

Cross Party Group on Eating Disorders Minutes

29 February 2024, 10:15 – 11:30
Microsoft Teams

In Attendance

- Sarah Murphy, MS
- Mark Isherwood MS
- Lynne Neagle – Deputy Minister for Health and Wellbeing
- Jo Whitfield, Beat
- Brandon Renard, Member Support Staff
- Tamsin Speight, Eating Disorders Clinical Lead, NHS Executive
- Carole Philips
- Rachel Humphreys, Cardiff & Vale UHB
- Matt Downton, Welsh Government
- Emma Hagerty, Clinical Lead Specialist Eating Disorder Service ABUHB
- Yolanda Snyman. Advanced Dietitian and Dietetic Lead, BCUHB
- Donna Jackson, CTMUHB
- Donna Mason, Mental Health Matters
- Martin Ball
- Sarah Crowley, NHS Executive
- Caroline Roberts, ABUHB
- Sian Taylor, Clinical Specialist & Strategic Lead Dietitian ABUHB
- Ruth Steggles
- Chloe Olds
- Victoria Gilchrist, Beat
- Amelia Holt, Beat
- Helen Missen
- Natalie Chetwynd, Hywel Dda UHB - Clinical Lead Tier 3 Eating Disorders
- Emily Hoskins
- Hazel Orchard
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Welcome, apologies & minutes from last meeting

Sarah Murphy welcomed everyone to the meeting.

Apologies were received from:

- James Downs
- Nia Holford, CTMUHB
- Sarah Tombs, CTMUHB
- Rebecca Bowen, Cardiff & Vale UHB - CAMHS
- Dr Umer Jalal, Cardiff & Vale UHB
- Isabella Jurewicz, RCPsych Eating Disorder Faculty / Cardiff & Vale UHB

The minutes from the last meeting were agreed as correct.

Sarah Murphy began the meeting by recapping a question she had posed to the First Minister during Eating Disorders Awareness Week. She had asked about the future of residential eating disorder treatments. The First Minister had answered Sarah's question by explaining that Wales now has 8 beds in a private unit; however, there is work and investigations being carried out to hopefully provide a further 15 beds for those who need them. This shows progress, which Sarah Murphy will continue to chase up.

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AGM, Election of Chair and Secretariat

Sarah Murphy was elected as Chair and Beat as Secretariat with unanimous support. Mark Isherwood formally nominated Sarah Murphy to continue as Chair, and this was seconded by Jane Dodds following the meeting.

Deputy Minister for Mental Health Welcome & Eating Disorder Awareness Week

Sarah welcomed Lynne Neagle, Deputy Minister for Mental Health to the meeting.

Sarah ran through the agenda and made everyone aware of Eating Disorders Awareness Week (EDAW) and the theme of Avoidant Restrictive Food Intake Disorder (ARFID). She then extended thanks to those in attendance. She reflected on the fact it has been two years since she shared her own lived experience in the Senedd and extended special thanks to The Deputy Minister for her work. She expressed that some of the improvements and movement she has seen are some of the first in decades: waiting time targets are coming down; people are finally getting support. She also explained she had been in contact with the CTMHB Tier 2 service and the charity Mental Health Matters regarding peer support.

The Deputy Minister stressed the importance of the work of cross-party groups and thanked Sarah for her work on raising the issues surrounding eating disorders within the Senedd and the wider community.

ARFID Service, Aneurin Bevan University Health Board (ABUHB)

Caroline Roberts and Sian Taylor delivered a presentation about the CAMHS ARFID service at ABUHB – Please see accompanying slides.

Caroline explained that adult and under-18 ARFID services are not just one service, but that there are good transition arrangements in place. Caroline explained the diagnostic criteria of ARFID according to the DSM5 and ICD11. They explained that symptoms and causes can overlap, and that sensory factors are one of the most prevalent contributing factors. It was also explained that if ARFID is associated with another disorder, it must exceed the significance of the other disorder to be considered ARFID. If not, it is best understood within the context of the other disorder. They explained that this shows a further need for interdisciplinary practices, clear assessment and understanding of needs and drivers of ARFID. Caroline Roberts shared an ARFID lived experience story from Beat's EDAW resources.

Sian explained that discussions in 2018 led to the ARFID model in Wales in answer to complaints and lack of services. Now – while they are still a small service, they have a three-level model.

Caroline and Sian explained that their services are not assessment first. They explained that their level one services increased awareness, provide clinical resources, training and support. Their level two services support existing services in response to a referral of a young person: such as access to webinars; advice; support; consultations and joint working. Their level three services include a 1.5 hour assessment – leading to intervention planning, parent workshops and follow ups.

Caroline and Sian went on to explain how they aim to stabilise risks and support individuals but wish they could do more. They went on to explain that services for children and adults have their own unique challenges: such as the heterogenous population; heterogenous presentation; child

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development and readiness and willingness; the lifelong nature of the condition; and the fact that the range of needs cannot be met by one service alone – and instead they may require paediatrics, mental health services, child development services, and community services. A whole system approach is needed, and one size does not fit all. They also explained that the aim is often to manage rather than treat ARFID - as it is a chronic and lifelong condition. Caroline and Sian then showed a graph of their referrals for 2023 – 50% of which were under 9 years old. The sources of their referrals were demonstrated to be very varied. Furthermore, they demonstrated the outcome of their referrals, and explained that they wish to be able to offer more clinic assessments. They then showed reviews from parents regarding their workshops, which were very positive.

Emma Hagerty then explained that the adult eating disorder service does not have a standalone ARFID service, but rather their ARFID treatment is part of their wider eating disorder services. The numbers of patients with ARFID are very low – at less than 10% - but they expect these to increase as awareness is raised. Emma Hagerty explained that their ARFID pathway is being formalised and they are developing an ARFID service.

Sarah thanked Caroline, Sian and Emma and acknowledged that the work is in response to a clear need. She acknowledged the need for multi-disciplinary approaches, and re-iterated that there are no National Institute for Health and Care Excellence (NICE) guidelines for ARFID.

Lived experiences of eating disorder recovery in Wales

Sarah handed over to Jo who welcomed Chloe, Ruth and Sara who shared their experiences of recovery and supporting someone with recovery from an eating disorder in Wales.

Chloe shared how her experience began around the age of 13. Her experience with CAHMS was inconsistent, and she received most of her help from a dietician. Her and her family were given unhelpful advice and used her weight as bargaining for psychological support. Her school also struggled to help her, through lack of understanding. She felt lost in the system and felt that the only concern was her weight restoration rather than her mental health. She called for extra support, training and more funding.

Ruth then shared her story of being a parent of a child with an eating disorder. She shared that there were feelings of denial, failure, frustrations and fear. She acknowledged that she was lucky with her GP, but that in Wales there is a postcode lottery. The system they were a part of wanted to wait until there was further weight loss before they could diagnose and help her daughter. She expressed the difficulties of navigating the guilt, insecurities and blame – and how difficult she found it to listen to professionals talk about what was going on with her daughter. She felt passed pillar to post and uninvolved in her daughters' treatment. Nobody showed her the importance of parents, intervention and support. Ruth called for further involvement and empowerment of parents and family in support of people with eating disorders. Ruth explained that she is now undertaking a master's degree and is recruiting parents who have a child with an eating disorder to take a strengths-based intervention for her dissertation.

Jo encouraged attendees to look at Ruth's [research](#) and suggested that Ruth might like to provide an update on her research in a future meeting.

Sara then described her experience of T1DE – Type 1 Diabetes and Disordered Eating. She

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described how she felt like a fraud, as there is no mention of an eating disorder in her notes at all. She explained the lack of information and how scary it was to have no help – as professionals have little to no knowledge of it. She described that 40% of young women with Type 1 Diabetes develop an eating disorder by age 25 – but commented that many go unreported, due to the steps people with diabetes having to take being very similar to the symptoms of disordered eating. She ran through the diagnosis criteria of eating disorders, and compared how close they are to what you must do if you have Type 1 Diabetes and described how this can cause T1DE to go undiscovered.

Jo and Sarah both thanked the volunteers. They praised the use of experience to improve the future for those with eating disorders.

Update on Welsh Government eating disorder service improvement work.

Sarah handed over to The Deputy Minister for Mental Health.

The Deputy Minister thanked the lived experience volunteers and expressed that those experiences are not what we want them to be.

The Deputy Minister explained that she had recently provided a written update to the Senedd. The Deputy Minister expressed her gratitude for the NHS staff who provide care and support, and described that partners continue to try to improve in the face of increasing need, challenging financial scenarios and complex backdrops.

The Deputy Minister spoke of her recent visit to the eating disorders team in Gwent - and while there is good work being done there is still much to improve on. Tamsin Speight is now on board as clinical lead and assists in driving mental health improvement across Wales.

The Deputy Minister acknowledged the variation across Wales in accessing treatment and acknowledged that the provision in ABUHB for ARFID is something that she would like to see replicated across Wales. The Deputy Minister told the group that the Clinical Lead will be setting up a task and finish group as a priority to look at scaling up ARFID specialist support across the whole of Wales and that terms of reference for this group were currently being produced. The Deputy Minister assured attendees that the task and finish group would be set up quickly that outcomes will be available as soon as possible.

The Deputy Minister told the group that all health boards are doing exceptional work, and that she had been able to visit the team in BCHUB where they have reduced the numbers of people with anorexia being admitted to hospital and made progress in reducing the use of feeding tubes. BCUHB have also recruited a specialist cardiologist to their team.

The Deputy Minister acknowledged that improving access to specialist support and inpatient support is important but that a focus on early intervention is also a priority to prevent the need for intensive care. The Deputy Minister explained that the Clinical Lead and her team are working with several health boards to explore the introduction of First Episode and Rapid Early Intervention in Eating Disorders (FREED) and looking at how the model could be

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adapted to the specific needs of Wales. The Deputy Minister explained that the goal of FREED is for treatment to start within 4 weeks of referral to an eating disorder service and that it has been designed to look at the specific needs of young people in the early stages of an eating disorder. The Deputy Minister reflected on listening to Chloe's testimony earlier, that FREED would have been of great help had it been in place when Chloe was unwell.

The Deputy Minister explained that FREED focusses on early and proactive engagement with the emphasis on the effects of eating disorders on the brain along with attention to social media use. The Deputy Minister explained that under the guidance of the Clinical Lead and the NHS Executive that health boards will be expected to align their services and ensure that wherever people are in the country they can expect to access a similar level of specialist treatment. The Deputy Minister told the group that there is work being carried out in various mental health services to draft service specifications to ensure equity across services.

The Deputy Minister acknowledged that inpatient care has been a source of concern and explained that as well as the 8 beds now available in Ebbw Vale, which can be extended to 15 beds. The Welsh Health Specialist Services Committee (WHSSC) will be publishing their long-term strategy soon.

The Deputy Minister concluded by reporting that the Welsh Government has just published its draft Mental Health Strategy setting out the longer-term actions to improve mental health across Wales, including eating disorders, and alongside the strategy they have also published their Suicide and Self Harm Prevention draft strategy. Both are out for consultation for 16 weeks and the Deputy Minister encouraged attendees to take a look and share their views and for MSs to encourage constituents to respond and help inform future work. Following the consultations both strategies will be published and be accompanied by a delivery plan which over the time of the strategy will be renewed and refreshed providing opportunity to identify new investments should the economic position change.

Sarah thanked The Deputy Minister, and confirmed that links to the consultations will be sent to group members.

Jo thanked the Deputy Minister for her update and reflected how encouraging it is to hear about the work that is being done to ensure that there isn't a postcode lottery when people reach out for specialist support. Jo asked the Deputy Minister what plans and timescales are in place for the work that the Deputy Minister had outlined. The Deputy Minister stressed that consistency of service provision is of top priority and that FREED is something that is new to Wales. The Deputy Minister also shared that ABUHB have developed their own model which is similar to FREED. The Deputy Minister was unable to provide precise timescales for FREED implementation at this stage but was able to reassure the group that the Welsh Government understands the importance of undertaking the work with as much

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pace as possible, and that she has been discussing with the Clinical Lead and NHS Executive about how to get more assurance in place about what is happening with the investments being made for eating disorder services. The Deputy Minister shared that it's not just eating disorder services that she has concern that we are a small country doing things differently in different Health Boards and that she wants to move to a much more consistent approach as soon as they possibly can. The Deputy Minister told that group that £2.2million had been dedicated to mental health resources in the NHS Executive and that isn't something that Wales has ever had before, and that she's hopeful that they'll be able to provide timescales in the not-too-distant future. She further explained that change isn't always easy in the NHS, health boards have their own methods, but the government is determined to try and take everybody with them on the journey and to have a really high quality service. The Deputy Minister stressed that the commitment's there, the resources are being put in and that now it needs to be translated into a consistent service for everyone. The Deputy Minister told the group that she hopes that if there is a CPG in five years' time, that they won't be hearing stories like that of Chloe's because that is not how the government want it to be for people who are accessing services.

Jo thanked the Deputy Minister and reflected that she too hoped that in 5 years' time we will be able to see much progress made.

Sarah thanked the Deputy Minister for her time, for providing an update, answering questions and listening to everyone's contributions.

Review of Actions

Sarah and Jo will work on a CPG plan for the year ahead and share with group members. Such plan will include:

- An update at a future meeting on the T1DE work underway across Wales
- Follow up on ARFID and lack of NICE guidelines, write collectively as a group to NICE.
- An update at a future meeting on the work BCUHB has done to reduce the numbers of people with anorexia being admitted to hospital the impact a specialist cardiologist has made to their team.
- A session focusing on older people and eating disorders
- A further update from ABUHB adult eating disorder team about the work they have been able to undertake in their service.
- An eating disorder support awareness day for MSs involving third sector organisations and voluntary groups.

Mark Isherwood requested some support about a specific case he's helping a constituent with. Jo will contact Mark outside of the meeting to discuss further.

Date of next meeting - TBC