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) AWB79
Ymateb gan Bwrdd Iechyd Prifysgol Betsi Cadwaladr
Evidence from Betsi Cadwaladr University Health Board

a) What are your views on the effectiveness of the current arrangements for improving autism services in Wales?

Currently children with ASD in Wales are assessed and supported by Neurodevelopmental Teams within each Health Board. It would be useful if the ASD bill linked in with the All Wales Neurodevelopmental pathway. Welsh Government has invested some additional funds for neuro development, this isn't adequate to meet the current demand, and reliance of on grants, creates uncertainty around the continuation of the service.

b) Do you believe Wales should have legislation requiring the Welsh Government to publish a national autism strategy for children and adults and issue guidance to local authorities and NHS bodies on implementing the strategy?

Legislation is a positive step, there is a hesitation that this could create an influx of expectations of services that are not adequately resourced, in terms of staffing.

Further information on the strategy and what would be expected from BCUHB for implementation will help the services to understand the time and staffing needed for implementation.

c) To what degree of detail do you think the content of a national autism strategy should be defined in legislation?

Outline of the minimum service input expected for all cases.

Detail to reflect the different aspects of the condition.

d) What (if any) consultation do you think the Welsh Government should be required in legislation to undertake, when developing, reviewing and updating a national autism strategy?

Consulting with Parent groups, Professionals, health, Education professionals and unions, Academics in the field in UK and experts from abroad. Need to make this a national discussion.

e) Do you believe that legislation should define how often a national autism strategy should be reviewed and updated? If so, how often should it be reviewed and updated?

Legislation should be reviewed; discussions held suggested every 3- 5years until established, and then 5-10 after.

f) Do you have any views on how Welsh Government should monitor what progress is being made and how public services should be held accountable for how they support autistic people and their families?

Progress should be monitored, to include both quantitative and qualitative data.

Links with outlined RTT targets for Neurodevelopment services.

g) What are your views on how easy it is to access a diagnostic assessment where you live?

The new neuro development pathway is evolving with plans on streamlining the referral eligibility and access point along with whole assessment process to provide equity in all areas for all service users. Transition to adult services is problematic with different criteria for referral being a barrier.

Waiting times are currently long making assessment processes and diagnosis difficult for families to manage, support to families waiting is provided.

h) What key challenges around how the diagnostic process works would you like legislation to address?

Terminology that is consistent with current diagnostic labels, the consultation bill states ‘autistic spectrum disorder conditions’, this is unclear and needs a consistent ICD or DSM label.

Important that families feel empowered, and recognise they are instrumental in their child’s life. Families can take responsibility of their Childs ASD, and work together with the Health Board and Education can make a positive change.

Empowering adults with ASD to take control of their future. Working together with the Health Board and Local Authority to find employment and social opportunities.

Educational or employment needs should not be diagnosis led, the Bill should highlight that any support should be based on that individual’s needs and functioning, rather than diagnosis specific. The reasons for this are that general diagnosis does not reflect the varied impact of the condition and whilst people are undiagnosed (either on a waiting list for assessment, or when they do not wish to pursue a label) they should not be denied the appropriate support. The Bill would benefit to highlight this, for clarity for families and professionals.

Health board and LEA joint working should be highlighted, as this is gap in our service.

Clarity on how point 16 would be implemented. The Bill needs to clearly define the pathway, if the Bill wants Health Boards to be accountable by law for this provision.

i) Do you believe that Local Health Boards and Local Authorities in Wales should be required to publish information on the pathway to diagnosis for children and adults living in their areas?

Yes publishing this information would be useful.

j) What are your views on the sufficiency of services currently provided to meet the needs of people with autism spectrum conditions in Wales?

The All Wales Neurodevelopmental pathway, is aimed at children presenting with symptoms and impairment in functioning that is indicative of a neurodevelopmental disorder.

In order to deliver a timely diagnosis, services will need an increase in staffing to implement, ensuring services are maintaining assessments which are informed by NICE guidance.

k) The legislation I am proposing would require the Welsh Government to issue statutory guidance that would put duties on local authorities and Local Health Boards on how they should be delivering services for autistic children and adults and their families.

Do you agree that legislation should require statutory guidance? If so, does the following list cover the right areas to be included under the duties on local authorities and Local Health Boards?

i.The provision of relevant services for the purpose of diagnosing autistic spectrum conditions in children and adults.

ii. The fact that assessment of the eligibility of children and adults for relevant services cannot be denied on the grounds of the person’s IQ.

iii. Planning in relation to the provision of relevant services to people with autistic spectrum conditions, as they move from being children to adults.

iv. Other planning in relation to the provision of relevant services to children and adults with autistic spectrum conditions.

v. Local arrangements for leadership in relation to the provision of relevant services to children and adults with such conditions.

Agree with the list of statutory guidance for local health boards.

l) 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?

Questions and issues raised by Childrens services Clinicians;

- What does the register entail, and what is the purpose, will it be just to collate numbers of diagnosis.
- ASD is a spectrum of a disorder, so there is a range of difficulties and people will have differing levels of functional impairment. Would the level of impairment also be recorded, and who would judge this as impairment.
- There are cases when Children, Young people or Adults don't wish to have a label, they may want an assessment to understand themselves but not want to use the label. Would there be an issues of consent regarding these cases going onto the register.
- A child under 16 cannot legally consent for themselves going on the register. Parents could put them on the register, but this could negatively impact that child, for future employment prospects.

Dr Dawn Wimpory's response;

There is strong support for a requirement that Local Health Boards and Local Authorities in Wales should be required to contribute to data collection practices around the numbers and needs of children and adults with Autism Spectrum Conditions so that local areas can plan services accordingly.

WG has already funded the development of a database to record diagnoses of Autism Spectrum Disorders (ASDs), 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.

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 this original (and still functioning) database 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.

Whilst LEA data can contribute to such database records, the Bangor team's experience is that 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. 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.

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.

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?

Effectively gather data via, Databases within BCUHB, Feeding into an RBA, Quarterly reports of quantitative and qualitative data and an annual report.

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?

BCUHB have access to effective training, more would be welcomed

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

Training needs to be Evidence-based training, the Bill needs to highlight importance of an evidence-base, and how service-users can be involved in facilitating training about their lived experience.

Need for clear guidance on the amount, frequency and quality of the training.

p) An alternative approach would be for legislation to specify that key staff working with people with autism spectrum conditions should undertake autism training.

Delivery of evidence-based training to teachers may need to be agreed locally, due to different LEAs and differences in voluntary sector services.

Need for clarity on who will be responsible to deliver the training, how it will be funded, and clarity on any national advice, which could be adapted locally.

q) Do you have any suggestions for additional action that could be taken through legislation to improve the rates of employment of people with autism spectrum conditions (bearing in mind that the National Assembly for Wales does not have the power to make changes to employment law)?

Praise individual health board for aspiring to employ through contracts, apprentices or volunteering opportunities to people with autistic spectrum within NHS.

Sharing and highlighting best practice.

r) Do you believe that a definition of autistic spectrum disorder should:

- be included on the face of legislation (which makes it more difficult to change in the future);
- be included in an autism strategy;
- be included in guidance; or,
- not be stated at all?

The definition needs to used consistent terminology inline with current diagnostic labels, the consultation bill states ‘autistic spectrum disorder conditions’, this is unclear and needs a consistent ICD or DSM label.

s) Can you identify any possible unintended consequences which could arise as a result of this legislation? If so, what steps could be taken to deal with them?

- Families taking legal action for not complying with RTT, informative communication could reduce this.

- Education unable to provide the help and support for families following diagnosis.

- Inability to find sufficient trained staff needed and therefore unable to meet the targets. Recruiting to permanent contracts, to aid with retention of staff.

- Centres of excellence becoming oversubscribed.

t) Do you believe that the proposals in this consultation would give rise to any substantial costs, in addition to the cost-areas already noted in this consultation? How can such costs best be mitigated

Difficult to respond to the financial aspect of the Bill, need for further detail in order for services to respond appropriately.

Areas which would need additional funding would be staffing cost for the highly qualified staff needed, training, IT and office space are all aspects BCUHB would need to review, once further detail has been added to the Bill.

In terms of funding the CAMHs service as a whole, it has been highlighted that a lot of the CAMHs funding is of a short term nature, staff are hesitant to apply or stay in short term funded posts (staff that have been trained by BCU are leaving the health board for permanent posts elsewhere). The CAMHs services are currently reacting to new funding opportunities, as they happen and this in itself is causing shortages of trained staff in core services. Mitigating these factors would require an increase in revenue funding for core services, so staff would be able to apply for permanent posts, and be able to work on areas such as the ASD strategy as part of their core work. This would lead to a higher retention of staff and opportunities for personal development, which could lead to promotion.

u) What would the impact or costs be in terms of:

i. producing a national autism strategy;

ii. placing duties on local authorities and NHS bodies to act under guidance;

iii. creating and maintaining data collection practices on the numbers and needs of adults and children with autism spectrum conditions; and,

iv. providing training for key staff?

v) Do you envisage any other additional administrative and regulatory costs as a result of this legislation and if so, how can any such impacts be mitigated?

Increased use of IT, with clinicians wanting to be a paperless service.

Detailed data collection and audits may be needed, dependant on the level of data required for this legalisation.

w) What factors should be measured to determine the cost-benefit analysis of this legislation should it become law?

Cost reduction of medication, such as ADHD medication reduced, melatonin.

x) Do you have any views on how savings that might arise from this legislation can most effectively be identified and calculated?

Reduction in;

- Use of medication
- Youth Justice
- Amount of children leaving school without qualifications
- Amount of children not in employment

y) Do you wish to make any other comments on my proposals?

- This service should be treated with as much importance as the Flying Start Service by the Welsh Government with the same reporting system, funding and commitment.
- Will private services who diagnose be considered as part of the Bill, to ensure patient consistency, safety and accuracy of diagnosis.
- The Bill needs to further highlight the need for joint working.
- How will children with low IQ, fit into this legislation.