

Agenda – Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Lleoliad: I gael rhagor o wybodaeth cysylltwch a:
Ystafell Bwyllgora 2 – Y Senedd Claire Morris
Dyddiad: Dydd Iau, 11 Hydref 2018 Clerc y Pwyllgor
Amser: 09.00 0300 200 6355
Seneddlechyd@cynulliad.cymru

Rhag-gyfarfod anffurfiol (09.00– 09.30)

1 Cyflwyniad, ymddiheuriadau, dirprwyon a datgan buddiannau

2 Bil Awtistiaeth (Cymru): Sesiwn dystiolaeth â chynrychiolwyr

Byrddau Iechyd Lleol a Choleg Brenhinol yr Ymarferwyr Cyffredinol

(9.30–10.15)

(Tudalennau 15 – 63)

Carol Shillabeer, Prif Swyddog Gweithredol, Bwrdd Iechyd Addysgu Powys a'r Prif Weithredwr Arweiniol ar Iechyd Meddwl

Dr Mair Hopkin, Cyd-gadeirydd, Coleg Brenhinol Ymarferwyr Cyffredinol Cymru

Dr Jane Fenton-May, Coleg Brenhinol Ymarferwyr Cyffredinol Cymru

Egwyl (10.15–10.20)

3 Bil Awtistiaeth (Cymru): Sesiwn dystiolaeth gyda Chymdeithas

Llywodraeth Leol Cymru a'r Gymdeithas Cyfarwyddwyr

Gwasanaethau Cymdeithasol

(10.20 –11.05)

(Tudalennau 64 – 79)

Naomi Alleyne, Cyfarwyddwr, Materion Gwasanaethau Cymdeithasol a Thai, Cymdeithas Llywodraeth Leol Cymru

Keith Ingram, Swyddog Arweiniol y Prosiect Anhwylder Sbectrwm Awtistiaeth,



Cyngor Bro Morgannwg

Claire Lister, Pennaeth Gwasanaethau Oedolion, Cyngor Bwrdeistref Sirol
Conwy

Jo Taylor, Rheolwr Gwasanaeth ar gyfer Anableddau Dysgu, Anawsterau
Corfforol a Nam ar y Synhwyr, Cyngor Sir y Fflint

Egwyl (11.05–11.10)

**4 Bil Awtistiaeth (Cymru): Sesiwn dystiolaeth gyda'r Gymuned
Ymarfer diagnosis oedolion ac ymarferwyr Gwasanaeth Awtistiaeth
Integredig**

(11.10–11.55)

(Tudalennau 80 – 87)

Dr Nicola Griffiths, Seicolegydd Clinigol, Gwasanaeth Awtistiaeth Integredig
Gwent

Sian Lewis, Rheolwr Gwasanaeth, Gwasanaeth Awtistiaeth Integredig Gwent

Dr Rona Aldridge, Seicolegydd Clinigol, Arweinydd Clinigol ar gyfer

Gwasanaeth Awtistiaeth Integredig Caerdydd a'r Fro

Wendy Thomas, Arweinydd Proffesiynol Cenedlaethol ar gyfer Awtistiaeth

Egwyl (11.55–12.45)

**5 Bil Awtistiaeth (Cymru): Sesiwn dystiolaeth gyda Choleg Brenhinol
y Seiciatryddion a Choleg Brenhinol Pediatreg ac Iechyd Plant**

(12.45 –13.30)

(Tudalennau 88 – 98)

Yr Athro Alka Ahuja, Seiceiatrydd Ymgynghorol Plant a'r Glasoed, Bwrdd

Iechyd Aneurin Bevan a Choleg Brenhinol y Seiciatryddion

Dr Amani Hassan, Cadeirydd, Cyfadran Seiceiatreg Plant a'r Glasoed, Coleg
Brenhinol y Seiciatryddion

Dr Catherine Norton, Pediatregydd Ymgynghorol Cymunedol,

Dr Martin Simmonds, Pediatregydd Cymunedol, Coleg Brenhinol Pediatreg a
Iechyd Plant

Egwyl (13.30–13.35)

6 Bil Awtistiaeth (Cymru): Sesiwn dystiolaeth gyda Chymdeithas Seicolegol Prydain a'r Gymdeithas Seicolegwyr Addysgol

(13.35 – 14.20)

(Tudalennau 99 – 107)

Nigel Atter, Swyddog Polisi, Cymdeithas Seicolegol Prydain

Dr. Kate Swindon, Seicolegydd addysgol, Gwasanaethau Addysg, Cyngor Bwrdeistref Sirol

Andrea Higgins, Prif Gydlynnydd a Chyfarwyddwr Academaidd, y Doethuriaeth mewn Seicoleg Addysg, yr Ysgol Seicoleg, Prifysgol Caerdydd

7 Papurau i'w nodi

(14.20)

7.1 Llythyr gan Ysgrifennydd y Cabinet dros Gyllid at Gadeirydd y Pwyllgor Cyllid ynglŷn â'r diffiniad o atal mewn perthynas â gwario

(Tudalennau 108 – 109)

7.2 Deintyddiaeth yng Nghymru: Gwybodaeth ychwanegol gan y Gymdeithas Ddeintyddol Prydain yng Nghymru

(Tudalennau 110 – 117)

8 Cynnig o dan Reol Sefydlog 17.42 i benderfynu gwahardd y cyhoedd o weddill cyfarfod heddiw ac ar gyfer y cyfarfod ar 17 Hydref, pan fydd y Pwyllgor yn gwneud gwaith ymgysylltu â rhanddeiliaid fel rhan o'i ymchwiliad ar effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

(14.20)

9 Bil Awtistiaeth (Cymru): Trafod y dystiolaeth

(14.20–14.30)

Mae cyfyngiadau ar y ddogfen hon

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	The Welsh NHS Confederation written response to the Health, Social Care and Sport Committee's scrutiny of the Autism (Wales) Bill.
Contact:	██████████ ██████████, Policy and Public Affairs Manager, Welsh NHS Confederation ██ ██ ██ ██
Date created:	11 September 2018

Introduction

1. The Welsh NHS Confederation, which represents the seven Health Boards and three NHS Trusts in Wales, welcomes the opportunity to respond to the Health, Social Care and Sport Committee's scrutiny of the Autism (Wales) Bill.
2. The Welsh NHS Confederation supports our members to improve health and wellbeing by working with them to deliver high standards of care for patients and best value for taxpayers' money. We act as a driving force for positive change through strong representation and our policy, influencing and engagement work.

Background

3. The Welsh NHS Confederation has provided written responses to Paul Davies AM's initial consultation on the need for a Draft Autism (Wales) Bill (November 2017) and the proposed Draft Autism (Wales) Bill itself (April 2018). Whilst fully supportive of the need to improve services for people with Autism Spectrum Disorder (ASD), both of our previous responses outlined a number of issues around whether the proposed legislation would be the most appropriate vehicle to achieve the desired outcomes for people with ASD.
4. Our response highlights:
 - That services should be based on need and be person-centred and child-centred;
 - The potential for increased rates of inaccurate or inappropriate diagnosis;
 - The need to consider the impact on and evaluation of existing programmes of work in Wales relating to Neurodevelopmental Disorders (ND) and ASD;
 - The potential implications of introducing condition-specific legislation; and
 - There is currently insufficient evidence to show that autism-specific legislation would enhance the services already being delivered across NHS Wales and local government and will lead to improvements in the support being provided to people with ASD.
5. Since Paul Davies AM invited views on the Draft Autism (Wales) Bill in April 2018, the Welsh NHS Confederation has worked closely with the Royal College of Psychiatrists, the

Royal College of Speech and Language Therapists, the Royal College of Paediatrics and Child Health and the Royal College of Occupational Therapists to produce a briefing that outlines our shared position in relation to the proposed Bill. This co-produced briefing will be submitted to the Committee separately.

6. Our response will address the general principles of the proposed Bill to more accurately reflect the views of our members on these issues.

Services should be based on need and be person-centred

7. We welcome the additional resources that have been provided to support people with ASD, but support should be provided on the basis of patient need and the capacity to deliver the best possible services for the person rather than solely diagnosis. In addition, the Bill is based on the current understanding of classification of disease and disorders, which are changing and evolving. As neuro science develops this will challenge existing diagnostic categories.
8. Many people with Neurodevelopmental Disorders (ND) including some with ASD-like traits, some learning disabilities and other diagnoses such as Attention Deficit Hyperactivity Disorder (ADHD) would not (nor would it be appropriated for them to) meet the criteria for a diagnosis of ASD (or any given definition in proposed legislation) even where their symptoms or their needs significantly impact their quality of life.
9. A needs-based approach means that resources and support is delivered according to need, not prioritised according to legislation or linked to receiving a diagnosis. This approach is consistent with existing legislation in the Social Services and Well-being (Wales) Act 2014, which already legislates for all patients regardless of the complexity of need, and the Additional Learning Needs and Education Tribunal (Wales) Act 2018. Services should not be based on diagnosis or be conditional on the receipt of other medical services.
10. When the Integrated Autism Service (IAS) was originally rolled out across Wales in 2017 with an all-age approach, individual Health Board teams were prohibited from assessing people with autism referred by secondary mental health services, regardless of the outcome of their mental health presentation at the first appointment stage. Some Health Boards have modified the pathway to be more inclusive and person-centred to address the needs of most patients, particularly those who may also have learning difficulties or other neurodevelopmental conditions. IAS teams are working collaboratively with other services, including Local Authority partners, to make appropriate adjustments to patient interventions to improve patient experience and outcomes.
11. In our joint briefing with Royal Colleges, the Royal College of Speech and Language Therapists say that the development of the all-Wales neurodevelopmental pathway, which has focussed on need rather than solely diagnosis, has been helpful in supporting a move towards person and needs led assessments and interventions. This has been particularly beneficial for vulnerable people, for example, those with ADHD or those who do meet the threshold for diagnosis to ensure they and their families also have access to

equitable and appropriate services, despite not necessarily meeting the criteria for autism that would be required under the proposed Bill. Similarly, the Royal College of Paediatrics and Child Health (RCPCH) have highlighted that the impact of the proposed legislation could be to exclude children from appropriate services with no clear pathway available to ensure their needs were met. The RCPCH say that whilst this clearly indicates the legislation is not child-focused it also presents the risk that adults would be directed to inappropriate care pathways under the proposed Bill.

12. Efforts to improving services should be devoted to exploring opportunities for integrated styles of working across Health Boards and Local Authorities, establishing co-ordinated multi-disciplinary teams and facilitating opportunities for sharing best practice. It is through these channels that outcomes for patients will be improved in the future.

Impact of legislation on rates of diagnosis

13. Our members and a number of Royal Colleges are concerned that a possible unintended consequence of linking resource to a particular diagnosis, whether it is autism, ASD or a given definition of ND disorders, is a risk that individuals or families will feel that their best opportunity to access the support they need is by securing that particular diagnosis. This may impact on services, families and individuals in a number of ways both in the short term e.g. the duration and nature of the assessment process, and longer term with undetermined theoretical impact of a perhaps unhelpful diagnostic label that defines an individual.
14. The symptoms of autism, particularly in children, are shared by a wide range of ASD-like conditions. The proposed legislation would dictate that the best way for individuals and families to receive the support they feel they require would be to secure an autism diagnosis. The legislation could artificially increase rates of diagnosis for autism when it may be that an alternative care pathway would be more appropriate for the individual and would lead to better outcomes for them in the long-term.

Existing programmes to improve outcomes for people with ASD in Wales

15. The Welsh Government in partnership with Local Authorities is already rolling out a number of initiatives aimed at raising awareness and improving services for people with ASD in Wales. We would strongly recommend that the impact of these initiatives, which are currently in the early stages of development, be assessed prior to the introduction of new legislation. It will be especially important to understand the demand for and capacity to provide services across the age range.

- The Social Services and Well-being (Wales) Act 2014 places a duty on public bodies in Wales to assess and address the needs of individuals. The Social Services and Well-being (Wales) Act 2014 required partnership arrangements to be made in each Local Health Board area, under the direction of a Regional Partnership Board (RPB). The RPBs have representation from Health Boards, Local Authorities and service users. These RPBs have been established for defined functions, focussed particularly on areas where successful integration between local government and health is essential

for the provision of effective support services to meet the needs of people within their localities. The Social Services and Well-being (Wales) Act 2014 and supporting statutory guidance requires joint planning, commissioning and the use of pooled budgets between health and local government. The RPBs are recognised as key drivers of transformation under the Welsh Government's long-term plan for health and social care, "A Healthier Wales".

- The Welsh Government's recently-published Autism Spectrum Disorder Action Plan Annual Reportⁱ supports this work and clearly recognises the key challenges to achieving an integrated and effective service.
- Under the Together for Children and Young People programme (T4CYP), there has been significant investment in neurodevelopmental services since its introduction in 2015. Nationally-agreed neurodevelopmental children and young people's diagnostic pathways and standards are now in place and are being adopted by all Health Boards.ⁱⁱ A new 26-week waiting time standard from referral to first appointment has also been introduced. Neurodevelopmental teams work within a clinical framework with a shared assessment pathway and common standards. They focus on quality improvement and delivering services to the entire population under the age of 18. Wales is the only UK country to achieve this without specific legislation relating to autism.
- The Welsh Government have also acknowledged that many people with ASD or similar conditions often find it difficult to find and maintain employment and have recently introduced an Employability Plan. The plan provides an individualised approach to employment support and gives advisers the autonomy and flexibility to address the needs, strengths and ambitions of the person preparing for work. The Welsh Government are also supporting the Getting Ahead 2 project, which is aimed at people between the ages of 16-25 with learning disabilities and/or ASD.
- The National Integrated Autism Service (IAS) has recently been established with the aim of creating consistent support structures for people with ASD across Wales. An interim evaluation reportⁱⁱⁱ has been published in March 2018 considering the initial development of IAS in the first four regions where it is being rolled out – Cardiff and Vale, Cwm Taf, Gwent and Powys. While the report highlights that establishing a new integrated service like the IAS is challenging it does find that *"important progress has been made in establishing an IAS in Cardiff and Vale, Cwm Taf, Gwent and Powys and this represents a considerable achievement. Stakeholders expect the service to make important improvements to the quality and timeliness of assessment, diagnosis and support"*. The final report is scheduled for January 2019 and it will explore how the IAS continues to develop and how the recommendations within the interim report have been taken forward.
- The Additional Learning Needs and Education Tribunal (Wales) Act 2018 has recently been given Royal Assent and implementation will begin in 2020. The Act will introduce a new system of supporting children and young people with ASD through by

supporting early identification of additional learning needs and targeted, needs-based interventions in the education of children and young people.

16. In terms of existing programmes and engagement networks, Health Boards across Wales are working collaboratively with Local Authorities to raise awareness of IAS initiatives and provide valuable support resources through the ASD Info Wales website.^{iv} Plans are in place to scale-up ASD training to mental health staff and social care professionals more widely, but we recommend that ambulance and dental staff also be brought within this remit.
17. The changes in waiting time targets as envisaged by the Bill, would have a significant impact on resources (both financial and workforce) as well as a team's capacity to provide other services such as follow-up support, which is as important as the treatment itself. Furthermore, waiting time to diagnosis targets are only concerned with arriving at the diagnosis rather than assessing the needs of the individual or the family. The current priority towards diagnosis rather than need also inhibits a multi-disciplinary team's capacity to deliver the required services in an effective and timely manner. As our briefing "Autism (Wales) Bill: A look at autism strategies and legislation in England, Northern Ireland and Scotland", submitted with this written response, highlights there does not appear to be any current evidence to demonstrate that the provision of ASD specific legislation has improved services for people with ASD.

Multi-disciplinary teams

18. In our previous response to the Draft Bill we said it would be helpful, if legislation is taken forward, to include a list of professionals who could form the multi-disciplinary teams that would be required for diagnostic assessments. NICE CG128^v and/or 142^{vi} should be referenced with an explicit list of multi-agency, multi-disciplinary professionals. In particular, a nurse practitioner and a suitably qualified dietician for those with restrictive eating patterns would be key components of an effective IAS team, and clarity on what professions can administer autism diagnostic assessment tools would also be essential.

Enacting condition-specific legislation

19. Autism-specific legislation could lead to people with other neurodevelopmental disorders and challenges receiving inequitable services. Through introducing Autism-specific legislation there is a risk of excluding and disadvantaging other groups with neurodevelopmental conditions such as hyperkinetic disorder, learning disabilities, tic disorders, sensory impairments etc. It could also lead to other interested parties, patient groups and third sector organisations to call for the introduction of specific legislation for other illnesses and conditions to ensure they also given equal status and provision. This does not mean that proposals for an Autism Act are entirely unwarranted, but it does mean that the evidence base for the introduction of such legislation must be extremely robust and convincing around improving patient outcomes. At present, this is not the case. Moreover, the financial pressures and significant challenges associated with recruiting and training the required multi-disciplinary teams that would be required to

deliver services as envisaged by the Bill would make it difficult to ensure effective implementation.

Data on autism spectrum disorder

20. Effective methods of data collection and analysis are essential to continual improvement of service delivery and it is positive that the Committee has recognised this in its terms of reference for this work.
21. The existing IAS implementation process includes the electronic recording of autism-related data and work is ongoing across Wales to deliver this through local teams. Likewise, the existing Welsh Community Care Information System (WCCIS) will support collaboration and facilitates a national approach to data collection. That said, we would emphasise that more work needs to be done to ensure that these systems interact with children's services more effectively to facilitate seamless transitions and continual data sharing between health and social care.
22. It is important to have prevalence estimates and data collection to gain an understanding of the proportion of people in the population that may be living with autism. This will also support service planning and development both on a local and a national level.
23. It is also important to consider the General Data Protection Regulations (GDPR), which have been in force since May 2018. The Regulations place a legal obligation on Health Boards and other public bodies to be fully transparent about what data they collect, their methods of collecting it, and how it will be used. Currently, IAS services across Wales are reviewing data items to inform service planning and development. The types of data accessed by NHS practitioners, clinicians and service planners tend to vary, which needs to be considered during the development of a data set as per the proposed Bill. This should not only take account of diagnostic information, but also include supporting activity and be focused on patient outcomes. Also, the list provided in the Draft Bill does not recognise the importance of post-diagnostic support data, which is central to informing suitable care pathways after diagnosis. The ND services are currently developing a data set for the collection of both qualitative and quantitative information.

Experiences from other nations around the introduction of Autism legislation

24. Evidence from the introduction of Autism Acts in England in 2009^{vii} and Northern Ireland^{viii} in 2011 suggests that legislation is not leading to improved outcomes for people with ASD.
25. The National Autistic Society report *Push for Action*,^{ix} which was published in 2013 and focused on the implementation of the Autism Act 2009 in England, concluded that whilst the strategy has been successful in establishing the building blocks for better planning and commissioning of services, "*for the most part, adults with autism and their families are still waiting for the support they need*". This is also supported by a recent detailed report by the National Autism Project^x (a UK-wide initiative which aims to provide authoritative recommendations on autism research and practice) which stated that "*nearly a decade*

on the needs of autistic people are still unmet and the expected economic dividend has never materialised”.

26. Similarly, in Northern Ireland the most recent Department of Health, Social Services and Public Safety report on implementation of the Act found that it was *“not currently possible to guarantee early intervention as outlined in the Autism Strategy without additional funding to further develop autism-specific assessment services, and to extend the portfolio of available family support”*.^{xi}
27. Parliamentary scrutiny of the proposed Autism Bill in Scotland, which was also introduced as a Members’ Bill in 2010, considered whether the proposed legislation would lead to improvements in services without significant additional funding for staff and resources. Scrutiny of the Bill also considered whether autism-specific legislation might create a two-tier system of strategies whereby strategies set out in legislation are seen to have *“more teeth”*.^{xii} These were highlighted as key issues in the Committee’s recommendation that the general principles of the Bill should not be supported. The Committee also felt that NHS organisations and Local Authorities would face significant costs relating to the restructuring processes that would need to be implemented across Scotland to allow for the necessary enforcement measures to take effect. The knock-on effect of such a proposal would have been to place greater demand on other services which were already working at or near capacity. In light of these concerns, the Autism (Scotland) Bill fell at the first stage of parliamentary scrutiny in January 2011.

Conclusion

28. Health Boards and Trusts across Wales have made significant progress in recent years to deliver high quality services to people with autism. In many areas, Health Boards have reconfigured their services to improve quality and access. This progress and improvement has been made possible thanks to closer collaboration between NHS Wales organisations and Local Government. Areas of best practice have recognised that achieving the best possible outcome for the patient must be the key priority of NHS services above all else.
29. Integrated working has also allowed individuals and teams across health and social care to come together and share ideas to tackle the increasing workforce and financial challenges. Against this background, it is our view that NHS Wales can develop and improve its services for people with autism further by looking more closely at ways to scale-up examples of best practice and drive transformation, as set out in the Parliamentary Review of Health and Social Care^{xiii} and included within the Welsh Governments recently published “A Healthier Wales” Plan, rather than introducing legislation.

ⁱ [Welsh Government, June 2018. Autism Spectrum Disorder Strategic Action Plan](#)

ⁱⁱ <http://www.1000livesplus.wales.nhs.uk/neurodevelopmental-services>

ⁱⁱⁱ [Welsh Government, March 2018. Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan. Interim Report.](#)

^{iv} www.asdinfo.wales.co.uk

^v NICE, Clinical guideline CG128. Published date: September 2011. Autism spectrum disorder in under 19s: recognition, referral and diagnosis <https://www.nice.org.uk/Guidance/CG128>

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- vi NICE, Clinical guideline CG142. Published date: June 2012. Autism spectrum disorder in adults: diagnosis and management. <https://www.nice.org.uk/guidance/CG142>
- vii [Autism Act 2009](#)
- viii [Autism Act \(Northern Ireland\) 2011](#)
- ix [The National Autistic Society, 2013. 'Push for Action campaign – Turning the Autism Act into action'](#)
- x [National Autism Project, January 2017. The Autism Dividend: Reaping the rewards of better investment.](#)
- xi [Department for Health, Social Services and Public Safety of Northern Ireland, 2015. 'The Autism Strategy \(2013 – 2020\) Action Plan \(2013 – 2016\) Progress Report](#)
- xii [The National Autistic Society, 2013. Push for Action campaign – Turning the Autism Act into action](#)
- xiii [Parliamentary Review of Health and Social Care in Wales, January 2018. Parliamentary Review final report – A revolution from within: Transforming health and care in Wales.](#)



RCGP Wales response to the Autism (Wales) Bill consultation

1. The Royal College of General Practitioners Wales welcomes the opportunity to respond to the National Assembly for Wales' Health, Social Care and Sport Committee's consultation on the Autism (Wales) Bill, and to provide oral evidence to the Committee.
2. RCGP Wales represents a network of around 2,000 GPs, aiming to improve care for patients. We work to encourage and maintain the highest standards of general medical practice and act as the voice of GPs on resources, education, training, research and clinical standards.

The general principles of the Autism (Wales) Bill and the extent to which it will make provision for meeting the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales and achieve the aim of protecting and promoting their rights:

3. We have concerns that the Bill would lead to diagnosis-based services, instead of services that are needs based and person-centred.
4. Autistic spectrum disorder has a broad range of presentations which can make diagnosis difficult. Individuals can fall between mental health and learning disability. The spectrum may be part of a physical disability, meaning patients do not get either learning disability or mental health support.
5. Those not diagnosed until they are adults may have greater problems accessing support; there are less services for adults and some preclude those who were not diagnosed as a child. There are difficulties in the transition between children and adult services. Services are limited for children but often there are no services available to move to when they are adults.
6. People with learning disabilities, neurodevelopmental disorders or other diagnoses such as attention deficit hyperactivity disorder may not meet the criteria for support under an Autism Bill. Obtaining services and support for these patients can be very difficult; the proposed Bill must not further restrict the support available to those without an autism spectrum disorder diagnosis.
7. We believe support services targeted specifically at those with suspected autism spectrum disorder may be difficult to implement. We have some doubts about support based on legislation or a particular diagnosis; instead we would prefer a

needs-based approach which allocates resources and support according to a person's needs.

Any potential barriers to the implementation of the provisions and whether the Bill takes account of them;

8. Workforce shortages across a number of professions are likely to be a barrier in improving services.
9. We know it is the case with GPs, where severe workforce pressures are having a negative effect on the quality of care GPs are able to give patients. As of September 2017, GP numbers per 10,000 population were the lowest they have been since September 2004, when this figure were first collected¹. While raising data quality issues, a Welsh Government statistical bulletin outlined that the number of GPs in Wales (excluding locums, retainers and registrars) has fallen to 1,926². This is the lowest since 2006/07. We are aware that other professions also face shortages.
10. Access to services will depend on the staff working in them. Increased support is unlikely to happen unless there is a boosted multidisciplinary workforce.

Whether there are any unintended consequences arising from the Bill;

11. We are concerned that making support dependent on a diagnostic label could exclude others who are equally in need of support. Again, this is a risk of making support diagnosis-based rather than needs-based.
12. There may be a risk that introducing diagnosis-based legislation may also lead to calls for specific legislation around other illnesses and conditions. We have doubts as to whether a series of separate pieces of legislation would deliver the best outcomes, as opposed to developing holistic services that are based on need.
13. There is a risk around the impact on diagnostic rates, given individuals or families may feel they are most likely to obtain support by securing a specific diagnosis.
14. We are aware of a number of existing programmes seeking to improve ASD patient outcomes, and there may be an unintended consequence that new legislation duplicates some of that work. The Social Services and Well-being Act, Together for Children and Young People, the National Integrated Autism Service, and the Additional Learning Needs Bill all contain measures that could improve patient outcomes. These are in various stages of development and implementation and may deliver improvements.

¹ <https://statswales.gov.wales/Catalogue/Health-and-Social-Care/General-Medical-Services/localhealthboardcomparisonsofgpworkforce-by-year>

² <https://gov.wales/docs/statistics/2018/180426-general-medical-practitioners-2006-2017-en.pdf>

The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum):

15. We believe additional investment would be better spent on developing needs-based services, rather than diagnosis-based services.
16. We note that general practice remains significantly under-resourced. In 2016/17 general practice received 7.30% of Welsh NHS spend; across the United Kingdom that figure was 8.88%. Proposals involving general practice to improve services will need to be backed with a shift in resource if they are to deliver positive outcomes.

The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Chapter 6 of Part 1 of the Explanatory Memorandum).

17. If a Bill is passed we would support flexibility to meet future needs developments, including in definitions to ensure the emphasis on autism does not restrict the support available to those who fall outside of a diagnosis of autistic spectrum disorder.

TYSTIOLAETH CLILC AR GYFER YMCHWILIAD Y PWYLLGOR IECHYD, GOFAL CYMDEITHASOL A CHWARAEON I FIL AWTISTIAETH (CYMRU)



CLILC • WLGA

Medi 2018

Amdanom Ni

Mae Cymdeithas Llywodraeth Leol Cymru (WLGA) yn cynrychioli'r 22 awdurdod lleol yng Nghymru, ac mae'r tri awdurdod parc cenedlaethol a'r tri awdurdod tân ac achub yn aelodau cyswllt.

Mae WLGA yn sefydliad trawsbleidiol y bydd gwleidyddion yn ei arwain, gydag arweinyddion o bob awdurdod lleol yn pennu polisiâu drwy'r Bwrdd Gweithredol a'r Cyngor WLGA ehangach. Mae'r WLGA hefyd yn penodi uwch aelodau fel Llefaryr ac Is-lefaryr i ddarparu arweiniad cenedlaethol ar faterion polisi ar ran llywodraeth leol.

Mae WLGA yn gweithio'n agos ag ymgynghorwyr proffesiynol a chymdeithasau proffesiynol o lywodraeth leol, ac yn aml yn cael eu cynghori ganddynt, fodd bynnag, WLGA yw'r corff cynrychiadol ar gyfer llywodraeth leol ac mae'n darparu llais torfol, gwleidyddol llywodraeth leol yng Nghymru.

Mae WLGA, yn gweithio mewn partneriaeth ag Iechyd Cyhoeddus Cymru, wedi cynnal Tîm Datblygu Anhwylderau'r Sbectwm Awtistiaeth (ASA) Cenedlaethol ers nifer o flynyddoedd. Chwaraeodd y tîm rôl allweddol mewn cefnogi'r gwaith o greu a ffurfio Gwasanaeth Awtistiaeth Integredig (GAI) ar gyfer Cymru ac maent wedi darparu ystod o adnoddau defnyddiol a chyngor er mwyn cefnogi gwasanaethau cyhoeddus i ymateb yn well i anghenion pobl awtistig. Mae'r tîm yn rhan annatod o Gynllun Gweithredu Strategol Anhwylderau'r Sbectwm Awtistiaeth sydd wedi'i ddiweddarau.

Cyflwyniad

Mae'n bwysig cydnabod y cynnydd a wnaed ers cyhoeddi'r cynllun gweithredu ASA gwreiddiol yn 2008, un o'r cyflawniadau allweddol oedd cynyddu proffil ac ymwybyddiaeth o awtistiaeth yng Nghymru. Ceir ystod eang o wybodaeth ac adnoddau i helpu pobl awtistig a'u teuluoedd a'u gofalwyr, yn ogystal ag adnoddau ar gyfer gweithwyr proffesiynol. Gwnaed y cynnydd hwn heb yr angen am ddeddfwriaeth. Fodd bynnag, rydym yn ymwybodol y gellir bob amser gwneud mwy ac y bydd rhai o'r gwelliannau a'r camau gweithredu'n cymryd amser i'w cyflawni. Rydym oll eisiau gweld gwir wahaniaeth yn y gwasanaethau, y gofal a'r cymorth sydd ar gael i bobl awtistig, eu teuluoedd a'u gofalwyr, felly mae'n briodol cymryd yr amser i ystyried y cynigion a nodir ym Mil Awtistiaeth (Cymru) a ph'un a fydd newidiadau deddfwriaethol yn wir yn cyflawni'r canlyniadau a ddymunir.

Rydym yn glir bod angen i unrhyw ddeddfwriaeth newydd ychwanegu gwerth, ynghyd â gwneud gwir wahaniaeth a chael effaith, o gymharu â'r hyn y gellid ei gyflawni heb ddeddfwriaeth benodol. Y realiti yw y byddai deddfwriaeth aneffeithiol yn siomi'r disgwyliadau uchel sydd gan bobl awtistig a'u teuluoedd a'u gofalwyr y bydd deddfwriaeth newydd ac ychwanegol yn gwneud newidiadau ystyrlon i'r gwasanaethau sydd ar gael iddynt.

Roedd WLGA wedi ymateb yn flaenorol i'r ymgynghoriadau ar y cysyniad cyffredinol o Fil Awtistiaeth (Cymru) arfaethedig ac ar Fil Awtistiaeth (Cymru) drafft lle amlygwyd ein pryderon sylfaenol am yr ymagwedd o greu deddfwriaeth ar wahân ar gyfer cyflwr penodol. Rydym yn credu, o ran deddfwriaeth fel Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014, Deddf Anghenion Dysgu Ychwanegol a'r Tribiwnlys Addysg (Cymru) 2018, Deddf GIG (Cymru) 2006 a Deddf Cydraddoldeb 2010, os ydynt yn gweithio'n iawn, y dylent gyflenwi ar gyfer ein holl ddinasyddion ar sail angen. O ystyried y sylfeini deddfwriaethol a'r pwerau sydd eisoes ar waith yng Nghymru, a'r ffaith ein bod eisoes wedi amlygu y byddai'n well pe bai sawl agwedd ar y Bil sydd wedi'u cynnig yn cael eu cynnwys o fewn canllawiau / codau ymarfer yn hytrach nag mewn deddfwriaeth sylfaenol, nid ydym wedi ein hargyhoeddi eto o'r angen i greu'r darn ar wahân hwn o ddeddfwriaeth. Byddai'n well gennym adeiladu ar y pwerau a'r mecanweithiau sydd eisoes ar waith a defnyddio'r rheiny i gryfhau'r gwasanaethau, y gofal a'r cymorth sydd ar gael i bobl awtistig, eu teuluoedd a'u gofalwyr.

Nid ydym felly'n cefnogi'r angen am Fil Awtistiaeth (Cymru). Rydym yn credu, drwy osod strategaeth awtistiaeth benodol mewn statud, bod perygl o ddsbarthu adnoddau'n annheg, heb o reidrwydd adeiladu datrysiad hirdymor cynaliadwy a strategol sy'n mynd i'r afael ag anghenion pobl awtistig. Yn

ein barn ni, y perygl yw y gallai'r Bil olygu y bydd adnoddau a gweithgareddau'n cael eu llywodraethu gan set gul o brosesau statudol, yn hytrach na chael eu cyfeirio yn ôl bwriad i gyflenwi gwell canlyniadau. Gallai hyn arwain at anawsterau penodol i gynghorau yng nghyd-destun cyllidebau sydd eisoes dan bwysau, a cheir pryder yn y diwedd y gallai arian gael ei gyfeirio i ffwrdd o wasanaethau cymorth eraill, ac y gallai unrhyw fuddion ar gyfer pobl awtistig fod ar draul pobl ag anableddau eraill. Ceir risg hefyd y bydd y Bil hwn yn ychwanegu cymhlethdod neu ddyblygu, yn achos gofawyr er enghraifft.

Mae angen ystyried yn o ddifrif hefyd y goblygiadau o ran gosod cynsail o'r fath wrth fynd ymlaen, gan nad gwasanaethau i bobl anabl yw'r unig faes lle bo angen gwella gwasanaethau i bobl â chyflyrau penodol. Mae'n hanfodol ei bod yn canfod ac yn ystyried holl ganlyniadau anfwriadol deddfwriaeth mewn perthynas ag unrhyw gyflwr penodol, a'n bod yn archwilio unrhyw risg y bydd deddfwriaeth o'r fath efallai'n effeithio ein gallu i ymateb i eraill ar sail angen.

Y cynnydd hyd yma

Wrth ystyried yr angen am ddeddfwriaeth ychwanegol, mae'n hanfodol i ni ystyried y cynnydd a wnaed eisoes yng Nghymru o dan y trefniadau deddfwriaethol a pholisi presennol, ynghyd â'r gwaith a gynlluniwyd sydd eisoes ar fynd, i'n helpu i bwysu a mesur pa werth ychwanegol fyddai'n dod o ganlyniad i unrhyw ddeddfwriaeth newydd, os oes unrhyw beth.

Ers datblygu'r Strategaeth Awtistiaeth yn 2008 a'r Cynllun Gweithredu Strategol ar gyfer ASA a ddiweddarwyd yn 2016, mae Cymru wedi gweld cryn gynnydd o ran gwasanaethau a chymorth i bobl awtistig, gyda chynnydd mewn ymwybyddiaeth, cynhyrchu ystod o adnoddau, ynghyd â hyfforddiant yn cael ei ddatblygu a'i roi ar waith. Gan weithio'n agos â Llywodraeth Cymru (LIC), mae awdurdodau lleol ac iechyd wedi sefydlu, neu maent yn y broses o sefydlu, 7 GAI rhanbarthol. Fe'u hariennir gan LIC drwy'r Gronfa Gofal Integredig (ICF), yn seiliedig ar ôl troed Byrddau Iechyd, o dan oruchwyliaeth y 7 Bwrdd Partneriaeth Rhanbarthol amlasiantaethol statudol, gan ganolbwyntio ar integreiddio iechyd a gofal cymdeithasol. Mae'r GAI ar y cyd yn cyfrannu tuag at yr hyn a welir fel gwasanaeth cenedlaethol a chanddo safonau ac ymarfer tebyg a chyson, sy'n darparu cyngor ac arweiniad, ac sy'n cynnig atebion ymarferol i ystod o heriau.

Yn ystod 2017/2018, lanswyd GAI Caerdydd a'r Fro, Cwm Taf, Gwent a Phowys yn y cyfnod datblygu cychwynnol a daethant i fod yn weithredol, tra cafodd un Gogledd Cymru ei lansio ym Mehefin 2018.

Mae Gorllewin Cymru a Bae'r Gorllewin yn parhau i wneud cynnydd yn barod ar gyfer eu lansio'n ddiweddarach eleni, a bydd GAI gweithredol ym mhob rhanbarth erbyn yr hydref 2018. Mae Tîm Datblygu ASA Cenedlaethol wedi cefnogi creu'r GAI hyn, ac mae'n parhau i wneud hynny ar gyfer yr ardaloedd hynny nad ydynt yn gwbl weithredol hyd yma.

Rhan o rôl y Tîm Datblygu ASA Cenedlaethol yw datblygu a darparu adnoddau mewn partneriaeth er budd unigolion awtistig, rhieni a gofalywyr a gweithwyr proffesiynol. Mae eu gwefan (www.ASDinfoWales.co.uk) yn rhan allweddol o'r cynnig hwn ac fe'i hariennir gan LIC fel rhan o Gynllun Gweithredu Strategol ASA ar gyfer Cymru. Mae'n cynnwys ystod eang o wybodaeth, cyngor ac adnoddau i bobl awtistig a'r rheiny sy'n eu cefnogi, yn ogystal â gweithwyr proffesiynol a chanddynt ddiddordeb a rôl mewn awtistiaeth, ac i sicrhau bod anghenion pobl awtistig yn cael eu cyfathrebu i randdeiliaid allweddol. Mae'r tîm yn parhau i godi ymwybyddiaeth o awtistiaeth ac yn datblygu hyfforddiant, yn codi ymwybyddiaeth ac yn darparu adnoddau cefnogol ar gyfer awtistiaeth y gellir eu defnyddio gan y GAI, gwasanaethau ehangach, pobl awtistig a phawb sy'n eu cefnogi. Mae'r Tîm Datblygu ASA Cenedlaethol hefyd yn cefnogi'r gwaith o gydlynu a chyflenwi hyfforddiant yn unol â Fframwaith Hyfforddiant Cenedlaethol Cymru. Mae cynllun "Weli Di Fi?" yn hyrwyddo ymwybyddiaeth a'r gallu i dderbyn awtistiaeth mewn cymunedau er mwyn gwella mynediad i ddarpariaeth gymunedol ar gyfer unigolion awtistig. (www.ASDinfoWales.co.uk/leisure-staff a www.ASDinfoWales.co.uk/housing-provider-scheme).

Mae rhai o'r adnoddau a ddatblygwyd ganddynt yn cael eu rhestru isod:

Tyfu gydag Awtistiaeth

Mae'r adnoddau Tyfu gydag Awtistiaeth ar gyfer rhieni a gofalwyr plant a'r glasoed iau. Mae ystod o adnoddau ar gael, gan gynnwys canllaw yn dilyn diagnosis, taflenni cynghori, lluniwr proffil personol plentyn, cardiau lluniau i strwythuro gweithgareddau dyddiol plentyn, 5 ffilm fer sy'n darparu trosolwg o awtistiaeth a chynghor ynghylch materion cyffredin eraill, gan gynnwys cynllunio cyfathrebu, ymdopi â newidiadau ac ymweld â gweithwyr iechyd proffesiynol.

Mae adnoddau i gefnogi cyfoedion a brodyr a chwirydd i ddeall awtistiaeth wedi'u datblygu hefyd. Ffilm animeiddiedig yw Teifi a'i Ffrindiau, gyda'r lleisiau gan gast Stella, sy'n dangos i blant ifanc sut i fod yn garedig ac i allu derbyn rhai sydd ag anghenion ychwanegol. Mae Archarwyr Awtistiaeth ar gael fel llyfr stori ac fel comig antur a ddyluniwyd i ddatblygu dealltwriaeth o awtistiaeth ar gyfer plant o oedran ysgol gynradd.

Dysgu gydag Awtistiaeth

Ceir cyfres o adnoddau ar gyfer lleoliadau addysgol o'r blynyddoedd cynnar i ysgolion uwchradd, ac mae rhaglen addysg bellach ac ar gyfer dysgu yn y gweithle yn cael eu datblygu ar hyn o bryd.

Dyluniwyd y rhaglenni Dysgu gydag Awtistiaeth i helpu staff i ddatblygu eu gwybodaeth a'u sgiliau i gefnogi'r rheiny ag awtistiaeth. Anogir plant a disgyblion hefyd i ddysgu gydag adnoddau Teifi a'i Ffrindiau, yr Archarwyr Awtistiaeth a Sgilti. Ar ôl i'r holl staff a disgyblion ymgymryd â'r hyfforddiant priodol, gall ysgolion wneud cais i fod yn lleoliad 'Ymwybyddiaeth am Awtistiaeth'.

Byw gydag Awtistiaeth

Mae'r adnoddau Byw gydag Awtistiaeth yn cynnwys canllaw cefnogol sy'n cynnwys awgrymiadau a chynghor i'r rheiny sydd wedi cael diagnosis o awtistiaeth. Gall unigolion hefyd chwilio geirfa idiomau a gallant greu a lawrlwytho proffil personol i amlygu eu cryfderau a'u hanawsterau a sut y gall eraill eu cefnogi.

Gweithio gydag Awtistiaeth

Ceir adnoddau ar gyfer y rheiny sy'n rhoi cymorth i bobl awtistig gael cyflogaeth ynghyd â rheolwyr a chydweithwyr o ran y rheiny sy'n gweithio ym maes Adnoddau Dynol. Ymhlith adnoddau i gefnogi cyflogwyr mae ffilm Byw gydag Awtistiaeth a hyfforddiant e-ddysgu. Er mwyn cefnogi unigolion i gael cyflogaeth, ceir lluniwr CV, pecyn chwilio am waith a lluniwr medrau. Ar gyfer cydweithwyr a rheolwyr, ceir cynllun Bod yn Fodlon Gweithio gydag Awtistiaeth sy'n cynnwys siarter i'w llofnodi, cyngor a chynllun hyfforddiant ar gyfer y rheiny sy'n gweithio ym maes Adnoddau Dynol.

Mae'r Tîm Datblygu ASA Cenedlaethol hefyd yn hwyluso Cymuned Ymarfer ar gyfer diagnosis i oedolion sy'n dwyn ynghyd gweithwyr proffesiynol ym maes iechyd a gofal cymdeithasol er mwyn datblygu llwybrau asesu, diagnostig a chymorth ledled Cymru. Mae'r Gymuned Ymarfer eisoes yn mynd i'r afael â meysydd allweddol fel datblygu arfer gorau mewn perthynas â: canfod a diagnosiso ASA; llwybrau; asesu; a chynllunio. Mae sawl un o'r agweddau hyn wedi'u harchwilio a'u cytuno eisoes, ac maent yn cael eu cyflwyno'n genedlaethol drwy'r GAI. Mae'r Tîm Datblygu ASA Cenedlaethol yn mynd ati ymhellach i hwyluso rhwydwaith o arweinwyr ASA mewn awdurdodau lleol, ynghyd ag arweinwyr GAI ledled Cymru. Bydd y Rhwydwaith Arweinwyr GAI Cenedlaethol sydd newydd ei sefydlu yn gweithio ar y cyd â'r tîm a LIC i gwblhau templedi adrodd ICF ar gyfer y flwyddyn ariannol nesaf i sicrhau bod gwybodaeth a gesglir yn darparu gwybodaeth ar ganlyniadau ac effaith y gwasanaethau. Gwneir rhagor o waith i alinio data a gesglir yn y GAI gyda hynny a gesglir yn y gwasanaethau Niwroddatblygiadol. Mae'r fforymau hyn yn hanfodol ar gyfer rhannu arferion da, cyfnewid gwybodaeth a chynnal y sylw allweddol ar anghenion unigolion awtistig, rhieni, gofalwyr a theuluoedd.

Mae'n werth nodi hefyd bod LIC eisoes wedi nodi eu bwriad i gyflwyno Cod Ymarfer ar gyflenwi gwasanaethau awtistiaeth a gyhoeddir o dan Ddeddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 a Deddf GIG (Cymru) y flwyddyn nesaf. Nod hyn yw egluro'r cymorth y gall pobl awtistig ddisgwyl ei dderbyn, a bydd yn darparu arweiniad ar sut y gall gwasanaethau addasu eu hymarfer i ddiwallu anghenion unigol pobl awtistig.

Mae'r Memorandwm Esboniadol sy'n eistedd ochr yn ochr â'r Bil yn cyfeirio'n aml at y ffaith bod y Bil yn adeiladu ar y trefniadau presennol a nodir uchod. Er enghraifft:

- “adeiladu ar yr enillion a wnaed gan y Cynllun Gweithredu Strategol”
- “adeiladu ar y trefniadau presennol ar gyfer casglu data, sy'n cael eu datblygu ar hyn o bryd”
- “adeiladu'n bennaf ar ddeunyddiau sydd eisoes wedi'u paratoi ar gyfer y Cod Ymarfer hwn [i'w datblygu o dan Ddeddf Gwasanaethau Cymdeithasol a Llesiant (Cymru)]”
- “bydd yr ymgyrch i wella ymwybyddiaeth am y Bil hwn yn adeiladu ar yr adnoddau presennol hyn [y rheiny a ddatblygwyd eisoes gan y Tîm Datblygu ASA Cenedlaethol, fel ymgyrch ‘Weli Di Fi?’]”
- “adeiladu ar ddyheadau Cynllun Gweithredu Strategol Llywodraeth Cymru ar gyfer Anhwylderau'r Sbectrwm Awtistig, a oedd yn sefydlu seilwaith ar gyfer awtistiaeth ym mhob ardal awdurdod lleol, gyda chydlynwyr a strategaethau lleol, a chydlynedd cenedlaethol ar gyfer Cymru.”

Mae hyn yn amlinellu'r ffaith bod llawer o'r hyn y mae'r Bil yn bwriadu ei gyflawni wedi cychwyn yn barod – gwnaed llawer o gynnydd eisoes, ac mae'r cynigion deddfwriaethol penodol ar gyfer awtistiaeth sy'n destun ymgynghori yn amlygu'r hawliau presennol sy'n bodoli eisoes, ac y gellir eu cyflawni drwy lwybrau eraill. Fodd bynnag, mae angen i ni hefyd gydnabod bod llawer o'r gwaith sydd wedi cychwyn yn dal i fod ar y gweill, fel sefydlu'r GAI rhanbarthol. Trwy'r Cynllun Gweithredu Strategol a chyflwyno'r GAI, rydym erbyn hyn yn gweld gwelliannau sylweddol yn ymddangos mewn gwasanaethau, ynghyd ag awydd unwaith eto i weithio ar y cyd ar draws sectorau. Mae angen i ni hoelio'n sylw ar gyflenwi'r gwasanaethau a'r cymorth sy'n gallu gwneud gwir wahaniaeth i fywydau pobl awtistig a'u teuluoedd drwy gefnogi sefydlu'r gwasanaethau hyn a rhoi amser iddynt wreiddio llwybrau newydd, yn hytrach nag efallai ansefydlogi neu rwystro peth o'r cynnydd hwn. Mae'r gwaith o weithredu'r GAI Cenedlaethol yn cael ei adolygu'n annibynnol ar hyn o bryd. Disgwylir canlyniad yr adolygiad hwn erbyn Mawrth 2019, ac felly mae angen i ni ddisgwyl am y canlyniad hwn cyn edrych i wneud unrhyw newidiadau pellach ac ystyried p'un a oes angen gwneud unrhyw newidiadau o ran polisi, neu yn wir deddfwriaeth, er mwyn gwella gwasanaethau.

Profiadau Lloegr a'r Alban

Mae'n werth nodi'r profiad yn Lloegr hefyd, a ph'un a yw cyflwyno deddfwriaeth awtistiaeth benodol yn wir yn arwain at wella gwasanaethau. Yn Lloegr, cafodd y Ddeddf Awtistiaeth Gydsyniad Brenhinol yn Nhachwedd 2009 a gosododd ofynion statudol ar y Llywodraeth i gyhoeddi strategaeth awtistiaeth ar gyfer oedolion, ynghyd ag arweiniad statudol cysylltiedig ar gyfer awdurdodau lleol a chyrrff iechyd lleol mewn perthynas â chefnogi anghenion oedolion awtistig. Cam gweithredu allweddol o'r strategaeth *Think Autism* oedd y byddai GIG Lloegr yn helpu i wella gwasanaethau diagnostig ar gyfer awtistiaeth, fodd bynnag, yn yr Ymarfer Hunanasesu Awtistiaeth a gyhoeddwyd gan Iechyd Cyhoeddus Lloegr, dim ond 22% o awdurdodau lleol oedd yn adrodd eu bod yn cyflawni'r amseroedd aros a argymhellir gan Y Sefydliad Cenedlaethol dros Ragoriaeth Mewn Iechyd a Gofal (NICE), gyda rhai ardaloedd yn Lloegr yn adrodd amseroedd disgwyl am asesiad o hyd at ddwy flynedd. Roedd y Gymdeithas Awtistiaeth Genedlaethol yn awgrymu bod y canlyniadau o'r adroddiad cynnydd diwethaf yn datgelu "the autism diagnosis crisis" yn Lloegr, er y deddfwriaeth sy'n bodoli yn y maes hwn. Mae hyn yn codi'r cwestiwn o ba mor effeithiol ydy cyflwyno deddfwriaeth newydd o ran gwella gwasanaethau i bobl awtistig, a ph'un a oes, mewn gwirionedd, perygl y bydd datblygu Bil Awtistiaeth ar hyn o bryd yn torri ar draws y gwaith sy'n cael ei wneud eisoes, ac yn ei dro'n creu anhawster o ran cyflenwi ymagwedd gyson.

Yn yr Alban, methu yn y cam cyntaf wnaeth y Bil Awtistiaeth arfaethedig, yn Ionawr 2011, ar ôl i Senedd yr Alban anghytuno ag egwyddorion cyffredinol y Bil. Y Pwyllgor arweiniol ar gyfer y Bil oedd y Pwyllgor Addysg, Dysgu Gydol Oes a Diwylliant a ddaeth i'r casgliad:

"legislation for a strategy for a specific disability group may create a two-tier system of strategies whereby strategies set out in legislation are seen to have "more teeth". The Committee is also concerned that this might lead to a perception of two-tier disabilities with some disabilities thought of as being more worthy of a legislative strategy than others. The Committee does not believe this would be helpful."

Teimlasant hefyd na fyddai'r Bil fel y cafodd ei gyhoeddi yn goresgyn y rhwystrau i ddarpariaeth gwasanaeth nac yn bodloni disgwyliadau pobl awtistig. Nodwyd y ffaith ganddynt fod darnau sylweddol o deddfwriaeth berthnasol, tebyg i hynny yng Nghymru, nad oeddynt wedi bod mewn grym am ddigon o amser i werthuso eu heffaith, ac felly nid oedd y Pwyllgor wedi'u hargyhoeddi o'r

angen am ddeddfwriaeth ychwanegol gan ddweud “resources would be better spent focusing on the implementation of existing legislation and duties”.

Sylwadau ar y Bil arfaethedig

Tra bo gennym amheuon mawr am yr ymagwedd sy'n cael ei hystyried o ran creu deddfwriaeth newydd ac ychwanegol, amlygwn isod rai sylwadau penodol mewn perthynas â'r Bil fel y mae wedi'i ddrafftio ar hyn o bryd, er, yn gyffredinol, y credwn y byddai angen cryfhau'r drafft o'r Bil, gan fod diffyg eglurder mewn rhai agweddau arno o ran disgwyliadau.

Y Strategaeth Awtistiaeth

O dan 1(7) cyfeirir at yr angen i gomisiynu adroddiad “annibynnol”, tra ein bod yn cydnabod yr angen i adolygu cynnydd ac adrodd ar ei weithrediad, byddwn yn cwestiynu'r defnydd o'r gair “annibynnol”, beth a olygir gan hyn a ph'un a oes angen ei roi ar wyneb y Bil?

O dan 2(1)(a) mae'r Bil yn nodi bod rhaid i'r Strategaeth Awtistiaeth ddiffinio model neu fodelau arfer gorau. Ymddengys fod hyn yn llawer rhy gyfyngol o ran rhagnodi'r modelau y mae'n rhaid eu diffinio, a gall rwystro newid i'r dyfodol. Efallai y byddai'n well amlygu llwybrau yn hytrach na modelau.

O dan 2(1)(c), mae'r Bil yn gofyn am ddechrau asesiadau diagnostig cyn gynted ag y bo'n rhesymol ymarferol yn dilyn atgyfeiriad, ac o leiaf o fewn unrhyw derfynau amser a nodir yn y Safon Ansawdd perthnasol a gyflwynir gan NICE (sef 13 wythnos ar hyn o bryd). Mae hyn yn wahanol i arweiniad presennol Llywodraeth Cymru, sy'n gosod targed o 6 mis (2 wythnos). Mae'r Gymuned Ymarfer ar gyfer diagnosis i oedolion ac ymarferwyr GAI yn ymateb i'r ymchwiliad ar wahân. Yn eu hymateb, amlygir yr elfen hon o'r Bil a'r heriau a'r goblygiadau cysylltiedig, ac rydym yn ategu eu sylwadau. Tra nad yw'n ddelfrydol peidio â chael unrhyw derfynau amser, mewn realiti, nid yw'r targed 26 wythnos cyffredinol presennol yn adlewyrchu cymhlethdod llawer o atgyfeiriadau. Byddai terfyn amser 13 wythnos yn herio hyn ymhellach, ac ni fyddai'n adlewyrchu'r cyfnod amser a fynnir i ymgymryd â'r hyn sy'n aml yn asesiadau cymhleth. Mae arfer gorau hefyd yn pennu y dylid gwneud diagnosis ac ymgymryd ag asesiadau ar sail amlasiantaethol, ac felly fe all gorfod gweithredu o fewn terfynau amser negyddu neu weithio yn erbyn ymagwedd o'r fath. Mae gwaith yn cael ei wneud ar hyn o bryd gan glinigwyr, ymarferwyr, Llywodraeth Cymru a'r Tîm Datblygu ASA Cenedlaethol i edrych ar derfynau amser ar gyfer gwneud diagnosis ac asesiadau fel rhan o'r gwaith parhaus yng nghyswllt

datblygu'r GAI. Rhagwelir y cyhoeddir yr arweiniad drafft ar gyfer ymgynghori yn y cyfnod 2018/19. Tra bo amser yn ffactor mewn cynnal asesiadau, rhaid i ansawdd yr asesiad gael blaenoriaeth.

Mae 2(1)(g) yn nodi bod rhaid i'r strategaeth awtistiaeth amlinellu sut y dylai cyrff perthnasol ddiwallu anghenion unigolion ag ASA mewn perthynas â'r canlynol, ond heb fod yn gyfyngedig iddynt: mynediad at wasanaethau gofal iechyd; mynediad at addysg; mynediad at gyflogaeth; mynediad at dai; mynediad at wasanaethau Cymraeg; mynediad at wasanaethau cyhoeddus eraill; cynhwysiant cymdeithasol; a mynediad at wasanaethau eirioli. Mae rhai o'r meysydd hyn yn llawer rhy gyffredinol, er enghraifft, sut fydd mynediad i gyflogaeth, neu fynediad i wasanaethau cyhoeddus yn cael sylw mewn unrhyw fodd ystyrlon? Yn hytrach na rhoi'r meysydd hyn ar wyneb y Bil, byddai'n well iddynt gael eu cynnwys o fewn canllawiau.

Mae 2(1)(l) yn nodi bod y strategaeth awtistiaeth yn gorfod "gwneud darpariaeth ar gyfer ystyried dymuniadau personau ag anhwylder sbectrw m awtistiaeth a theulu a gofalwyr y personau hynny", fodd bynnag, o dan 4(6)(b) cyfeirir at "personau a ddosberthir fel gofalwyr at ddibenion y Ddeddf hon". Nid yw'n glir beth a olygir gan y rheiny a ddosberthir fel gofalwyr at ddibenion y Ddeddf hon, sut mae hyn yn cyd-fynd â'r Ddeddf Gwasanaethau Cymdeithasol a Llesiant, ynghyd â'r diffiniad o ofalwr o dan y ddeddfwriaeth honno? A ydym yn creu gwahanol ddiffiniadau ar gyfer gofalwyr o dan wahanol ddarnau o ddeddfwriaeth? Mae hyn yn amlygu'r cymhlethdodau sy'n gysylltiedig â chreu deddfwriaeth ychwanegol ar gyfer grwpiau y maent eisoes yn dod o dan ddeddfwriaeth bresennol, ynghyd â'r angen i fod yn glir ynghylch beth yw hawliau a disgwyliadau pobl, gan sicrhau bod deddfwriaeth newydd yn ategu cyfraith bresennol.

Canllawiau gan Weinidogion Cymru

Mae 4(2) yn nodi bod rhaid i'r canllawiau gael eu dyroddi o fewn 3 mis o gyhoeddi'r strategaeth. Yn ein hymatebion i'r ymgynghoriad blaenorol, codwyd pryderon am y terfyn amser hwn gan fod rhaid gwneud y gwaith i ddatblygu'r canllawiau ar y cyd, felly mae angen rhoi digon o amser i ganiatáu hyn. Rydym felly'n dal i gwestiynu p'un a fyddai'r cyfnod o dri mis a nodir yn y Bil yn ddigonol, ac awgrymwn fod angen caniatáu rhagor o amser.

O dan 6(f) mae'r Bil yn nodi "rhaid i ganllawiau a ddyroddir o dan yr adran hon gynnwys yn benodol ganllawiau ynghylch trefniadau lleol ar gyfer arweinyddiaeth mewn perthynas â darparu

gwasanaethau". Nid yw'n glir beth a olygir gan y cymal hwn, neu beth y mae'n ceisio ei gyflawni, felly mae angen eglurhad pellach.

Data ar Anhwylder Sbectrw m Awtistiaeth

Mae angen eglurhad pellach o ran ar gyfer beth y cesglir y data, sut, ac ar gyfer pa bwrpas y bydd yn cael ei ddefnyddio, a pham fod rhai mathau o ddata'n cael eu nodi ond nid eraill? Er enghraifft, pam fod rhywedd yn cael ei nodi, ond nid nodweddion gwarchoddedig eraill? Byddai o gymorth hefyd i nodi'r terfynau amser sydd dan sylw, ac ystyried i ba raddau y gellir cyflawni'r disgwyliadau dros amser o ran y data y nodwyd fod angen ei gasglu.

Goblygiadau Ariannol

Yn ein tystiolaeth mewn ymateb i ddatblygiad Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru), amlygwyd yn gyson gennym y goblygiadau o ran adnoddau ar gyfer gweithredu'r darn hwnnw o ddeddfwriaeth, ac mae'r un peth yn wir am y Bil Awtistiaeth. Mae sawl awdurdod yn gorfod jyglo pwysau o bob math heb gyllid, a hynny gyda gostyngiadau mewn cyllid na welwyd eu tebyg o'r blaen. Credwn y dylid mynd ati'n fuan i ymgysylltu'n llawn â'r holl randdeiliaid yn y gwaith o ffurfio deddfwriaeth, ac na ddylid asesu'r effeithiau ariannol ar wahân, ond fel rhan o'r rhaglen gyfan. Mae'n hanfodol i unrhyw ddyletswyddau a beichiau newydd sy'n cael eu creu gael eu nodi a'u hariannu'n llawn. O ran unrhyw ddeddfwriaeth sy'n cael ei chyhoeddi, mae'n rhaid ei hasesu hefyd ar ôl ei gweithredi'n annibynnol o'r llywodraeth. Y realiti yw, os nad yw gwir gostau gweithredu'r ddeddfwriaeth a'r canllawiau arfaethedig hyn yn cael eu canfod, yna gallai eu cyflwyno olygu y bydd adnoddau'n cael eu cyfeirio i ffwrdd o wasanaethau cymorth eraill er mwyn darparu'r gwasanaethau perthnasol i bobl awtistig.

Mae'r Memorandwm Esboniadol yn nodi costau ychwanegol o dros £7 miliwn, mae hyn yn ofyn sylweddol o ran adnoddau y byddai angen ei ariannu a'i gefnogi'n llawn, gyda'r costau hyn yn cael eu monitro'n barhaus i sicrhau bod y cyfrifoldebau ychwanegol yn parhau i gael eu hariannu'n llawn. Tra bo'r memorandwm yn dadlau bod tystiolaeth y byddai'r Bil yn arwain at fuddion sylweddol, rhai uniongyrchol ac anuniongyrchol, nid yw'n nodi beth ydynt, gan ddweud "nid yw'n bosibl mesur y rhain, ac felly maent yn anhysbys." Y costau mwyaf a briodolir i'r Bil yw'r rheiny mewn perthynas â'r gost o gyflawni'r gofyn ychwanegol o ran yr amser disgwyl 13 wythnos. Fel y nodwyd yn ymateb y Gymuned Ymarfer ar gyfer diagnosis oedolion ynghyd â'r ymarferwyr GAI, dim ond un cam yn nhaith bobl mewn perthynas â gwasanaethau awtistiaeth yw'r asesiad diagnostig, a thra ei bod yn bwysig

nad yw pobl yn cael eu gadael yn disgwyl am asesiad diagnostig, mae hyn yn rhan fechan iawn o'r hyn y bydd ei angen arnynt gan wasanaethau. Ni ddylid canolbwyntio ar gyflawni amseroedd aros yn unig, mae'n rhaid ystyried yr holl waith arall sy'n cael ei gyflenwi gan wasanaethau awtistiaeth arbenigol. Mae angen symiau sylweddol o gyllid ychwanegol i allu clirio rhestrau aros presennol ac i allu cadw o fewn y terfynau amser arfaethedig wedyn, fel nad ydynt yn peryglu'r gwaith arall sy'n cael ei gyflenwi ganddynt. Mae angen hefyd sicrhau bod cymorth priodol ar gael ar ôl cael diagnosis, sydd hefyd yn gofyn am fuddsoddiad ychwanegol er mwyn gallu diwallu'r gofynion ychwanegol ar wasanaethau.

Fodd bynnag, ni wnaiff dim ond darparu rhagor o arian ddatrys y mater o amseroedd disgwyl yn rhwydd, oherwydd mai rhan o'r broblem hefyd yw bod diffyg diagnostegwyr, ac mae recriwtio i rai gwasanaethau ar draws Cymru yn broblem oherwydd y diffyg staff a chanddynt y sgiliau a'r profiad angenrheidiol.

Casgliad

Gwnaed cynnydd sylweddol yng Nghymru mewn blynyddoedd diweddar o ran gwella gwasanaethau a chymorth ar gyfer pobl awtistig, gydag ymwybyddiaeth yn codi ac ystod o adnoddau'n cael eu llunio a'u cyflwyno. Gwnaed y cynnydd hwn heb yr angen am deddfwriaeth ychwanegol. Mae deddfwriaeth bresennol yng Nghymru fel Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru), Deddf Anghenion Dysgu Ychwanegol a'r Tribiwnlys Addysg (Cymru) 2018, Deddf GIG (Cymru) 2006 a Deddf Cydraddoldeb 2010, ar waith eisoes ac yn darparu hawliau presennol i bobl awtistig, ac os ydynt yn gweithio'n iawn, byddant yn cyflenwi ar gyfer ein holl ddinasyddion ar sail angen, a gellir eu defnyddio i gyflawni dyheadau'r Bil arfaethedig. Ceir goblygiadau hefyd o ran gosod cynsail wrth fynd ymlaen o ran cyflwyno deddfwriaeth ar gyfer cyflyrau penodol, a allai arwain at alwadau eraill am gyflwyno deddfwriaeth benodol ar gyfer mathau eraill o salwch a chyflyrau, heb fodolaeth tystiolaeth gadarn.

Mae tystiolaeth yn awgrymu, lle cyflwynwyd deddfwriaeth benodol ar gyfer awtistiaeth, fel yn Lloegr, nad yw wedi arwain at well canlyniadau ar gyfer pobl awtistig, ac nid yw wedi cyflawni'r buddion a ragwelwyd yn wreiddiol. Credwn yn gryf y dylai'r sylw yng Nghymru fod ar ddefnyddio'r adnoddau sydd ar gael i ganolbwyntio ar weithredu deddfwriaeth a dyletswyddau presennol, gan roi sylw i'r gwaith sydd eisoes wedi cychwyn, y mae'r Bil yn ceisio adeiladu arno, gan hoelio ein sylw ar gyflenwi'r gwasanaethau a'r cymorth sydd eisoes yn cael eu datblygu, sy'n gallu gwneud gwir wahaniaeth i fywydau pobl awtistig, teuluoedd a'u gofalwyr.



National Assembly's Health, Social Care and Sport Committee: **Autism (Wales) Bill** Contribution by ADSS Cymru

Authority	██████████, President
Completed by	██████████, Policy and Research Lead
Date	3 October 2018

General Comment

- 1.1 The Association of Directors of Social Services (ADSS Cymru) is the professional and strategic leadership organisation for social services in Wales and is composed of statutory Directors of Social Services and the Heads of Service who support them in delivering social services responsibilities and accountabilities; a group of more than 80 social services leaders across the 22 local authorities in Wales.
- 1.2 As the national leadership organisation for social services in Wales, the role of ADSS Cymru is to represent the collective, authoritative voice of Directors of Social Services, Heads of Adult Services, Children's Services and Business Services, together with professionals who support vulnerable children and adults, their families and communities, on a range of national and regional issues of social care policy, practice and resourcing. It is the only national body that can articulate the view of those professionals who lead our social care services.
- 1.3 As a member-led organisation, it is uniquely placed as the professional and strategic leadership organisation for social services in Wales, to lead on national service development initiatives to ensure a consistent efficient and high standard of delivery for people who access care services across Wales.
- 1.4 ADSS Cymru is committed to using the wealth of its members' experience and expertise, working in partnership with other agencies, to influence important decisions around social care to the benefit of the people it supports and the people who work within care services. Therefore, we welcome the opportunity to comment on the proposals contained in the Autism (Wales) Bill.
- 1.5 While ADSS Cymru appreciates that the fundamental objectives at heart of the Bill is to ensure that there is consistent and continued provision to meet the needs of the 34,000 autistic people in Wales, we continue to believe that, at this stage, there is not a requirement for specific legislation to address the needs expressed by this particular group, their families or their carers and we will set out the reason for that further in this paper.
- 1.6 However, it should be noted that the Welsh Government has made strides to strengthen public service provision for people with autism and their families and carers, which has built on its innovative and leading 2008 Autism Spectrum Disorder (ASD) Strategic Action Plan. That plan has been recently reviewed and revised and in addition to the establishment of the All-Age National Integrated Autism Service (IAS) in 2016, there has been increased levels of investment in both national and local structures,

all of which has helped raise the profile of the condition, as well as the development of improved services and the establishment of new services.

Current Legislation

- 2.1 The principle reason why ADSS Cymru is, at this stage, reticent to support new specific legislation, is that there are two fundamental pieces of legislation in place – *the Social Services and Well-being (Wales) Act 2014* (SSWBA) and *the Well-being of Future Generations (Wales) Act 2015* (FGA) – which aim to develop a common understanding of what public services are required in an area and to develop joint working between public bodies, so that local activity and national goals are aligned and centred around the needs of the citizen.
- 2.2 This needs-based approach is very important, particularly in relation to the SSWBA, as it provides the legal framework for improving the well-being of people who need care and support carers who need support. The SSWBA is transforming the way social services are delivered through an integrated approach that is focused on achieving the outcomes necessary to promote a person’s well-being - as an individual, as part of a family and as part of their community; an approach that is person rather than condition specific. This needs-based approach means that resources and support is delivered according to need, not prioritised according to legislation or just linked to receiving an assessment and a diagnosis. One of the fundamental concerns that we have, given that resources in local government are so stretched, is if IAS service managers are being directed under this legislation to focus all their psychology resource to assessment and diagnosis, then this will be to the detriment of post diagnosis support. Our belief is that diagnosis is only a small part of the total input people need but practitioners will not be able to rationalise this with the legislation.
- 2.3 We should also take into account the recent enactment of the Additional Learning Needs and Education Tribunal (Wales) Act (2018). The needs-based approach is also consistent with this important piece of legislation that has the potential to bring tangible benefits to children and young people with ASD by supporting early identification of additional learning needs and effective interventions to support these needs throughout a child and young person’s education.
- 2.4 The Well Being Plan in the FGA is the overarching strategy for public service activity in an area and therefore, the SSWBA is required to fit in with this broader context for both corporate planning and work across Public Service Boards, as well as being a discreet activity. However, given that there has not been sufficient time to imbed and assess the impact of both pieces of legislation in relation to citizens with ASD, ADSS Cymru believes it would not be prudent at this stage to invest into a resource intensive process to implement additional legislation until that further assessment work has been done.
- 2.5 Moreover, we are also concern about legislation incompatibility. The legislation is attempting to deal with barriers to people with autism receiving services they need, ensuring that IQ and illness are not reasons to exclude people from services. The SSWBA, if implemented as the Act intends, already determines who has eligible needs and who does not through National Eligibility Criteria. There is a real danger if this legislation is implemented that the two pieces of legislation may be incompatible, which will cause confusion, may raise unnecessary expectation and be unfair to those without a diagnosis of autism who are in similar circumstances.

Guidance

3.1 The other fundamental reason why ADSS Cymru believes that specific legislation is not required at this stage is the commitment Welsh Ministers have made to strengthen statutory guidance on autism under the SAA. The oral statement the Cabinet Secretary made in the National Assembly on 25th September updating the Autistic Spectrum Disorder Strategy Delivery Plan, we believe, is significant to fulfilling that commitment. The revised Plan reflects important new obligations which we believe will strengthen and improve services. These new commitments reflect feedback Welsh Government and its partners have heard from autistic people, their families and carers, and wider stakeholders. These new commitments include:

- Issuing a statutory Code of Practice on the delivery of autism services under SSWBA and the NHS Act 2006;
- Issuing a Code of Practice on the Additional Learning Needs and Education Tribunal Act 2018 and roll out of the new ALN system from 2020;
- Updating and expanding Welsh Government autism guidance for housing providers.
- Improving data collection through developing GP autism registers;
- Consulting on making autism a stand-alone theme for future population needs assessments;
- Raising awareness by improving engagement and involvement of autistic people in policy development; and
- Expanding the independent evaluation to look at alignment between children's neurodevelopmental and wider autism services and to address the continuing barriers to reducing diagnostic waiting times.

3.2 We believe that these new commitments will ensure that statutory bodies understand their responsibilities towards people with autism and take action to meet those needs. Moreover, the Cabinet Secretary has stated that the consultation document on the statutory Code of Practice will focus on five key areas which capture many of the issues set out in the Bill, these are:

- assessment and diagnosis;
- accessing care and support;
- staff training;
- planning; and
- stakeholder engagement in service planning and delivery.

3.3 Regional Partnership Boards (RPBs) established under the SSWBA, are already responsible for ensuring that there are integrated care and support services to meet the need of people in their area localities. Autism has been identified as one of their priority areas for integration and Boards will need to report annually on progress, including in relation to the delivery of the National Integrated Autism Service. However, if the Code provides additional guidance to RPBs in relation to service planning and existing duties to undertake a population needs assessment, which is coupled with making autism a mandatory stand-alone core theme for future assessments, we believe this will ensure that regions have robust and clear plans in place to deliver and monitor autism services.

3.4 ADSS Cymru believe that this recent Government announcement adds further weight to our view that, at this stage, it would not be prudent to add a further layer of legislation to meet the needs of people living with ASD, their families and carers.


President
ADSS Cymru

Item 4



Dr Dai Lloyd, AM
Chair
Health, Social Care and Sport Committee

To the Chair of the Committee

Re: Consultation on the Autism Bill

We write on behalf of the Community of Practice (CoP) for adult diagnosis and Integrated Autism Service (IAS) practitioners.

The Community of Practice brings together those who are involved in adult autism diagnosis and practitioners from the IAS.

The CoP have collated a response to the proposed autism bill, which evidences our reservations and concerns regarding certain aspects of the bill. This response has previously been submitted by Wendy Thomas (National Professional Lead Autism), however, for ease I have resent with this letter so that they can be read in conjunction. In addition to this response the CoP would welcome the opportunity to present verbal evidence to the Committee.

Please also find enclosed a written response from the CoP.

We therefore kindly request an audience with the committee at their convenience. We hope this opportunity could be granted.

We thank you for your time in considering this request and we will await your reply.

Yours faithfully



Tudalen y pecyn 80

On behalf of the Community of Practice for Adult Diagnosis and IAS Practitioners

Endorsed by: (PTO)

[Redacted]

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Community of practice (CoP) for Adult diagnosis and IAS practitioners' response to the proposed autism bill.

The Community of Practice brings together those who are involved in adult autism diagnosis and practitioners from the IASs. This CoP replaces the Adult Diagnostic Network. It is the view of the CoP that the additional legislation is not required and if implemented then it will adversely impact existing and developing services. It is our view that introducing legislation at this point in the implementation of the IAS's is unnecessary and unhelpful.

- **Strategy**

The development of an Autism strategy in 2008 was ground breaking and has already had a positive impact in Wales e.g. ASD awareness has increased, a range of resources has been developed, training has been developed and rolled out, the development of children ND services and the IASs. The impact has been evaluated and the refreshed strategy 2016 reflected the findings of that evaluation. The Integrated Autism Services have now been operational in several Health Board areas for a relatively short time but in that time they have made significant progress, recognising that service development, achieving best practice etc. takes time. It is anticipated that every health board area will have an operational IAS in place by the end of March 2019. No further legislation or policy should be considered pending the outcome of the formal review of the Implementation of the National Integrated Autism Service currently being undertaken by the People & Work Unit, completion due March 2019. The Integrated Autism Services should be given time to establish and embed new Pathways etc. In addition, making the strategy a statutory requirement will add no value. In England, where the development of an Adult Strategy was a requirement of the ASD Act, the NAS report 2016 and the parliamentary report 2017 actually evidence that there has been no significant improvement to the lives of autistic people.

- **Diagnostic waiting times and support**

Firstly, we wish to emphasise that for a person to receive a positive autism diagnosis is so significant and life changing that the diagnostic assessment must be robust, timely and of high quality. Having a 13-week timescale for all diagnostic assessments does not reflect a person centred approach nor the length of time required to undertake often quite complex multi-disciplinary assessments.

Some assessments can take longer than others depending on the complexity of the presentation, the difficulties for the person in attending and organising themselves to the assessment. A rushed assessment can lead to erroneous conclusions, therefore a fixed timescale and turnaround for completion of the assessment is not always within the Clinician's gift.

Secondly, it must be clearly understood that the emphasis upon diagnostic waiting times will have an adverse effect upon the level and quality of support that the IASs can deliver.

There are a number of key issues and concerns with the proposed legislation:

There are considerable difficulties of achieving a target of completing a diagnostic assessment within 13 weeks from referral. We are unclear why 13 weeks has been chosen as a figure as it doesn't align with any other standards for work to commence let alone be completed. To help illustrate the difficulties with a 13 week wait we have outlined the impact for one of the IAS in Wales as follows.

The Gwent IAS, as an established service, which launched in September 2017 now have 196 Individuals on a waiting list for diagnosis, which is currently resulting in a 12 month waiting list. They

have received 100 appropriate referrals this financial year alone. They have been piloting alternative approaches to diagnostic clinics (still adhering to NICE guidelines and agreed national minimum standards through the Community of Practice), they are therefore confident that they can increase the number of diagnostic clinics going forward. However, best case scenario is that they can reduce the diagnostic waiting time to nine months (this assumes there will be no DNA's, no cancellations due to sickness etc.). The impact of this will be a reduction in the time clinicians have to provide support as around 80% of their time will be committed to diagnostic clinics, MDTs, supervision, CPD, mandatory training etc. However, even with an increased number of diagnostic clinics, they are currently receiving referrals on a weekly basis at a higher rate than they have capacity to meet. If they cleared the waiting list they may just be able to maintain a waiting list of 13 weeks, utilising the majority of their funding to do so. They only have 3 full time equivalent diagnosing clinicians so support staff would need to replace with qualified clinicians to make this possible. There are also issues around the availability of suitable trained and qualified staff to deliver this if this was the course of action agreed.

Gwent IAS estimate that to reduce their current waiting list the costs for meeting a 13 week to completion target would be an additional one off amount of £352,800. These are additional costs above the current funding allocation. (An assessment at the Dyscovery Centre is £1800 per person so costs have been based on that). In addition, there is little evidence as to demand both current and future as the IASs have been operating for such a short time. However, with the current waiting times across Wales it is evident that to meet a 13-week target then all areas would have to greatly increase the focus on the number of diagnostic assessments that they undertake. The People and Work unit are going to be looking at demand in their evaluation.

Cardiff and the Vale IAS have considered a number of options for undertaking diagnostic assessments to maximise efficiency, whilst not compromising on quality. They have secured additional diagnostician time from other local services wishing to work jointly with the IAS, which increases their capacity for assessments. However, if a 13-week target for starting the assessment were to be introduced, this would put pressure on numbers and undoubtedly reduce the quality of the assessments being provided. It is possible that assessments could be 'started' within the proposed times but this would be a misrepresentation of the actual times for people to receive a diagnosis as they would then have to go back on a waiting list for the assessment to be completed.

As at 2017, Powys had a waiting time of 17 months and approximately 70 adults waiting for an autism diagnostic assessment. Current capacity includes 2WTE staff trained to assess for autism spectrum but their roles are wider than just diagnostic assessment. It is anticipated that the team be fully staffed by autumn 2018. To reduce the length of time that people were on diagnostic waiting list, the Dyscovery Centre were commissioned to undertake adult autism diagnosis whilst the IAS was being established. This has resulted in 32 people accessing a diagnostic assessment. In addition, a suitably trained locum has been recruited temporarily to address the backlog Powys are currently operating a 10 month waiting time. Powys has reviewed the diagnostic process to explore how best to meet the ongoing demand but even so. As a result, it is evident that even when the IAS has a full complement, a waiting time target of 13 weeks will not be achievable unless the IAS becomes exclusively a diagnostic assessment service.

Across Wales it is anticipated that moving the focus for IAS services to meet a diagnostic assessment completion target would undermine the action planned commitment for IAS services to organise their services to deliver 60% support and 40% diagnostic assessments. The focus on assessment would undermine their capacity to offer any ongoing support post diagnosis. To meet a 13-week target would require, for example in Gwent, a serious reduction in support staff to recycle the

funding to employ additional diagnosing clinicians. So, whilst an assessment of need could be completed the IAS would no longer be in a position to offer anything other than a one appointment, drop-in sessions on a monthly basis and a post diagnostic six-week course. The impact would be similar in all the other IAS services and details can be provided if needed. It would be impossible to resource a keyworker for anyone with ASD let alone everyone with ASD, as the NICE Quality Standards recommend.

CAV IAS is very concerned that a 13-week target would seriously impact the IAS capacity to deliver all of the other support it provides. 1:1 and group intervention to adults with autism and the parents and carers of adults and children and to provide the training, consultation and support to other organisations (essential in up-skilling the wider workforce). This would mean that adults with ASD and carers/parents of children and adults with ASD would not receive the support from the IAS that is currently available to them and for which they receive extremely positive feedback. Training, advice, consultation and joint working with other services would also be greatly reduced; this is essential to ensuring that people with ASD have improved experiences in all services they access, not just the specialist services. The impact of this would be that many services who are currently motivated to learn more about how they can support people with Autism would not access IAS support to broaden their knowledge and increase their confidence in this area, reducing the possibility of these services becoming more accessible for autistic people. It is well documented that mainstream services report a lack of skills, knowledge and experience in working with adults with autism and value support in this regard.

1. Whilst CAV IAS allocate significant resources to their diagnostic clinic, they also provide many hours of individual and groups support.
2. Examples of the feedback from people accessing the non-diagnostic services of the IAS:
 1. Because this is so necessary for us and other parents of autistic adults. We feel so positive about our situation after so many years of desperation, and the stress of not knowing which way to turn.
 2. Friendly service / support worker – (staff name). Help with structuring goals. Giving me more focus for my next steps.
 3. More confident in talking to other people. I now have the building blocks to build better coping mechanism for social situations. Made friends.
3. An example of feedback from a Mental Health Team professional:

‘I wish all of our services were as pleasant and straightforward to deal with..... Replies to email queries and support on offer to patient’s as well as referral process has been invaluable.’
4. Some examples of achievements of people using our service in the last few months include:
 - Two people who have received support from the IAS this quarter are also now attending Radio Platform and several people have said that they are making friends for the first time. This is in part due to their participation in the Socialeyes group.
 - Two people with ASD are now attending university following IAS support to link in the appropriate support services.

- Two people who were not able to leave the house are now leaving the house to attend IAS appointments. Furthermore, one is being supported to use public transport to learn Bee Keeping and the other has gained the confidence to drive again, is going to places independently, and is attending the Allotment group.
- Another person with ASD had wanted to attend a gaming group and had been playing on-line for two years without the confidence to attend in person. Following their attendance in the Socialeyes group, they felt able to join the group.
- A client with significant difficulties engaging in activities and with others now meets regularly with IAS staff for intervention, and also attends the weekly Allotment group. This person has said that this the first time they feel like have had help that meets their needs.

There is also a clear flaw in the proposals. Nationally we are aiming for individuals (in the majority of cases) to be given their diagnosis the same day the assessment is completed. When this does not occur it is because further assessment i.e. ADOS or a second opinion around a co-morbid diagnosis needs to be considered. The Bill proposes a timescale as recommended in the NICE Quality standards of: diagnostic assessment should be started within 13 weeks of receipt of referral. This is completely achievable, but is, in our view, poor practice. This will force an alternative approach where the diagnostic process will be split into a pre-diagnostic discussion/appointment and/or information gathering through the use of structured self-reports or observations from other professionals. Theoretically all assessment could be started in a 13 week period to meet the target but it would not lead to a more efficient process as the assessment might not be concluded for 12 months. The IAS COP suspect many individuals pushing for this legislation are not fully appreciative of this and believe the legislation will achieve a timely diagnosis NOT a timely start of the diagnostic process. Gwent IAS have received very positive feedback in relation to their diagnostic Pathway and process. It includes the following comments:

93% of individuals rated their experience as 'very good'

"It was a long wait but worth it"

"clarity of information was excellent and the support to feel ok about autism"

"I felt listened to and understood"

There is a real risk that if we have to meet a 13-week target, then this quality will be compromised.

The established Community of Practice is already addressing key areas such as developing best practice in relation to the: identification and diagnosing of ASD, Pathways, assessment and planning. Many of these have already been explored, agreed and are being rolled out on a national basis through the Integrated Autism Service. - How can we develop standards if we are constrained by waiting list targets which aren't taking the broader quality issues into consideration? There are agreed national standards and pathways for diagnosis, and support in place.

The Integrated Autism Service already ensures that diagnostic assessments are carried out using a range of multi-disciplinary professionals as required. The Integrated Autism Service also ensures that no adult falls through the gap of service eligibility criteria i.e. based on IQ. The Integrated Autism Service are also establishing strong links with the local authority ASD Leads to consider strategic/policy/commissioning issues.

It is also concerning that the Bill would appear to be including all other neurodevelopmental disorders in its powers. Meaning at any time, without any other consideration i.e. staff competence, funding & resource issues individuals with any other neurodevelopmental disorder would have the same entitlements. At present the IAS Services are designed, set up, funded and staffed to meet the needs of people on the Autism Spectrum as defined by the diagnostic and statistical manual (DSM5 or ICD10). This would again cause significant resources issues and further impact on the IAS ability to provide a quality service.

The Autism Bill could also potentially be seen as positive discrimination. No other service user group has its own specific legislation they are all bound by the Social Services & Well-Being Act and access to services assessed against an Outcomes Framework, which does not guarantee the provision of a support plan, key worker nor services. By adopting the NICE Quality Standard as the basis for legislation anyone with ASD will have an entitlement to these and a standard of service that no-one else will i.e. a named keyworker.

What would be lost by focusing on Diagnostic Assessments?

A further complication of the Bill's focus on diagnostic assessments is that the IAS are also committed to resource other services (in both diagnostic and support work). The professionals in IAS services need time to undertaking training, joint work and offer consultation to other professionals undertaking assessments in Learning Disability or Mental Health Services. This work would be not achievable under the proposed bill. For example, in Gwent, they have already provided training courses to mental health teams, DWP, Supported Housing Providers etc. They have jointly worked around 10 cases with mental health services. They also provide three one hour slots a month for professionals from secondary services to discuss complex cases. All of this support would be lost if we need to hit the recommendation of the NICE Quality Standards as outlined in this Autism Bill. NB

The financial implications

It is evident that to meet the needs of the Autism Bill and the NICE Quality standards a significantly greater level of funding is required to meet identified time scales and to ensure the ongoing provision of support. Each IAS would need increased funding to the cost of meeting the additional demand of the 13 week waiting time. It would be anticipated that additional funds would need to be found with this new Bill from within the Welsh Government.

The diagnostic assessment is one step in people's journey with regards to autism services and whilst it is important that people do not have to wait for a significant amount of time for a diagnostic assessment, it must be recognised that this is a very small part of what they will require from services. It is short-sighted for the focus to be on meeting diagnostic waiting times, rather than taking into account all of the other work that is delivered by specialist autism services. The services would need a significant amount of additional money to clear their waiting lists and to keep within the proposed time-scales so that they do not compromise on the other work they deliver. However,

simply providing more money will not easily solve the issue with waiting times, because it is also about a lack of suitably qualified diagnosticians. Recruitment to some autism services across Wales is problematic because of a lack of staff with the necessary skills and experience. An additional role of the IASs is about generating interest in working in autism in those who are going through training, working across others services etc. Currently the Cardiff and Vales IAS provide support and advice about how others can develop their skills and offers placement opportunities. Increased pressure on diagnostic waiting times is going to reduce the time that the IASs can offer to students etc. It will also reduce the opportunities to conduct research, which is essential given the lack of research regarding effective interventions for this client group.

- **Data**

Data sets are being developed and rolled out within the IASs and ND teams therefore, the issues around autism data will be addressed. The level of data required and collected within the bill appears to be onerous and will offer little additional relevant information to inform both planning and commissioning. It does appear to be collecting data for data's sake and how GDPR compliant would this be?

- **ASD awareness, acceptance and understanding**

There is a great deal of work already being undertaken with regard to this by the IASs, the National ASD team, key professionals and individuals in each local authority area. Legislation would not add anything to this and may, by focusing funding on waiting times, and erroneous data, actually take resources away from this essential activity.

Community of practice August 2018

**Tystiolaeth ysgrifenedig a gyflwynwyd gan y
Coleg Brenhinol y Seiciatryddion yng Nghymru
i ymgynghoriad y Pwyllgor Iechyd, gofal cymdeithasol a chwaraeon
Cymru (awtistiaeth) Bil
Mis Medi 2018**

Mae Coleg Brenhinol y Seiciatryddion yn gorff meddygol proffesiynol sy'n gyfrifol am gefnogi Seiciatryddion drwy gydol eu gyrfa, o hyfforddiant i ymddeol, a gosod a chodi safonau seiciatreg yn y Deyrnas Unedig.

Nod y coleg yw gwella canlyniadau pobl â salwch meddwl, ac iechyd meddwl unigolion, eu teuluoedd a'u cymunedau.

Er mwyn cyflawni hyn, mae'r Coleg yn pennu safonau ac yn hyrwyddo rhagoriaeth mewn seiciatreg; arwain, cynrychioli a chefnogi seiciatryddion; yn gwella dealltwriaeth wyddonol salwch meddwl; gweithio gyda chleifion, gofalwyr a'u sefydliadau ac eiriolwyr ar eu cyfer. Yn genedlaethol ac yn rhyngwladol, mae gan y Coleg rôl hanfodol o ran cynrychioli arbenigedd y proffesiwn seiciatrig i lywodraethau ac asiantaethau eraill.

Am fwy o wybodaeth, cysylltwch â:

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Cyflwyniad

Mae Coleg Brenhinol y Seiciatryddion yng Nghymru yn croesawu'r cyfle i roi tystiolaeth ysgrifenedig bellach i Bwyllgor Iechyd, gofal cymdeithasol Cynulliad Cenedlaethol Cymru.

Mae anhwylder sbectrwm awtistiaeth yn anhwylder cymhleth sy'n cyd-forbid, sy'n cyflwyno mewn ffordd wahanol i wahanol unigolion a grwpiau demograffig.

Mae anhwylder ar y sbectrwm awtistig ac anhwylderau niwrolegol eraill y bydd y ddeddfwriaeth arfaethedig yn effeithio arnynt yn rhan o amrywiaeth o arbenigeddau ar draws y coleg.

Rydym wedi ymgynghori â'n cyfadrannau ein hunain drwy gydol y broses o ddatblygu ein hymateb i'r ddeddfwriaeth arfaethedig.

- Cyfadrannau seiciatreg glasoed
- Cyfadrannau seiciatreg anableddeu deallusol.

Er eu bod yn gwbl gefnogol i'r angen i wella canlyniadau i bobl ag anhwylder ar y sbectrwm awtistig, mae ein haelodau yng Nghymru wedi mynegi pryder ynghylch ai ddeddfwriaeth fyddai'r cyfrwng mwyaf priodol i gyflawni'r uchelgeisiau a nodir yn y Bil. Byddem yn gofyn i'r Pwyllgor ystyried y canlynol:

- y dylai gwasanaethau fod yn seiliedig ar angen a bod yn canolbwyntio ar yr unigolyn a chanolbwyntio ar y plentyn;
- y potensial ar gyfer cyfraddau uwch o ddiagnosis anghywir neu amhriodol;
- yr angen i ystyried effaith rhaglenni gwaith presennol yng Nghymru sy'n ymwneud ag anhwylderau niwroddatblygiadol (nd) ac anhwylder sbectrwm awtistiaeth a'u gwerthuso;
- Goblygiadau posibl cyflwyno ddeddfwriaeth sy'n benodol i awtistiaeth; A bod
- ar hyn o bryd, nid oes digon o dystiolaeth i ddangos y byddai ddeddfwriaeth sy'n benodol i awtistiaeth yn gwella'r gwasanaethau a ddarperir eisoes ar draws GIG Cymru a Llywodraeth Leol ac y bydd yn arwain at welliannau yn y ddarpariaeth o gymorth i bobl ag awtistiaeth

Cefndir

Yn ogystal â chyflwyno ein barn ein hunain, rydym hefyd wedi gweithio gyda Cholegau Brenhinol ar draws y sector wrth ystyried y ddeddfwriaeth arfaethedig. Yn unol â hynny, rydym wedi cyd-gynhyrchu briff yn amlinellu ein safbwynt cyffredin mewn perthynas â'r ddeddfwriaeth arfaethedig, ynghyd â:

- Cydffederasiwn GIG Cymru,
- Coleg Brenhinol y therapyddion iaith a lleferydd,
- Coleg Brenhinol yr ymarferwyr cyffredinol,
- Coleg Brenhinol Pediatreg ac iechyd plant,
- Coleg Brenhinol y therapyddion galwedigaethol.

Egwyddorion cyffredinol y Bil awtistiaeth (Cymru) ac i ba raddau y bydd yn gwneud darpariaeth ar gyfer diwallu anghenion plant ac oedolion ag anhwylder sbectrwm awtistiaeth yng Nghymru ac yn cyflawni'r nod o ddiogelu a hyrwyddo eu hawliau;

Teimlwn ei bod yn bwysig i'r Pwyllgor ystyried profiad o rannau eraill o'r DU o ran cyflwyno deddfwriaeth anhwylder sbectrwm awtistiaeth.

Mae tystiolaeth o'r Deddfau awtistiaeth yn Lloegr (2009) a Gogledd Iwerddon (2011) yn awgrymu nad yw deddfwriaeth yn arwain at ganlyniadau gwell i bobl ag anhwylder sbectrwm awtistiaeth. Tra yn yr Alban, methodd Bil awtistiaeth (yr Alban) yn ystod cam cyntaf y broses graffu seneddol (2011).

Byddem yn gofyn i'r Pwyllgor ystyried y briff manwl ar y cyd a gynhyrchwyd gyda Chydffederasiwn y GIG a'r Colegau Brenhinol o bob rhan o'r sector sy'n edrych yn benodol ar y mater hwn. Bil awtistiaeth (Cymru): golwg ar strategaethau a deddfwriaeth awtistiaeth yn Lloegr, Gogledd Iwerddon a'r Alban.

Rydym wedi amlygu ychydig o ystyriaethau o'r briff hwn.

o adroddiad Cymdeithas Genedlaethol Awtistiaeth, mae push for Action (2013) yn canolbwyntio ar weithredu Deddf awtistiaeth (2009) yn Lloegr, yn dod i'r casgliad er bod y strategaeth wedi llwyddo i sefydlu'r conglfeini ar gyfer cynllunio a chomisiynu'n well gwasanaethau, "ar y cyfan, mae oedolion ag awtistiaeth a'u teuluoedd yn dal i aros am y cymorth sydd ei angen arnynt".

o wrth ystyried y Ddeddf Awtistiaeth (2009) yn Lloegr, dywedodd y prosiect awtistiaeth Cenedlaethol ymhellach fod "bron i ddegawd ar anghenion pobl awtistig yn dal heb ei fodloni ac nad yw'r difidend economaidd disgwylidig erioed wedi cael ei wireddu".

o Yng Ngogledd Iwerddon Canfu'r adroddiad diweddaraf gan yr adran iechyd, gwasanaethau cymdeithasol a diogelwch cyhoeddus ar weithredu'r ddeddfwriaeth nad oedd hi'n bosibl ar hyn o bryd i warantu ymyrraeth gynnar fel yr amlinellwyd yn y strategaeth awtistiaeth heb gyllid Yn ychwanegol at ddatblygu gwasanaethau asesu penodol i awtistiaeth ymhellach, ac ymestyn y portffolio o gymorth sydd ar gael i deuluoedd "

o craffu Seneddol ar y ddeddfwriaeth awtistiaeth arfaethedig yn yr Alban, ystyriodd a fyddai'r ddeddfwriaeth arfaethedig yn arwain at welliannau mewn gwasanaethau heb arian ychwanegol sylweddol ar gyfer staff ac adnoddau. Roedd craffu ar y ddeddfwriaeth hefyd yn ystyried a fyddai deddfwriaeth sy'n benodol i awtistiaeth yn creu system ddwy haen o strategaethau lle gwelir bod gan strategaethau a nodir mewn deddfwriaeth "fwy o ddannedd". Nodwyd y rhain fel materion allweddol yn argymhelliad y Pwyllgor na ddylid cefnogi egwyddorion cyffredinol y ddeddfwriaeth arfaethedig.

Yng Nghymru, mae nifer o gynlluniau ar hyn o bryd sydd â'r nod o wella gwasanaethau i bobl ag anhwylder sbectrwm awtistiaeth yng Nghymru. Byddem yn argymhell bod y mentrau hyn yn cael eu hasesu gan eu bod ar gam cynnar yn eu datblygiad.

o Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 yn gosod dyletswydd ar gyrff cyhoeddus i asesu a mynd i'r afael ag anghenion unigolion. Mae byrddau partneriaeth rhanbarthol a sefydlwyd o dan y Ddeddf yn gyfrifol am sicrhau bod gwasanaethau gofal a chymorth integredig ar gael i ddiwallu anghenion pobl yn eu hardal. Mae awtistiaeth wedi cael ei nodi fel un o'i feysydd blaenoriaeth ar gyfer integreiddio (Llywodraeth Cymru, 2016 a Llywodraeth Cymru, 2018). Deallwn y bydd cod ymarfer ar ddarparu gwasanaethau awtistiaeth yn cael ei gyhoeddi o dan y Ddeddf Gwasanaethau Cymdeithasol a Llesiant yn 2019.

o O dan y rhaglen law yn llaw at blant a phobl ifanc, a lanswyd ym mis Chwefror 2015, cafwyd buddsoddiad sylweddol mewn gwasanaethau niwro-ddatblygol. Mae llwybrau a safonau diagnostig Cenedlaethol ar gyfer plant a phobl ifanc

bellach ar waith ac yn cael eu mabwysiadu gan bob Bwrdd Iechyd. Mae safon amser aros newydd o 26 wythnos o atgyfeiriad i apwyntiad asesiad cyntaf hefyd wedi'i chyflwyno (Llywodraeth Cymru, 2018).

o Sefydlwyd y gwasanaeth awtistiaeth integredig cenedlaethol yn ddiweddar gyda'r nod o greu cefnogaeth gyson i bobl ag anhwylder sbectrwm awtistiaeth ledled Cymru. Mae adroddiad gwerthuso interim gydag argymhellion wedi'i gyhoeddi ac mae'r adroddiad gwerthuso llawn wedi'i drefnu ar gyfer mis Ionawr 2019 (Dr Duncan Holtom a Dr Sarah Lloyd Jones, 2018).

o Deddf anghenion dysgu ychwanegol a Thribiwnlys Addysg (Cymru) 2018 wedi cael Cydsyniad Brenhinol yn ddiweddar a bydd y gweithredu'n dechrau yn 2020. Gobeithir y bydd y system newydd yn dod â manteision pendant i blant a phobl ifanc sydd ag anhwylder sbectrwm awtistiaeth drwy helpu i nodi anghenion dysgu ychwanegol yn gynnar ac ymyrryd yn effeithiol i gefnogi'r anghenion hyn drwy gydol addysg plentyn a pherson ifanc.

Canlyniadau anfwriadol yn deillio o'r ddeddfwriaeth arfaethedig

Fel yr amlygwyd yn y pwynt cyflwyno, mae anhwylder ar y sbectrwm awtistig yn gyflwr cymhleth sy'n codi'n wahanol mewn gwahanol unigolion, yn rhannol pam ei bod yn anodd ei ddiagnosisio. Ni fydd anghenion dau berson yr un fath. Yn yr un modd, mae llawer o blant â chyflyrau niwroddatblygiadol eraill megis ADHD nad ydynt o bosibl yn bodloni'r meini prawf ar gyfer diagnosis, ond cyfanswm eu hanawsterau yw'r hyn sy'n creu'r nam ac yn effeithio ar ansawdd bywyd.

Credwn y dylai cymorth a thriniaeth gael eu teilwra drwy anghenion yr unigolyn drwy lunio sy'n seiliedig ar ddealltwriaeth amlfactorol o bob achos, nid drwy ei ddiagnosisio ac ni chaiff ei ragnodi drwy ddeddfwriaeth.

Credwn na fydd deddfwriaeth awtistiaeth o reidrwydd yn ysgogi arfer da a gallai arwain at ymdrech i gael cyfraddau diagnosis uwch yn hytrach na chanolbwyntio ar ddiwallu anghenion yr unigolyn. Bydd yr angen am ddiagnosisio i wthio am adnoddau ond yn cynyddu cyfraddau diagnosisio yn artiffisial am y rhesymau anghywir.

Byddem yn cytuno â Choleg Brenhinol y therapyddion iaith a lleferydd, fod datblygu'r llwybr niwroddatblygiadol i Gymru gyfan, sydd wedi canolbwyntio ar angen yn hytrach na diagnosis yn unig, wedi helpu cefnogi symudiad tuag at asesu mwy priodol a ymyrraeth ar gyfer unigolion. Mae hyn wedi bod yn arbennig o fuddiol i bobl sy'n agored i niwed, er enghraifft, y rheini ag ADHD neu'r rhai sy'n cyrraedd y trothwy ar gyfer diagnosis er mwyn sicrhau eu bod hwy a'u teuluoedd hefyd yn gallu manteisio ar wasanaethau teg a phriodol, er nad ydynt o reidrydd yn bodloni y meini prawf ar gyfer awtistiaeth a fyddai'n ofynnol o dan y Bil arfaethedig.

Rhwystrau posibl i weithredu'r darpariaethau ac a yw'r ddeddfwriaeth arfaethedig yn eu hystyried

Pryderwn y byddai'r pwysau ariannol a'r heriau sylweddol sy'n gysylltiedig â recriwtio ac addysg i alluogi timau amlddisgyblaethol i ddarparu gwasanaethau fel y'u rhagwelwyd gan y ddeddfwriaeth arfaethedig yn ei gwneud yn anodd sicrhau Gweithredu. Byddai'r newidiadau i'r targedau amseroedd aros fel y'u rhagwelwyd gan y ddeddfwriaeth arfaethedig hefyd yn cael effaith sylweddol ar gapasiti yn erbyn yr adnodd presennol ar gyfer timau amlddisgyblaethol.

Byddem hefyd yn ailddatgan canfyddiadau'r gwaith craffu Seneddol ar y ddeddfwriaeth awtistiaeth arfaethedig yn yr Alban yn 2010. Teimlai'r Pwyllgor y byddai sefydliadau'r GIG ac awdurdodau lleol yn wynebu costau sylweddol yn gysylltiedig â'r prosesau ailstrwythuro y byddai angen eu gweithredu ar draws yr Alban er mwyn i'r mesurau gorfodi angenrheidiol gael effaith. Effaith cynnig o'r fath fyddai rhoi mwy o alw ar wasanaethau eraill a oedd eisoes yn gweithio yn ôl capasiti neu'n agos at ei gapasiti. Yng ngoleuni'r pryderon hyn, methodd y ddeddfwriaeth arfaethedig yng nghan cyntaf y broses graffu seneddol ym mis Ionawr 2011.

Yn olaf, rydym yn pryderu y gallai deddfwriaeth sy'n benodol i anabledd arwain at bobl ag anhwylderau niwroddatblygiadol eraill a heriau o ran cael gwasanaethau anghyfartal. Gallai hefyd arwain at gynnydd yn nifer y galwadau am gyflwyno deddfwriaeth benodol ar gyfer cyflyrau eraill er mwyn sicrhau bod ganddynt yr un statws a darpariaeth.

Cyfeiriadau

[Welsh Government, June 2018. Autism Spectrum Disorder Strategic Action Plan](#)

[Welsh Government, March 2018. Evaluation of the Integrated Autism Service and Autistic Spectrum Disorder Strategic Action Plan. Interim Report.](#)

[Autism Act \(England\) 2009](#)

[Autism Act \(Northern Ireland\) 2011](#)

[The National Autistic Society, 2013. 'Push for Action campaign – Turning the Autism Act into action'](#)

[National Autism Project, January 2017. The Autism Dividend: Reaping the rewards of better investment.](#)

[Department for Health, Social Services and Public Safety of Northern Ireland, 2015. 'The Autism Strategy \(2013 – 2020\) Action Plan \(2013 – 2016\) Progress Report](#)

[The National Autistic Society, 2013. Push for Action campaign – Turning the Autism Act into action](#)

<http://www.senedd.assembly.wales/documents/s69972/AWB81%20Royal%20College%20of%20Speech%20and%20Language%20Therapists.pdf>

[NICE, Clinical guideline CG128. Published date: September 2011. Autism spectrum disorder in under 19s: recognition, referral and diagnosis](#)

[NICE, Clinical guideline CG142. Published date: June 2012. Autism spectrum disorder in adults: diagnosis and management.](#)



Evidence submitted by the Royal College of Paediatrics and Child Health (RCPCH) to the Autism (Wales) Bill Consultation, September 2018

About the RCPCH

The RCPCH works to transform child health through knowledge, innovation and expertise. We have over 500 members in Wales and over 17,500 worldwide. The RCPCH is responsible for training and examining paediatricians. We also advocate on behalf of members, represent their views and draw upon their expertise to inform policy development and the maintenance of professional standards.

Summary: RCPCH's position on the draft Bill

We welcome calls for increased resource to support children with Autism Spectrum Disorder (ASD) and their families and welcome also opportunities to explore changes to improve outcomes for children and young people with ASD or being referred into neurodevelopmental (ND) disorder pathways. The RCPCH shares the aspiration to make provision for meeting the needs of children with ASD in Wales and protecting and promoting their rights. However, RCPCH members in Wales have expressed concerns about possible unintended consequences of the proposed legislation. In particular, members have expressed concerns about:

- The risk of parents seeing an ASD diagnosis as a requirement for accessing services and the potential for increased numbers of children and young people being inappropriately diagnosed with ASD
- The risk of adopting an approach that is not child-centred because it is based on diagnosis rather than need
- The risk to provision of all community paediatric services including ASD if demand increases without sufficiently increasing resource
- The risk to non-ASD community paediatric services such as disabilities or safeguarding if existing resource is allocated on the basis of legal requirement rather than clinical need
- The risk that legislation that will not improve outcomes for children and young people with ASD

For further information please contact [REDACTED], External Affairs Manager for Wales:
[REDACTED] or [REDACTED].

General principles of the Autism (Wales) Bill and the extent to which it will make provision for meeting the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales and achieve the aim of protecting and promoting their rights;

We are concerned that the proposed legislation will not meet the needs of children with ASD in Wales. Our concerns are based partially on the experience from other parts of the UK: evidence from the introduction of Autism Acts in England (2009) and Northern Ireland (2011) suggests that legislation is not leading to improved outcomes for people with Autism Spectrum Disorder. In Scotland, proposals for an Autism Bill were rejected at Committee stage.

Evidence of the experience from other parts of the UK is set out in the briefing we have produced jointly with the NHS Confederation and the Royal Colleges of Psychiatrists, Speech and Language Therapists and Occupational Therapists, which we will re-submit to the Committee with this response. Since then, the Welsh NHS Confederation has produced a detailed briefing looking specifically at this issue, which we encourage Committee members to note.

The first joint briefing also discussed a number of areas of policy and legislation that will have an impact on the evolution and delivery of ASD and ND services in Wales, so we will not repeat the detail here. However, we would urge the Committee to consider the impact and need for evaluation of these areas of work ahead of making recommendations as to whether legislation is the best way to improve outcomes for children and young people with ASD. These include:

- The Social Services and Well-being (Wales) Act 2014
- The Together for Children and Young People programme
- The National Integrated Autism Service
- The Additional Learning Needs and Education Tribunal (Wales) Act 2018

This list is not exhaustive and given the links with mental health, education and trauma, other programmes and policy areas with which there will likely be interaction include ACEs, the First 1000 Days programme and any developments in children and young people's mental health.

Unintended consequences arising from the Bill

RCPCW members in Wales are concerned that in linking resource to a diagnosis – whether autism, ASD or a given definition of ND disorders - there is a risk that families will feel that their best opportunity to access the support they need is by securing that diagnosis. This is not child-centred, because children presenting with a range of issues or symptoms that may be similar to or overlap with ASD but where ASD is not an appropriate diagnosis, may then be excluded from a pathway to receiving the appropriate care and resources.

RCPCH and our members believe that policy, legislation and services should meet the needs of all individuals with traits similar to ASD or ND, that impair their everyday social, psychological and intellectual functioning - whether or not they meet a diagnostic criteria. Otherwise we risk alienating vulnerable populations who have no diagnosis and a weaker voice to advocate for themselves. These issues were raised by RCPCH member [REDACTED] during the Children, Young People and Education Committee's inquiry into the mental and emotional health of children and young people:

"A child could have a specific learning difficulty, a child could have a specific motor problem with dyspraxia. But, functionally, that child is struggling. The problem is at the moment that maybe we are driving our resources towards a specific diagnosis, and therefore that leads to frustration and challenge on the part of parents if they do not receive that diagnosis. They may well have got an accurate description of their child's needs, but they cannot secure the support they need or the resources they need."¹

Another potential consequence of this is drawing resources away from people who do not have ASD or ND but require Community Paediatric services, or from other areas of work such as safeguarding. As one RCPCH member in Wales told us, "an Autism specific Bill may improve services and provisions for children with ASD, but without further resources in all sectors, existing resources are likely to be focused on children and young adults with ASD and away from others with ND disorders or learning disabilities who may have on an individual basis a lesser or greater need".

All of this risks creating additional (and sometimes inappropriate) demand on community paediatric services where this is seen as the 'gateway' to diagnosis without a commensurate increase in resource. Community paediatricians have told us that they are already struggling to meet demand. We also know that there are gaps in the community paediatric workforce and a need for more community paediatricians. Further investment would also be required into the associated services and other professions working as part of multidisciplinary teams to meet any additional requirements and would therefore be key to delivering improved ASD services without risking unintended consequences for other services.

Potential barriers to the implementation of the provisions and whether the Bill takes account of them

As previously stated, the biggest barrier to implementation would be a possible increase in demand on Community Paediatric services, along with Psychiatry and a range of other services including Speech and Language Therapy and Occupational Therapy. Many services are already operating at capacity, or have waiting lists, or have workforce shortages placing additional pressure on existing staff who have to cover gaps. Provisional analysis of the 2017 census (please note: these figures are unpublished and we may need to revise if we receive further data) suggests that:

- The number of community career-grade doctors in community child health in Wales has reduced from 87 in 2015 to 81 in 2017.

¹ <http://record.assembly.wales/Committee/4529#A40906> item 388. See also items 386 and 369.

- There are five vacancies for community paediatric consultants in Wales according to the 2017 census, up from two in 2015. As a proportion of total vacancies in Wales, 50% were community posts in 2017 (5/10) and 29% were community posts in 2015 (2/7).
- The career-grade community paediatric workforce in Wales is increasing in age, with no evidence of replacement doctors for those nearing retirement.
- 74 individuals, trained in Wales, achieved their CCT or CESR between 2011 and 2017. Of those, only 4 specialised in Community Child Health.

Community paediatricians are therefore under pressure and any additional demand could have an impact on services if there is not an immediate and commensurate increase in resource.

Another potential barrier is around waiting lists to access assessments. Due regard needs to be placed on current and future demand to diagnose children with autism. Many referrals are not appropriate and this needs to be addressed with education for referrers on what the other potential solutions or diagnoses could be other than autism. Waiting times could be reduced if mental health and community paediatric services were accessed appropriately, consistently.

We stress again that whether a person has a formal diagnosis or has identified needs but not a formal diagnosis, a timely multiagency commitment must be established to ensure that these children and their carers have their concerns addressed and support initiated. The resources to support identified needs do not necessarily rest with the diagnostic teams. This has implications for both children's social care and education in addition to health services. Legislation on waiting times may therefore not improve outcomes.

The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Chapter 6 of Part 1 of the Explanatory Memorandum).

The Explanatory Memorandum says that "The regulation-making powers in this section allow the Welsh Ministers to make regulations, by which include, for the purposes of this Bill only, other neurodevelopmental disorders in addition to the WHO International Classification of Diseases definition of 'autism spectrum disorder'" and "the affirmative procedure is appropriate given that these regulations may significantly extend the scope of the disorders to which the Bill will apply".

Classifications will change and no matter how much this is emphasized in small print this may contribute to confusion for non-specialist individuals. Further discussion and agreement would be required to define what is meant by ND in the context of the legislation - there is considerable variation among professionals and families in their use and understanding of this term.

The inclusion in future of other ND would also create challenges in terms of service delivery as it represents a change from ASD specific services – this would have significant implications. Extending the scope and remit of the proposed legislation to cover conditions beyond ASD could have implications and impact different to that intended by the introduction of condition-specific legislation for autism.



**The British
Psychological Society**
Promoting excellence in psychology

British Psychological Society response to the National Assembly for Wales

Autism (Wales) Bill

The British Psychological Society, incorporated by Royal Charter, is the learned and professional body for psychologists in the United Kingdom. We are a registered charity with a total membership of just over 50,000.

Under its Royal Charter, the objective of the British Psychological Society is "to promote the advancement and diffusion of the knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of members by setting up a high standard of professional education and knowledge". We are committed to providing and disseminating evidence-based expertise and advice, engaging with policy and decision makers, and promoting the highest standards in learning and teaching, professional practice and research.

The British Psychological Society is an examining body granting certificates and diplomas in specialist areas of professional applied psychology.

Publication and Queries

We are content for our response, as well as our name and address, to be made public. We are also content for the NAW to contact us in the future in relation to this inquiry.

Please direct all queries to:-

██████████, Policy Advice Administrator (Consultations)

██
██

About this Response

The response was led on behalf of the Society by:

██████████, BPS Policy Advisor

With contributions from:

██, Division of Clinical Psychology

██, Division of Clinical Psychology

██, Division of Clinical Psychology

We hope you find our comments useful.



British Psychological Society response to the National Assembly for Wales

Autism (Wales) Bill

	<p><u>The general principles of the Autism (Wales) Bill and the extent to which it will make provision for meeting the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales and achieve the aim of protecting and promoting their rights;</u></p>
1.	<p>Comments:</p> <p>The Society welcomes proposals for meeting the needs of children and adults with autism spectrum conditions in Wales. We welcome the introduction of a strategy to meet their needs. We support the notion that local authorities and health boards have a statutory duty to provide appropriate and timely support for children and adults with autism. Furthermore, we welcome health boards being compliant with NICE guidelines on assessment. The creation of a register will be helpful to plan support. All key staff working with people with autism should receive autism training. Local authorities and health boards should routinely highlight and publish information on services for people with autism. The Society welcomes the development of commissioning plans for services for people with autism and the need to review them annually.</p> <p>Clinical, educational and occupational psychologists represent a professionally trained and highly skilled workforce which can provide support to children and adults, their families, carers, schools and colleges, workplaces and communities. Applied psychologists take a holistic approach to working with people with Autism. This includes psychological assessment and formulation. Clinical and educational psychologists work with children, including in schools. This includes psychological assessment and formulation with children and adults. In schools they are adept at working with individuals, groups of children, support and teaching staff and senior managers. Training is an important part of the remit when working with other education, health and care professionals.</p> <p>Early identification of ASD leads to significantly increased better outcomes (Dawson et al, 2010). Nonetheless, presently there are long waiting lists and delays for assessment. It is important that people with ASD receive support pre and post assessment. Applied psychologists are well placed to provide evidence based support and interventions. However, it should be noted that there are significant workload pressures on staff. Multi-disciplinary teams (e.g. paediatrician, child psychiatrist, clinical and/or educational psychologist, speech and language therapist) should undertake assessments. As a minimum, assessment should aim to bring together the views of children, families, and</p>

professionals to reach a shared understanding about the child and family's difficulties and protective factors (BPS, 2015).

The Society supports the implementation of NICE guidelines and Standards related to the:

Autism spectrum disorder in adults: diagnosis and management (CG142)
Autism spectrum disorder in under 19s: recognition, referral and diagnosis (CG128)
Autism spectrum disorder in under 19s: support and management (CG170)
Quality standards: Autism (QS51).

Assessment is essential to the process of formulation and psychological intervention and should be a comprehensive process. (BPS, 2015). Only clinical and educational psychologists, in particular, should carry out cognitive assessment with children.

There is a significant gender discrepancy between girls and women and boys and men with autism. Autism may be under-diagnosed in girls and women; many girls and women may be initially diagnosed with other conditions (including OCD, eating disorders, personality disorders or learning disability etc). Autism may look different in males and females, and this is complicated by the fact that the criteria used for the assessment of autism are biased towards males, and this can lead to girls with Autism being missed – and going 'under the radar'. For example, 'There is limited large-scale research into the lived experiences of female adults who have an autism spectrum disorder with no co-occurring intellectual disability...[there are] diverse and complex challenges faced by women with high-functioning autism spectrum disorder, including high levels of mental health disorder, unmet support needs in education settings and the workplace, and social exclusion and isolation.' (Baldwin and Costley, 2016).

Children with neurodevelopmental difficulties are far more likely than the general population to experience poor mental health (Van Steensel, Bogels and Perrin 2011) and behavioural signs of psychological distress are easily overlooked (Read and Schofield 2010). The need for multi-professional assessment is clear and ideally would not be limited to diagnostic pathways. Even within such pathways, capacity and availability impacts on intervention, particularly preventative work. (Hunt and Laffan, in print)

The Society wishes to draw attention to autism specific CBT resources. One such example is the Homunculi approach, which offers an autism-specific CBT resource for children and adolescents on the autism spectrum. Its key features are drawn from psychologists working with young people on the autism spectrum in their clinical and educational practice. 'Its underlying features have been comprehensively founded on autism theory and evidence-based interventions, with a view to addressing the full triad of autism features, with a particular focus on addressing mental health issues and fostering social and emotional wellbeing. It is flexible in that it can be used by anyone working with young people on the autism spectrum, it can be used in individual or group settings and it can be adapted to suit the specific needs and interests of the young person. Quantitative and qualitative findings to date have shown encouraging results regarding its effectiveness in supporting children and adolescents with autism. It has also shown good results with young people who have emotional and behavioural problems similar to those experienced by children with autism, and preliminary findings point to its potential in building resilience and fostering mental health at a whole class and year group level. This may provide pointers to more inclusive approaches to supporting young people in general. Instead of situations where those with autism are often subject to interventions designed for the general population but with no autism-specific focus, it may be that well-designed interventions for those on the

	autism spectrum prove also to be beneficial for young people in general, therefore allowing for a more inclusive approach.’ (MacKay and Greig, 2013).
	Any potential barriers to the implementation of the provisions and whether the Bill takes account of them;
2.	<p>Comments:</p> <p>There are long waiting lists for assessment and support – these difficulties will remain unless there are improvements in the workforce and specialist service provision.</p> <p>There is a need for specialised counselling, psychology and social support services that can contribute to improved well-being and quality-of-life for people with Autism. People with autism who are in need of mental health services should be able to access them and access staff who understand autism and have the right autism specific training. Mental health interventions are only needed when there are mental health difficulties - many people with autism feel they don't need anything different at all (e.g. Clarke, J. & van Ameron, G. (2008). Asperger's syndrome: Differences between parents' understanding and those diagnosed. <i>Social Work in Health Care</i>, 46(3), 85–106).</p> <p>Funding to implement the provisions of the Bill should be ring-fenced.</p> <p>The transition from child to adult services present a significant challenge with many young people falling through the gap between services. This leads to families and carers providing support with no provision for themselves.</p> <p>Support for adults is limited – only 16 percent of adults with Autism are in full time employment, compared with 80 per cent of the general population and 47 per cent of people with disabilities overall (BPS, Psychology at work, 2017).</p>
	Whether there are any unintended consequences arising from the Bill;
3.	<p>Comments:</p> <p>The Society has no comment to make.</p>
	The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum);
4.	<p>Comments:</p> <p>The Society has no comment to make.</p>
	The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Chapter 6 of Part 1 of the Explanatory Memorandum).

5.	<p>Comments:</p> <p>The Society has no comment to make.</p>
	<p>References</p>
	<p>Baldwin, S. and Costley, S. (2016) 'The experience and needs of female adults with high-functioning autism spectrum disorder.' <i>Autism</i>, Vol.20 (4), 485-495.</p> <p>British Psychological Society (BPS), (2017) <i>Psychology at work: improving wellbeing and productivity in the workplace</i>. Leicester: BPS.</p> <p>British Psychological Society (BPS), Division of Clinical Psychology (2017) <i>What good likes like in psychological services for schools and colleges</i>. Leicester: BPS.</p> <p>British Psychological Society (BPS), Division of Clinical Psychology (2015) <i>What good likes like in psychological services for children, young people and their families</i>. Leicester: BPS.</p> <p>Clarke, J. & van Ameron, G. (2008). Asperger's syndrome: Differences between parents' understanding and those diagnosed. <i>Social Work in Health Care</i>, 46(3), 85–106.</p> <p>Hunt, K. and Craig, J. (2015) 'Delivering psychological services for children and young people with neurodevelopmental difficulties and their families.' <i>The Child & Family Clinical Psychology Review</i>, 3, 141–152.</p> <p>Falconbridge, J., Hunt, K. and Laffan, A, (Eds) (In press) <i>Improving the Psychological Wellbeing of Children and Young People: Effective Prevention and Early Intervention Across Health, Education and Social Care</i>, Jessica Kingsley Publishers, London and Philadelphia.</p> <p>MacKay, T. and Greig, A. (2013) 'The Homunculi: a flexible CBT approach to social and emotional wellbeing in children and adolescents on the autism spectrum.' <i>GAP</i>, 14, Supplement 1.</p>

End.



Autism (Wales) Bill
Health, Social Care and Sport Committee Inquiry
Response from the Association of Educational Psychologists

1. Summary

1.1 The Association of Educational Psychologists (AEP) is the professional association and trade union for the 3,200 Educational Psychologists across the UK. In Wales the AEP has around 200 members.

1.2 The educational psychology (EP) profession is a highly skilled and essential element in the nation's workforce, expert in responding to the SEND and mental health issues of children and young people (CYP) and supporting their emotional well-being.

1.3 EPs work to provide support to pupils with special educational needs across multiple levels in both mainstream and alternative provision (AP). In Wales EPs have duties to contribute to statements of SEN in Wales.

1.4 The AEP recognises the difficulties faced by individuals with autism, and the problems that arise when they cannot access services.

1.5 However, the AEP believes that it is vital to recognise potential pitfalls of singling out one group of people with different needs.

1.6 The AEP is concerned that new legislation focused on autism alone could undermine the new additional learning needs (ALN) reforms in Wales. Any new legislation must focus on co-ordination and co-operation, better training on understanding autism and other needs, and effective information-sharing.

1.7 EPs and other professionals are facing significant workload pressures, reducing their ability to provide wider support. We urgently need a well-funded, upskilled workforce who can support individuals whatever their needs. This means that further legislation must be matched by increased funding in order to deliver this.

2. The general principles of the Autism (Wales) Bill and the extent to which it will make provision for meeting the needs of children and adults with Autism Spectrum Disorder (ASD) in Wales and achieve the aim of protecting and promoting their rights

2.1 The AEP recognises the difficulties faced by individuals with autism, and the problems that arise when they cannot access services.

2.2 AEP members have identified a number of difficulties with the current system in Wales:

- The effectiveness of the current arrangements for improving autism services in Wales is inconsistent.
- Many services are not operating in a joined-up manner.



- Despite the newly established Neuro-Developmental Services in each Health Board, long waiting lists have remained consistent. Delays in diagnosis and the post-diagnosis process should be addressed as a priority.
- There is a postcode lottery when it comes to services currently provided to meet the needs of people with autism spectrum conditions in Wales.
- There are concerns about the sufficiency of provision in schools, as well as the provision of appropriate out-of-school activities that CYP with autism can join in.

2.3 Clarity is also required on pathways to diagnosis.

2.4 The diagnostic process should be multi-disciplinary, not only involving medical professionals. It is crucial that EPs are involved closely in this process, in order to help to advise parents, schools and local authorities when planning appropriate educational provision.

2.5 For the multi-disciplinary diagnostic process to be effective and timely there is an urgent need for enough specialist professionals, including educational psychologists, to be available to support the process.

2.6 Any legislation and guidance must be flexible enough to accommodate changes and advancements in, for example, diagnostic criteria. It is also important that it complies with legislative reforms, and the ALN Code of Practice.

2.7 Provision to support the inclusion of children with autism or emerging diagnoses in pre-school settings is essential.

2.8 The AEP supports proposals for Local Health Boards and Local Authorities in Wales to be required to publish information on the pathway to diagnosis for children and adults living in their areas.

3. Any potential barriers to implementation

3.1 EPs and other professionals are facing significant workload pressures, reducing their ability to provide wider support. We urgently need a well-funded, upskilled workforce who can support individuals whatever their needs. Further legislation must be matched by increased funding in order to deliver this.

3.2 A lack of training may create problems in implementation:

- AEP members report that delays in diagnoses are linked to a lack of training on Autism Diagnostic Observation Scheduled (ADOS) assessments.
- Diagnosis should be multi-disciplinary, and it is crucial that EPs are involved closely in this process, alongside the professionals mentioned on the face of the Bill. Better training for school staff on autism and the difficulties that CYP with autism face would help to combat these inconsistencies reported. EPs are well-placed to provide this.
- The AEP recommends that EPs should be trained to carry out ADOS assessments and contribute to the multi-disciplinary and multi-professional assessment processes (along with CYP and their families) which are recognised



as the best practice in order to make diagnoses and recommend appropriate interventions, support and provision for CYP with autism.

- More broadly, members highlight that there is a significant amount of effective training currently being supported. It is important to understand what this is and how best to build on it, rather than developing something entirely new.

4. Whether there are any unintended consequences arising from the Bill

4.1 The AEP does not believe that a definition of an autistic spectrum disorder should be included on the face of the legislation. This would contradict the spirit of the new ALN legislation.

4.2 To single out a definition in any legislation would be very difficult and could exclude people who show signs of autism but do not fully meet the criteria. We share the views of our members on the importance of addressing types of need, rather than focusing on a rigid definition. It should be noted that there is already more than one diagnostic manual for autism, each stating different definitions.

4.3 The AEP recognises that receiving a diagnosis of autism provides many individuals and their families with a measure of certainty, greater insight into the difficulties they experience, and access to services.

4.4 However, it is very important to consider that this is not the experience of all individuals and their families, who may not wish to pursue a diagnosis of autism.

4.5 Additionally, there is a risk that individuals who do not receive a diagnosis but still show signs of autism, do not receive the same level of support, leading to unequal treatment.

4.6 It is vital that support is also provided for those who do not have a specific diagnosis of autism but who demonstrate a similar profile of behaviour to those CYP who have autism.

4.7 Statutory guidance and data collection practices must be linked back to wider ALN reforms, and children who do not meet diagnostic criteria but still demonstrate a similar profile of behaviour to those CYP who have autism must also be supported.

4.8 It is essential that support is based on need, and not a diagnosis alone. If the latter is the case, the AEP is concerned that there could be a rise in the number of individuals and families exploring a diagnosis to receive support, leading to more challenges when that support is not forthcoming.

4.9 The AEP is concerned that an increased demand for diagnosis, if met with a failure to increase resources, will result in poor assessments and more false positives.

5. The financial implications of the Bill

5.1 When developing and implementing a national autism strategy the AEP anticipates extra costs, particularly for: additional duties for local authorities and NHS bodies;



improving the timeliness of the diagnostic process; providing support for families; the training of staff.

5.2 Overall, we would anticipate that improving the way in which mental health needs are met, not just meeting the needs of those diagnoses with autism, would represent a significant saving.

5.3 Long term benefits and savings could include: reduced absences from work, reducing offending; increasing employment rates.

6. The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation

6.1 Any powers in the Bill for Welsh Ministers to make subordinate legislation must not supersede existing ALN legislation and practice.

Eitem 7.1

Mark Drakeford AM/AC
Ysgrifennydd y Cabinet dros Gyllid
Cabinet Secretary for Finance



Llywodraeth Cymru
Welsh Government

Eich cyf/Your ref
Ein cyf/Our ref

Llyr Gruffydd
Cadeirydd Dros Dro
Y Pwyllgor Cyllid
Cynulliad Cenedlaethol Cymru
Bae Caerdydd
Caerdydd
CF99 1NA

30 Medi 2018

Annwyl Llyr,

Cyn i Gyllideb ddrafft amlinellol 2019-20 gael ei chyhoeddi, rwy'n ysgrifennu i roi'r diweddaraf ichi am y gwaith i sefydlu cyd-ddealltwriaeth o'r diffiniad o atal.

Pan roddais dystiolaeth i'r Pwyllgor Cyllid yn ystod o broses o graffu ar Gyllideb y llynedd, dywedais fod trafodaethau ar y gweill gyda'n partneriaid yn y sector cyhoeddus a'r trydydd sector i ddiffinio gwariant ataliol.

Rydym wedi bod yn gweithio gyda nifer o sefydliadau, gan gynnwys Cyngor Gweithredu Gwirfoddol Cymru a Chomisiynydd Cenedlaethau'r Dyfodol, er mwyn bwrw ymlaen â'r agenda bwysig hon. Arweiniodd y trafodaethau at ddigwyddiad o amgylch y bwrdd ym mis Gorffennaf, wedi'i drefnu gan swyddfa'r Comisiynydd ac yn cynnwys swyddogion Llywodraeth Cymru, y trydydd sector, Iechyd Cyhoeddus Cymru, y gwasanaeth tân ac academyddion. Roedd yn drafodaeth adeiladol ac mae wedi helpu i lywio ein syniadau.

Rydym bellach wedi cytuno ar ddiffiniad o atal. Rwy'n gobeithio y bydd yn rhoi fframwaith defnyddiol a fydd yn caniatáu cynnal gwerthusiad holistaidd o wariant y llywodraeth.

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1NA

Canolfan Cyswllt Cyntaf / First Point of Contact Centre:
0300 0604400

Gohebiaeth.Mark.Drakeford@llyw.cymru
Correspondence.Mark.Drakeford@gov.wales

Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

Tudalen y pecyn 108

Atal yw gweithio mewn partneriaeth i gyd-gynhyrchu'r canlyniadau gorau posibl, gan ddefnyddio'r cryfderau a'r asedau sydd gan bobl a lleoedd i'w cyfrannu. Rhennir hyn yn bedair lefel a gall pob lefel leihau'r galw am yr un nesaf:

- **Atal sylfaenol** – meithrin cadernid – creu'r amodau fel nad yw problemau'n codi yn y dyfodol. Dull gweithredu cyffredinol.
- **Atal eilaidd** – targedu camau gweithredu mewn meysydd lle mae risg uchel y bydd problem yn digwydd. Dull gweithredu wedi'i dargedu sy'n cadarnhau egwyddorion cyffredinoliaeth gynyddol*
- **Atal trydyddol** – ymyrryd pa fydd problem er mwyn ei rhwystro rhag mynd yn waeth ac i'w hatal rhag digwydd eto yn y dyfodol. Dull gweithredu sy'n ymyriad.
- **Gwario aciwt** – gwario sy'n gweithredu i reoli effaith sefyllfa negyddol iawn, ond sy'n gwneud ychydig neu ddim i atal problemau rhag digwydd eto yn y dyfodol. Dull gweithredu adferol.

***Cyffredinoliaeth gynyddol** yw bod yn benderfynol o ddarparu cymorth i bawb, rhoi llais a buddiant i bawb a phopeth, ond gan gydnabod y bydd angen mwy o gymorth ar y bobl neu'r meysydd hynny sydd â mwy o angen.

Byddwn yn defnyddio'r diffiniad hwn i ddsbarthu maes gwario ym mhob un o'r chwe Phrif Grŵp Gwariant (MEG) yn y cylch cyllidebol hwn.

Bydd dadansoddiad o'r canlyniadau, a fydd yn cael ei nodi yn y gyllideb ddrafft fanwl sydd i'w chyhoeddi ar 23 Hydref, yn rhoi cipolwg cychwynnol o ran cyfran y gwariant ym mhob categori. Bydd y canfyddiadau hyn yn helpu i lywio ein syniadau ymhellach a bydd yn rhoi llwyfan defnyddiol y gallwn barhau i adeiladu arno yn y dyfodol.

Rwy'n edrych ymlaen at gydweithio â'r Pwyllgor Cyllid wrth iddo graffu ar y Gyllideb ddrafft.

In gywir,
Mark

Mark Drakeford AM/AC
Ysgrifennydd y Cabinet dros Gyllid
Cabinet Secretary for Finance

Eitem 7.2

The Welsh Assembly's Health, Social Care and Sport Committee's Inquiry into Dentistry in Wales 2018

Post-Hearing Note to the Chair

by the BDA Wales

4 October 2018



The BDA

We are the voice of dentists and dental students in the UK. We bring dentists together, support our members through advice and education, and represent their interests. As the trade union and professional body, we represent all fields of dentistry including general practice, community dental services, the armed forces, hospitals, academia, public health and research.

Introduction

Dr Dai Lloyd
Chair of the Health Social Care and Sport Committee

4 October 2018

Dear Dr Lloyd,

We wish to convey our sincere thanks to the members of the Committee for the opportunity to present our evidence about dentistry in Wales at the Inquiry hearing on 27 September 2018.

BDA Wales members were pleased to have the opportunity to explain the challenges that dentists are facing in their day to day work and how patients are being adversely impacted by the constraints of the current contract.

On your advice, this is an additional note of information to furnish the committee with some further detail that the panel members were asking for regarding numbers of private practices and Designed to Smile data.

In addition, there is some further evidence included herein regarding the decline in access to NHS dentistry, which will help to demonstrate the concerning trends.

We look forward to receiving the transcript from the day and the final report from the Committee.

Yours sincerely,

Dr Caroline Seddon

National Director BDA Wales

The BDA Wales Pledge

BDA Wales will undertake to:

- **Conduct further research into UDA values, clawback, contract reduction, and patient access to dentistry**
 - **Undertake further quantitative and qualitative data analysis - to build up a picture of the state of NHS dentistry in Wales to determine the trends**
 - **Challenge the Government and the Health Boards to improve access to dentistry for all**
 - **Lobby for a contract that is fit for purpose and a sufficient workforce to deliver it**
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Trends in Access to NHS Dentistry

The BDA would strongly refute the Government's latest reaction to our new patient access figures - that the numbers can be 'variable' - suggesting they can be ignored in effect. The Government is not taking our research seriously. We met with the CDO and Dental Policy Advisor in August to share the headline data on access for new patients saying we would include them in our Inquiry response. We explained that the detailed data at Health Board level were included in the paper submitted to the BDJ. However, it may be helpful for the committee to see the results for Cardiff and Vale which showed the lowest access numbers, in order convey the severity of low access in some parts of Wales.

Since 2012, access for new patients has more than halved, down from an average of 37% to an average of 15% for new adult patients. Moreover, the averages hide the contrasting data in our paper to the BDJ, which includes a breakdown by Health Board. In Cardiff and Vale, the access is shockingly low with just 3% of practices taking on adults and 6% accepting children for NHS treatment.

The data produced by others go back several years. *There is an undeniable trend that access to NHS care is plummeting for new patients.* Here is a summary of data taken from the press:

March 2012

ITV - 27 March 2012 *Dentistry in Wales still inadequate*

<http://www.itv.com/news/wales/2012-03-27/dentists-in-wales-still-inadequate/>

The Welsh Liberal Democrat survey of all dental practices in Wales shows that only 37% are currently accepting new NHS patients. Of those practices accepting NHS patients, 63% have waiting times of more than two months long. One extreme case showed a waiting list of six years before a new NHS patient could be accepted.

The Welsh Liberal Democrat survey also revealed that:

More than half of dentists (53%) reported problems with the way the current dental contract operates. 31% believe that the contract needs to change.

It is far easier for patients to access private dentists. 70% of dentists in Wales are currently accepting new patients - almost double the number of practices accepting new NHS patients.

May 2014

BBC - 30 May 2014 NHS dentists: *Nearly half of adults have not been seen*

<https://www.bbc.co.uk/news/uk-wales-27626199>

Government figures show that 52% of adults in Wales were treated by a dentist in the 24 months before 31 December last year. Plaid Cymru said the fact that almost half of adults had not received any NHS treatment highlighted a problem with the number of available NHS dentists.

Health spokeswoman Elin Jones said: "It's obvious from the number of people who are still unable to find an NHS dentist, even for children, that we need to increase the NHS capacity even further."

Liberal Democrat assembly member, Eluned Parrott, added: "This Welsh Labour government has completely overlooked the dentistry service in Wales. Just stating that everyone should have access to a dentist isn't enough - there has to be action too."

September 2018

BBC - 27 September 2018 *NHS dental patients 'face 90-mile trip', union claims*

<https://www.bbc.co.uk/news/uk-wales-45660819>

BDA figures show that on average 15% of Welsh NHS dental clinics accepted new adult patients last year, with 28% taking on new child patients.

[*Post publication note:* In Cardiff and Vale, the access is shockingly low with just 3% of practices taking on adults and 6% accepting children for NHS treatment.]

This lack of access is having significant impacts on patients. Data from NHS Direct shows people living in Aberystwyth face a near 90-mile (144km) round trip to see an NHS dental practice which is accepting new patients. People in Newtown face 80-mile (128km) journeys while those in Cardiff could travel almost 30 miles (48km).

NHS Dentistry Activity Statistics

The BDA is concerned about the way dentistry activity data are portrayed by the Government and we have already alluded to these concerns in our written evidence, including that the data are not normalized for population changes (growth).

- Over the past six years - any increase in treatment numbers has just kept pace with the increase in the population
- In six years, there has been an average increase of approx 0.5% per year of courses of treatment and patients treated
- However, increases mostly reflect the population increases
- Percentage of patients receiving NHS treatment has remained almost static: 54.2% in 2011 compared with 54.9% in 2017

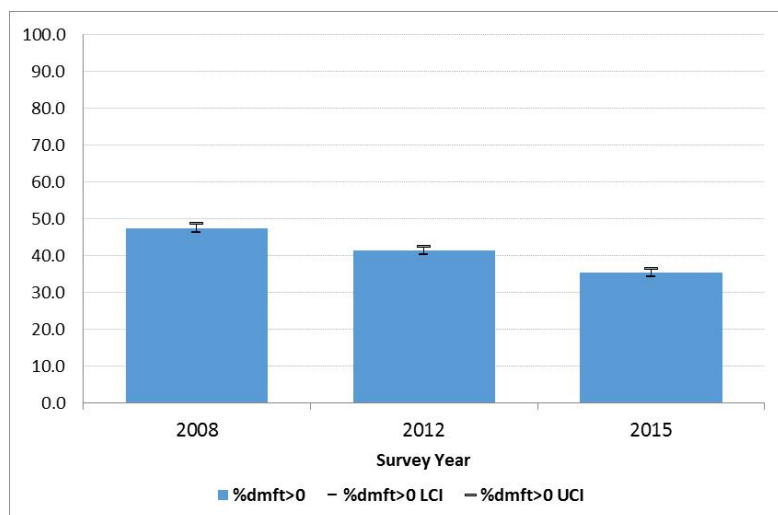
Numbers of Practices that solely conduct private work

Using figures obtained in 2017 from HIW, below, together with NHS Direct information on services provided by practices, it was calculated that there are 80 practices (18 per cent) in Wales that do only private work and do no NHS work. We believe that number is likely to grow in the next few years as more and more practices hand back their NHS contracts, assuming they do not close altogether.

Health board	Number of Practices listed by HIW
ABMU	77
Aneurin Bevan	79
Betsi Cadwaladr	90
Cardiff and Vale	74
Cwm Taf	40
Hywel Dda	48
Powys	26
All Wales	434

Designed to Smile

Welsh Government reported a 12% reduction in the level of dental decay amongst five-year old's in Wales between 2008 and 2015. That works out at 1.7% fall each year on average. The latest survey carried out in 2015 shows that on average 35% of five-year old's in Wales had dental decay.



The BDA welcomes the results and would like to see the Committee challenge the Government to top up the funding from £4m to £6m to ensure that 5 and 6-year-old children do not lose out on the fluoride varnish with the Refocus of Designed to Smile. As we said in our evidence, we welcome the extension to very young children, but fear that any advantage in the early years will be lost at the critical age when the permanent teeth erupt without the fluoride varnish to protect them. These are children who are less likely to visit a high street dentist. And given the declining access for new child patients are less likely to be successfully treated on the NHS.

These data might very well correlate with Government dentistry data showing that approximately 33% of children do not visit a General Dental Practice, which seem unnervingly close to 35% of children with decay. With new child access to NHS dentistry now falling to such low levels - particularly in Cardiff and Vale at just 6% - we are greatly concerned that children will be left with nowhere to turn to other than Accident and Emergency, their GP, or private dentistry if they are fortunate to have sufficient family income.

The BDA would like to see the government follow NICE guidelines and look to have age-appropriate programmes for older children who are still showing unacceptably high levels of dental caries. We are concerned that this idea is being actively resisted by the CDO and would suggest that NICE guidelines should be paid the attention they deserve.

References

Welsh Government April 2016 '*Children's oral health in Wales - something to smile about*'
<https://gov.wales/docs/phhs/publications/160503smileen.pdf>

**The Welsh Assembly's Health, Social Care and Sport Committee
Inquiry into Dentistry in Wales 2018**

Post-Hearing Note to the Chair from the BDA Wales

Submitted on 4 October 2018

Dr Caroline Seddon
National Director BDA Wales
Report Editor

BDA Wales has a policy of publishing key documents in Welsh and English (see our website)

<https://www.bda.org/bdawales>

The Welsh translated report to the Committee is now available on our landing page