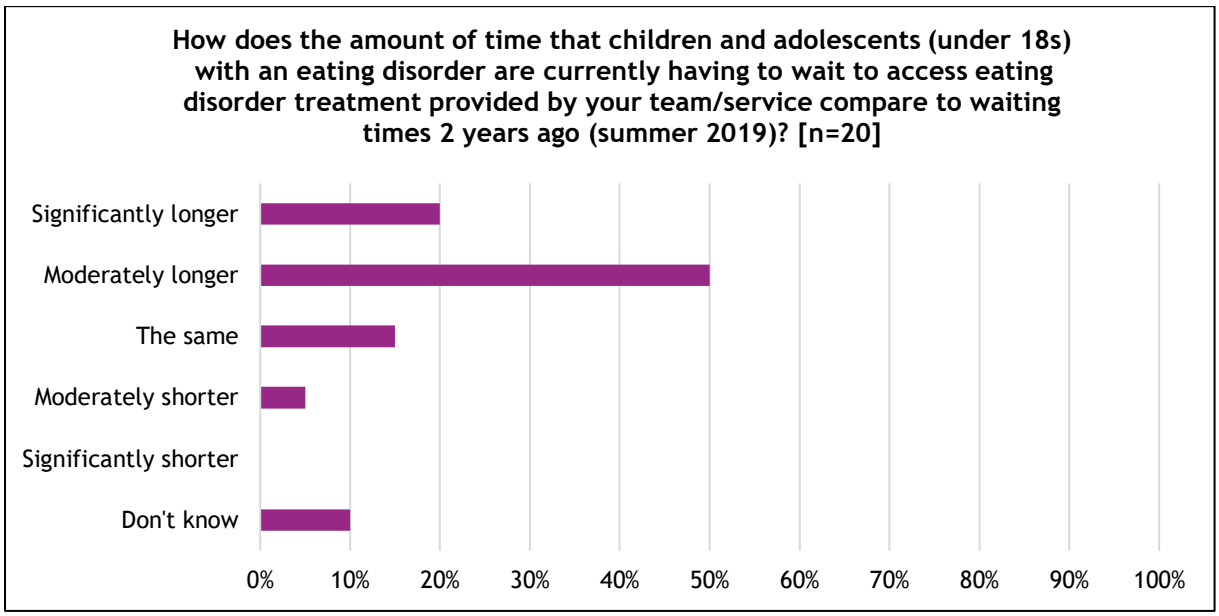

Figure 4. Responses received from health and care staff and volunteers to survey question. Number of responses = 20.

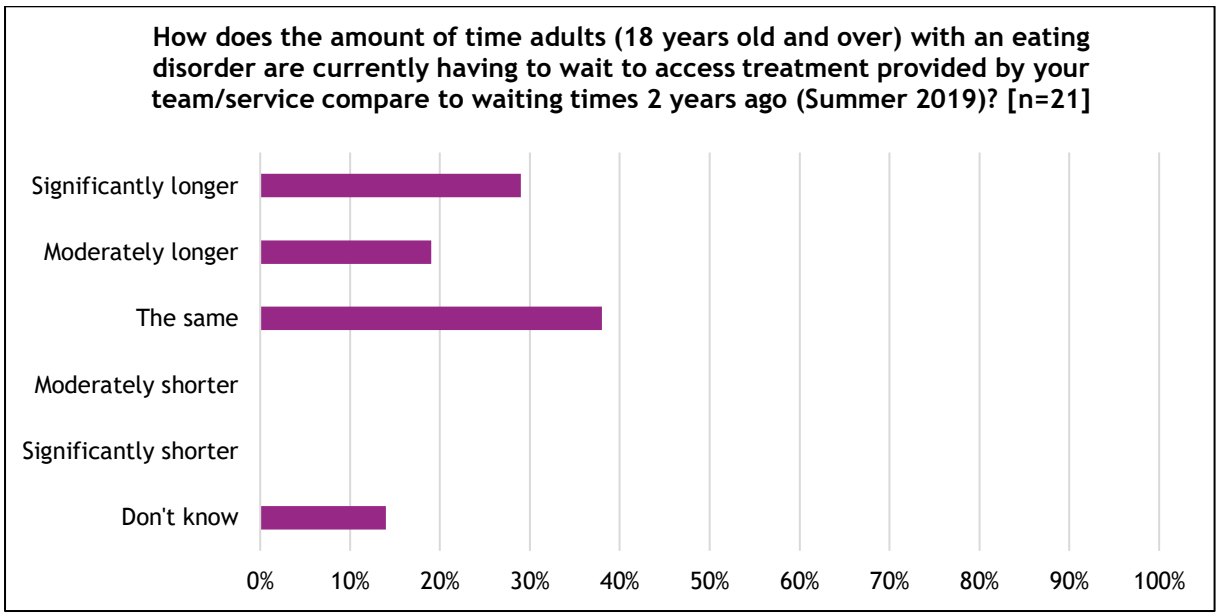

Figure 5. Responses received from health and care staff and volunteers to survey question. Number of responses = 21.

"*All research points to early intervention for positive outcomes for young people with an eating disorder. Which currently makes working within a CAMHS eating disorder service, extremely worrying – given the huge waiting times for families to access an assessment and ongoing work.*" (Community CAMHS clinician: #6)

> *"Assessments: 3 month wait from date of referral. Treatment: 3-6 months from assessment (previously we did not have a waiting list)"* (Adult community eating Disorder service clinician: #4)
>
> *"As our service is a high risk community team we do not have a waiting time for assessments however we are starting to need a waiting list for certain interventions/treatments (trauma therapy, psychological therapy, dietetics etc.)…lower tier services have high waiting lists and are unable to provide early interventions for individuals with eating disorders."* (Adult community eating disorder service clinician: #6).

Significant gaps persist in the collection of data on waiting times to access eating disorder treatment. Responses to our survey from clinicians across Wales suggest that overall, there is now even greater cause for concern around the length of waiting times to start eating disorder treatment than there was at the time of the service review[13].

Integrated care

The eating disorder service review explained that early intervention and evidence-based treatment require an integrated approach, with good communication and collaboration between services[13]. In particular it focused on improving integration between eating disorder services and primary care, weight management services, diabetes services, autism/neurodevelopmental services, other mental health services and the voluntary and community sector.

In our survey of health and care professionals and volunteers, 'Lack of integrated/collaborative working with other health or social care services' and 'Lack of integrated/collaborative working with schools/colleges/Universities' were commonly identified as restricting the ability of their teams/services to meet the current demand for eating disorder treatment (see figures 6 and 7).

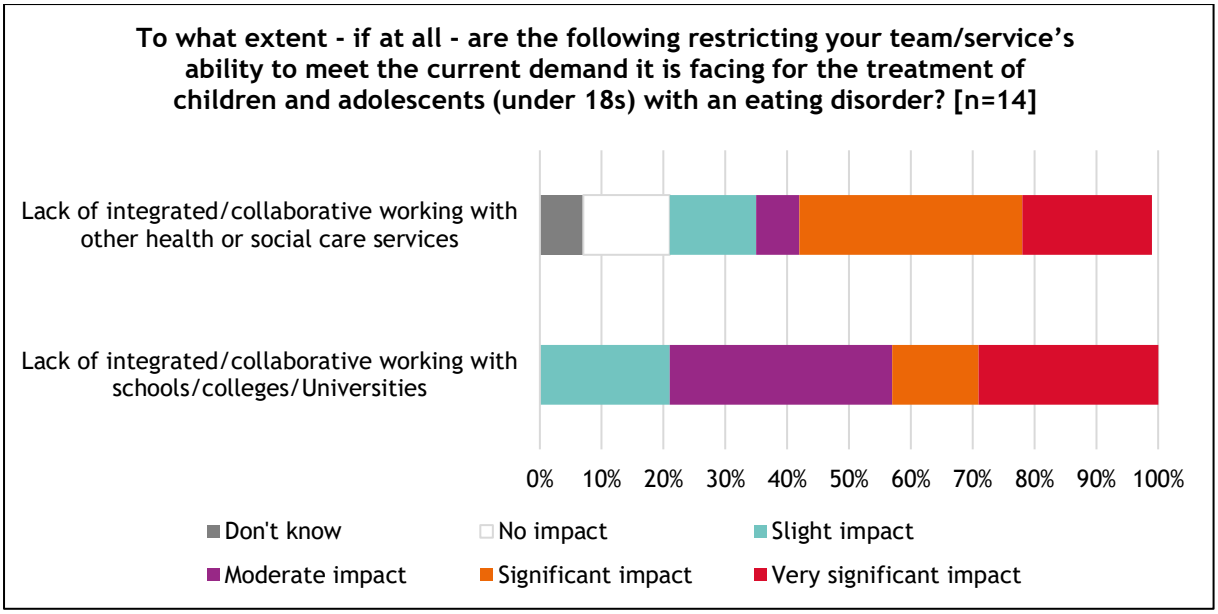

Figure 6. Responses received from health and care staff and volunteers to survey question. Number of responses = 14.

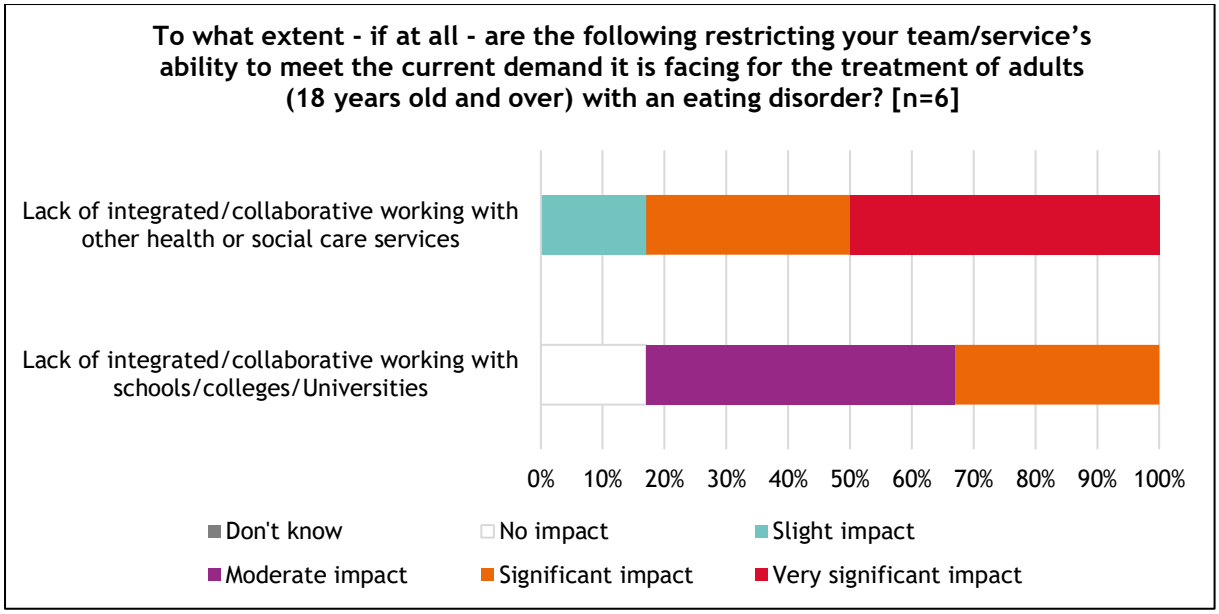

Figure 7. Responses received from health and care staff and volunteers to survey question. Number of responses = 6.

We also asked the health and care professionals and volunteers about their perceptions around how well mental health and other health and social care services in their area work together to provide integrated care for people who have an eating disorder and comorbidities such as autism, diabetes or obesity. Although some reported good co-working between services in their area and 14% said that they did not know, 45% reported that this was either 'poor' or 'very poor' (see figure 8).

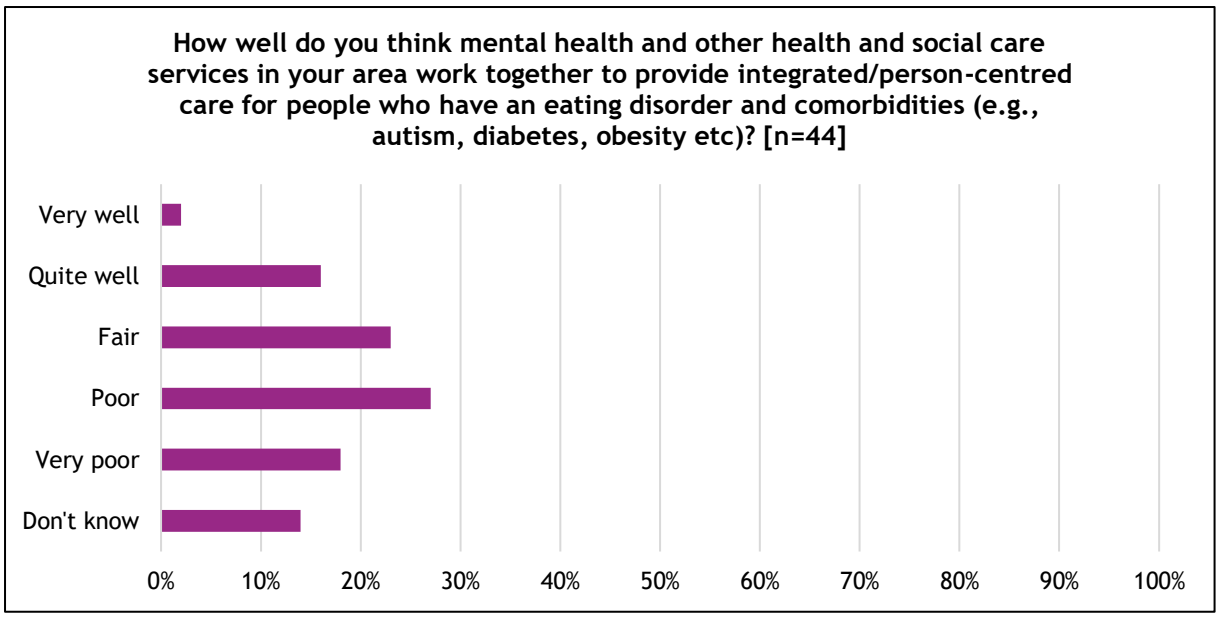

Figure 8. Responses received from health and care staff and volunteers to survey question. Number of responses = 44.

FOI responses from some health boards referred to eating disorder teams/services taking part in regular meetings with paediatric and diabetes services. Some reported that there were psychologists working within these teams.

During 2021 the National Clinical Lead for Eating Disorders led various initiatives to improve communication and collaboration between eating disorder teams/services and other health and social care services. This work has included:

- A trial of the use of regular online case discussions to facilitate learning across health boards around the care of patients with diabetes and an eating disorder.
- Facilitating meetings between eating disorder and weight management service leads.
- Development of a specific care pathway and delivery of training to perinatal mental health services to improve the identification of people with eating disorders by perinatal mental health services, and the experience of care for these patients.

Responses to our survey of clinicians suggests that, in many areas at least, much more work must be done to ensure consistent communication and collaboration between relevant health services. However, important initiatives have begun this year which could provide a foundation for further progress.

Supporting and empowering families and other carers

The eating disorder service review found that "*the role of the families in the current eating disorder service is under-utilised*" (p.9)[13]. Ensuring that families and other carers are fully informed, supported, and empowered was key to the vision set out by the service review. It said that they should be consulted and involved in treatment, and that their perspectives should be accounted for in the design of services, research and policy.

In a recent Beat survey[22], families and other carers in Wales commented on the importance of being able to access information and support:

> "*I believe that one-to-one support for carers is vital to provide information, guidance and just somewhere to offload as no one understands just how hard it is…*" (Jill*)
>
> "*I live with my daughter and if care advice and guidance was provided to me it would create a unified, holistic approach to her care*." (Mark*)
>
> "*I have a weekly online carers support meeting which keeps me on the right track*." (Sarah*)
>
> **Pseudonyms have been used for these quotes.*

Our survey of health and care professionals and volunteers asked whether they felt that families and other carers are listened to, informed and supported in their area (see figure 9). Although there was a mix of answers, a greater proportion (43%) of respondents rated this as either 'poor' or 'very poor', than those who rated it either 'quite well' or 'very well' (27%).

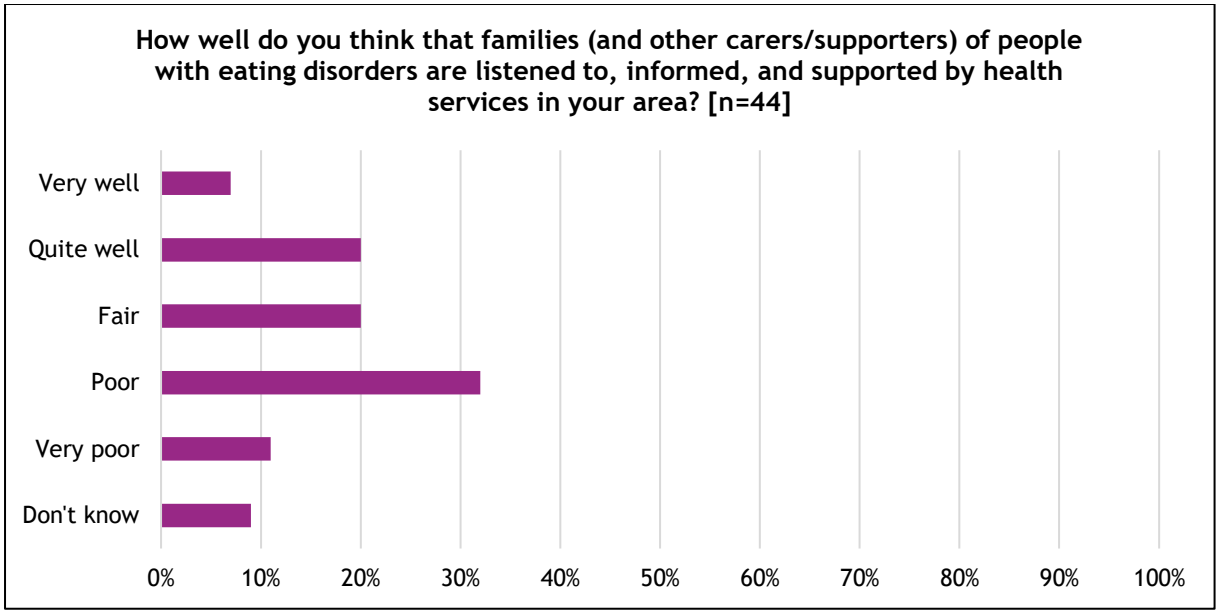

Figure 9. Responses received from health and care staff and volunteers to survey question. Number of responses = 44.

Respondents to our survey highlighted the following concerns about the information and support available to families:

> "*I am a family member of someone with an ED* [eating disorder] *and family support is limited in my area, one information session was provided.*" (Primary care clinician: #2)

> "*There needs to be more direct support for families due to the complexities of eating disorders and the demand this places on family members.*" (Adult community eating disorder service clinician: #6)

> "*We have worked with carers/parents who felt unsupported and had been unsure where to go for support.*" (Voluntary and community sector/third sector staff or volunteer: #8)

One clinician working in a community CAMHS service said that:

> "*we aim to provide as much information and support to families and carers via self-help resources, family meals, educational sessions, MFGT* [Multi-Family Group Therapy] *and family therapy.*" (Community CAMHS clinician: #13).

Responses to our survey, and our experience of providing support for families and other carers in Wales show that much more work also needs to be done to ensure that families and other carers of people with eating disorders are always supported in every part of Wales.

Regarding learning from the perspectives of families and other carers, the National Clinical Lead for Eating Disorders has led the development of an online forum for people with lived experience of eating disorders, including families and other carers. This has been established to help facilitate their involvement in the improvement of eating disorder services. The National Clinical Lead has also helped co-produce guidance for services on involving family members. However, there is not yet a formal process in place to ensure that families and carers are fully involved in the development of all eating disorder services in Wales.

Factors that have impacted progress

Several factors have been responsible for the uneven progress made over the last three years toward the vision set out by the eating disorder service review.

Delayed response from the Welsh Government to the review report

There was a significant delay before the Welsh Government issued a substantive formal response to the review report.

The terms of reference for the eating disorder service review stated that:

> "*It is intended that an outline report on initial findings, issues and priorities will be presented to the Welsh Government by Winter 2018 and the final iteration of the new Framework will be published by Welsh Government Spring 2019.*"(p.15)[13]

The review team submitted their report in November 2018. The Welsh Government commissioned a workshop in May 2019 to consult with clinicians on the content of the review and its recommendations[16].

The Welsh Government's first substantive public response to the review report was published on 26 September 2019, when Vaughan Gething MS, the then Minister for Health and Social Services released a written statement, along with a copy of the executive summary of the final report[16]. Despite the Government's terms of reference for the service review[13] having described an intention to publish a "*new framework*" (p.15) in spring 2019, no framework for improving services has yet been published.

On the previous day, the minister had written to all health board chief executives asking them to consider the review report and its recommendations and to develop plans for reducing waiting times, supported by a baseline review[17]. This letter asked health boards to make incremental changes "*to ensure that longer term planning can align with the vision set out in the review*" (p.2)[17].

The Minister said that there was a need for "*a prioritisation exercise to consider what could be achieved in the short, medium and long term*" and said that he had "*agreed to fund a central resource*" to support that process and to "*support health boards to develop plans to improve services in a way that does not destabilise existing provision*" (p.1)[17].

A National Clinical Lead for Eating Disorders was not appointed until January 2021. In June 2020 the Minister wrote that there had been "*inevitable delays…due to the current pandemic*", including to "*recruitment of a central resource to coordinate a national response* [to the eating disorder service review]. *As soon as it is possible we will work with the NHS to redouble efforts to focus on achieving these actions, including the recruitment of a central resource.*"(p.1)[23].

Limited and variable investment

The service review found that eating disorder services in Wales were "*severely under-resourced with respect to recommendations for services*" (p.6) and called for significant

new investment, to enable a shift towards early intervention and prevention and ultimately deliver significant cost savings that could be re-invested[13].

In our survey of health and care professionals and volunteers, 'Lack of funding for sufficient staff' was commonly identified as restricting the ability of their teams/services to meet the current demand for eating disorder treatment (see figures 10 and 11).

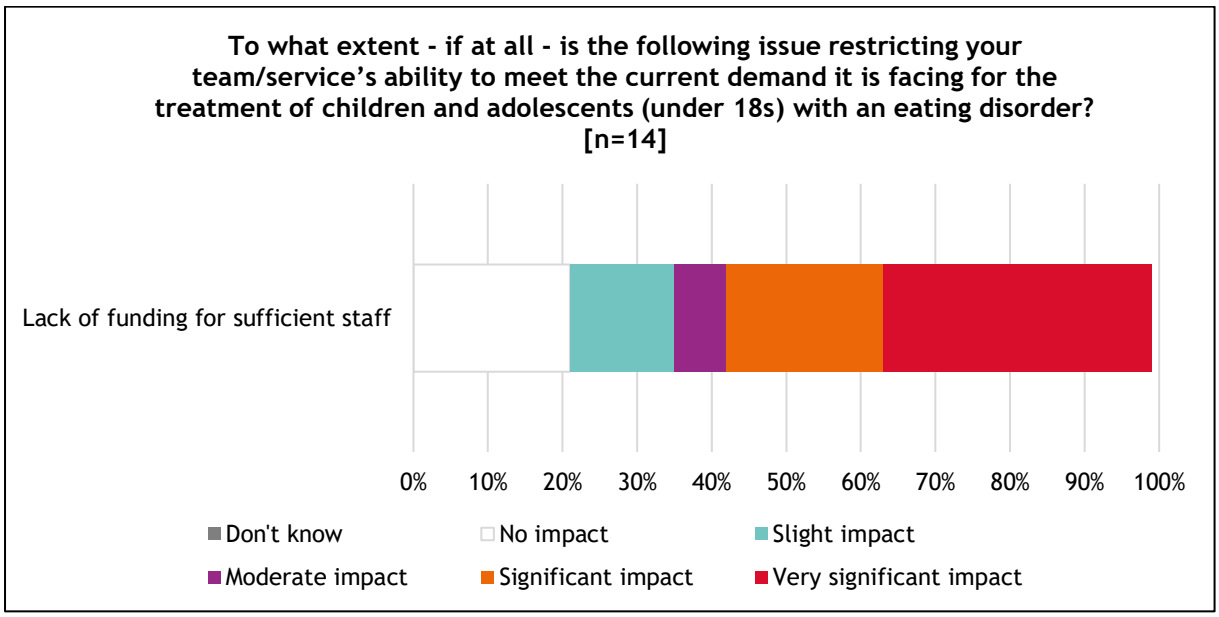

Figure 10. Responses received from health and care staff and volunteers to survey question. Number of responses = 14.

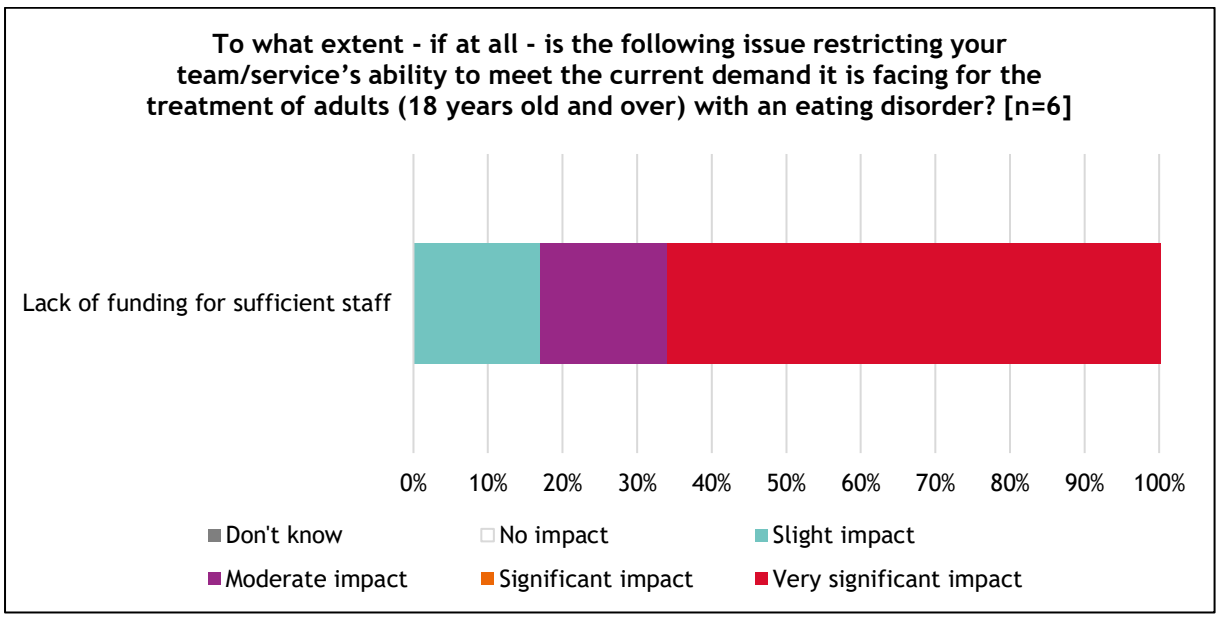

Figure 11. Responses received from health and care staff and volunteers to survey question. Number of responses = 6.

Many patients with eating disorders in Wales currently receive treatment from non-specialist/general mental health services and most of these services only record diagnoses within patient notes. As a result, health boards were unable to calculate their total spend on the treatment of patients with eating disorders. Figure 12 shows that from 2018/19 to 2020/21 investment in tier 3 adult community eating disorder services only increased by 1% in real terms[24].

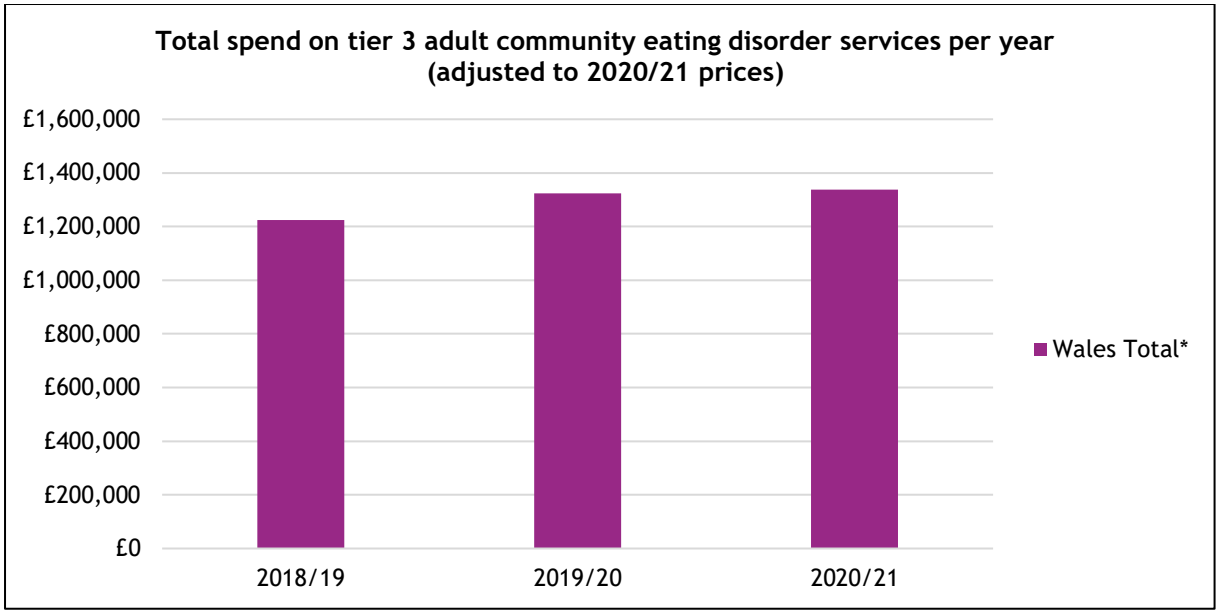

Figure 12. *Excluding Cardiff and Value UHB, which did not provide this data.

Despite the service review having highlighted inequity in the provision of specialist eating disorder treatment[13], spending on tier 3 adult community eating disorder services varied widely between health boards in 2020/21, after accounting for differences in the sizes of the populations served[18] (see figure 13).

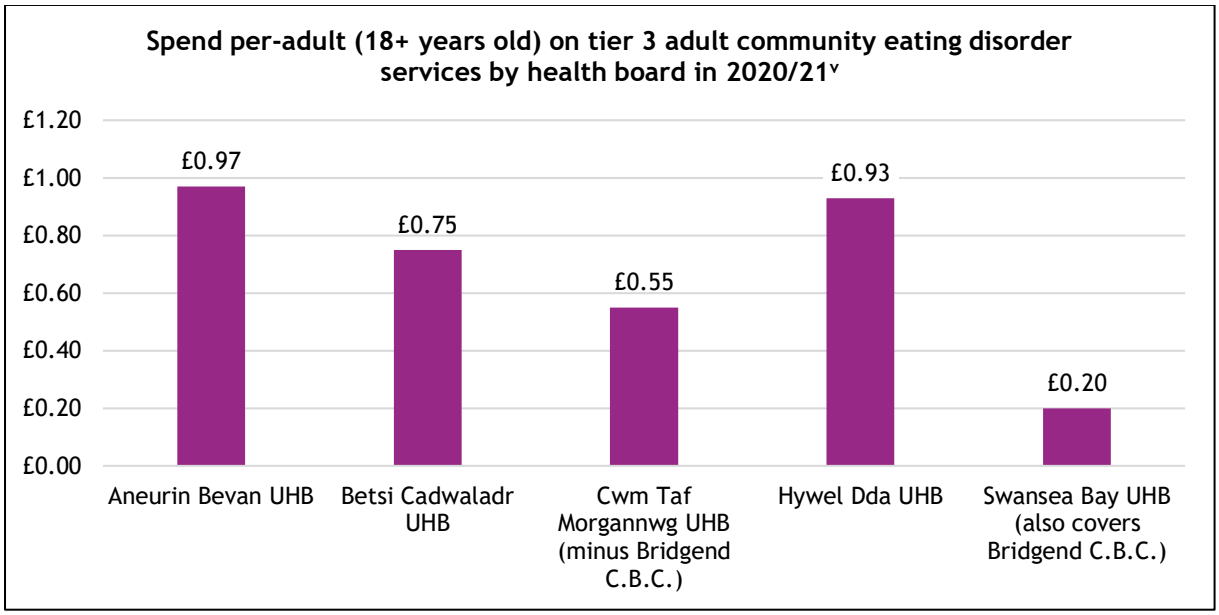

Figure 13. This represents the total spend divided by the total number of adults resident within the relevant catchment areas[v].

[v] This data was not provided by Cardiff and Value UHB. In line with service catchment areas the population used for Cwm Taf Morgannwg UHB excludes Bridgend County Borough Council area, and the population used for Swansea Bay UHB includes this population[25]. Powys THB does not provide a tier 3 adult community eating disorder service. Patients in South Powys can be referred to the service provided by Aneurin Bevan UHB; those in North Powys can be referred to the service provided by Betsi Cadwaladr UHB and those in South West Powys can be referred to the service provided by Swansea Bay UHB. Due to lack of detailed information about these boundaries the population of Powys THB could not be accounted for.

Since 2019/20 the Welsh Government has operated a centrally held 'Service improvement fund' which it has made available to health boards for investment in a series of priority areas, including eating disorders (see table 1)[26;27].

	2019/20	2020/21	2021/22
Service Improvement Funding (SIF) invested in eating disorders	£718,329 (10% of total SIF funding)	£501,385 (7% of total SIF funding)	Planned figure not available

Table 1.

In response to questions about Service Improvement Funding (SIF) in our FOI request, most health boards provided either draft or final copies of funding bids prepared for submission to the Welsh Government. However, little further recorded information was disclosed around the decision-making process followed by senior health board mental health managers that will have ultimately determined how much SIF funding reached eating disorder services.

In 2019/20 although the Welsh Government told health boards that it would welcome funding proposals on eating disorders, submitting a proposal on this area was not compulsory[28]. As a result, some health boards did not submit bids for eating disorder services to receive any of the available SIF funding that year.

In guidance sent to health boards on additional mental health funding for 2020/21 and 2021/22, the Welsh Government specified – within the sections on eating disorders – that health boards must submit at least one proposal for funding to be utilised in that area[29;30]. While this represented an improvement, this still did not provide a guarantee that eating disorder services would receive a reasonable share of this funding.

In our survey some clinicians expressed frustrations about eating disorder services missing out on this funding. One clinician based in a community CAMHS service (#7) referred to "*funding from Government being diverted elsewhere*" and another referred to a proposal not being supported by their health board senior management:

> "*An ED* [eating disorder] *bid providing early intervention and specialist interventions was submitted to our health board as requested covering all aspects of what you would expect an ED* [eating disorder] *team to provide but this was not supported due to other competing demands on the service…this has left our ED* [eating disorder] *team over stretched with high caseloads. In terms of delivering the Maudsley family-based model we have had to make compromises and therefore the treatment is nowhere near as intensive as it needs to be*" (Community CAMHS clinician: #13).

The service review found that failure to provide early access to quality treatment was leading to many distressing and costly referrals to specialist inpatient units in England[13]. Data supplied by the Welsh Health Specialised Services Committee (WHSSC) showed that the number of out of country admissions for eating disorders has remained at a similar level across the last three years to that reported in the service review, and similarly is costing the Welsh Government around £1.6m per year (in 2020/21 prices[24]). The total cost of these admissions alone is similar to the total spend by health boards on specialist tier 3 adult community eating disorder services and is more than three times greater than the total 'Service Improvement Funding' that was invested in eating disorder services in Wales

in 2020/21.

Insufficient staff and poor staff wellbeing

The service review found that eating disorder staffing levels in Wales were significantly below those recommended by the Royal College of Psychiatrists, or NHS England[13]. Ensuring that there are enough well trained and properly supported staff working in eating disorder services will be key in achieving the vision set out by the service review.

Many of the staff that provide eating disorder treatment in Wales work in generic mental health services rather than specialist eating disorder teams or services, and due to limitations in data collection this section of the workforce cannot be properly accounted for[vi]. The data obtained from our FOI request represents the staffing levels that health boards were able to identify as being used specifically for eating disorder treatment.

Staffing levels in CAMHS

In our survey we asked health and care professionals and volunteers about staffing levels in their team/service. This question was answered by 16 clinicians that work with children and adolescents, with most (82%) indicating concern about staffing levels (see figure 14).

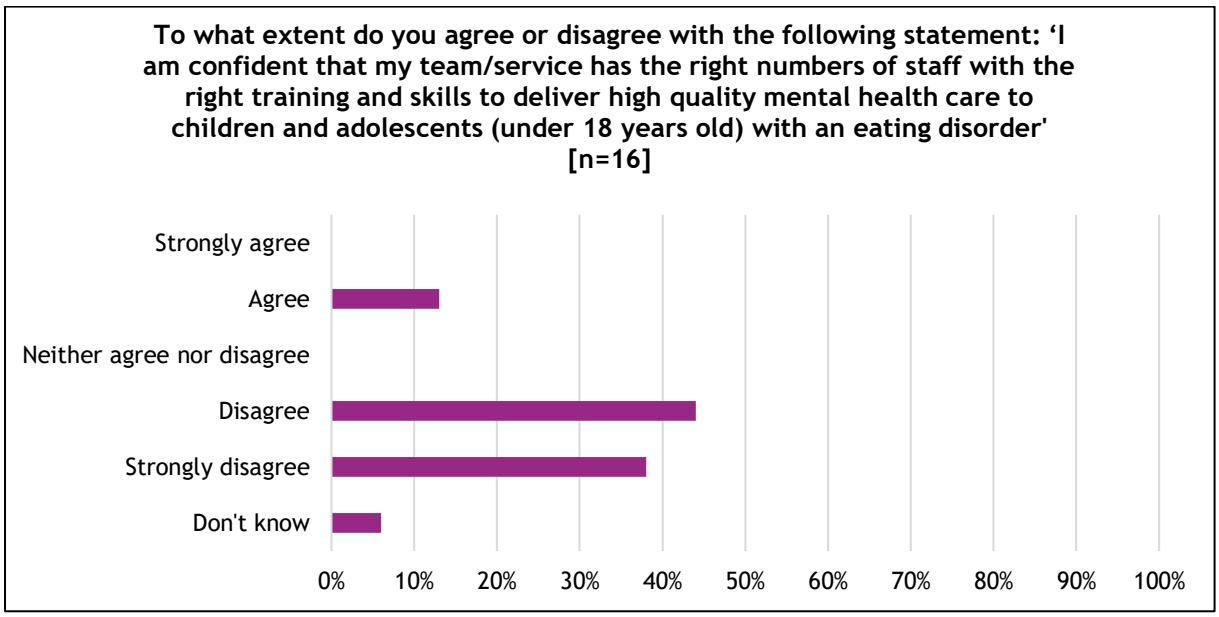

Figure 14. Responses received from health and care staff and volunteers to survey question. Number of responses = 16.

In response to our survey several clinicians working in CAMHS services in Wales commented on staffing levels and expertise in their teams/services:

> "*staff numbers are woefully low*" (Community CAMHS clinician: #6)

[vi] Adult mental health services for people with eating disorders in Wales are generally arranged through separate tiers as recommended by the Eating Disorder Framework for Wales 2009[19]. Tier 1 services provide primary-care based mental health support, tier 2 denotes more specialist treatment generally provided by staff based in Community Mental Health Teams (CMHTs), tier 3 denotes specialist adult community eating disorder services, and tier 4 refers to inpatient mental health units.

> *"CAMHS/Paediatric services are very much lacking the staff with expertise in eating disorders"* (Community CAMHS clinician: #8)
>
> "*We require funding to invest in more clinicians to provide part 1 and 2 of the Mental Health Measure and specialist clinician's to provide the FBA* [Family Based Approach] *model of therapy*." (Community CAMHS clinician: #13).

There was little change in the number of CAMHS staff – in terms of Working Time Equivalent (WTE) – used specifically for the treatment of eating disorders between 31 March 2018 and 31 March 2021[vii], with the notable exception of Aneurin Bevan UHB, where this increased by 50%.

On 31 March 2021 the number of identifiable CAMHS eating disorder staff varied widely between health boards (see figure 15). This indicates that the capacity to provide specialist eating disorder treatment for children and adolescents is highly variable between health boards.

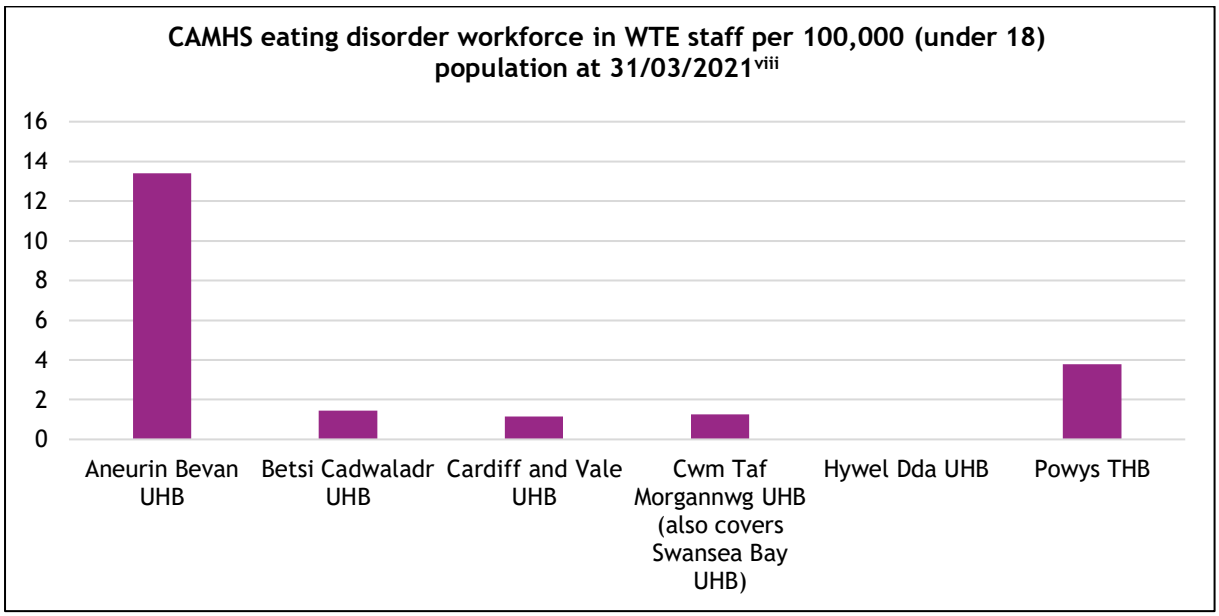

Figure 15.

This variation also applies after accounting for differences in the number of patients treated (the size of caseloads), although this calculation was only possible for two health boards. On 31 March 2021, Aneurin Bevan UHB had four times more CAMHS eating disorder staff per 100 patients, when compared to Powys Teaching Health Board (THB).

Staffing levels in adult eating disorder teams/services

[vii] Staffing levels at these services may have changed since 31 March 2021, due to recruitment and/or departures. At least two health boards reported that they were or would be aiming to recruit additional staff for these services during 2021/22.

[viii] The values of 0 WTE staffing for Hywel Dda UHB is due to this health board not having a separate CAMHS eating disorder team/service in place on 31 March 2021, and not being able to disaggregate the proportion of its CAMHS staff time spent on eating disorders. Within health boards that do have a distinct CAMHS eating disorder team/service, some patients with eating disorders may still receive treatment from other CAMHS clinicians.

In response to our survey, 17 clinicians that work with adults answered a question on the staffing levels in their team/service (see figure 16). Although the responses were more mixed, more answered either 'disagree' or 'strongly disagree' (47%) in response to the statement than those who answered 'agree' or 'strongly agree' (30%).

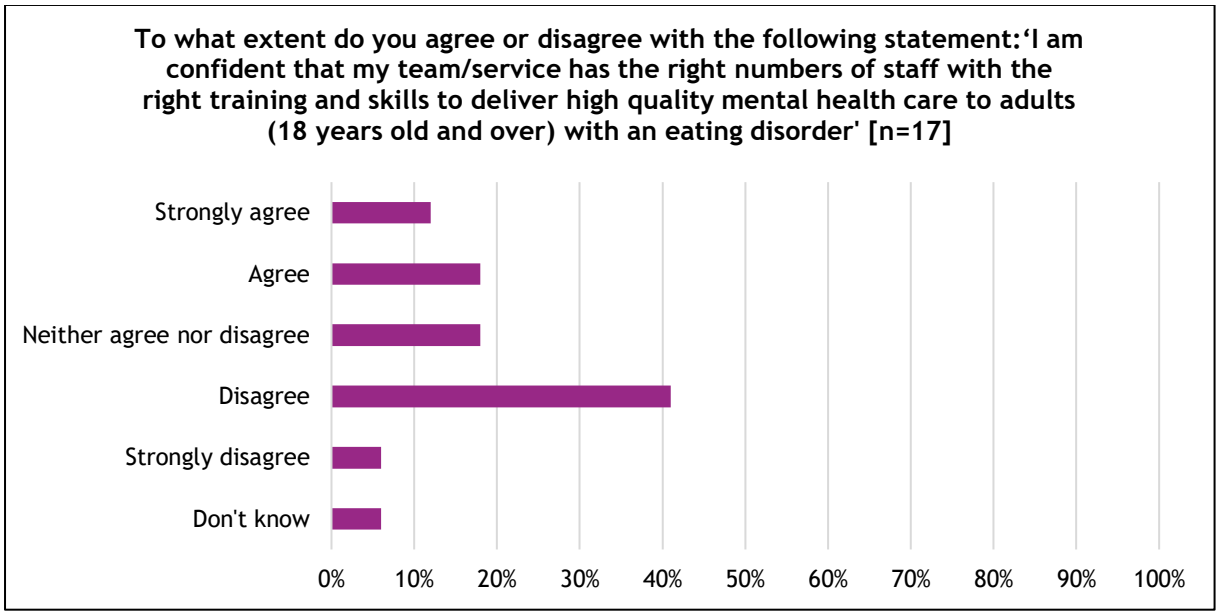

Figure 16. Responses received from health and care staff and volunteers to survey question. Number of responses = 17.

In response to our survey several clinicians working in adult community mental health services or adult community eating disorder services in Wales commented on staffing levels and expertise in their teams/services:

> "*Although we do have an ED* [eating disorder] *team… they cover* [a] *wide area and can become overwhelmed with referrals.*" (Primary care-based adult mental health clinician: #3)

> "*As a team we do not have the capacity to perform intense home support or an alternative to inpatient admissions.*" (Adult community eating disorder service clinician: #6)

> "*Focus is on assessing and waiting lists. Many services can see people but do not provide meaningful treatment so people get stuck in the system and don't resolve the problem. Eating disorders services do need CMHT* [Community Mental Health Team] *to be functional and at the moment they are struggling.*" (Adult community eating disorder service clinician: #7).

Between 31 March 2018 and 31 March 2021 there were no staff dedicated specifically to the treatment of eating disorders within primary care-based (tier 1) adult mental health support services, although two health boards reported plans to address this during 2021/22. In recent years additional staff have been recruited to provide eating disorder treatment within 'tier 2' adult community mental health services in some areas. These health boards reported that this has enabled wider access to eating disorder treatment for adults in their areas given the referral/eligibility criteria associated with accessing

treatment from tier 3 adult community eating disorder services. These tier 2 eating disorder teams were small at 31 March 2021 (see figure 17), although four health boards said that they were aiming to recruit additional staff for these teams during 2021/22.

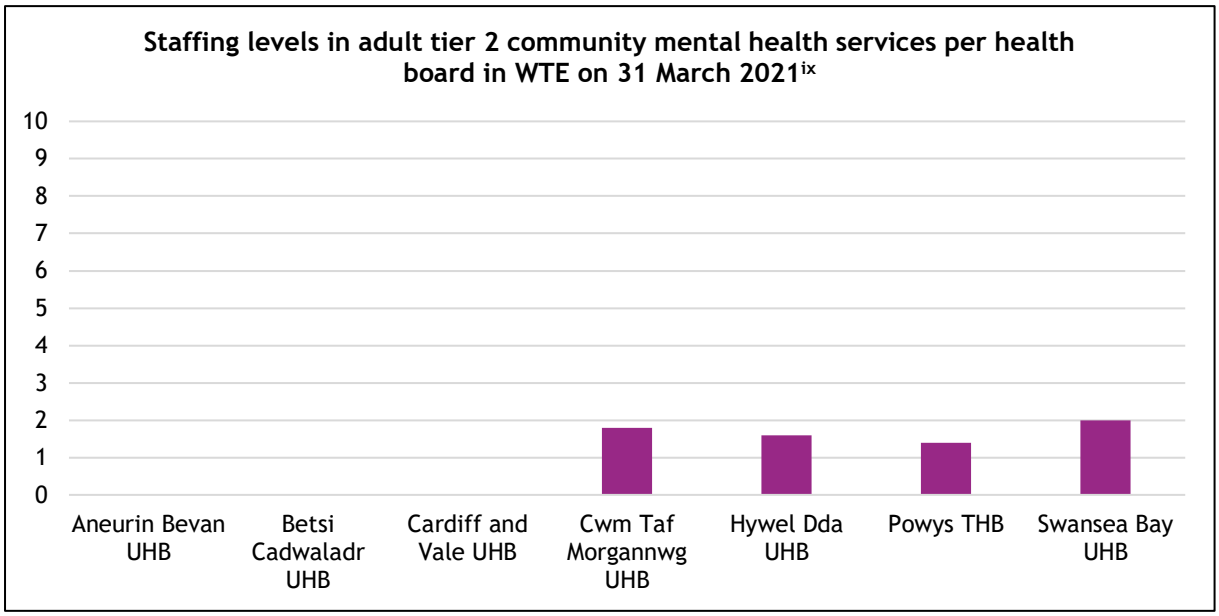

Figure 17. Note: Cardiff and Vale UHB are shown with the value of 0 WTE as they did not provide the relevant data.

There was little change in staffing levels at tier 3 adult community eating disorder services between 31 March 2020 and 31 March 2021[x], with the exception of Cardiff and Vale UHB, where this increased by 18% from 7.7 WTE to 9.1 WTE (see figure 18).

[ix] It should be noted that some of these services cover larger populations and geographic areas than others. Cardiff and Vale UHB did not provide data for their tier 2 adult community eating disorder service. The values of 0 WTE staffing for the other UHBs is due to them not having a distinct eating disorder team in place within their tier 2 services on 31 March 2021, and not being able to disaggregate the proportion of staff time within these services spent on eating disorders.

[x] Staffing levels at these services may have changed since 31 March 2021, due to recruitment and/or departures. Two health boards reported that they were aiming to recruit additional staff for these services during 2021/22.

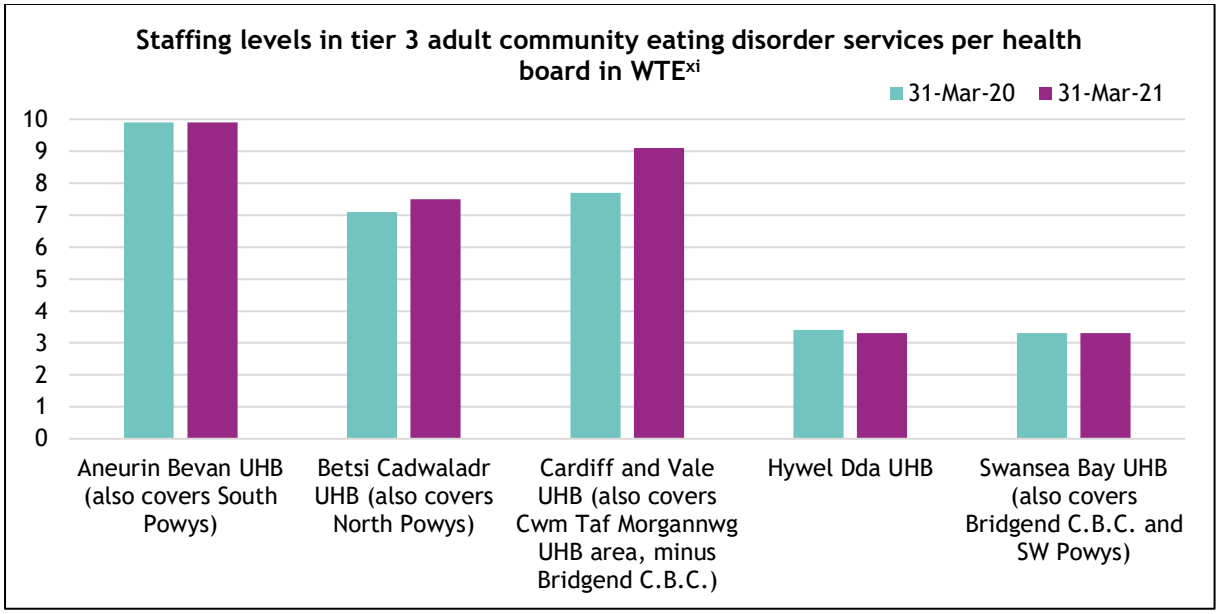

Figure 18.

Comparing staffing levels at tier 3 adult community eating disorder services by accounting for differences in the number of patients treated (the size of their caseloads) indicates significant variation in the capacity of these services (see figure 19). On 31 March 2021, Aneurin Bevan UHB had three times more tier 3 adult community eating disorder staff per 100 patients, when compared to Cardiff and Vale UHB.

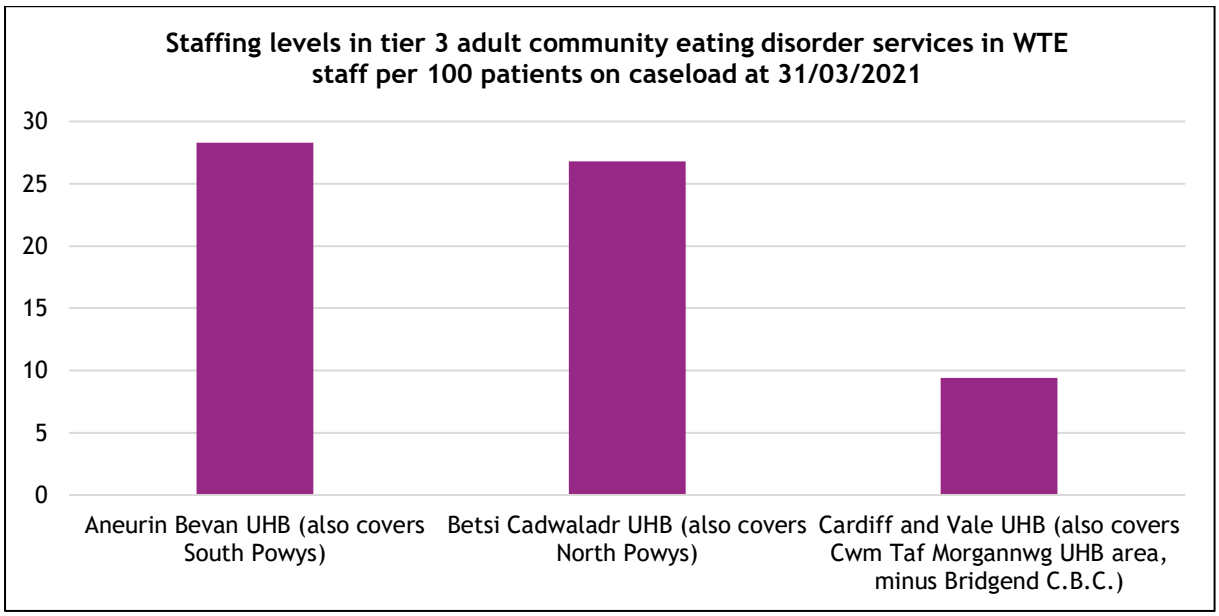

Figure 19.

[xi] Powys THB does not provide a tier 3 adult community eating disorder service. It should be noted that some of these services cover far larger populations and geographic areas than others. Three of the five health boards that provide a tier 3 adult community eating disorder service were unable to supply data on staffing levels at these services on 31 March 2018 or 31 March 2019.

Access to treatment provided by multi-disciplinary teams

Due to the complexity of eating disorders and their impacts on physical health it is important that eating disorder teams/services include staff with a mix of skills, from a range of professional backgrounds[31]. The eating disorder service review raised particular concern about the medical and dietetic workforce in eating disorders[13]. It recommended "*a prioritisation of the medical needs of people with eating disorders*" (p.8) and reported that at their public workshops "*many patients and families have complained of the lack of skilled eating disorder specific dietitian support*" (p.42)[13].

As shown in table 2, in 2018 the service review estimated the total medical workforce in eating disorder services in Wales at just 2.2 WTE. Based on the data supplied in response to our FOI request this appears to have fallen to just 1.7 WTE in post at 31 March 2021[xii]. There appears to have been small increases in the number of dietetic and occupational therapy staff working in eating disorders over the last three years (see table 3).

Professional discipline	CAMHS		Adult	
	Service review 2018	31 March 2021	Service review 2018	31 March 2021
Psychiatry	0.8 WTE	0.4 WTE	0.7 WTE	0.8 WTE
Paediatric	0.5 WTE	0.5 WTE	N/A	N/A
Physician	0 WTE	0 WTE	0.1 WTE	0 WTE
Speciality Doctor	0 WTE	0 WTE	0.1 WTE	0 WTE
Medical professions total =	1.3 WTE	0.9 WTE	0.9 WTE	0.8 WTE

Table 2. Comparison of identifiable medical workforce in eating disorders in Wales as estimated in the eating disorder service review 2018[13], and as in place on 31 March 2021, based on Working Time Equivalent (WTE).[xii]

Professional discipline	CAMHS		Adult	
	Service review 2018	31 March 2021	Service review 2018	31 March 2021
Dietetic	3.7 WTE	5.36 WTE	4.8 WTE	5.3 WTE
Occupational Therapy	1 WTE	2 WTE	1 WTE	2.5 WTE

Table 3. Comparison of identifiable dietetic and occupational therapy workforces in eating disorders in Wales as estimated in the eating disorder service review 2018[13], and as in place on 31 March 2021, based on Working Time Equivalent (WTE).[xii]

Based on the available data there has been very limited progress in increasing the number of medical, dietetic and occupational therapy staff working in eating disorder services in Wales. In response to concerns about the size of the medical workforce in Welsh eating disorder services, the National Clinical Lead for Eating Disorders has helped produce resources and deliver training to paediatricians working outside eating disorder services in order to improve links and encourage greater interest in the field.

Difficulties in recruiting new staff

In our survey of health and care professionals and volunteers, 'Insufficient eligible

[xii] The values in tables 2 and 3 may be slight underestimates due to not having received staffing data from Cardiff and Vale UHB for its tier 2 adult community eating disorder service. Also, it is important to note that these refer to staff that can be identified as used specifically for eating disorder treatment, so will not include staffing from generic mental health services.

candidates applying to fill vacancies' was commonly identified as restricting the ability of their teams/services to meet the current demand for eating disorder treatment (see figures 20 and 21).

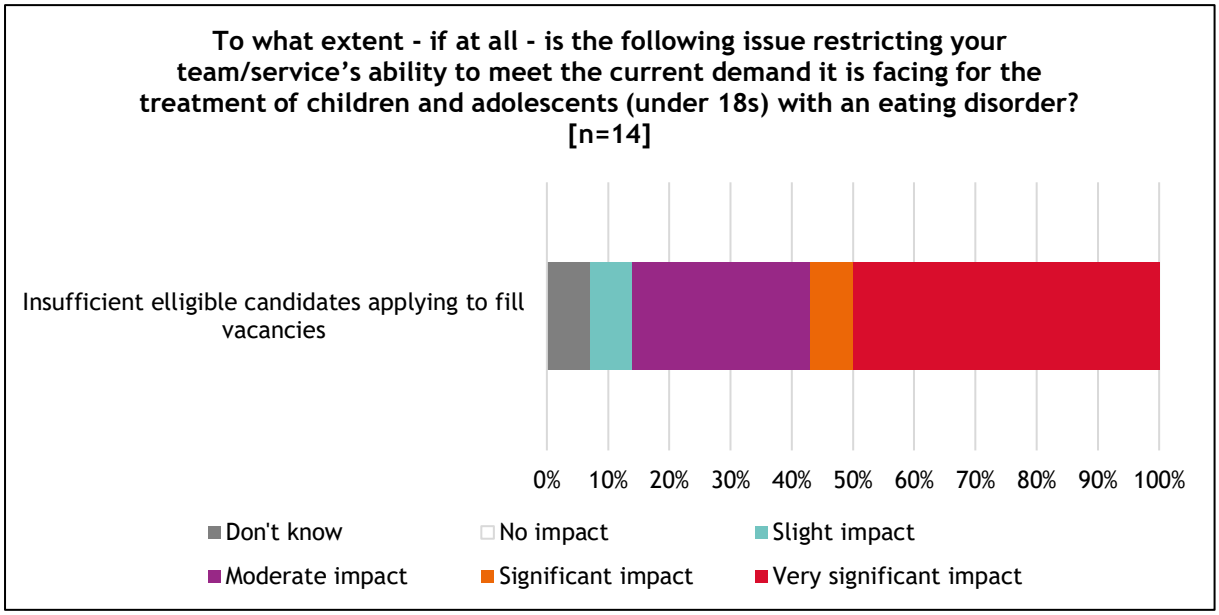

Figure 20. Responses received from health and care staff and volunteers to survey question. Number of responses = 14.

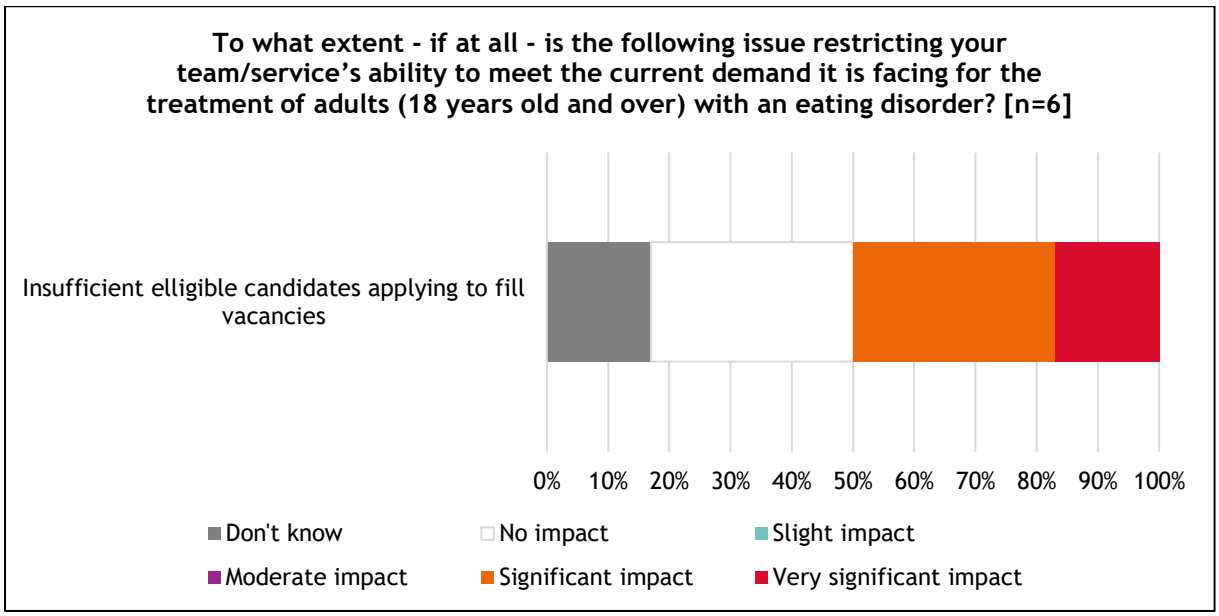

Figure 21. Responses received from health and care staff and volunteers to survey question. Number of responses = 6.

One respondent that worked in a community CAMHS service (#5) reported: "*Significant difficulty recruiting skilled and experienced staff*". Further evidence of services finding difficulty in recruiting the right staff were also contained in copies of past bids for service improvement funding supplied by health boards in response to our FOI request.

One health board stated that:

> "*an initial recruitment exercise of* [Redacted] *did not receive any applicants, therefore the posts were re-developed at a higher band and have now been out to advert twice*".

Another health board also reported that:

> "*There are two small, part-time vacancies – one in* [Redacted] *and one in* [Redacted] – *which need to be uplifted, as they are not attractive in their current position, and we have not been able to recruit.*"

It is clear that at least in some areas of Wales efforts to expand the eating disorder workforce have been hampered by a lack of eligible candidates applying to fill vacancies.

Staff wellbeing and burnout

Expanding and improving eating disorder services in line with the vision set out by the eating disorder service review will depend on the wellbeing of the workforce.

When our survey asked clinicians about staff wellbeing and levels of stress and burnout in their team/service almost half of those that responded reported being 'very concerned' about this (see figure 22).

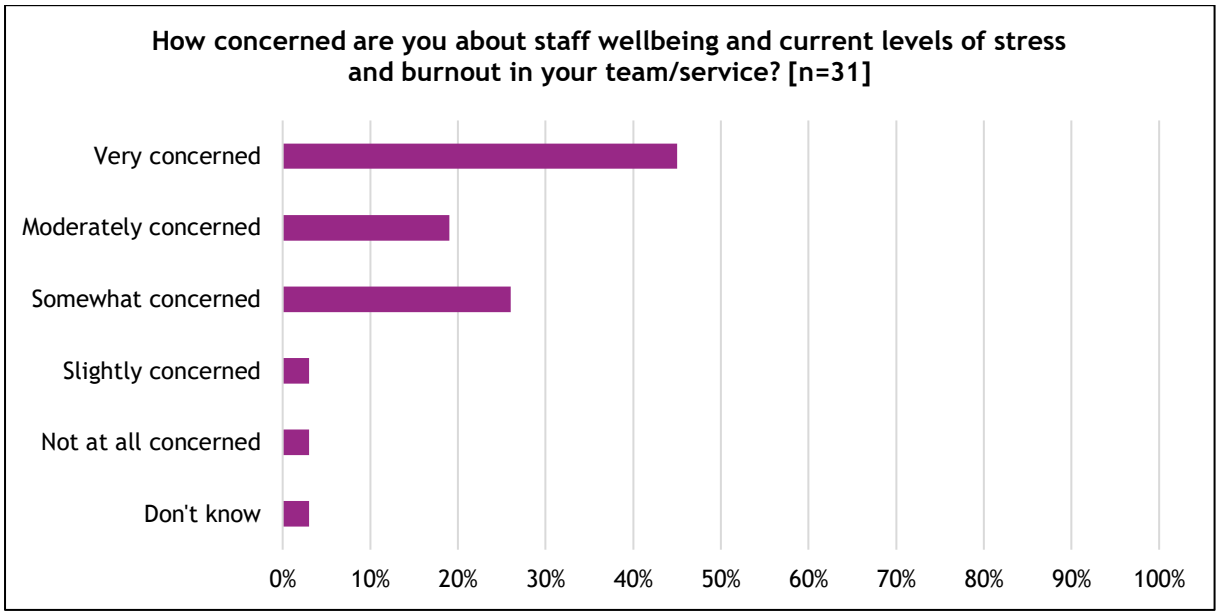

Figure 22. Responses received from health and care staff and volunteers to survey question. Number of responses = 31.

Many of the respondents to our survey added comments that provide insight into the level of strain that clinical staff and their respective teams/services are experiencing:

> "*Lots of staff have experienced burnout recently in our service and have been finding it difficult to cope with the high demand and high level of risk in our service at present.*" (Adult community eating disorder service clinician: #6)

> "*Management have a view that we are well-staffed because we do so much MDT* [Multi-Disciplinary Team] *work. Very high turnover of staff. Big staff sickness rates.*" (Community CAMHS clinician: #5)

> "*I think that all ED* [eating disorder] *services are facing significant challenges as the levels of complexity and risk within ED* [eating disorder] *cases have increased substantially since the pandemic. I don't think there is always an appreciation of the level of stress and demand that staff working in this speciality face.*" (Adult community eating disorder service clinician: #5).

Several clinicians reported that being unable to provide the level of service they would like has left them concerned about the welfare of patients and their families, and as a result has negatively impacted upon their wellbeing:

> *It's personally very stressful knowing that patients are having to wait for a long time before starting treatment as you know that the illness has more time to become more entrenched which is very harmful for patients. It's also difficult knowing that families are left to cope on their own whist witnessing their child becoming more unwell.*" (Community CAMHS clinician: #4)
>
> "*It is not felt that we have enough staff in the team in order to allocate young people to key workers. This has an impact on waiting time, but also experience of burnout from staff – feeling overwhelmed and under pressure.*" (Community CAMHS clinician: #12)
>
> "*The pressures over the last year had led to some staff requiring periods of sick leave and we have managed this by having a small wait for certain therapies so that people do not feel overstretched at work, however this is at a delay of specialist treatment for some patients. Which again does not feel ideal*" (Adult community eating disorder service clinician: #2).

The impact of the COVID-19 pandemic

COVID-19 has had profound, negative impacts on people affected by eating disorders. The disruption caused to routines, living arrangements, social isolation, and access to treatment make the pandemic especially challenging for people with eating disorders and their families and other carers[32;33]. It has led to a major rise in demand for eating disorder treatment[34;35;36].

Very little data is collected on eating disorder referrals in Wales. The data available on eating disorder referrals made to CAMHS is illustrated in figure 23.

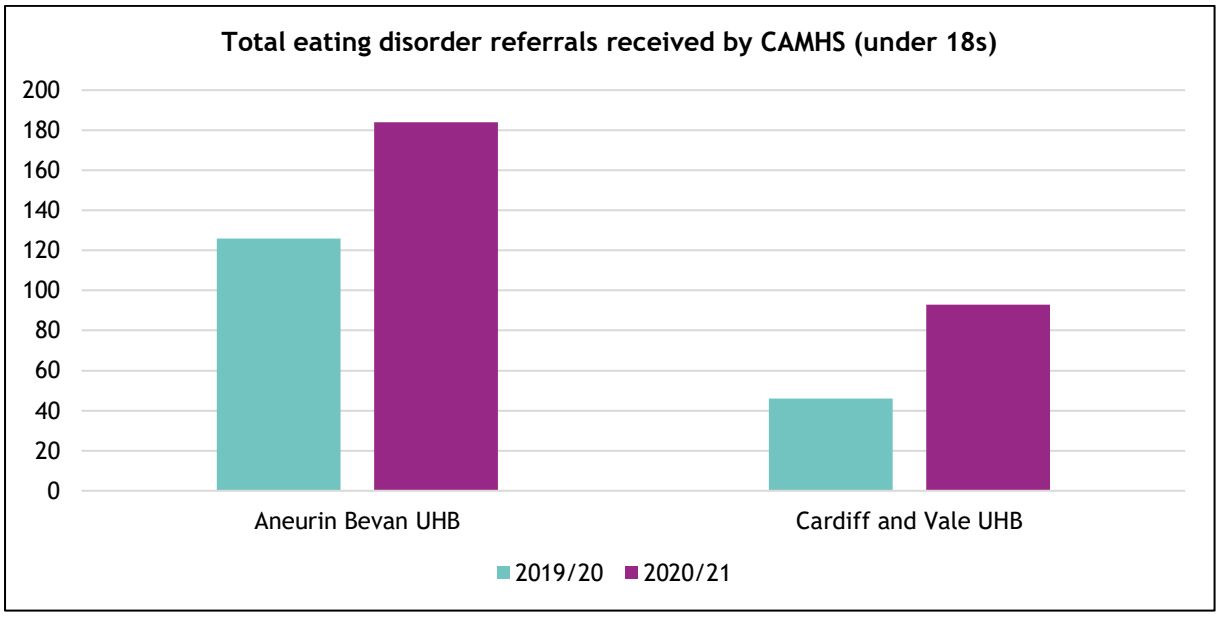

Figure 23.

Although unable to provide data on referrals, Powys THB reported that the number of children and adolescents (under 18s) starting eating disorder treatment at their CAMHS

service more than doubled, rising from 22 in 2019/20, to 45 in 2020/21. In a recent presentation about the work of the SPEED CAMHS eating disorder team[37] that is provided by Betsi Cadwalladr UHB, Dr Louise Phillips, its paediatric lead, said:

> *"For us in North Wales, we were seeing about 70 cases a year before COVID…We're now seeing between double and treble that number."*

Eating disorder referrals to Aneurin Bevan UHB's tier 3 adult community eating disorder service reduced slightly each year since 2018/19, however referrals to its tier 2 service increased by a third from 2019/20 to 2020/21 (rising from 91 to 121).

Responses to our survey of health and care professionals and volunteers indicate that overall, there has been a significant increase in demand for eating disorder treatment (see figures 24 and 25).

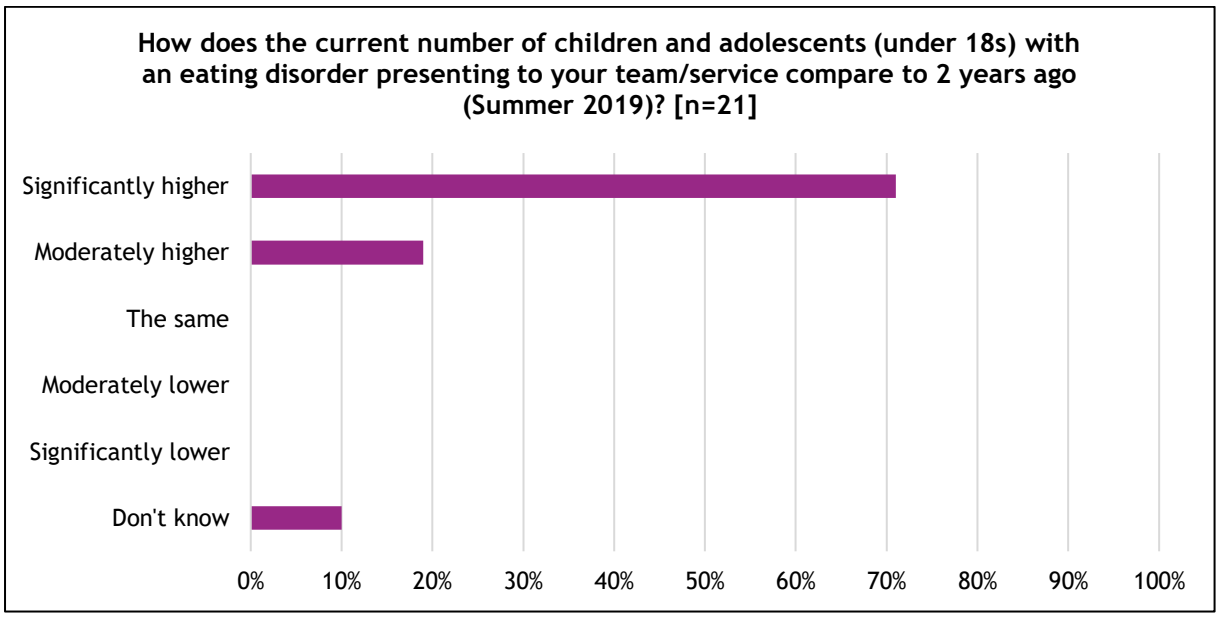

Figure 24. Responses received from health and care staff and volunteers to survey question. Number of responses = 21.

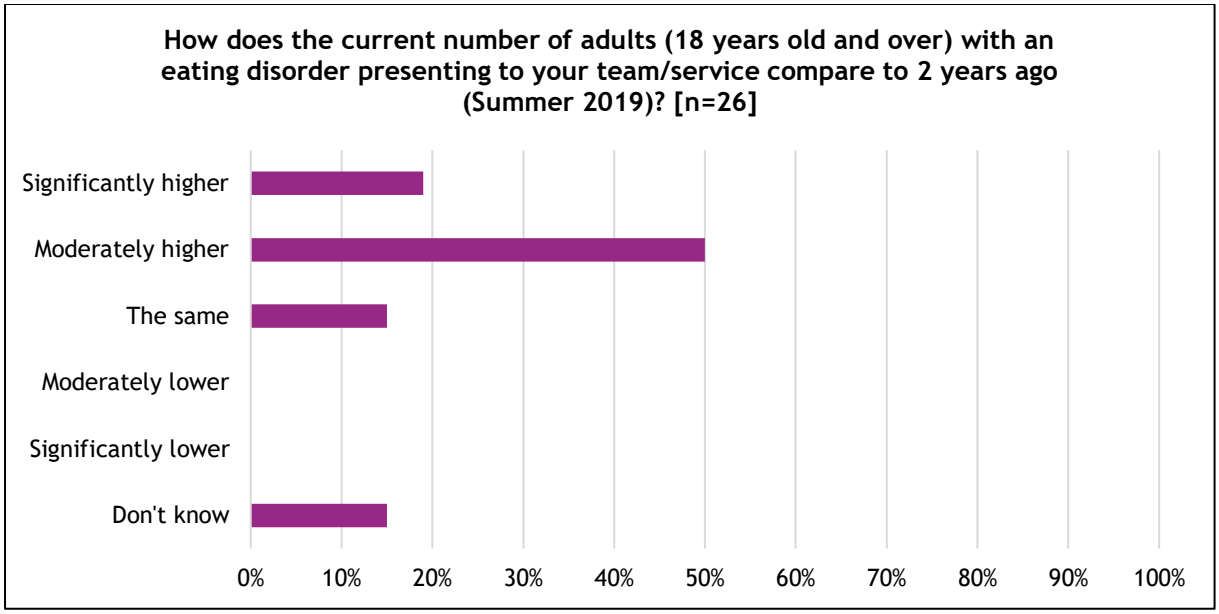

Figure 25. Responses received from health and care staff and volunteers to survey question. Number of responses = 26.

Several clinicians that responded to our survey highlighted the rise in demand for eating disorder treatment at their team/service:

> "*The demand for the eating disorder service has increased dramatically since the start of the pandemic. Not being able to have the support of friends and family, over exercising and increased use of social media have had huge impacts on individuals*" (Community CAMHS clinician: #8)

> "*Experienced a significant change in demand. At assessment, the majority of young people will state that their difficulties started in March 2020, in an initial attempt to 'get healthy'.*" (Community CAMHS clinician: #12)

> "*The majority of our referrals this year all have one thing in common. During the assessment the family always start with "it all started around March last year in lockdown"* (Community CAMHS clinician: #13).

Most survey respondents reported that on average people being referred for eating disorder assessment and treatment to their team/service are now more severely ill than before the pandemic (see figures 26 and 27).

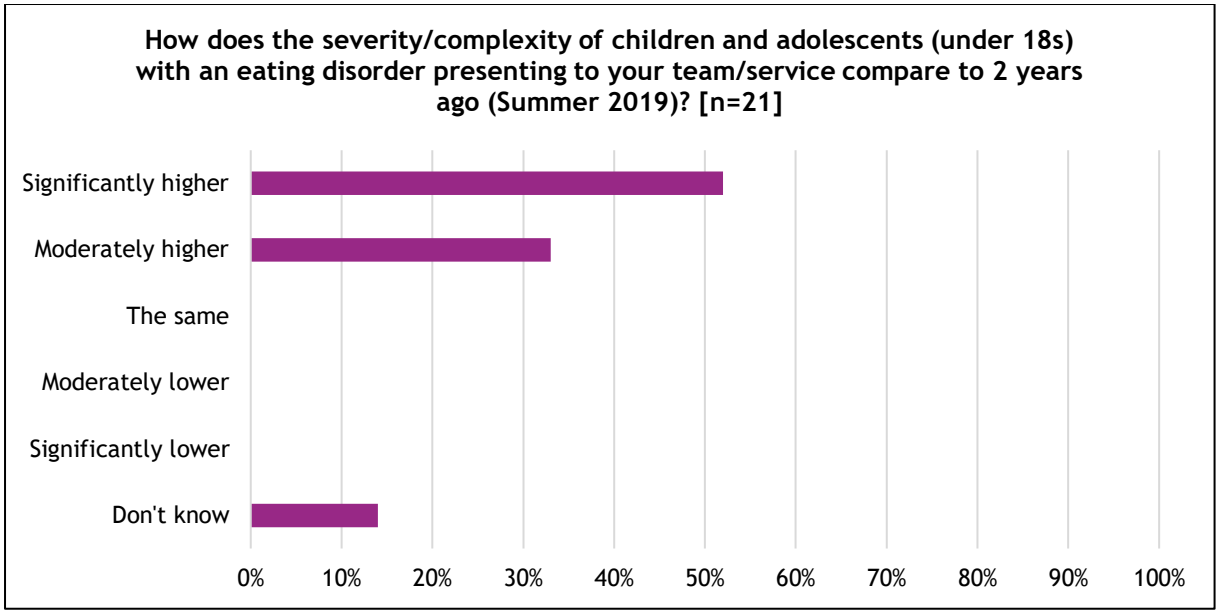

Figure 26. Responses received from health and care staff and volunteers to survey question. Number of responses = 21.

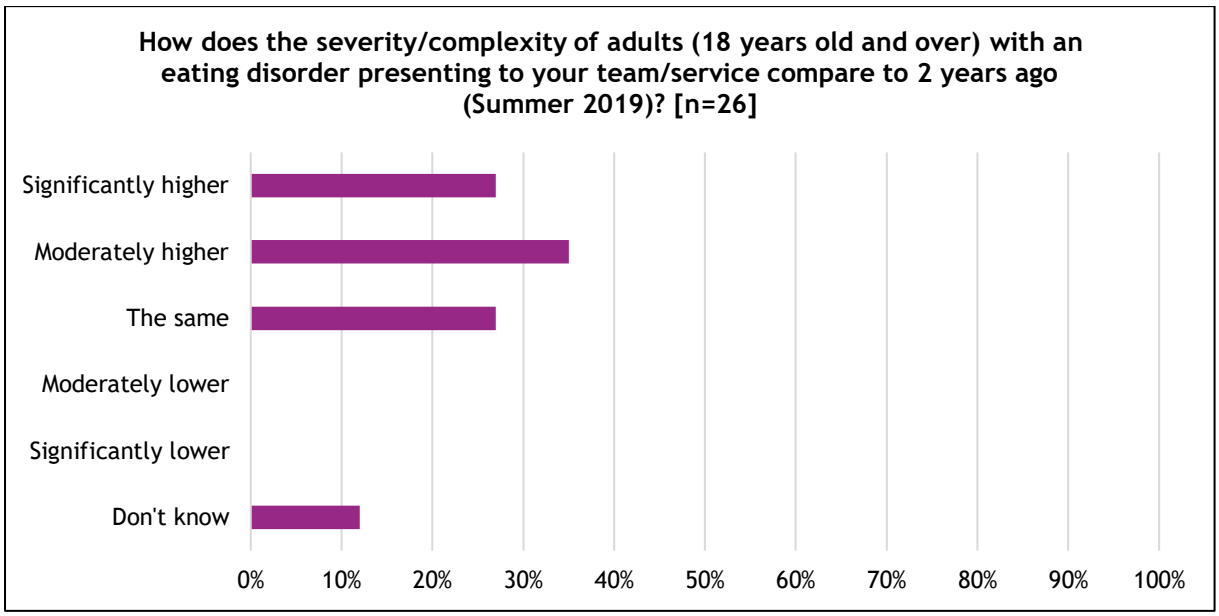

Figure 27. Responses received from health and care staff and volunteers to survey question. Number of responses = 26.

Through our survey we also heard from clinicians describing how they have been seeing more severely ill cases than before.

> *"…having analysed the data there has been an increase in referrals but also complexity and deterioration of clients prior to referral"* (Adult community eating disorder service clinician: #2)

> *"Since the start of the pandemic many young adults have been having a hard time with the psychological impacts of lockdown and the pandemic, many adults in my area have presented with an eating disorder for the first time and it's has gotten a big worry for the staff at my workplace (adult acute admissions ward)"* (Adult tier 4 mental health service clinician: #2)

There has been an increase in severity and relapse since the coronavirus pandemic and an increased need and long wait for specialist eating disorder inpatient units." (Adult community eating disorder service clinician: #6).

Data obtained through an FOI request sent to Digital Health and Care Wales (DHCW) shows that from 2019/20 to 2020/21 there was a 72% increase in inpatient admissions for under 18s where the primary diagnosis was recorded as an eating disorder (see figure 28).

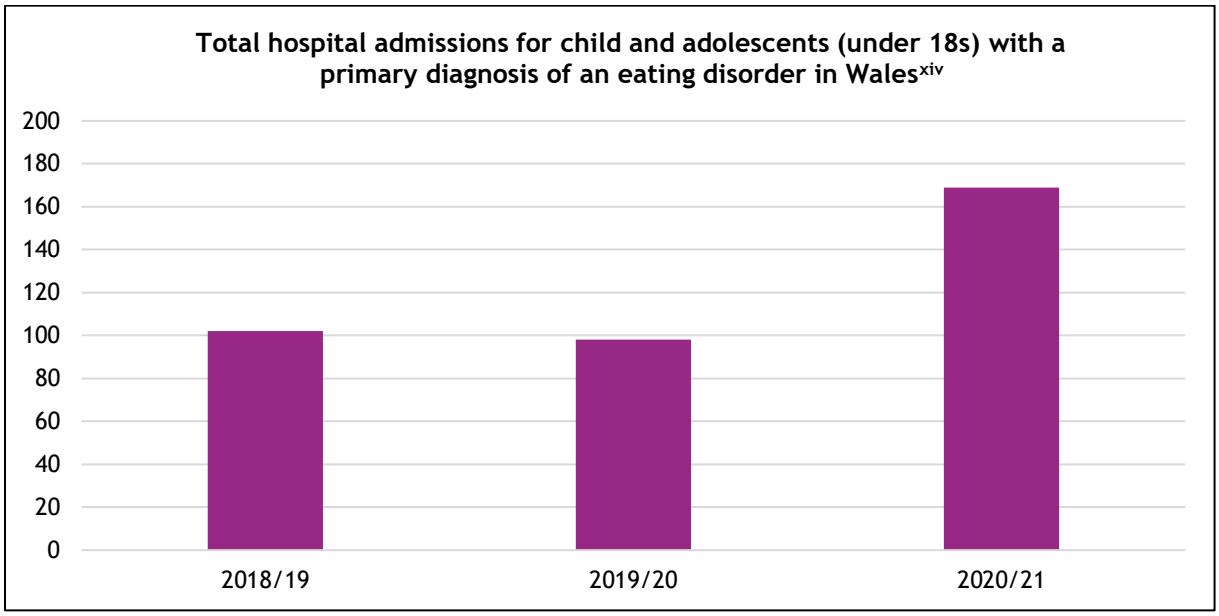

Figure 28.

The COVID-19 pandemic has led to a significant increase in demand for eating disorder treatment and has also resulted in a greater proportion of patients presenting to eating disorder services in an already severely ill state.

[xiii] 'Admissions' denote episodes of inpatient treatment that have begun (but not necessarily ended) within the specified financial year. Patients may be admitted more than once during a year. 'Primary diagnosis' can be defined as: "*the main condition treated or investigated during the relevant episode of healthcare*"[38].

Conclusions

While some progress has been made toward the vision set out by the eating disorder service review in the last three years this has been very uneven, continuing the inequity documented by the review.

A delayed initial response to the review report by the Welsh Government, insufficient and variable levels of investment and staff, and poor staff wellbeing have impacted on progress made in expanding and improving eating disorder services.

The COVID-19 pandemic has led to many more people seeking treatment for an eating disorder in Wales, and clinicians report patients presenting in a more severely unwell state than before the pandemic.

A renewed commitment is now needed, with actions taken to enable faster and in particular more equitable progress toward the vision set out by the Welsh eating disorder service review, so that people in all parts of Wales affected by eating disorders can benefit from early access to high quality treatment and support.

Recommendations

In 2009 the Welsh Government published 'Eating disorders – a framework for Wales', which helped steer the development of services in the years that followed[19]. The terms of reference for the service review referred to publishing a "*new framework*" in 2019[13]. So far, the Welsh Government has only set out initial high-level priorities for eating disorder services[16]. The Welsh Government's 'Together for Mental Health 2019-2022' strategy commits it to:

> "*work with service users, carers and health boards to develop a new model of service in response to the recent independent review*." (p.38)[39]

- **Beat recommends that the Welsh Government publishes a new framework or model for eating disorder services that contains timelines for the achievement of each milestone. This should focus on:**
    - **Early intervention and prevention**
    - **Integrated care**
    - **Support for families and other carers**
    - **Investment in the workforce, including support for staff wellbeing**

The publication of such a framework or model would demonstrate renewed commitment from the Welsh Government to ensuring that the eating disorder service review shapes future services in Wales. Such endorsement of an ambitious, long-term vision for eating disorder services would be likely to support staff recruitment and retention.

In order to make implementation of a new framework or service model achievable changes are needed to ensure sufficient and equitable investment in eating disorder services across Wales. A community CAMHS clinician (#13) told us that: "*if the Welsh Government wants this development, they need to be very clear and directive to the health boards*."

- **Beat recommends that the Welsh Government specify a minimum spend on eating disorders from the Service improvement funding that it allocates to health boards and that it holds health boards to account over their investment in eating disorders.**

The National Clinical Lead for Eating Disorders has provided valuable support to health boards, services and clinicians across Wales. The extent of the challenges facing services, and continued variation in service provision across Wales underly the importance of a central resource to help guide improvements.

- **Beat recommends that the Welsh Government makes the position of 'National Clinical Lead for Eating Disorders' a permanent post.**

The work to improve eating disorder services must be grounded in the underlying principles that people with lived experience of eating disorders in Wales, including

families and other carers, articulated to the service review team[13]. During 2021 the National Clinical Lead for Eating Disorders has often consulted with people that have lived experience of eating disorders to help inform her work and that of health boards. This must now be built on to ensure that the voices of patients and families are always heard in the development of services – both at the national and local levels.

- **Beat recommends that the Welsh Government and NHS Wales ensure that people with lived experience of eating disorders, including families and other carers are formally incorporated into the monitoring, development and evaluation of eating disorder services in Wales, both at the national and local levels.**

We found that there are significant gaps in the data on eating disorders that is collected by health boards. If this continues it will limit the ability to monitor progress and deliver accountability. An eating disorders audit is expected to be commissioned in 2022. At present this audit is only due to cover England, however it could be extended to also cover Wales.

- **Beat recommends that the Welsh Government funds an eating disorders clinical audit, as part of efforts to ensure that all health boards collect and report a standard and comprehensive set of high quality data.**

Appendix – Methodology

Survey of health and care professionals and volunteers

Beat conducted a brief and anonymous online survey of health and care professionals and volunteers involved in the treatment of eating disorders in Wales from September to October 2021.

The survey included questions covering the following themes:

- The number of people with an eating disorder presenting to services and the severity of these presentations compared to pre-COVID-19.
- Eligibility criteria to access treatment
- Waiting times
- Staffing levels, staff wellbeing and burnout
- How services for people with eating disorders are provided
- Support for families and other carers
- Positive changes made to the way support and treatment is provided since the start of the COVID-19 pandemic
- What health boards, NHS Wales, and the Welsh Government should do to provide more help for people affected by eating disorders.

A total of 56 people that were currently employed or volunteering in health or care services in Wales responded to the survey. Within the main body of this report data is presented showing quantitative and qualitative answers to some of the survey questions. In graphs or charts that represent data from the survey, the total number of people that responded is specified. The response rate to the survey should be considered in the context of the small size of the eating disorder workforce in Wales. The total staffing that health boards could identify as being used specifically for the treatment of eating disorders in Wales on 31 March 2021 amounted to just 63 WTE.

A copy of all the survey questions asked, and the answer options presented can be accessed here - research.net/r/eating_disorders_Wales_copy.

Freedom of Information (FOI) requests

In August 2021 Beat submitted Freedom of Information (FOI) requests to all seven NHS Wales health boards. The questions within these FOI requests covered the following themes:

- Demand for eating disorder treatment
- The capacity of their mental health services to provide eating disorder treatment
- Plans and investment made in response to the Welsh eating disorder service review 2018

Responses were received from each health board. A significant amount of the data requested was not provided. In most cases the health board explained that this was due to the data requested not being centrally recorded or collated, meaning that extracting it would only be possible through an extensive manual search through individual patient records. Gaps in the data available and presented have been clarified within the main body of this report, in some cases within footnotes.

FOI requests were also submitted to Digital Health and Care Wales (DHCW) requesting data on hospital admissions for people with eating disorders and to the Welsh Health Specialised Services Committee (WHSSC) seeking data on the number and cost of out of country admissions.

Copies of these FOI requests are reproduced below:

Freedom of Information (FOI) request sent to Health Boards

Demand and capacity regarding eating disorder treatment

1. Please complete the table below with data on referrals to mental health services provided by the Health Board, for patients with a suspected eating disorder. *Please note that 'Adult Tier 3' should include any adult eating disorder service.*

Financial year	Total eating disorder referrals received				Number of eating disorder referrals assessed by a mental health or eating disorder service as having an eating disorder but closed without starting eating disorder treatment				Number of eating disorder referrals closed without receiving clinical eating disorder assessment from a mental health or eating disorder service.			
	CAMHS	Adult Tier 1	Adult Tier 2	Adult Tier 3	CAMHS	Adult Tier 1	Adult Tier 2	Adult Tier 3	CAMHS	Adult Tier 1	Adult Tier 2	Adult Tier 3
2018/2019												
2019/2020												
2020/2021												
2021/2022 to date (if available, please specify the months covered)												

CAMHS = Child and Adolescent Mental Health Service

2. Please detail any service restrictions/eligibility criteria around accessing eating disorder treatment from your Health Board, in the following financial years. *Please list answers separately for each relevant mental health service including any Tier 3 adult eating disorder service.*
   a) 2018/2019
   b) 2019/2020
   c) 2020/2021
   d) 2021/2022

3. Does the Health Board provide treatment specifically for child and adolescent patients (under 18 years old) assessed as meeting diagnostic criteria for Avoidant Restrictive Food Intake Disorder (ARFID)? If Yes, which Health Board service/s is this treatment provided by?

4. Does the Health Board provide treatment specifically for adult patients (18 years old and over) assessed as meeting diagnostic criteria for Avoidant Restrictive Food Intake Disorder (ARFID)? If Yes, which Health Board service/s is this treatment provided by?

5. Please complete the table below regarding the total staffing dedicated to eating disorder treatment - in Whole Time Equivalents (WTE) and broken down by professional discipline - at your Health Board, as this was on the dates below. (Please see the fictional example entered in the table below). *Please include all staff in post, whether or not they happened to be at work on these dates. Please also include any bank or agency staff that were working on those dates.*

Date	Total dedicated and identifiable eating disorder staffing (in WTE and broken down by professional discipline)			
	CAMHS	Adult Tier 1	Adult Tier 2	Adult Tier 3 (including adult eating disorder service)
At 31 March 2018				
At 31 March 2019				
At 31 March 2020				
At 31 March 2021				*[FOR EXAMPLE: 0.1 WTE Consultant Psychiatrist, 0.5 WTE Clinical Psychologist, 0.7 WTE Dietician, 2 WTE Nurse, 1 WTE Assistant Psychologist, 2 WTE Support workers]*

CAMHS = Child and Adolescent Mental Health Service

6. Please complete the table below with the number of patients who were under treatment for their eating disorder and had not yet been discharged on the dates specified, broken down by the category of mental health service they were primarily receiving treatment from. *Please note that this question is asking about the services' total caseloads on the dates specified, not the number of appointments that took place on those dates.*

Date	Size of eating disorder caseload (number of patients)			
	CAMHS	Adult Tier 1	Adult Tier 2	Adult Tier 3 (including adult eating disorder service)
At 31 March 2018				
At 31 March 2019				
At 31 March 2020				
At 31 March 2021				

CAMHS = Child and Adolescent Mental Health Service

7. Does your Health Board provide eating disorder treatment for patients who are normally resident within the geographic area of any other Health Board in Wales? If so, please provide information on this below, including the number/s of such patients (if any) included in answer to question 6, on each of the dates specified in question 6.

8. Please complete the table below, regarding median referral to start of treatment waiting times for outpatient eating disorder treatment provided by your Health Board. *Please do not provide data which relates to Inpatient treatment. Please measure this as the length of time between the referral being received by the service and the date of the second appointment. Please specify whether figures are in days, weeks or months.*

Financial year	Median Referral To Treatment (RTT) waiting times for outpatient eating disorder treatment (please specify whether figures are in days, weeks or months)			
	CAMHS	Adult Tier 1	Adult Tier 2	Adult Tier 3 (including adult eating disorder service)
Patients added to the caseload during 2018/19				
Patients added to the caseload during 2019/20				
Patients added to the caseload during 2020/21				
Patients added to the caseload during 2021/22 (if available, please specify the months covered)				

CAMHS = Child and Adolescent Mental Health Service

9. Please attach any formal protocol that the Health Board has in place to govern co-working between mental health services and diabetes services for patients who have both an eating disorder and diabetes.

10. Please attach any formal protocol that the Health Board has in place to govern co-working between mental health services and neurodevelopmental services for patients who have both an eating disorder and autism

Plans and investments made in response to the Welsh Eating Disorder Service review 2018

On 25 September 2019 Vaughan Gething MS, the-then Minister for Health and Social Services, wrote to all Health Board Chief Executives about the Welsh Eating Disorders Service review 2018. In this letter the Minister asked Health Boards to begin developing plans and making service improvements in line with the vision set out in the service review. All Health Boards were asked to "*conduct a baseline review of current waiting times and to develop improvement plans*" and the letter ended with: "*Please respond with your views on the report* [the Service review] *and recommendations and with your improvement plans following baseline reviews by 8th November* [2019]."

11. Please supply recorded information on the baseline review of waiting times for eating disorder treatment conducted by the Health Board and the correspondence, including improvement plans, that the Health Board sent to the Welsh Government in response to this letter.

Action 6.2(i) of the Welsh Government's *Review of the Together for Mental Health Delivery Plan 2019-2022 in response to COVID-19* commits the Government to "*work with service users, carers and health boards to develop a new model of service in response to the recent independent review*." The milestones set for this action for 2020 and 2021 were to "*Develop and begin implementation on local improvement plans*" (p.38).

12. Please supply recorded information on how the Health Board has developed and begun implementation of local improvement plans in response to the Welsh Eating Disorder Service review 2018, in:
    a) 2020, and
    b) 2021 (to date, please specify the months covered)

13. Since the publication of the Welsh Eating Disorder Service review 2018, the Government has asked Health Boards to submit proposals for funding to support planning and service improvements in line with the service review. Please enclose recorded information that relates to:
    a) The proposals submitted by the Health Board's clinical staff to relevant Health Board senior management
    b) The response of relevant Health Board senior management to these proposals, including whether they were funded, in part or in whole.

14. Please state how much money the Health Board has spent on its Tier 3 adult eating disorder service (if applicable) in the following financial years:
    a) 2018/19
    b) 2019/20
    c) 2020/21

d) 2021/22 (if available, please specify the months covered)

15. Please state how much money the Health Board has spent specifically on the treatment of eating disorders (excluding that detailed in answer to Question 14) in the following financial years:
    a) 2018/19
    b) 2019/20
    c) 2020/21
    d) 2021/22 (if available, please specify the months covered)

Freedom of Information (FOI) request sent to Digital Health and Care Wales (DHCW)

1. Please disclose the number of child and adolescent patients (under 18 years old) in Wales **assigned a GP Read code (or SNOMED CT code) for any eating disorder** in the following financial years, broken down (if possible) by the Health Board where they were normally resident:
   a) 2016/17
   b) 2017/18
   c) 2018/19
   d) 2019/20
   e) 2020/21 (If available, please specify the months covered)

2. Please disclose the number of adult patients (18 years old and over) in Wales **assigned a GP Read code (or SNOMED CT code) for any eating disorder** in the following financial years, broken down (if possible) by the Health Board where they were normally resident:
   a) 2016/17
   b) 2017/18
   c) 2018/19
   d) 2019/20
   e) 2020/21 (If available, please specify the months covered)

Please note:

- *If data for any Health Boards must be withheld/redacted due to small numbers, please also provide national totals.*

- *'Emergency admissions' are to be defined as admission episodes with an 'admission method' indicating the admission was an emergency (codes 21 to 25 or 27 to 28 in the Admitted Patient Care Dataset, See: NHS Wales Data Dictionary for details regarding these codes).*

3. Please provide the following data regarding **inpatient treatment** for child and adolescent patients (under 18 years old) with a **primary diagnosis of an eating disorder** (ICD10 4 Characters: F500-F509 or ICD11: 6B80; 6B81; 6B82; 6B83; 6B8Y; 6B8Z) in the following financial years: 2018/19; 2019/20; 2020/21 and 2021/22 (If data for 2021/22 is available, please specify the months covered), broken down (if possible) by the Health Board where they were normally resident:
   a) Finished Consultant Episodes
   b) Total number of admissions:
   c) Number of emergency admissions
   d) Median waiting time (please specify whether in days or weeks)
   e) Median length of stay (please specify whether in days or weeks)
   f) Total number of bed-days

4. Please provide the following data regarding **inpatient treatment** for adult patients (18 years old and over) with a **primary diagnosis of an eating disorder** (ICD10 4 Characters: F500-F509 or ICD11: 6B80; 6B81; 6B82; 6B83; 6B8Y; 6B8Z) in the following financial years: 2018/19; 2019/20; 2020/21 and 2021/22 (If data for 2021/22 is available, please specify the months covered), broken down (if possible) by the Health Board where they were normally resident:
   a) Finished Consultant Episodes
   b) Total number of admissions:
   c) Number of emergency admissions
   d) Median waiting time (please specify whether in days or weeks)
   e) Median length of stay (please specify whether in days or weeks)

f) Total number of bed-days

5. Please provide data regarding the number of **emergency hospital admissions** for child and adolescent patients (under 18 years old) with **either a primary or secondary diagnosis of an eating disorder** (ICD10 4 Character codes: F500-F509 or ICD11: 6B80; 6B81; 6B82; 6B83; 6B8Y; 6B8Z) in the following financial years, broken down (if possible) by the Health Board where they were normally resident:
   a) 2018/19
   b) 2019/20
   c) 2020/21
   d) 2021/22 (if available, please specify the months covered)

6. Please provide data regarding the number of **emergency hospital admissions** for adult patients (18 years old and over) with **either a primary or secondary diagnosis of an eating disorder** (ICD10 4 Character codes: F500-F509 or ICD11: 6B80; 6B81; 6B82; 6B83; 6B8Y; 6B8Z) in the following financial years, broken down (if possible) by the Health Board where they were normally resident:
   a) 2018/19
   b) 2019/20
   c) 2020/21
   d) 2021/22 (if available, please specify the months covered)

Freedom of Information (FOI) request sent to Welsh Health Specialised Services Committee (WHSSC)

If data for any Health Boards must be withheld/redacted due to small numbers, please also provide national totals.

1. Please disclose **the total number of admissions to specialist inpatient eating disorder units in England** that have been made for patients with an eating disorder referred from Wales, broken down (if possible) by the Health Board where they were normally resident, in the following financial years:
   a) 2018/19
   b) 2019/20
   c) 2020/21
   d) 2021/22 (if available, please specify the months covered)

2. Please disclose **the total costs of the admissions detailed in answer to Question 1**, broken down (if possible) by the Health Board where the patients were normally resident, in the following financial years:
   a) 2018/19
   b) 2019/20
   c) 2020/21
   d) 2021/22 (if available, please specify the months covered)

References

1. Schmidt, U., Adan, R., Böhm, I., Campbell, I.C., Dingemans, A., Ehrlich, S., Elzakkers, I., Favaro, A., Giel, K., Harrison, A., Himmerich, H., Hoek, H.W., Herpetz-Dahlman, B., Kas, M.J., Seitz, J., Smeets, P., Sternheim, L., Tenconi, E., van Elburg, A., van Furth, E., and Zipfel, S. (2016) Eating disorders: the big issue. *The Lancet Psychiatry*. Vol.3(4), p.313-315.

2. Beat (2018) *How many people have an eating disorder in the UK?*

3. Sweeting, H., Walker, L., MacLean, A., Patterson, C., Räisänen, U., and Hunt, K. (2015) Prevalence of eating disorders in males: a review of rates reported in academic research and UK mass media. *International Journal of Men's Health*. Vol.14(2).

4. Micali, N., Martini, M.G., Thomas, J.J., Eddy, K.T., Kothari, R., Russell, E., Bulik, C.M., and Treasure, J. (2017) Lifetime and 12-month prevalence of eating disorders amongst women in midlife: a population based study of diagnoses and risk factors. *BMC Medicine*. Vol.15(12).

5. Conceição, E.M., Gomes, F.V.S., Vaz, A.R., Pinto-Bastos, A., and Machado, P.P.P. (2017) Prevalence of eating disorders and picking/nibbling in elderly women. *International Journal of Eating Disorders*. Vol.50(7), p.793-800.

6. Waller, G., Schmidt, U., Treasure, J., Emanuelli, F., Alenya, J., Crockett, J., Murray, K. (2009) Ethnic origins of patients attending specialist eating disorders services in a multiethnic urban catchment area in the United Kingdom. *International Journal of Eating Disorders*. Vol.42(5), p.459-463.

7. Huryk, K.M., Drury, C.R., and Loeb, K.L. (2021) Diseases of affluence? A systematic review of the literature on socioeconomic diversity in eating disorders. *Eating Behaviours*. Vol. 43(101548).

8. Arcelus, J., Mitchell, A.J., Wales, J. and Nielsen, S. (2011) Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies. *Archives of General Psychiatry*. Vol.68(7), p.724-31.

9. Chesney, E., Goodwin, G.M., and Fazel, S. (2014) Risks of all-cause and suicide mortality in mental disorders: a meta-review. *World Psychiatry*. Vol.13(2), p.153-60.

10. Royal College of Psychiatrists (2019) *PS03/19 Position statement on early intervention in eating disorders*

11. Beat (2017) *Delaying for years, denied for months*

12. Beat (2021) *Family Empowerment*

13. Tan, J., Lewis, M., Missen, H., Taylor, B., and Johns, G. (2018) *Welsh Government Eating Disorder Service Review 2018*. [Executive summary available at: https://gov.wales/eating-disorders-service-review-2018].

14. Welsh Government (2021) *A healthier Wales: long term plan for health and social care*

15. Welsh Government (n.d.) *The Well-being of Future Generations*

16. Gething, V. (2019) *Written Statement: Review of Welsh Eating Disorder Services*

17. Gething, V. (2019) [letter to Chief Executives of Health Boards; Sent 25 September 2019] [Not published].

18. StatsWales (2021) *Population estimates by local health boards and age*

19. Welsh Assembly Government (2009) *Eating Disorders - A Framework for Wales*

20. Beat (Forthcoming) *Experiences of people with Binge Eating Disorder*

21. Welsh Government (2021) *Specialist Child and Adolescent Mental Health Services (sCAMHS) first appointment waiting times: quality report*

22. Beat (2021) Carer's survey [Not published]

23. Gething, V. (2020) *Ein cyf/Our ref: WQ80512/WQ80513*

24. HM Treasury (2021) *GDP deflators at market prices, and money GDP October 2021 (Budget and Spending Review)*

25. Cwm Taf Morgannwg University Health Board (2018) *Bridgend boundary change*

26. Goodall, A. (2018) *Health Board 2019-20 Allocations* [Letter to Chief Executives – Local Health Boards; Chief Executives – NHS Trusts]

27. Morgan, E. (2021) [Answer to Written question] *WQ82217 (e)*

28. Welsh Government (2019) Additional Resources for Mental Health 2019-20 Onwards [Letter to Chief Executives of Health Boards, Adult Mental Health Clinical Leaders, CAMHS Clinical Leaders, General Managers and Strategic Leads, Directors of Finance] [Not published]

29. Welsh Government (2020) Additional Resources for Mental Health 2020-21 [Letter to Adult Mental Health Clinical Leaders, CAMHS Clinical Leaders, General Managers and Strategic Leads, Directors of Finance] [Not published]

30. Welsh Government (2021) Additional Resources for Mental Health 2021-22 [Letter to Adult Mental Health Clinical Leaders, CAMHS Clinical Leaders, General Managers and Strategic Leads, Directors of Finance] [Not published]

31. Academy for Eating Disorders (2020) *A Guide to Selecting Evidence-based Psychological Therapies for Eating Disorders (1st edition)*

32. Branley-Bell, D., and Talbot, C.V. (2020) Exploring the impact of the COVID-19 pandemic and UK lockdown on individuals with experience of eating disorders. *Journal of Eating Disorders*. Vol.8(44).

33. Royal College of Psychiatrists (2021) *Hidden epidemic of eating disorders because of COVID-19, new research finds*

34. UK Parliament (2021) *Eating Disorders: Mental Health Services - Question for Department of Health and Social Care - UIN 61184, tabled on 22 October 2021*

35. The Scotsman (2021) *Eating disorders among under-18s in Scotland soared in lockdown, psychiatrists warn*

36. Welsh Government (2021) *Health and Social Care in Wales – COVID-19: Looking forward*

37. Phillips, L., and Jones, M. (2021) *Eating disorders and Paediatrics presentation*. [Published by NHS Wales Health Collaborative Mental Health Network].

38. Digital Health and Care Wales (2021) *NHS Wales Data Dictionary*.

39. Welsh Government (2021) *Review of the Together for Mental Health Delivery Plan 2019-2022 in response to COVID-19*

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About Beat

Beat is the UK's eating disorder charity. We exist to end the pain and suffering of eating disorders, and we are here to help anyone affected by these serious mental illnesses. We provide information and support through Helplines, which people can call, text or email. We also run online support groups and HelpFinder, an online directory of support services.

We campaign for change in policy and practice, provide expert training, resources and consultancy to health and education professionals, and support and encourage research into eating disorders.