

Cynulliad Cenedlaethol Cymru | National Assembly for Wales
Datblygu Bil Aelod | Development of Member Bill
Y Bil Awtistiaeth (Cymru) - Datblygu'r Bil | The Autism (Wales) Bill - Bill Development
DMB(5) AWB66
Ymateb gan Canolfan Ymchwil Awtistiaeth Cymru
Evidence from Wales Autism Research Centre (WARC)

The Wales Autism Research Centre (WARC) is a research centre at Cardiff University's School of Psychology within the Centre for Human Developmental Science. It was set up in 2010 to create research capacity in response to the WG's 2008 Autism Spectrum Disorder Strategic Action Plan and supported by a unique collaboration between the two charities Autism Cymru and [Autistica](#) with [Cardiff University](#) and the [Welsh Government](#).

Answers from the Wales Autism Research Centre are given below and relate to questions on data collection and on training.

1) Do you believe that Local Health Boards and Local Authorities in Wales should be required to establish and maintain new data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly?

Other countries have shown significant success from recording autism at a population level. For example, the National Patient Register in Sweden has been used to document rates of and reasons for mortality in autism (Hirvikoski et al., 2016) as well as stability of rates of diagnosis over time (Lundström et al., 2015). The Danish Psychiatric Central Register was used to demonstrate that there is no evidence linking the measles, mumps and rubella (MMR) vaccine to autism (Madsen et al., 2002).

References

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder, *British Journal of Psychiatry*, 208, 232–238.

Lundström, S., Reichenberg, A., Anckarsäter, H., Lichtenstein, P., & Gillberg, C. (2015). Autism phenotype versus registered diagnosis in Swedish children: Prevalence trends over 10 years in general population samples. *British Medical Journal*, 350:h1961

Madsen, K., Hviid, A., Vestergaard, M., Schendel, D., Wohlfahrt, J., Thorsen, P., Olsen, J., & Melbye, M. (2002) A population-based study of measles, mumps, and rubella vaccination and autism. *New England Journal of Medicine*, 347, 1477–1482

We strongly support the need for systematic data collection that captures the number and needs of autistic people in Wales. Not only does this enable local areas to plan services but it gives scope for capturing the effectiveness of initiatives (e.g. take up, outcomes) and changes to individuals over time. Analysis of data can be fed back to improve services and to better understand the profile of the autistic community in Wales. Such a database could be a valuable resource for policymakers, health professionals and researchers and bring these professional groups together.

In Wales such data collection systems have already been established. WG funded the development of a database to record diagnoses of Autism Spectrum Disorders (ASDs), as part of the work of the ASD Strategic Action Plan. The database work was led by Dr Dawn Wimpory, Consultant Clinical Psychologist for ASD & Lecturer, BCUHB & Bangor University) with Professor Sue Leekam, of WARC in Cardiff University, as co-PI on the original stage of this pilot for an ASD Database, for children in Wales.

In 2012, the ASD database module was established within the Community Child Health 2000 database (now transitioning/transitioned to CypRIS). Although the software is already in place throughout NHS Wales, via CCH2000/CypRIS, the 6 counties of BCU Health Board are those where data collection has taken place since 2012. Although only child diagnoses have been entered, those children who become adults are retained within this ASD database.

m) Do you have a view on how data can most effectively be gathered, on the numbers and needs of children and adults with autism spectrum conditions in different Local Health Board and Local Authority areas in Wales?

Our view is that data can most effectively be gathered through the NHS. Given the evidence on data collection to date, the Bangor team's experience shows that whilst LEA data can contribute to such database records, there is greater diagnostic accuracy about which cases should be included, where diagnoses are logged by the agency primarily responsible for those diagnoses, in this case, the NHS.

Dr Dawn Wimpory is currently working with WG's Neurodevelopmental (ND) Steering Group (hosted by Les Rudd of Public Health Wales) in an initiative to develop a cross-agency development of the original (and still functioning) database (see l) above) via WCCIS, for initial cross-agency trial in Powys. This development is compatible with the original ASD Module so that the first 6yrs of

data collection in BCUHB can be used as a baseline against which to compare the consequences of WG's more recent Neurodevelopmental (ND) initiatives for ASD. Experience in BCUHB/Bangor University indicates that some clinically-informed research staffing is an essential element of such an enterprise. The WCCIS developments outlined here could well enable inclusion of adults with ASD in the future.

It is hoped that any new relevant developments will build upon, and therefore be strengthened by, the existing progress and developments outlined above. Areas of data recorded on ASD since 2012 (and still on-going) include the following: incidence & prevalence; clients' gender, intelligence and communication levels, age at diagnosis; diagnostic service involvement (CAMHS vs non-CAMHS etc., including waiting list times; use of diagnostic tools/scores; clarification of cross-agency professional groups' involvement) and cases' comorbidities. Communication/collaboration with Dr Dawn Wimpory on these issues is therefore strongly encouraged.

With respect to cost-benefit it should be noted that calculations about the proposed costs should recognise that diagnoses are sometimes made at a higher rate than the 1% (point 32, p 11) and this could impact on actual database development costs. However, Wales' diagnostic rates cannot be compared with published standard prevalence rates, established through research, unless Wales has an adequate ASD database recording system

n) Do you have a view on the current scope and effectiveness of training in Wales for key staff working with people with autism spectrum conditions?

We welcome the proposal that the Autism (Wales) Bill will promote consistency of training outcomes across regions, ensuring a means for implementation and maintenance of standards and secure delivery of training.

Background

We are aware of the scope of training available within the Welsh Government led ASDInfoWales website. See <http://www.asdinfowales.co.uk/resource/Training-Framework-digital-eng.pdf>

The training framework includes e-resources tailored to different levels of background knowledge and the training schemes include a certification scheme linked to training outcomes.

Research by the Wales Autism Research Centre (WARC); ([10.1016/j.rasd.2014.10.003](https://doi.org/10.1016/j.rasd.2014.10.003)) provided input for part of the autism awareness training, by contributing to the SIGNS posters below.

Primary care referral

<http://www.asdinfo.wales.co.uk/recognise-asd-child>

<http://www.asdinfo.wales.co.uk/recognise-asd-adult>

Learning with Autism

http://www.asdinfo.wales.co.uk/resource/2015_Autism-A-Guide-for-Mainstream-Primary-Schools-ENG.pdf

http://www.asdinfo.wales.co.uk/resource/A-Guide-for-Early-Years-Settings_Eng.pdf

http://www.asdinfo.wales.co.uk/resource/2017_Autism-A-Guide-for-Mainstream-Secondary-Schools-Eng.pdf

WARC also worked in a partnership with the ASD National Development Team to produce a training film on the SIGNS of autism for autism awareness in front-line professionals. The film, the Birthday Party was funded by the Economic and Social Research Council and Welsh Government and is now part of the autism toolkit provided by the Royal College of General Practitioners.

<http://www.asdinfo.wales.co.uk/autismchildsigns>

Evidence on scope and effectiveness.

We have evidence on the scope and effectiveness of the training materials above. In terms of scope, the SIGNS posters have been distributed to all GP surgeries in Wales and web statistics show that the Birthday Party SIGNS film has been accessed more than 3,200 times between June 2017 (release date) and Sept 2017. 400 views have come from outside of Wales including USA, Australia, Singapore, Spain, Latvia and Lithuania.

We carried out an evaluation of the Birthday Party SIGNS film with 270 professionals and 120 family members across all regions of Wales. More than 200 left spontaneous comments. <http://sites.cardiff.ac.uk/warc/files/2017/07/Film-Evaluation.-21st-July.pdf>. Amongst these, the majority requested that the film be made accessible to all sectors of the population and not just professionals (the film is now open access). Many expressed the need for additional similar films focusing

on adults or females, and a number requested permission to use the film in their own autism training and requested translation into other languages beyond Welsh. The evidence in support of the film has come from professionals with a range of backgrounds and indicates that it can be a beneficial way of training people to identify the signs and the various ways that they can be presented.

WARC is also undertaking an evaluation of the effectiveness of the Learning with Autism programme and the effectiveness of SIGNS poster items and the results will be available in April 2018.

o) Do you believe that legislation should specify outcomes that training should achieve, thereby providing greater flexibility around the delivery of such training?

We are in support of an outcomes based approach to training. Where there is flexibility in content of training, we would like to see a system in place that can record the impact pathway and audit the impact of training. Those who receive training should be competent to apply their training in practice. Evidence should be provided that the training is being applied by the person receiving it through specific outcomes (e.g. referrals for diagnosis being made, support or adjustments put in place).

Training should be reviewed not only for job-specific continuing professional development, but for training provided as an integral part of professional undergraduate or postgraduate degrees (e.g. occupational therapy, speech and language therapy, teaching, clinical psychology, educational psychology, GPs).

More broadly, training is relevant to parents and non-autistic children (e.g. siblings, school peers). Our work with the Birthday Party SIGNS film and school-wide adoption of the Learning with Autism programme has demonstrated the strong desire for educational and training resources to be accessible community-wide.

The explanatory memorandum (p.12) says “Part of the development process of this Bill will be to take a view on whether the current provision of training being implemented is sufficient.” It will be important to identify what this sufficiency relates to, which may vary, and therefore learning objectives for different types of training will need to be clarified before making this judgement.

The response from the Wales Autism Research Centre was led by;

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