

Cyflwynwyd yr ymateb hwn i ymchwiliad y [Pwyllgor Plant, Pobl Ifanc ac Addysg i gymorth iechyd meddwl mewn addysg uwch](#)

This response was submitted to the [Children, Young People and Education Committee inquiry into Mental Health support in Higher Education](#)

MHHE 31

Ymateb gan: Diabetes UK Cymru

Response from: Diabetes UK Cymru

Nodwch eich barn mewn perthynas â chylch gorchwyl yr ymchwiliad. | Record your views against the inquiry's terms of reference.

1. Maint yr angen | Extent of need

People living with Diabetes (PLWD) experience higher levels of psychological distress than people without diabetes¹. This is due to the additional stresses and pressure of diabetes, but also because there are specific psychological issues that only PLWD experience.

Unfortunately, PLWD have double the risk of suicide or intentional self-injury compared with the general population. Further, most people with diabetes won't admit they are suicidal and will fail to inform healthcare professionals for fear of their response. Many suicide attempts might be mistaken for accidental hypoglycaemia or diabetic ketoacidosis. One study of 160 cases of insulin overdose leading to severe hypoglycaemia found that 90% were suicidal or parasuicidal, and only 5% accidental. (Parasuicide is severe and deliberate selfharm with or without suicide intent that does not lead to death)².

Student (18 – 25) living with type 1 diabetes who have just recently moved to Wales and transferred from paediatric care are the most vulnerable age group of PLWD. In r Rose Stewart's Report, Missing to Mainstream, the report highlights the need for dedicated psychological support for young adults as they are a particularly vulnerable group and are at an increased risk of DKA (Diabetic Ketoacidosis)³.

Unmet psychological need significantly affects all areas of diabetes care; it increases psychological and physical risks to PLWD and their families and adds substantial

¹ Missing to Mainstream, A Values Based Action Plan for Diabetes Psychology in Wales, Dr Rose Stewart 2022, <https://diabetespsychologymatters.files.wordpress.com/2022/04/missingtomainstream-final-pdf.pdf>

² Diabetes UK, 2022, Reducing the Risk of Suicide in People with Diabetes, https://www.diabetes.org.uk/about_us/news/reducing-risk-suicide-people-diabetes

³ Diabetes UK Cymru, 2019, Too Often Missing: 'Making Emotional and Psychological support in routine diabetes care – What needs to happen in Wales'. [Diabetes UK emotional wellbeing policy document \(Wales\).pdf](#)

burden and cost to an already overstretched NHS. Links between increased psychological distress and worsening diabetes self-management are also well established, with high diabetes distress predicting higher average blood glucose levels (as measured by HbA1c) in both people with type 1 and type 2 diabetes⁴.

The experience of students who would have been diagnosed with diabetes or moved to a different part of the country during Covid-19 would have experienced a different level of care than expected pre-pandemic.

Before the pandemic, we highlighted in our report "Too Often Missing" that seven in ten people living with diabetes felt overwhelmed by the day-to-day management of their condition⁵. The same number of people also reported that they could not access the specialist care and mental health support they needed. Meaning that they could not access the care they needed to live well with their diabetes.

In our most recent report, Diabetes is Serious, people living with diabetes found that not much had changed, and access to services had worsened for some⁶. During the pandemic, 35% of people living with diabetes experienced poor mental health, with a third feeling that they did not have sufficient access to emotional and psychological support. Access to services to manage diabetes is crucial to maintaining a healthy mindset, as regular check-ups are critical to keeping diabetes under control in reducing the chances of amputations, stroke, heart failure and diabetic retinopathy.

Diabetes UK Cymru has heard from many parents concerned about their children's safety and emotional well-being throughout the pandemic. The most recent National Paediatric Diabetes Audit found lower completion rates of all recommended health checks than in previous years⁷. This also led to an increase of children and young people with type 1 diabetes (46.5% compared to 43.9% in 2019/20) assessed as requiring additional psychological support in the UK⁸. As noted in Dr Rose Stewart's report, the gulf between increased need and current provision continues to widen, increasing the number of young adults unable to find the support that they need.

⁴ Type 1 : Hessler, D. M. (2017). Diabetes distress is linked with worsening diabetes management over time in adults with type 1 diabetes. *Diabetic Medicine*, 34(9), 1228-1234

Type 2: Fisher, L. M. (2010). Diabetes distress but not clinical depression or depressive symptoms is associated with glycemic control in both cross-sectional and longitudinal analyses. *Diabetes Care*, 33(1), 23-28.

⁵ Diabetes UK Cymru, 2019, Too Often Missing: 'Making Emotional and Psychological support in routine diabetes care – What needs to happen in Wales'. [Diabetes UK emotional wellbeing policy document \(Wales\).pdf](#)

⁶ Diabetes UK Cymru, 2022, Diabetes is Serious; https://diabetes-resources-production.s3.eu-west-1.amazonaws.com/resources-s3/public/2022-04/Diabetes%20is%20Serious%20Report%20Digital_0.pdf?VersionId=ILpcXWRXhAli4Y3D_y7BABGqrGOq9IcB

⁷ Royal College of Paediatrics and Child Health (2022), National Paediatric Diabetes Audit – National Report 2020/21: Care Processes and Outcomes

⁸ Royal College of Paediatrics and Child Health (2022), National Paediatric Diabetes Audit – National Report 2020/21: Care Processes and Outcomes

Therefore, we expect that students living with diabetes who are now entering higher education may require additional support.

2. Adnabod a darpariaeth | Identification and provision

The Diabetes Delivery Plan estimates that 41% of people living with diabetes in Wales have poor psychological well-being; however, none of the key service actions of the plan are related to mental health⁹. This gap in the delivery plan needs to be addressed by a successor Quality Statement and any Action Plan that focuses on delivering mental health services within the diabetes multi-disciplinary team.

Without a successor plan or quality statement in place, DUK Cymru is concerned that there will be insufficient joint thinking between Higher Education Institutions and local health services as future delivery outcomes and pathways have not been set, especially for mental health provision and transition from paediatric care to adult mental health services.

The Equality Act 2010 legally defines children with diabetes as people living with a disability; as such, Higher Education Institutions and the NHS must ensure that students living with diabetes are not disadvantaged.

Measures to ensure that PLWD are supported include reasonable adjustments such as adequate space and time to manage their blood glucose levels and administer medication. Welsh Government regulations which support institutions such as Universities and Colleges are set out in the guidance by Welsh Government¹⁰. Further, the Additional learning needs Education Tribunal (Wales) Act 2018, sets out how children and young people under 25 years with ALN should be supported.

A new statutory measure, called Individual Development Plans, supports students by requiring educational settings to develop a supportive framework for the student and to ensure that their academic, physical and supportive needs are met. Recent research reviewing the impact of living with diabetes and educational attainment found a negative association between diabetes and overall grade attainment. The most significant divide is found in physical subjects such as sports/athletics, with the least difference in subjects such as Mathematics¹¹. The study found that students living with type 1 diabetes generally are more likely to have an increased number of days away from school related to the condition. These missed days of education related to the management of the condition and diabetes burnout, a psychological byproduct of living with diabetes which in turn affected academic performance.

⁹ Welsh Government, 2016, Diabetes Delivery Plan 2016 – 2020, <https://gov.wales/diabetes-delivery-plan-2016-2020>

¹⁰ The Equality Act 2010 (Disabled School Pupils) (Wales) Regulations 2021, <https://gov.wales/equality-act-2010-disabled-school-pupils-wales-regulations-2021>

¹¹ Oakley NJ, Kneale D, Mann M, et al. Type 1 diabetes mellitus and educational attainment in childhood: a systematic review. *BMJ Open* 2020;10:e033215. doi:10.1136/bmjopen-2019-033215.

In a recent survey conducted during the Summer of 2022 of people living with diabetes as part of the 'Missing to Mainstream', DUK Cymru found that 37% of PLWD continued to face stigma associated with their diabetes.¹² The survey also found that 77.6% of respondents feel that the General Public doesn't understand diabetes at all or not very well compared to 26% of respondents giving the same response for Health Care Professionals (general) understanding. Therefore, a greater understanding of the condition is needed with welcomed awareness of hidden conditions such as diabetes by educational institutions, especially for lecturers and peers who may be unaware of the overall impact of the condition.

Support should also be granted with reference to documentation (provided by charities like DUK Cymru) on workplace support for PLWD. In our Summer survey, we also found qualitative results referring to poor work practices where insufficient adjustments were made to support PLWD to manage their diabetes well whilst at work. Students undertaking part-time employment whilst in education is not uncommon; for many, this may be the first time they have undertaken employment. Support should therefore be readily available to help students understand their rights when working during their studies and as they enter the general workforce after they have completed their education. The same support and guidance should be available for students and young adults undertaking traineeships, work experience and apprenticeships.

The current cost of living crisis was also mentioned, especially regarding eating well and the 'hidden costs' of living with type 1 diabetes, such as storing insulin and travel costs to meet medical appointments. As Universities and Higher Education institutions review the support of students during these difficult times, extra thought and care should be given to students living with long-term conditions such as diabetes.

3. Polisiau, deddfwriaeth a chyllid Llywodraeth Cymru | Welsh Government policy, legislation and funding

Diabetes UK Cymru continuously calls for psychological support to be a routine part of diabetes care. The stresses associated with self-management, especially for people who use insulin to treat their diabetes, require care and support from diagnosis throughout a person's life as they live with diabetes. Currently, for many, those living with diabetes are not given the opportunities to discuss their emotional or psychological issues with their diabetes team because current consultations focus on other clinical outcomes. In a recent survey as part of Diabetes UK's 'Diabetes is Serious Campaign', two-thirds of PLWD who had experienced difficulty managing

¹² Missing to Mainstream Summer 22 PLWD Survey, DUK Cymru, 2022

their diabetes in 2021 attributed their difficulties with insufficient access to their healthcare team¹³.

The ideal would be for specialist adult clinical psychology services to be available in every health board in Wales, but we are some way from achieving this ambition. Where specialist services exist, their current workload exceeds the team available to support people with their condition. Further, it can be difficult for diabetes teams to secure sustained funding for psychological input into multi-disciplinary teams, even when the evidence supports further investment and indicates clear benefits for patient care and long-term health in reducing complications and further pressures on the NHS. Diabetes UK Cymru is therefore calling for further action by:

- Improving workforce planning to prioritise increasing the number of trainee physical health psychologists.
- Developing an integrated pathway for diabetes that includes emotional support and access to specialist psychological services for those who need it.
- Providing emotional wellbeing training for all healthcare professionals supporting general diabetes care to help identify psychological distress.
- A nationwide framework for transitional care (paediatric to adult services) which includes provision for psychological services.

Dr Rose Stewart's Report, *Missing to Mainstream*, sets out a framework for integrated specialist diabetes psychological care across Wales at all levels of need. The key recommendations of the report echo calls made by DUK Cymru with specialist support for high-risk groups such as young adults with the integration of psychological thinking across all diabetes service developments.

Higher Education institutions could ensure that support is made available by supporting PLWD from their first day at the University as part of their induction. Highlighting where support services are available, referencing them to local health amenities and ensuring that access to psychological services to support their mental health are readily available and accessible.

Local Health Boards, working with Higher Education Institutions, should consult each other when seeking increased/improved provision of mental health services for young adults, especially those living with conditions like diabetes who are more at risk of poor mental health.

4. Argymhellion ar gyfer newid | Recommendations for change

- Increased access to dedicated psychological services for people living with diabetes

¹³ Diabetes is Serious, 2022, DUK, https://www.diabetes.org.uk/get_involved/campaigning/diabetes-is-serious

- Increased awareness of 'unseen' conditions such as diabetes at Higher Education Provision with support for students accessing services or seeking employment with bodies outside of the educational setting; this includes traineeships, work experience and apprenticeships.
- Dedicated support for people living with conditions such as diabetes as required through the Additional learning needs Education Tribunal (Wales) Act 2018
- A nationwide framework for transitional care (paediatric to adult services) which includes provision for psychological services.

5. Arall | Other