

**Grŵp Iechyd a Gwasanaethau Cymdeithasol
Health and Social Services Group**



Llywodraeth Cymru
Welsh Government

Ref: ATISN 18836

22 August 2023

Dear ,

ATISN 18836 – ADHD assessments

Thank you for your request to the Welsh Government for information under the Freedom of Information Act (2000) received on 12 August 2023. I have interpreted your request as follows:

You refer to the Deputy Minister for Social Services written statement (August 2022) and a previous FOI request (ATISN 16570).

- 1. Please provide the latest data available on waiting times for ADHD and Autism clinical assessments for adults in Wales, if possible, by Local Health Board but if not for Wales as a whole.*
- 2. If the Welsh Government is not collecting waiting time data, please provide details of what other quantitative evidence has been found of unmet demand / waiting time pressures for these assessments.*
- 3. Please indicate by what means, improvements in waiting time pressures (because of the funding and the improvement programme) will be measured if waiting times are not being collected?*

Response

The Welsh Government does not collect the data requested on adults with ADHD or autism. The delivery of ADHD and autism services is the responsibility of each local health board in Wales, you may wish to contact each individually to request this information. I have added a link below that provides contact points for each health board: [Contact Us - NHS Wales](#)

To ensure sustainable neurodivergence services there is a need for robust national data on prevalence, service specific demand and outcomes for the population of Wales. The Demand and Capacity Review report, published in October 2022, made a range of recommendations in relation to service improvement based on improved data collection and reporting mechanisms.

“Improve the comprehensiveness of data on the demand for services, their performance and funding, in order to better understand the challenges services face and their performance. “

Welsh Government are prioritising the development a new reporting framework which will capture high level data and outcomes for children, young people and adults, including waiting times. This will replicate the information already collected for children’s neurodevelopmental services.

To support this work Welsh Government are in the process of seeking advice from our Ministerial Advisory Group, Stakeholder Advisory Group, Clinical Advisory Group, children’s neurodivergence network, Integrated Autism Services and Adult ADHD services. Welsh Government are seeking the views of professionals and individuals with lived experience to understand what will be meaningful in relation to data requirements and the collation of additional qualitative information that will measure improvements in outcomes, quality of life and individual experiences of services.

Welsh Government are also working with internal digital policy colleagues, local health boards and external stakeholders to identify the most appropriate and efficient methods of collating data and qualitative information to ensure compatibility with the our long term digital plan. This is a complex landscape and requires due diligence which will take time.

Whilst we work on a national neurodivergence reporting framework, we are establishing an adult ADHD Pathway Task & Finish Group. One of the first priorities for this group will be to establish the current position then agree, develop and implement a minimum viable data set. Welsh Government will be recommending that Health Boards make arrangements to collate data on numbers of referrals received, waiting times, number of people waiting, number of people assessed.

Whilst the Integrated Autism Service does not have any mandatory performance measures the services collate a range of data, at a local Health Board level. This includes robust information about referral numbers, average length of wait for assessment. This information is collated by Data Cymru and shared with the National Neurodivergence Team. Welsh Government are able to access this information and the data was used to inform the Demand and Capacity Review.

Whilst Welsh Government do not directly collect this data we are able to engage with local Health Boards and the National Neurodivergence Team to measure progress. Welsh Government will also be engaging with all of the Regional Autism Strategic Groups in Wales in the Autumn to consider progress made with the Neurodivergence Improvement Programme Funding.

Next Steps

The request you sent me contains personal information about you - for example, your name and address. The Welsh Government will be the data processor for this information and, in accordance with the General Data Protection Regulation, it will be processed in order to fulfil our public task and meet our legal obligations under the Act to provide you with a response.

We will only use this personal information to deal with your request and any matters which arise as a result of it. We will keep your personal information and all other information relating to your request for three years from the date on which your request is finally closed. Your personal information will then be disposed of securely.

Under data protection legislation, you have the right:

- to be informed of the personal data we hold about you and to access it
- to require us to rectify inaccuracies in that data
- to (in certain circumstances) object to or restrict processing
- for (in certain circumstances) your data to be 'erased'
- to (in certain circumstances) data portability
- to lodge a complaint with the Information Commissioner's Office (ICO) who is our independent regulator for data protection

For further information about the information which the Welsh Government holds and its use, or if you wish to exercise your rights under the GDPR, please see contact details below:

Data Protection Officer
Welsh Government
Cathays Park
CARDIFF
CF10 3NQ
Email: DataProtectionOfficer@gov.wales

If you are dissatisfied with the Welsh Government's handling of your request, you can ask for an internal review within 40 working days of the date of this response. Requests for an internal review should be addressed to the Welsh Government's Freedom of Information Officer at:

Information Rights Unit,
Welsh Government,
Cathays Park,
Cardiff,
CF10 3NQ

or Email: Freedom.ofinformation@gov.wales

Please remember to quote the ATISN reference number above.

You also have the right to complain to the Information Commissioner. The Information Commissioner can be contacted at:

Information Commissioner's Office,
Wycliffe House,
Water Lane,
Wilmslow,
Cheshire,
SK9 5AF.

However, please note that the Commissioner will not normally investigate a complaint until it has been through our own internal review process

Yours sincerely,