Agenda - Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Lleoliad:	I gael rhagor o wybodaeth cysylltwch a:
Ystafell Bwyllgora 1 - Y Senedd	**Claire Morris**
Dyddiad: Dydd Mercher, 3 Hydref 2018	Clerc y Pwyllgor
Amser: 09.15	0300 200 6355
	SeneddIechyd@cynulliad.cymru

Rhag-gyfarfod anffurfiol (09.15- 09.45)

1 Cyflwyniad, ymddiheuriadau, dirprwyon a datgan buddiannau

(09.45)

2 Bil Awtistiaeth (Cymru): Sesiwn dystiolaeth gyda Chymdeithas Genedlaethol Awtistiaeth Cymru ac Autistic Spectrum Connections Cymru

(09.45 - 10.30) (Tudalennau 15 - 289)

Jane Harris, Cyfarwyddwr Materion Allanol a Newid Cymdeithasol, Cymdeithas Genedlaethol Awtistiaeth Cymru

Meleri Thomas, Rheolwr Cysylltiadau Allanol, Cymru, Cymdeithas Genedlaethol Awtistiaeth Cymru

Gareth Morgan, Rheolwr Prosiectau, Autism Spectrum Connections Cymru

Ymatebion i’r ymgynghoriad

Briff Ymchwil

Papur 1 - Cymdeithas Genedlaethol Awtistiaeth Cymru

Egwyl (10.30-10.35)

3 Bil Awtistiaeth (Cymru): Sesiwn dystiolaeth gyda Dr Duncan Holtom

(10.35-11.20) (Tudalennau 290 - 296)

Dr Duncan Holtom, Pennaeth Ymchwil, Pobl a Gwaith

Papur 2 - Dr Duncan Holtom

Egwyl (11.20-11.25)

4 Bil Awtistiaeth (Cymru): Sesiwn dystiolaeth gyda Dr Dawn Wimpory a Dr Elin Walker-Jones

(11.25 - 12.10) (Tudalennau 297 - 310)

Dr Dawn Wimpory, Seicolegydd Clinigol Ymgynghorol, Arweinydd Anhwylder Sbectrwm Awtistiaeth, Bwrdd Iechyd Prifysgol Betsi Cadwaladr, a Darlithydd, Prifysgol Bangor

Dr Elin Walker-Jones, Seicolegydd Clinigol Ymgynghorol, Bwrdd Iechyd Prifysgol Betsi Cadwaladr

Papur 3 - Dr Dawn Wimpory

Papur 4 - Dr Elin Walker-Jones

5 Cynnig o dan Reol Sefydlog 17.42 i benderfynu gwahardd y cyhoedd o weddill y cyfarfod hwn

(12.10)

6 Bil Awtistiaeth (Cymru): Trafod y dystiolaeth

(12.10 - 12.20)

7 Blaenraglen Waith

(12.20-12.30) (Tudalennau 311 - 313)

Yn rhinwedd paragraff(au) vi o Reol Sefydlog 17.42

Atodiad i'r A

Mae cyfyngiadau ar y ddogfen hon

Yn rhinwedd paragraff(au) vi o Reol Sefydlog 17.42

Eitem 2

Mae cyfyngiadau ar y ddogfen hon

Response to the Autism (Wales) Bill consultation by the National Autistic Society Cymru September 2018

Introduction

We welcome the publication of the Autism (Wales) Bill and fully support the need for specific autism legislation in Wales.

Wales has had an Autism Action Plan for ten years now and yet autistic people and their families are still being let down and not having their needs met. Autistic people in Wales continue to experience poor outcomes and it's not right that this continues. For example:

- In a report we published in 2011, some 58 per cent of respondents said they'd waited too long for a diagnosis. In a similar report published in 2016 the figure had risen to 63 per cent.
- In 2011, some 53 per cent of respondents said that getting a diagnosis was stressful. In 2016 that figure was 56 per cent.
- In 2011, some 24 per cent of respondents said that they were satisfied that the information given to them afterwards helped them get the support they needed. In 2016 that figure was 21 per cent.

It's time to ensure that key changes that will make a tangible difference in the lives of autistic people are made mandatory so that public services don't view them as 'nice to haves'. This would include training for professionals, ensuring that data is collected, and support is available wherever people live in Wales.

We believe that if passed, this Bill will show real leadership by the National Assembly for Wales and the Welsh Government. It could send a clear message to autistic people as well as public bodies in Wales that autism is a policy priority in Wales. This legislation is about giving autistic people a level playing field and getting the basic things right.

We were pleased to have contributed to the previous two consultations – both on the development of the content of the Bill and the subsequent draft Bill. This included holding a number of focus groups across the country with our members and supporters, many of whom are autistic adults themselves. The vast majority of those who took part in focus groups and who engaged in the consultation process supported autism legislation. In a report that we published in 2016, nearly 90 per cent of those who responded to our survey said that autism legislation is needed.

Meeting the needs of autistic people

We are pleased that the Bill covers both children and adults as autism is a lifelong disability. In our view the Bill is further strengthened by specifically mentioning the need to provide help during the transition between childhood into adulthood which should help ease the move between children's services and adult services.

The original Action Plan recognised the need for early diagnosis and further actions to improve waiting times through neurodevelopmental teams where announced in 2015. The refreshed action plan that was published in November 2016 introduced a new 26 week waiting time from referral to first assessment for children and young people.

However, we know that this isn't being met across Wales. According to the Hywel Dda Health Board the waiting time from referral to first assessment for the neurodevelopmental team in May 2018 was 18 months. Anecdotally, parents in Pembrokeshire in particular have told us that the actual waiting time is much longer. Furthermore one of the recommendations of the Children, Young People and Education Committee's 'Mind Over Matter' report published earlier this year was that 'the Welsh Government develop an immediate recovery plan for neurodevelopmental services in Betsi Cadwaladr to address unacceptably long waiting times faced by over a thousand children and young people.' Relevant data for the neurodevelopmental teams in the five other Health Boards is not currently available and so we do not know if the needs of autistic children and young people are being met. This is despite a commitment in the refreshed Action Plan that Health Boards should report a 26 week waiting time from referral to assessment by March 2017.

We know that getting a diagnosis can be the key that unlocks support and services for autistic people and welcome the proposal to link to the relevant Quality Standard issued by the National Institute for Health and Care Excellence (NICE). We welcome the inclusion in the Bill of the need to ensure that support is in place regardless of whether a person has a diagnosis, and that support should include wider family.

We therefore welcome the certainty in the proposed legislation gives around the diagnosis process in its entirety.

We welcome the fact that the Bill seeks to address the wider needs of autistic people including support around meeting employment and housing needs. More than half (55 per cent) of autistic people who responded to our 2016 survey said that they'd like more support around employment and only one in ten were in full time paid employment.

Recent development in services to address the needs of autistic children and adults are welcome, particularly the creation of Integrated Autism Services in each Health Board region. These teams are best placed to deliver many of the provisions contained in the Bill and therefore the legislation supports the role of these new services and is designed, we feel, to help ensure they can become embedded in local health and care services. We feel that this would be better than the Integrated Autism Service having to be reliant on short-term funding up until 2021.

Similarly, while some good work has been done in the development of awareness resources and training, uptake in accessing these has in our view been too slow and is inconsistent across the country. For example, not all local authorities are taking up the 'Learning with Autism' programme for schools. And since the scheme was extended in September 2017, only three secondary schools have achieved the 'Learning with Autism Award.'

We believe that legislation should clearly set out which professionals need what levels of training to ensure that autistic people are supported by professionals who understand them.

Current initiatives recognise the importance of collecting the necessary data to plan future support and services. For example there is a requirement on Regional Partnership Boards to include autism and learning disabilities as a key theme in regional plans. However, this is difficult as very little data on autism is collected in practice and existing plans focus heavily on learning disabilities. Making the data collection mandatory through legislation will make sure that services understand that this is not just a nice to have and give strength to the hand of Regional Partnership Boards and other public services to ask for the data.

In our view, one opportunity in this legislation in ensuring that autistic people's needs are met is by offering an opportunity to embed the necessary training for relevant professionals while obtaining their initial professional qualification and through subsequent continuous professional development. The aim here is not to make things more onerous or difficult for professionals but to provide them with support and clarity, for example, through access to the right training for the right professionals. Professionals we talk to say they want this training and autistic children and adults should at the very minimum expect to be supported by professionals who understand them.

Protecting and promoting the rights of autistic people

As stated on the face of the Bill, this legislation makes provision for meeting the needs of children and adults with autism spectrum disorder in Wales and protecting and promoting their rights. This is consistent with the social model of disability. We believe that this will ensure that societal barriers faced by autistic people are removed. Training and the awareness campaigns are examples of this and we welcome the inclusion of both of these elements in the Bill. Similarly, the Bill makes provision in relation to social issues such as housing and employment. We welcome the ambition in the Bill to look at an autistic person in a holistic way throughout their lifetime as well as the needs of their families and careers.

We note the specific reference in the Bill to have regard to the UN Principles and Conventions. This would bring this piece of legislation in line with the duties on co-existing legislation including most recently the Social Services and Wellbeing Act, and the Additional Learning Needs Act.

We welcome the ambition in the legislation to enable autistic people to live as independently as possible through ensuring that relevant bodies ensure the rights of autistic people to access the provisions listed in section 2 (1) (g). While the list is not limited we particularly welcome the inclusion of social inclusion.

We know from our own research that one of the main barriers facing autistic people in particular is social isolation. For example, nearly four of every five autistic people (79 per cent) who responded to one our surveys said that they felt socially isolated.

We also note the specific mention in the Bill that autistic people should be able to access Welsh Language Services. This combined with the Welsh Government's Active Offer framework strengthens the rights of autistic people to access services in the language they choose.

Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. This Bill will ensure that where autistic people don't fit into current existing structures, local services will be under a duty to make sure there is a pathway for them to get the support they are entitled to, helping create a level playing field for autistic children and adults. Furthermore we welcome the explicit duty in the Bill that adults with autism cannot be denied access to services because of their IQ. This will make it clear to services that the needs of autistic people across the spectrum need to be identified and met.

We recognise that the Bill links to the WHO definition of autism and NICE guidelines and Quality Standards. This means that if and when our understanding of autism improves and develops, any changes made to the WHO definition or NICE guidelines will be reflected in the interpretation of the Bill, and its subsequent guidance and we welcome its inclusion.

We are also pleased that the Bill requires an independent report on the autism strategy, including its ongoing implementation and progress. Furthermore we particularly welcome the requirement to reflect on recommendations made by the independent review. Although the Welsh Government's Action Plan has been evaluated, recommendations have not always been taken on board or implemented in the development of support. This means that many of the issues autistic people face now are exactly the same as they were when the original action plan was first developed in 2008 and which this Bill seeks to address. Examples include getting a timely diagnosis, collecting data for planning services, raising awareness, and training for practitioners.

Barriers and unintended consequences

The Bill is clear that a diagnosis shouldn't prevent support from being made available either for the autistic person themselves or their families and carers, from the point at which their needs first become apparent. Support should be available regardless of a diagnosis.

As currently written, the Bill says that the waiting time from which a referral for diagnostic assessment of autism is made and an initial diagnostic appointment should be no longer than 13 weeks. This is in line with NICE guidelines and has been developed by experts, including clinicians and commissioners, as well as autistic people, and their families.

Welsh Government already base many of their guidelines for autism provision on NICE standards, such as the use of multi-disciplinary teams. This suggests that they are already content with the NICE evidence base. This Bill seeks to ensure full compliance with the NICE recommended timeframe.

This isn't about taking up resources to focus only on diagnosis at the risk of not being able to provide other pre and post diagnostic support. The Bill is clear that a diagnosis shouldn't prevent support from being made available either for the autistic person themselves or their families and carers, from the point at which their needs first become apparent. Support should be available regardless of a diagnosis.

The Welsh Government has had an autism Action Plan in place for the past ten years. There is no evidence to suggest that these provisions have privileged autism above other conditions or are responsible for demands for other condition-specific policy.

Autism legislation already exists in Northern Ireland and in England. There have been specific challenges in implementing the Northern Ireland Act and the suspension of the Assembly and wider political issues have also had an impact on the legislation. In addition, the Act hasn't made as much impact as we would have liked because it didn't result in legally binding duties for local delivery bodies in the same way as the England Act.

Where the England Act has made significant impact has been around making sure that there is a pathway to diagnosis in every area. In 2016, a survey of local authorities found that only three local authorities reported not having an adult diagnostic pathway. This simply wasn't the case before the Act and one of the reasons we argued for it.

Before the Act, our autism services directory could only identify 14 NHS teams/individuals who diagnosed adults in the whole of England. There is also clearer 'infrastructure' at local level in terms of local leadership and local planning, including an autism lead in more than 90 per cent of local authorities.

It is also important to remember that we are not suggesting taking the England Act and the Northern Ireland Act and implementing them in Wales. From the Northern Ireland Act, we learn that we need clear duties on local public services to deliver. In terms of the England Act we want to make sure that the Wales Act is all ages.

Notably, despite the England and NI Act being in force since 2009 and 2011 respectively, there hasn't been a recognised link between this and campaigns for other condition-specific legislation.

As mentioned above we welcome the proposal in the legislation to address the barriers facing autistic adults in accessing services because of their IQ.

Financial implications

The Explanatory Memorandum is clear in where costs would occur. A net initial cost of around £7million is estimated. However, this needs to be measured against the cost effectiveness of current provision, resource and policy. It is also anticipated that there will be longer term savings due to the effective identification and support of individuals with autism.

The Explanatory Memorandum also states that 'There is little information in the public domain to estimate the current provision and future plans with regard to both the administrative costs of providing services to people with ASD… The Welsh Government was unable to provide specific information regarding the cost of the status quo.' It's therefore difficult to estimate the current costs of provision in its entirety due to a lack of reliable data, which is something the Bill seeks to address.

While we recognise that there will be some cost involved in introducing and implementing legislation, we believe that introducing autism legislation will not result in significant burdens. This must also be balanced against the cost of not intervening and the economic impact of having to access acute services.

Economic modelling in England by the National Audit Office showed that identifying and supporting a relatively small number of autistic adults would bring about significant cost savings to the public purse. In their model, they suggested that if just a 14 per cent of the autistic adult population were identified and supported, the savings that could be made would be £5,000 per 1,000 working age population. In Wales, this could mean that a 14 per cent identification and support rate would save £10 million a year to the public purse in Wales. These figures from the NAO are from 2009 and need refreshing and updating for a Welsh context, but do indicate that significant savings can be made from the proper identification and support for autistic adults.

Subordinate legislation

We are content with the affirmative procedures to make subordinate legislation in the three areas listed in Part 2 of the Explanatory Memorandum.

Conclusion

As mentioned above, 10 years of the autism Action Plan hasn't achieved the necessary changes to the lives of autistic people in Wales. We believe that changes that will make a tangible difference are mandatory. Legislation is supported by our members and supporters and the overwhelming majority of the hundreds of responses to both the consultation on both the development and the draft autism bill. The Bill has therefore been shaped by autistic people who will be directly affected by it. We believe that legislation will give autism support parity with other existing support provided to those with learning disabilities and mental health, whilst ensuring better outcomes for autistic children and adults.

In drafting our comments we have done so based on the experience of learning from what works and what hasn’t worked so well in other countries that have implemented autism-specific legislation. It’s also important to note that this is a Wales bill and should be fit for purpose for the benefits of autistic people in Wales.

Cynulliad Cenedlaethol Cymru
Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Bil Awtistiaeth (Cymru)
Ymatebion i'r Ymgynhoriad

Medi 2018

Cynulliad Cenedlaethol Cymru yw'r corff sy'n cael ei ethol yn ddemocrataidd i gynrychioli buddiannau Cymru a'i phobl, i ddeddfu ar gyfer Cymru, i gytuno ar drethi yng Nghymru, ac i ddwyn Llywodraeth Cymru i gyfrif.

Gallwch weld copi electronig o'r ddogfen hon ar wefan y Cynulliad Cenedlaethol:
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Gellir cael rhagor o gopïau o'r ddogfen hon mewn ffurfiau hygyrch, yn cynnwys Braille, print bras, fersiwn sain a chopïau caled gan:

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Cynnws | Contents

* Saesneg yn unig | English only
** Cymraeg yn unig | Welsh only
*** Ar gael yn ddwyieithog | Available bilingually

Rhif | Number	**Sefylliad**	**Organisation**
A01*	Unigolyn	An individual
A02*	Coleg Brenhinol yr Ymarferwyr Cyffredinol	Royal College of General Practitioners
A03*	Unigolyn	An individual
A04*	Comisiwn Cydraddoldeb a Hawliau Dynol	Equality & Human Rights Commission
A05*	Coleg Brenhinol Pediatreg a Iechyd Plant	Royal College of Paediatrics and Child Health
A06*	Bwrdd Iechyd Prifysgol Hywel Dda	Hywel Dda University Health Board
A07*	Conffederasiwn GIG Cymru	Welsh NHS Confederation
A08*	Gwasanaeth Awtistiaeth Integredig Gwent	Gwent Integrated Autism Service
A09*	Cymuned Ymarfer ar gyfer Diagnosis Oedolion ac Ymarferwyr Gwasanaethau Awtistiaeth Integredig	Community of Practice for Adult Diagnosis and Integrated Autism Service Practitioners
A10*	Cyngor Tref y Bari	Barry Town Council
A11*	Bwrdd Iechyd Lleol Cwm Taf	Cwm Taf University Health Board
A12***	Ludlow Street Healthcare	Ludlow Street Healthcare
A13*	Cymdeithas Genedlaethol Awtistiaeth Cymru	The National Autistic Society Cymru
A14*	Coleg Brenhinol y Therapyddion Iaith a Lleferydd	Royal College of Speech and Language Therapists

A15*	Cyngor Cymuned Mochdre gyda Phenstrywaid	Mochdre with Penstrowed Community Council
A16*	Comisiynydd Plant Cymru	Children's Commissioner for Wales
A17*	Gwasanaeth Awtistiaeth Integredig Gogledd Cymru	North Wales Integrated Autism Service
A18*	Coleg Nyrsio Brenhinol Cymru	Royal College of Nursing Wales
A19*	Unigolyn	An individual
A20***	Coleg Brenhinol y Seiciatryddion	Royal College of Psychiatrists
A21*	Gwasanaethau Cymdeithasol Cyngor Caerdydd	Cardiff Council Social Services
A22*	Bwrdd Rhaglen Dyfodol Anabledd, Cyngor Caerdydd	Disability Futures Programme Board, Cardiff Council
A23*	Cymdeithas Seicolegol Prydain	British Psychological Society
A24*	CollegesWales	ColegauCymru
A25***	Cymdeithas Llywodraeth Leol Cymru	Welsh Local Government Association
A26*	Dr Dawn Wimpory	Dr Dawn Wimpory
A27*	Rheolwyr y Gwasanaethau Anableddau a Phobl Agored i Niwed, Adran Gofal Cymdeithasol Conwy	Managers of the Disabilities and Vulnerable People Services, Conwy Social Care Department
A28*	Cymdeithas y Seicolegwyr Addysg	Association of Educational Psychologists
A29***	Dr Elin Walker-Jones	Dr Elin Walker-Jones
A30*	Cymdeithas Siartredig Ffisiotherapi	Chartered Society of Physiotherapy
A31*	Coleg Brenhinol y Therapyddion Galwedigaethol	Royal College of Occupational Therapists
A32**	UCAC	UCAC

A33***	Barnardo’s Cymru	Barnardo’s Cymru
A34*	Dr Duncan Holtom	Dr Duncan Holtom

A01

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Unigolyn

Response from an individual

Dear Health, Social Care and Sport Committee at the National Assembly for Wales.

I'm writing to you to inform you of the anger and disappointment that I'm feeling in the light of the fact that the Welsh Government has failed to ensure continuity for the services offered by Autism Spectrum Connections Cymru (ASCC).

Please find enclosed documents which consist of the recent information regarding the changes to their services as well as information relating to ASCC which is included with this this email.

It was announced this week that ASCC will be changing and cutting down on their services from September due to lack of funding.

I'm an individual living with a diagnosis of Asperger's Syndrome and ADHD. I use the specialised services for people with autism that is offered by ASCC's One Stop Shop on a daily basis.

I have been using the services for at least 4 days a week for over 2 years.

I have had many 1:1 appointments, have attended group support for anxiety management, benefits support, support with friendships, relationships and specialised group sessions for people with autism who are also LGBT, employment seeking in general, as well as accessing the drop-in facility at 21 High Street.

This building acts a safe space in the community for me as a person living with autism. The flexibility provided by this unique safe-space which is open up to 6 days a week is essential for me as a person living with autism.

The services offered by ASCC are essential for me as a person living with autism. At ASCC I get the chance to feel accepted for who I am and included socially. I have previously struggled to make and maintain friendships. ASCC has helped to prevent the anxiety and depression which was previously caused from loneliness. ASCC have helped by constantly providing a sense of friendship for me during drop-in hours. In the past, this loneliness has previously led to suicidal thoughts which have been relieved from the services offered by ASCC.

The services offered by ASCC aren't offered anywhere else. These services haven't been mentioned as part of the National ASD Strategic Action Plan. The Integrated Autism Service do not and will not provide the same level of support as the One Stop Shop at 21 High Street run by ASCC.

I was told the news yesterday that ASCC will be cutting down on their services due to lack of funds and I believe that this is unacceptable considering the amount of money that has been made available for autism specific services in Wales.

Due to the changes that will be happening from September, I have been encouraged by ASCC to consider volunteering at the charity in order to help them to continue with their work. However, despite needing the services from the perspective of a service user rather than as a volunteer, I have agreed to volunteer for them and I will continue to do so in order for the place to continue giving me support.

I thoroughly condemn the Welsh Government's action for not helping to fund the services offered by ASCC to any extent despite being completely necessary for me as an individual living with autism.

I desperately need these services. ASCC has been invaluable for me in the process of recuperating from severe mental health which led to being sectioned less than 5 years ago.

I presented a petition to the Welsh Assembly to call on the Welsh Government to help fund their work and you have not listened to any of my concerns or worries in this process.

As a person living with autism, this is in fact discrimination against me as a person with a disability whose needs will not be met as soon as they discontinue their services. These services are necessary for me and when these services are discontinued, it will have a huge impact on my everyday life.

The proposed Integrated Autism Service (IAS) has many weaknesses. To start with, they will not operate a safe space drop-in centre for individuals with autism up to 6 days a week in the centre of Cardiff. It is outrageous to think that this sort of support isn't seen as necessary in the community for adults living with autism.

I have had very bad experiences with the Integrated Autism Service (IAS). I was recently told by [redacted] that having autism would not stop me from being able to do daily living tasks such as cooking and cleaning, therefore suggesting that a care plan was unnecessary for me despite having a disability under the Equality Act 2010. I am entitled to a care plan and social care assessment as well as direct payments.

This is completely incorrect and shows that he is completely incompetent for leading the Cardiff and Vale IAS. I have been making complaints.
They have failed to address my needs as a person with a disability.

The IAS has failed to provide an adequate level of support services for my needs as a person living with autism and they will never be as good as the One Stop Shop at 21 High Street in Cardiff.

I am very concerned that the IAS will not fulfil what is required for people living with autism and I have no confidence in the National ASD Strategic Action Plan.

Therefore, I come to the conclusion that I demand a full explanation of why you are not helping to fund ASCC and why you do not value their services. You have expressed that you do not value their work in the fact that you will not help to to fund the organisation. The proposed IAS will not even be close to replicating the services offered by ASCC despite claiming to do so.

Yours Sincerely,

[redacted]

21 High Street (Autism One Stop Shop)- services are changing

ASCC delivers a one stop shop/ flexible support service from 21 High Street in Cardiff city centre. The service was opened in January 2015 to meet a gap in service provision which existed for adults (16+) with Asperger syndrome in the South East Wales region. The service meets the needs of a largely hidden population with high levels of comorbid mental health difficulties. The service works proactively to address unmet support needs of people who might otherwise need the input of other, more cost intensive, reactive services.

Key to the development of the One Stop Shop was the idea of developing and facilitating a “safe place” for people to meet others, engage in positive social activities and to be able to access support which was developed in partnership with each person and tailored to suit their needs and intended outcomes.

Key achievements include the development of the first post diagnostic support groups for autistic adults in Wales. These workshops have been developed over the past three years in partnership with people with autism and Cardiff & Vale UHB. We have recently redeveloped these and they are now being delivered by Cardiff and Vale IAS and Gwent IAS with plans for them to be shared and be delivered across Wales.

Through our employment services we have developed close working partnerships with many of Wales’ leading employers and supported people accessing the One Stop Shop to pursue workplace opportunities which range from work experience through to full time paid work. In total 126 people have been helped into employment and 27 people have been helped to retain their existing roles as a result of our intervention.

The flexible, drop-in element of the service has meant that a community has developed where autistic people can meet with others, feel safe and comfortable and access resources including, computer equipment (PCs/iMacs/ iPads) , musical equipment (instruments and recording equipment) and recreational equipment including games consoles, pool table, a library of books and many others.

Over the past three years 21 High Street has supported over 743 autistic people to achieve the following outcomes: This is based on a full 3 years from April 2015-end of March 2018

OSS Service since 2015 (please see appendix A):

- Total number of people engaged: 716 formally registered, average of 174 different individuals accessing each month.
- Total number of Drop-in/ social group hours: 21,519
- Total number of individual visits: 39,873
- Total number of Focussed Support Hours: 17,921 (key areas listed below)
    - Housing: 1263
    - Employment: 4623
    - Crisis Intervention: 1647
    - Relationships: 589
    - Benefits (including tribunals): 3676 with a success rate of 89%, the national average is 64%.
    - Student Support/ Education: 783
    - Anxiety Management: 1459

  - Sexuality/ Gender Identity: 564
  - Criminal Justice System: 989
- Post Diagnostic Workshops - Total Number of Groups (6 week course): 27
- Post Diagnostic Workshops - Total Number of People supported: 142
- Employment Support Services - Total Number of Groups (10 week course): 34
- Employment Support Services - Total Number of People supported: 184
- Total number of people in Workplace Opportunities: 126

Referrals for services have come from the following Health Board areas:

- Cardiff & Vale: 420
- Aneurin Bevan: 158 (not including individuals supported for post diagnostic workshops co-delivered with Gwent IAS)
- Cwm Taff: 121
- Powys: 1
- Abertawe Bro Morgannwg: 14
- Hywel Dda: 2
- Betsi Cadwaladr: 0

We are saddened that we have been unable to secure sustainable funding to continue to deliver this unique flexible service for people in south Wales in the way that we previously have.

Funding has been unforthcoming from Welsh Government and others partly due to the development of the Integrated Autism Service. It is with regret that funding of £200,000 per year could not be sourced from the £13 million budget for the Integrated Autism Service to sustain this valuable and value for money service. We will be working with Cardiff and Vale IAS, Gwent IAS and Cwm Taff IAS as well as local authorities to ensure that people can access their services.

Autism Spectrum Connections Cymru, will still continue to provide domiciliary care, supported living services and student mentoring services throughout South Wales.

We are particularly proud of the feedback and support that we have received from people who have accessed the service and those close to them. We are aware of how deeply valued this service has been by the people it has touched and hope that the services now developed by Welsh Government across Wales will adequately fill the void that will be left.

“21 High Street has literally saved my life- before I came here I wanted to end my life” Registered user

“I love being able to drop-in and feel a part of a community” Registered User

“Being able to drop in is a lifesaver” Registered User

“Thank you. I’ve never worked before and now I have a job and feel so much more confident” Registered User

“Without you I don’t know what we would have done as a family- no one else we have spoken to has helped!” Parent

“You are our specialist point of call” CMHT staff member

“There’s no other service like yours- without you we’d be lost” IAS staff member

One Stop Shop Service since 2015

ascc autism spectrum connections cymru

21 High Street

focussed support

17,921 Total number of Focussed Support Hours: **17,921**

Housing	**1263**
Employment	**4623**
Crisis Intervention	**1647**
Relationships	**589**
Benefits (including tribunals) A success rate of **89%** - the national average is **64%**	**3676**
Student Support/Education	**783**
Anxiety Management	**1459**
Sexuality/Gender Identity	**564**
Criminal Justice System	**989**

hours

people

715 **715** formally registered with an average of **174** different individuals accessing each month

engaged

employment

34 Total number of **groups** (10 week course)

support service

employment

184 Total number of **people** supported

support service

post diagnostic

142 **142** people supported across a total of **27** 6-week course groups

workshops

people into

126 Total number of people **supported** into workplace opportunities

workplace opportunities

visits to

39,873 Total number of **Individual** visits

21 high st

referrals from health board areas

Cardiff & Vale	420
Aneurin Bevan	158
Cwm Taff	121
Abertawe Bro Morgannwg	14

in total

drop in & social group

21,519 Total number of drop-in and social group **hours**

hours

21 High Street is a flexible support service based in a 4 storey building in Cardiff city centre for people aged 16+, who have a diagnosis of high functioning autism or Asperger syndrome. To date we have **715** people registered and over **174** different individuals accessing the service each month.

21 High Street is a service delivered by the charity Autism Spectrum Connections Cymru (ASCC).

What is 21 High Street?

ASCC is a Welsh charity which provides specialist autism services. ASCC is part of the well respected Autism Initiatives group of charities.

ASCC in numbers

39,873 individual visits

17,921 Focussed support hours including:

Housing: **1263**

Employment: **4623**

Crisis Intervention: **1647**

Relationships: **589**

Benefits: **3676** with a success rate of **89%**,

(national average is 64%.)

Student Support: **783**

Anxiety Management: **1459**

Sexuality/Gender Identity: **564**

Criminal Justice System: **989**

27 Post Diagnostic Workshop Groups supporting **142** people

34 Employment Support Services Groups supporting **184** people

126 people in Workplace opportunities

> “I love being able to drop in and feel a part of a **community**”
>
> Registered User

> “21 High Street has literally **saved my life** - before I came here I wanted to end my life”
>
> Registered User

The 21 High Street Team offer focused 1:1 support, housing, employment and benefits advice. They can also meet with you to discuss problem solving in a number of areas, as well as providing a variety of social opportunities throughout each month.

You can also access independent advocacy through 21 High Street.

> “With the support of ASCC I have been able to **re-engage** with the world and rediscover my **self esteem** and **confidence**. Consequently, I now have a full time job that I enjoy as well as running my own company - things I never thought would be possible just a year ago”
>
> Registered User

We work in partnership with autistic people and other stakeholders to ensure our services are relevant, person-centred and reflect what is important to each individual and their families.

We understand that each person’s autism will impact upon them in unique ways and work in partnership with them and those close to them, to develop and achieve their own goals utilising a strength based model of support, shaped around each individual.

How do I access the service?

To self-refer email: info@asc-cymru.org or call: 029 2022 8794. A member of staff will then arrange an initial meeting with you at 21 High Street.

The purpose of this meeting is to:

Tell you about the service in more detail

Give you the opportunity to ask questions

Complete a short ‘about me’ form which includes your contact details & information which will help us support you in the future.

This meeting should take around 30 minutes to an hour.

> “You are our **specialist** point of call”
>
> CMHT Staff Member

> “Thank you. I’ve never worked before and now I have a job and feel so much more **confident**”
>
> Registered User

You’ll be able to:

Visit 21 High Street during drop-in hours (check our website for up to date drop-in times).

The building is a safe place where you can make use of the various facilities or just relax and meet other people.

Access a variety of activity based social groups.

Arrange 1:1 appointments with staff for specialist advice/ support.

Receive a monthly newsletter keeping you up to date with our available services and one-off events.

Contact us

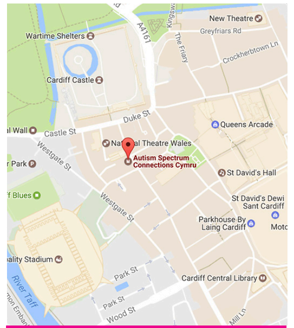
Autism Spectrum Connections Cymru

Registered Office
The One Stop Shop
21 High Street
Cardiff, CF10 1PT
info@asc-cymru.org
02920 228 794

www.asc-cymru.org

Twitter: @ASCCymru
Facebook: /ASCCymru

Charity No: 1158045 Company No: 08461023



> “For the first time in my life I have a sense of **hope** & feel positive for the **future**. 21 High Street’s support has been invaluable”
>
> Registered User

ascc
autism spectrum
connections cymru

> “There’s no other service like **yours** - without you we’d be lost”
>
> IAS Staff Member

> “Without you I don’t know what we would have done as a **family** - no one else we have spoken to has helped!”
>
> Parent

21 High Street

Offering tailored support for adults with autism in a safe, friendly and **non judgemental** space in the heart of Cardiff

Support for adults with autism

August Activities at 21 High Street

				WEDNESDAY 1 AUG	THURSDAY 2 AUG	FRIDAY 3 AUG
				Drop In 2pm - 7:30pm Social Drop In 6pm - 7:30pm	Benefits Drop in 12pm - 3pm Creative Writing 3pm-4:45pm	Supported Drp-In 11:30-1:30 Drop In 2pm-5:30pm D&D 4pm-5:45pm
SATURDAY 4 AUG	SUNDAY 5 AUG	MONDAY 6 AUG	TUESDAY 7 AUG	WEDNESDAY 8 AUG	THURSDAY 9 AUG	FRIDAY 10 AUG
		Job Club 1pm-4pm Drop In - 1:30pm-6:30pm Anime Society 5:30-6:45pm	Drop In - 1pm-5:30pm Creative Drop-in 1pm-4pm Pool Group 16:00 -17:30	Drop In 2pm - 5:30pm	Benefits Drop in 12pm - 3pm Creative Writing 3pm-4:45pm	Supported Drp-In 11:30-1:30 Drop In 2pm-5:30pm
SATURDAY 11 AUG	SUNDAY 12 AUG	MONDAY 13 AUG	TUESDAY 14 AUG	WEDNESDAY 15 AUG	THURSDAY 16 AUG	FRIDAY 17 AUG
		Job Club 1pm-4pm Drop In - 1:30pm-6:30pm CALM Drop In 2pm-4:30pm Gaming @21 High Street 5pm -7p	History Group 11am-1pm Drop In - 1pm-5:30pm Creative Drop-in 1pm-4pm	Drop In 2pm - 5:30pm	Creative Writing 3pm-4:45pm	Supported Drp-In 11:30-1:30 Drop In 2pm-5:30pm
SATURDAY 18 AUG	SUNDAY 19 AUG	MONDAY 20 AUG	TUESDAY 21 AUG	WEDNESDAY 22 AUG	THURSDAY 23 AUG	FRIDAY 24 AUG
		Drop In - 1:30pm-6:30pm	Drop In - 1pm-5:30pm	Drop In 2pm - 5:30pm	No Drop In Sessions	Drop In 2pm-5:30pm
SATURDAY 25 JULY	SUNDAY 26 JULY	MONDAY 27 JULY	TUESDAY 28 JULY	WEDNESDAY 29 JULY	THURSDAY 30 JULY	FRIDAY 31 JULY
		Bank Holiday 21 High Street Closed	No Drop In Sessions	No Drop In Sessions	No Drop In Sessions	No Drop In Sessions

RCGP
CYMRU
WALES
Royal College of
General Practitioners
Coleg Brenhinol
Meddygon Teulu

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 collected[1]. 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 1,926[2]. 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.

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[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.

A03
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Unigolyn
Response from an individual

I am writing to you in a personal capacity. My son, who is now 26, was diagnosed with autism at the age of 5. He then attended a local special school and currently lives with us in the family home. It might seem to a casual observer that an autism bill would be good news for my son and I but this is simply not true. I honestly feel that if you make this law it will be harmful to my son and the wider family.

Excerpt The autism strategy must—

(a) establish a best practice model or models for the—

(i) identification and diagnostic assessment of autism spectrum disorder;

(ii) assessment of the care and support needs of persons with autism spectrum disorder; and

(iii) planning for and meeting the care and support needs of persons with autism spectrum disorder;

(b) make provision for the development of a pathway, that includes access through defined points of referral, to map the services that are available and required for persons with autism spectrum disorder;

(c) provide for diagnostic assessments and any post-diagnostic meetings to be commenced as soon as reasonably practicable following a referral and at least within any timescales set out in the relevant Quality Standard issued by the National Institute for Health and Care Excellence (but this shall not prevent the provision of any other services prior to the commencement of a diagnostic assessment);

(d) make provision for individual diagnostic assessments to be conducted by a multidisciplinary team of professionals;

(e) provide for an assessment of care and support needs to be completed as soon as reasonably practicable and in any event within 42 working days of a diagnosis of autism spectrum disorder or any post-diagnostic meeting, whichever is the later;

(f) make provision to ensure that persons are not denied access to services on the grounds of IQ or receipt of services for other medical conditions;

(g) outline how the needs of persons with autism spectrum disorder are to be met by relevant bodies in respect of, but not limited to,—

(i) access to healthcare services;

(ii) access to education;

(iii) access to employment;

(iv) access to housing;

(v) access to Welsh language services;

(vi) access to services in other languages;

(vii) access to other public services;

(viii) social inclusion; and

(ix) access to advocacy services;

The autism bill as presented places a huge emphasis on diagnosis. I understand the reasons behind a Pembrokeshire AM placing this emphasis as there is a long standing local situation of parent's waiting an extended period for a diagnosis. Yes this should be addressed in Pembrokeshire but not at the expense of everything else. You can't make a national change in a misguided attempt to solve a local problem.

The Welsh Government formally adopted the Social Model of disability in 2002. The Social Model of Disability makes the important difference between 'impairment' and 'disability'. It recognises that people with impairments are disabled by the barriers that commonly exist in a society. In simple terms, it is not the inability to walk that prevents a person entering a building unaided but the existence of stairs that are inaccessible to a wheelchair-user. In other words, 'disability' is socially constructed. The Social Model of Disability requires society to remove the barriers in order that all people have equality. (Welsh Government, 2013) This return to diagnosis seems to drive a coach and horses through this long established policy and indicates a return to the archaic medical model.

Diagnosis is just one short moment in a person's life and by no means the most important. If it takes say 1 year to gain a diagnosis out of a 70 year life span how can such a disproportionate amount of resource be directed in that direction compared to more general assistance. In terms of adults the bill therefore has the potential to cause more harm than good. There are new services being set up that provide diagnosis for adults and then a range of activities etc after that event. The bill is seeking to reduce the diagnosis time to 3 months which is mind blowing. This could mean that a disproportionate amount of resource will have to be diverted to achieve this artificial target. Getting a diagnosis is good but a piece of paper from a doctor saying you have autism doesn't actually help you progress anywhere in life. My personal experience is that having a diagnosis has become less and less relevant to my son as the years have gone by. It's the people he has met along the way, the support assistants, the teachers the employment coaches they are the ones who've made the difference. He hasn't seen a clinician other than his GP in many years. Being able to access other things around employment or social opportunities these are actually helpful but if everything goes into diagnosis those things simply won't be there.

The bill goes on to assume that every person following a diagnosis should then be referred to social services for an assessment of need. Leaving aside the sheer folly of diverting that amount of clearly limited social worker resources to one specific group what on earth gives you right to say my son must be referred to social services. If his needs ever escalate to a point that he and we as a family can't cope we might consider social services but we have managed well for the last 20 years. He is very proud of every step he takes towards being an independent contributing member of our society. These steps may be small like learning to cook a meal or catch a train, but he makes them.

He does not need or want to be taken into care or institutionalised he just wants to live his life. What on earth does the writer of this bill think autistic people are like !! It indicates a horribly skewed view of people with autism. It even implies that despite his high IQ (a-levels and university maths) he must still need a care and support plan. Some people with autism do need a lot of help some, like my son a bit less and some really none at all. This cavalier assumption that the next step after a diagnosis is to get social services involved because such people simply can't cope is horribly insulting. It implies that people with autism are incapable of looking after themselves and perhaps should be shut away somewhere, I thought, hoped that society had moved on from such archaic notions.

The other major concern I have is the sheer volume of personal data the act thinks it is appropriate to collect. Would it just make it easier if I sewed a yellow star on his jacket !!! It is outrageous to think that this level of intrusion is appropriate. My son is an active contributing member of our society. Yes, he has a condition but he makes the best of his life as we all do. He volunteers for a charity and has recently begun actual work 3 mornings a week. It is ridiculous to think that it is OK just because he has a disability to gather data on him as if he is some kind of a lab specimen.

I urge you not to pass this bill

[redacted]

[redacted]

[redacted]

[redacted]

September 2018

Equality and Human Rights Commission response to the Health, Social Care and Sport Committee's consultation on the draft Autism (Wales) Bill

The Equality and Human Rights Commission welcomes the Health, Social Care and Sport Committee's consultation on the Autism (Wales) Bill.

The draft Bill presents opportunities for the further protection and promotion of equality and human rights in Wales. Therefore, we support the Bill's development and are keen to offer advice during its legislative process.

During Paul Davies AM's previous consultation on the Bill, the Commission welcomed the Bill's reference to 'protecting and promoting rights'. We called for this commitment to be reflected by the face of the Bill and any following guidance making direct reference to human rights, such as the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities.

It is welcome that the Bill has been amended to reflect our submission, with the Bill now placing a duty on Welsh Ministers and any relevant body exercising functions under the Act to have due regard to the UN Principles for Older Persons, the UN Convention on the Rights of Persons with Disabilities and the UN Convention on the Rights of the Child. The conventions provide clear principles to ensure people's human rights are at the forefront of service delivery. The Committee's may wish to consider further how the Bill can ensue the protection of human rights for autistic people in Wales.

It is important that during the Bill's development due consideration is given to the protected characteristics (as set out in the Equality Act 2010) of autistic people. For example, evidence shows that a person's age, disability status or race can have an impact on their access to services, with inequalities likely to be multiplied when a person has multiple protected characteristics.

In addition, the Bill should be taken forward with the Equality Act 2010 and its Public Sector Equality Duty (PSED) provisions in mind. This duty places responsibilities on public bodies to promote equality and tackle discrimination. The Bill includes opportunities for public bodies to take forward work relevant to these aims. It is important that the requirements of the draft Bill and the PSED complement each other. For example, this is likely to be relevant in terms of reporting requirements and the lists of bodies covered by the different legislation.

About the Equality and Human Rights Commission

The Equality and Human Rights Commission (the Commission) is a statutory body established under the Equality Act 2006. It operates independently to encourage equality and diversity, eliminate unlawful discrimination, and protect and promote human rights. It contributes to making and keeping Britain a fair society in which everyone, regardless of background, has an equal opportunity to fulfil their potential. The Commission enforces equality legislation on age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation. It encourages compliance with the Human Rights Act 1998 and is accredited by the UN as an 'A status' National Human Rights Institution. Find out more about the Commission's work at:www.equalityhumanrights.com.

A05
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Goleg Brenhinol Pediatreg a Iechyd Plant
Response from Royal College of Paediatrics and Child Health

RCPCH
Royal College of
Paediatrics and Child Health
Wales
Coleg Brenhinol
Pediatreg a Iechyd Plant
Cymru
Leading the way in Children's Health

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

RCPCH 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.

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[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.

A06
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Fwrdd Iechyd Prifysgol Hywel Dda
Response from Hywel Dda University Health Board

Response Form
Autism (Wales) Bill

	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;
1.	Comments:
1.1	This response should be read in conjunction with the Health Board's responses to earlier consultations. Whilst we strongly applaud the sentiments of this endeavour, we continue to have major reservations. We are grateful that the consultation was accompanied by the explanatory memorandum.
1.2	We remain not persuaded that a legal framework will act as a driving force to achieve the aspired outcomes. We are unaware of any robust evidence that the Autism England and Northern Ireland Acts have shown enhanced outcomes for autistic people. The explanatory memorandum does not cite any positive evidence acknowledging no apparent detrimental impacts. Some of our reservations are due to the principal of legislating for specific conditions leading to many potential unintended consequences (noted below in section 3).
1.3	There are no ready incentives or enforcers within the proposed structure of the bill, except for the data collection systems. Such systems would have to be significantly enhanced and empowered to drive and ensure compliance. Obviously such infrastructure would have its own internal costs. We question the ability to effect change without incentives and enforcement eg the limited to date impact of the ASD Employment Ambassador. As in an earlier Health Board response we continue to believe regulatory bodies including Estyn, HIW and CSSIW need to be explicitly mandated within any statutory instrument.
1.4	We welcome the honesty within the memorandum of recognising autistic people are receiving both effective and unfortunately ineffective interventions. The latter lead to lack of prudence in service provision with associated, potentially inappropriate financial consequences. However, we would suggest the modelling to date does not acknowledge the significant public attitude and service changes required to bring about the aspirations voiced within the bill.
1.5	There is no mention of the Mental Health Measure within the bill or explanatory document. The latter provides a potentially invaluable example of evaluating the impact of Welsh legislation on the population. Additionally, many autistic people will have been subject to the provisions of the act due to the high rates of mental health problems in autistic people. Experiencing emotional distress, development of behavioural issues and frank mental illness often leads to seeking a diagnosis across the lifespan. More sophisticated implementation of the measure could potentially enhance diagnosis assessment and interventions for autistic people without the need for additional legislation.
1.6	There is no recognition of the impact of the act in conjunction with the Mental Health Act (MHA England and Wales). The MHA is currently within a formal consultation stage and there has been much discussion about its impact for autistic people.

1.7	Singling out autism appears to oppose the long held political and social policy endeavours to reduce concepts of disability and difference. It could potentially hinder approaches to encourage inclusiveness and acceptability.
1.8	Whilst awareness and diagnosis are important issues, far greater is the need for skills in actually accepting and understanding different developmental and personality styles across the lifespan. If a Bill were to proceed it would need to reflect such fundamental aspirations and strategic vision including recognition of the significant changes needed in public attitudes as well as services.
1.9	We would support continuing observation of international and UK guidance; including the use of NICE standards, however, it should be noted that expert opinion indicates diagnostic processes need to be proportionate and competent. Unfortunately the bill appears to concentrate more on the identity of different professional groups and data collection. There is no mention of the requirement for different competencies and supervision structures. For example it would be unlikely if a multi-disciplinary autism team comprised of junior inexperienced practitioners, however broad the spread of specialities, could assess the full potential range of diagnostic and assessment challenges. Additionally there is also expert opinion that no single or combination of instruments equates to automatic valid and reliable diagnosis. Instruments are helpful in aiding clinicians to gain competencies and provide consistent assessments but do not automatically translate into valid and reliable assessments. Assessments are always reliant on the clinicians experience, judgement and interpretation.
1.10	Unfortunately autistic people are vulnerable to having a number of comorbid general and mental health conditions across the lifespan. The bill and memorandum fail to recognise the complexity of the assessment processes sometimes required. People with other neurodevelopmental conditions are similarly vulnerable to comorbidities, a consideration if the remit of the bill were broadened to cover these client groups.
	Any potential barriers to the implementation of the provisions and whether the Bill takes account of them;
2.	Comments:
2.1	We believe devolved educational structures need to be specifically included as relevant bodies. It is increasingly recognised skilled educational provision can ameliorate many of the disabilities associated with autism. Unfortunately, many of the comorbid social and emotional difficulties evolve during adolescence. Many autistic people do not achieve their potential educational attainment levels and particularly need the opportunities for skilled, adapted lifelong learning approaches. Additionally there is emerging evidence autistic people have an uneven pattern of abilities and impairments. Educational opportunities need to be strategically planned to acknowledge these differences.
2.2	Recent years has seen the development in West Wales of a multi-agency board to implement the Integrated Autism Service. Unfortunately there is no mention in either the bill or the memorandum of the need for integrated strategic, operational and financial arrangements. Whilst local developments are encouraging we are aware of the fragility of such structures, especially to effect change.
2.3	

	In common with other rural areas, we have difficulties in recruiting staff to professional groups, such recruitment difficulties could act as powerful barriers to implantation.
2.4	We appreciate the arrangements for professional training are not a devolved issue, however, we would suggest that without such approaches it will be difficult to bring about the changes required in this bill; and the already established autism acts/strategies in the other UK countries. We would respectfully suggest that this area is more formally explored at a strategic level between the UK Governments. We are aware there are already endeavours in the Royal College of Psychiatrists to change the training curriculum to reflect the need for enhanced competencies in neurodevelopmental conditions, including autism.
2.5	The Health Board welcomes the targeted funding of services for children via the Together for Children and Young People Neurodevelopmental Programme and the Integrated Autism Service. However these initiatives have been associated with the funding of mainly staffing costs. Identification plus funding of staff bases and clinical settings are not included leading to challenges in new service development. Similar possible barriers to enhanced neurodevelopmental services could arise if further funding only concentrated on direct staffing costs without acknowledging the demands of vital infrastructure.
	Whether there are any unintended consequences arising from the Bill;
3.	Comments:
3.1	We would like to echo previous comments about the risks of a service based on a diagnostic category rather than proactive prevention of disability and meeting assessed need. The bill could result in pressures to under diagnose to act as a mechanism for rationing services and financial responsibilities. Over diagnosis could arise as a result of trying to obtain service especially in the current climate of constraints. There are real risks of services and resources being allocated disproportionately according to diagnosis rather than need. Additionally there are risks of sequential appeals and reassessments with associated distressing consequences for individuals and diversion of precious resources
3.2	From its innovative beginning Welsh Government's strategic approaches to autism have promoted awareness and enhancing adaptions so autistic people develop fewer disabilities. These sentiments are totally in line with Wales' long standing stance trying to reduce the stigma and marginalisation of people with neurodevelopmental conditions including people with learning disabilities. Initiatives have always aimed to improve access to universal services as well as providing specialist services for those not able to have their needs successfully met even with significant adaptions. Whilst sometimes slow, there have been advances in universal services' competencies in supporting autistic people. Promoting single diagnosis specific teams can lead to halting of such developments if not carefully managed. The explanatory memorandum concentrates on direct diagnostic work without the balance of trying to ensure that enhanced diagnosis is also offered within generic services e.g. community mental health teams, in-patient psychiatric units, specialist learning disability services, educational and student support services, primary care.
3.3	In the Hywel Dda area we are attempting to promote the above approaches of both offering direct services and enhancing competencies within generic services. Such duality of direct and indirect service approaches is also integral to WG's new Integrated Autism Services – due for

local implementation in 2018. We are aware significant energies are needed to prevent silo formation.

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

4. Comments:

4.1 We welcome that some financial modelling has occurred, but there is no mention of forming integrated commissioning, contracting or other financial arrangements.

4.2 We would suggest further financial modelling would be enhanced by recognising the autistic people currently within specialist education, mental health and elderly care.

4.3 West Wales has had a history of long waiting lists for neurodevelopmental disorders. When the new Health Board ASD service model commenced in November 2015, the service acquired a historic waiting list of 633 people waiting for an assessment with some waiting over 5 years. Alongside this, the ASD Service received 373 referrals since November 2015, giving a challenge of 1006 referrals in total waiting for an assessment.

In April 2017 the Welsh Assembly introduced a new 26 week performance target for Neurodevelopmental Disorders and Health Boards are expected to reach 80% compliance against this target. To date, we have received 438 new referrals since April 2017. The new 26 week Welsh Government Performance Target is set at measuring the time from when a referral is received by the ASD Team to the first face to face assessment. There have been significant improvements in ASD waiting times for children and young people and the current waiting lists report the following:

ASD	Jan-18	Feb-18	Mar-18	Apr-18	May-18	Jun-18
Patients waiting >26 Weeks	263	256	249	222	198	191

For children Welsh Government has supported via the Together for Children and Young People's Neurodevelopmental Programme initiatives which are broader than a single diagnosis via recurrent funding. For example since 2015, the small multidisciplinary Neurodevelopmental team has assessed over a 1000 referrals for ASD and thus has made significant progress in reducing the historic waiting list. Additional recent funding from IAS has enabled us to prioritise the historic waiting list and young people approaching transitional age.

We have had a small adult Autism Diagnostic Service for over 5 years. The Health Board elected to retain the service originally formed from the All Wales Adult Network. The service consists of 1 WTE practitioner and 0.4 WTE Consultant Psychiatrist. Our current pattern of adult referral includes a monthly average of 20 referrals over the first 2 quarters of 2018. Over the five years in which the Adult diagnostic service has been operational the monthly average referrals per year has consistently increased. Our waiting time from referral to the start of assessment is currently fourteen months. This includes a waiting list initiative over the past 6 months. The new Integrated Autism Service (IAS) is due to become operational locally

	in early 2019 with recent recruitment of key personnel. The IAS should allow greater capacity for adult ASD diagnosis but we would predict as with other IAS teams across Wales we will experience even greater demand and have accompanying lists. To enhance diagnostic provision would require increased revenue and recruitment of skilled personnel across all age groups.
	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.	Comments: We respectfully suggest this section is considered in conjunction with the above, especially section 1.
5.1	There is increasing recognition and actual diagnosis of neurodevelopmental conditions across the lifespan. Factors influencing this development include greater recognition, changes in diagnostic classification systems and genuine increases in prevalence; the latter is associated with advances in clinical genetics, increased survival of premature and very sick babies, and the increasing survival rates for people with neurodevelopmental disorders. Additionally conditions such as schizophrenia and personality disorder are being recognised as having a neurodevelopmental trajectory. In summary an increasing proportion of the population could become eligible for the rights within the bill. There would be inevitable pressure to include more categories if associated with prioritisation and rights to service
5.2	People with neurodevelopmental conditions including autism are at higher risk of mental health conditions. If implemented the Bill would potentially prioritise some of their clinical journey in comparison with other service users. If they were being assessed for an autism diagnosis it would not be professionally and ethically appropriate to ignore comorbid conditions. People with neurodevelopmental disorders are increasingly recognised as also having a number of physical health conditions as an integral part of the disorders eg joint problems. Inevitably such conditions would be recognised within any diagnosis and assessment framework for neurodevelopmental conditions. Thus a Bill could influence the pattern of all universal health services to allow prioritisation according to diagnosis and not based on clinical acuity and need. We would suggest energies would be better used enhancing the competency and efficacy of universal services in including people with neurodevelopmental conditions and more ably recognise the heightened morbidity associated with these conditions; this needs to include public health and wellbeing preventative as well as reactive approaches.
	References

A07

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Gonffederasiwn GIG Cymru

Response from Welsh NHS Confederation

	The Welsh NHS Confederation written response to the Health, Social Care and Sport Committee's scrutiny of the Autism (Wales) Bill.
Contact:	[redacted] [redacted], Policy and Public Affairs Manager, Welsh NHS Confederation [redacted] [redacted], Policy and Research Officer, Welsh NHS Confederation [redacted]
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 Report[i] 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 report[iii] 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.

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[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.asdinfowales.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

[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.

A08

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales)Bill

Ymateb gan Gwasanaeth Awtistiaeth Integredig Gwent

Response from Gwent Integrated Autism Service

[redacted]

[redacted]

To Whom It May Concern

Re: Consultation on the Autism Bill

It is the view of the Gwent Integrated Autism Service that this additional legislation is not required and will in fact, adversely impact on the delivery of service development and the provision of support services. In fact the Autism Bill has the potential to do harm.

There is already an Autism Strategy in place. This Strategy is well under way in terms of implementation and achieving change, in time this will result in improved quality of lives for those individuals with ASD. The Integrated Autism Service has now been operational in the Aneurin Bevan Health Board area for just under 12 months and has made significant progress, recognising that service development, achieving best practice etc. take time. No further legislation or policy needs to 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 Service should be given time to establish and embed new Pathways etc. There are a number of key issues and concerns with the proposed legislation:

1. There are considerable difficulties of achieving a target of completing a diagnostic assessment within 13 week from referral. We are unclear why a 13 week timescale has been proposed, it is not in accordance with any other standards for work to commence let alone be completed. As an established services, which launched in September 2017 we now have 196 Individuals on a waiting list for diagnosis, which is currently resulting in a 12 month waiting list. We have received 100 appropriate referrals this financial year alone. We have been piloting alternative approaches to diagnostic clinics (still adhering to NICE guidelines and agreed national minimum standards through the Community of Practice), we are therefore confident that we can increase the number of diagnostic clinics going forward. However, best case scenario is that we 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, we are currently receiving referrals on a weekly basis at a higher rate than we have capacity to meet. If we cleared the waiting list we may just be able to maintain a waiting list of 13 weeks, utilising the

majority of our funding to do so. We only have 3 full time equivalent diagnosing clinicians so support staff would need to replaced with qualified clinicians to make this possible.

2. To reduce the current waiting list we anticipate the costs for meeting a 13 week to completion target would be an additional one off amount of £352,800. These are additional fees on top of the current costs. (An assessment at the Dyscovery Centre is £1800 per person Presently there is little evidence as to demand 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 number of diagnostic assessments that they undertake.

3. 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 our capacity to offer any ongoing support post diagnosis. To meet a 13 week target would require, for example in Gwent, a serious reduction in our 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 post diagnostically, other than a post diagnostic appointment, drop in sessions on a monthly basis and a post diagnostic six week course. It would be impossible to resource a keyworker for anyone with ASD let alone everyone with ASD, as the NICE Quality Standards recommend.

4. 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 Clinicians gift.

5. There is also a clear flaw in the proposals. Currently, whilst we have a significant waiting list for diagnosis, individuals are (in the majority of cases) given the diagnosis the same day the assessment is completed. At present only around 10% of individuals do not receive this, usually because a 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 counselling appointment and/or information gathering through the use of structured self-reports or observations from other professionals. So, whilst the timescale of starting the

[redacted]

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assessment will be met, in reality, the conclusion of the process and confirmation of diagnosis will still be 12 months in the Gwent area. We 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. In Gwent we have received very positive feedback in relation to our 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 I we have to meet a 13 week target, then this quality will be compromised.

6. The establish 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

7. 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.

8. 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, we have already provided training courses to mental health teams, DWP, Supported Housing Providers etc. We have joint worked around 10 cases with mental health services. We 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.

[redacted]

[redacted]

9. 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.

10. 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.

11. 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.

Please also find attached an anonymised response we have received from an autistic adult who has accesses our services. This response was received as part of our service evaluation process. The individual has given consent for us to share this as part of our response the Autism Bill.

Yours faithfully

[redacted]
Aneurin Bevan University Health Board

A10

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Gyngor Tref y Bari

Response from Barry Town Council

Members of Barry Town Council have considered the various consultations that have been presented over the past 12 months in relation to the introduction of an Autism (Wales) Bill and have supported the introduction of the Bill.

They have now considered the Autism (Wales) Bill that was published in July 2018 and asked that I forward their comments on that “Barry Town Council continue to support the Bill and would refer you to any previous comments on the consultations provided previously.”

[redacted]

[redacted]

[redacted] [redacted]

Response from Cwm Taf University Health Board, collated by:

[redacted], Head of Planning, Children, Young People and Families.

Overview

There has been significant progress made locally, regionally and nationally across Wales since the original ASD action plan in 2008, with one of the key achievements being the increased profile and awareness of autism in Wales, as well as many others.

Through working collectively with the National ASD development team, we have seen significant developments in the wide range of information and resources available to help autistic people and their families and carers, as well as resources for professionals.

From initial consideration of the proposed Bill, it is clear that any new legislation should and need to add value to individuals, families, carers and professionals alike. It is not clear how in regard to what is proposed how specific improvements will be made without the broader consideration of the national action plans being worked to along with other key legislation currently being implemented and or drafted.

Wales currently has a refreshed Autistic Spectrum Disorder Strategic Action Plan Wales (ASD SAP), which was first published in 2008 and revised in 2016. This has led to significant investment into services for people with ASC from Welsh Government. The work to create a national IAS, in addition to the revised ASD SAP and local action plan is delivering the outcomes that an Autism (Wales) Bill would promote. Regional Partnership Boards across Wales have shown commitment and resources to drive forward improvement and change for individuals with Autism and some areas have already invested core funding to improve service development. The IAS and the ASD SAP provide the guidance and direction to underpin requirements

Further legislation would be costly – potentially using resources that could directly benefit people with ASDs in other ways, time consuming and bureaucratic with emphasis on legal requirements and tribunals. This approach would be unlikely to offer additional benefits not offered by the current ASD SAP. This could affect services by impacting their input to deliver direct care and support, with the potential requirements of new legislation reducing the creativity to develop services based on needs.

As a UHB and region we have previously responded to the consultations on the general concept of a proposed Autism (Wales) Bill and on the draft Autism (Wales) Bill in which we highlighted our fundamental concerns about the approach of creating separate legislation for a particular condition. We believe that legislation such as the Social Services and Well-being (Wales) Act, the Additional Learning Needs and Education Tribunal (Wales) Act and the Equality Act 2010 should, if they are working correctly, deliver for all on the basis of need.

We are therefore not supportive of the need for an Autism (Wales) Bill. We believe that placing a specific autism strategy in statute risks distributing resources inequitably. As a UHB we have a duty to ensure we consider the need of all individuals referred to us for assessment, diagnosis and ongoing intervention and support in line with all other statutorily responsibilities expected of our services jointly with our partners.

Serious consideration also needs to be given to the implications of setting such a precedent going forward, as services for autistic people is not the only area where there is a need for service improvement for people with specific and associated conditions. It is essential that we fully identify and consider any unintended consequences of legislating on a particular condition, and that we explore any risk that such legislation may impact on our ability to respond to others on the basis of need.

In particular, the Social Services and Well-being (Wales) Act already places a duty on both health boards and social services to assess the needs for care and support services in their areas and identify the range and level of services required to meet them, the Additional learning Needs Bill also reinforces these expectations jointly across both health organisation's and education authorities. In addition, the Social Services and Well-being (Wales) Act also places a statutory duty on local public sector services to establish information, advice and assistance services, including to people with autism spectrum conditions, their families and carers.

As referenced earlier, we have reservations about the approach of legislating for a particular condition, as we believe that legislation such as the Social Services and Well-being (Wales) Act 2014 and the ALN Bill, The Well-Being and Future Generations (Wales) Act currently going through the Assembly should, if they are working correctly, deliver for all our citizens on the basis of need. Consideration also needs to be given to the implications of setting such a precedent going forward, as services for people with autism is not the only area where there is a need for service improvement and as UHB's we would struggle to ensure that only priority is only given to this area of need specifically within the requirements of such a Bill when responding to other aspects of legislative guidance and statutory responsibility as outlined within this response.

The Act in England was a useful force to drive development of a strategy for implementation and was helpful for clinicians to 'persuade' commissioners of the gaps and the need to fund services.

However, it seems that we are now beyond this point in Wales and it would be an unnecessary use of public funds. Services now need time and buy-in from partnership organisations in order to be able to deliver with an emphasis on a national agreement and quality standards to address delivery of services across Wales. This would require solid partnership working and cross-departmental government support, there would need to be a mechanism to achieve this to achieve status and prioritisation given austerity.

Legislation is a slow and costly process, applying too much detail could slow it down further and the strategy detail would soon become obsolete rather than being able to change over time in response to the work that is being done and the experience of people with ASC. It would potentially also remove the mechanisms for engagement in the details of adopting and updating an autism strategy. There are critical interfaces with developmental trauma, ADHD, learning disability, specific learning difficulties and so forth that any ASD specific legislation could ignore to the detriment of our population. Autism legislation is too specific, it immediately creates inequity, and we need to ensure strong linkages with neuro-developmental disorders more widely as opposed to only concentrating on the needs of individuals on the spectrum. Many families may express frustration at services if an autism diagnosis is not achieved, due to a perception that a diagnosis of autism will offer the suggested benefits of ASC specific services. This would lead to a perverse incentive to apply this diagnosis when in reality a broader description and a variety of approaches may be more constructive.

If an Autism (Wales) Bill were passed, the detail would need to be similar to that within the Social Services and Well Being Act, Prudent Health Care and the ALN Bill and The Well-Being and Future Generations (Wales) Act, which have strength in being inclusive and based on need, given the inextricable links for citizens across existing legislation. Should the content require more detail, then the advice of specialist professionals within the field must be sought to provide a robust clear set of guidelines that will stand the test of time as developments in assessment, treatment and interventions emerge within the field of ASC and other neurodevelopmental conditions.

Comments on the proposed Bill

Below we highlight some specific comments related to the Bill as currently drafted outlining some specific areas of concern we wish to share for wider consideration:

Autism Strategy

Under 2(1)(a) the Bill identifies that the Autism Strategy must establish a best practice model or models. It seems far too restrictive to prescribe the models that must be established, it may be better to highlight pathways rather than models.

Under 2(1)(c) the Bill requires diagnostic assessments be commenced as soon as reasonably practicable following a referral, and at least within any timescales set out in the relevant Quality Standard issued by NICE (currently 13 weeks). The current Welsh Government guidance, setting a 6 month (26 week) target would cause significant lack of clarity over expectations for those with assessment and diagnostic responsibilities. Whilst it is not ideal to not have any timescales, in reality, the current blanket 26 weeks' target does not reflect the complexity of many referrals, with a 13-week timescale further challenging this and not reflecting the length of time required to undertake what are often complex assessments.

2(1)(g) identifies that the autism strategy must outline how the needs of persons with ASD are to be met by relevant bodies in respect of, but not limited to: access to healthcare services; access to education; access to employment; access to housing; access to Welsh language services; access to services in other languages; access to other public services; social inclusion; and access to advocacy services. Some of these areas are far too general, for example how will access to employment, or access to public services be covered in any meaningful way? This is not clear and would require further consideration and consideration to the ALN Bill and the expectations being outlined here.

As a UHB we wish to work in an integrated manner with partners in support of any guidance and or legislation that is put to challenge and focus our attention's on meeting the needs and improving services locally. However we feel that there is suitable and appropriate legislation and guidance already in place to push us in the right direction and challenge our vision to improve early intervention and prevention as well as timely assessment, diagnosis and support.

However as a UHB we have a collective responsibility to all children, young people adult individuals and their families with any form of additional learning and or support needs and wish to be able to ensure we prioritise our service according to the need of all.

A12
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Ludlow Street Healthcare
Response from Ludlow Street Healthcare

Welsh Autism Bill

Consultation Response 12/09/2018

Reviewing Team

- Ludlow Street Healthcare is a provider of services for people with complex Autism Spectrum and Asperger's conditions in Wales, specifically:
  - Beechwood College in Sully; an educational facility offering residential and day services for young adults between 16 and 25
  - Ocean Community Services; providing transition and longer-term care in small residential community-based units
- Our clinical and educational MDT teams have reviewed the draft Bill and the following is a summary of their comments.

Section 2

- How will the Welsh Autism Bill link with the ALN Act, and how will they work together to enhance the provision for children and adults in Wales? In terms of assessment and support, how will these provisions link into the Individual Development Plans?
- When mapping services, how will independent providers be integrated into the service network? What consideration will be built into the service selection process for parental choice?
- What are the rights of the young person and/or families in terms of processes of appeal if they disagree with diagnosis and recognition of any independent assessments gained?
- How will the Bill ensure all services involved with diagnosis are aligned? Who will have input into the diagnosis process (e.g. families, residential care settings, education providers etc), and will all parties involved with the service user be able

to contribute? How will the Bill ensure that everyone who accesses support services are provided for appropriately and at the level needed?

Section 2

- Ensuring the continuity of service in the child to adult transition is imperative. The Bill needs to ensure ALN and education funding changes with funding responsibility moving from central government to local authorities is fully considered and appropriate management protocols included. Will the Bill allow for service provision outside of the local offer and area?
- Education provision – does this include independent providers and post compulsory education?
- How can service providers expect to access support from the bodies outlined in 2.1g – e.g Welsh language resources and services?

- Continuity of service from child to adult- imperative that this is clear especially in regard to changes within ALN and education funding moving from central government to local authorities. Will they look outside of local offer and area.
- In relation to training for professionals, what process will there be for independent providers to ensure they have sufficient training?

Section 6

- In regard to data collation – how will independent providers be required to submit data and what data rules will they need to comply with?
- Will the data requirements only cover Welsh people accessing Welsh services, or will the data requirements included English people accessing Welsh services and Welsh people accessing English services?

General Comments

- The general principles of the Bill are good, but it is important that the Bill covers the full range of services available such as independent providers in order to provide a comprehensive approach to Autism service provision.
- The Bill also needs to ensure the rights of service users and their parents/ families to be involved in their service choices are recognised and protected.
- Full consideration is needed for how the Autism Bill will link with the ALN Act and targets/ provisions outlined for young people through IDP provision.
- A current failing of the existing service provision is a lack of integration between service commissioners and service providers; including recommendations for inter-agency communication improvements would strengthen the identification of the most successful solutions for service users.

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Gymdeithas Genedlaethol Awtistiaeth Cymru
Response from The National Autistic Society Cymru

The National Autistic Society Cymru
Cymdeithas Genedlaethol Awtistiaeth Cymru

Response to the Autism (Wales) Bill consultation by the National Autistic Society Cymru September 2018

Introduction

We welcome the publication of the Autism (Wales) Bill and fully support the need for specific autism legislation in Wales.

Wales has had an Autism Action Plan for ten years now and yet autistic people and their families are still being let down and not having their needs met. Autistic people in Wales continue to experience poor outcomes and it's not right that this continues. For example:

- In a report we published in 2011, some 58 per cent of respondents said they'd waited too long for a diagnosis. In a similar report published in 2016 the figure had risen to 63 per cent.
- In 2011, some 53 per cent of respondents said that getting a diagnosis was stressful. In 2016 that figure was 56 per cent.
- In 2011, some 24 per cent of respondents said that they were satisfied that the information given to them afterwards helped them get the support they needed. In 2016 that figure was 21 per cent.

It's time to ensure that key changes that will make a tangible difference in the lives of autistic people are made mandatory so that public services don't view them as 'nice to haves'. This would include training for professionals, ensuring that data is collected, and support is available wherever people live in Wales.

We believe that if passed, this Bill will show real leadership by the National Assembly for Wales and the Welsh Government. It could send a clear message to autistic people as well as public bodies in Wales that autism is a policy priority in Wales. This legislation is about giving autistic people a level playing field and getting the basic things right.

We were pleased to have contributed to the previous two consultations – both on the development of the content of the Bill and the subsequent draft Bill. This included holding a number of focus groups across the country with our members and supporters, many of whom are autistic adults themselves. The vast majority of those who took part in focus groups and who engaged in the consultation process supported autism legislation. In a report that we published in 2016, nearly 90 per cent of those who responded to our survey said that autism legislation is needed.

Meeting the needs of autistic people

We are pleased that the Bill covers both children and adults as autism is a lifelong disability. In our view the Bill is further strengthened by specifically mentioning the need to provide help during the transition between childhood into adulthood which should help ease the move between children's services and adult services.

The original Action Plan recognised the need for early diagnosis and further actions to improve waiting times through neurodevelopmental teams where announced in 2015. The refreshed action plan that was published in November 2016 introduced a new 26 week waiting time from referral to first assessment for children and young people.

However, we know that this isn't being met across Wales. According to the Hywel Dda Health Board the waiting time from referral to first assessment for the neurodevelopmental team in May 2018 was 18 months. Anecdotally, parents in Pembrokeshire in particular have told us that the actual waiting time is much longer. Furthermore one of the recommendations of the Children, Young People and Education Committee's 'Mind Over Matter' report published earlier this year was that 'the Welsh Government develop an immediate recovery plan for neurodevelopmental services in Betsi Cadwaladr to address unacceptably long waiting times faced by over a thousand children and young people.' Relevant data for the neurodevelopmental teams in the five other Health Boards is not currently available and so we do not know if the needs of autistic children and young people are being met. This is despite a commitment in the refreshed Action Plan that Health Boards should report a 26 week waiting time from referral to assessment by March 2017.

We know that getting a diagnosis can be the key that unlocks support and services for autistic people and welcome the proposal to link to the relevant Quality Standard issued by the National Institute for Health and Care Excellence (NICE). We welcome the inclusion in the Bill of the need to ensure that support is in place regardless of whether a person has a diagnosis, and that support should include wider family.

We therefore welcome the certainty in the proposed legislation gives around the diagnosis process in its entirety.

We welcome the fact that the Bill seeks to address the wider needs of autistic people including support around meeting employment and housing needs. More than half (55 per cent) of autistic people who responded to our 2016 survey said that they'd like more support around employment and only one in ten were in full time paid employment.

Recent development in services to address the needs of autistic children and adults are welcome, particularly the creation of Integrated Autism Services in each Health Board region. These teams are best placed to deliver many of the provisions contained in the Bill and therefore the legislation supports the role of these new services and is designed, we feel, to help ensure they can become embedded in local health and care services. We feel that this would be better than the Integrated Autism Service having to be reliant on short-term funding up until 2021.

Similarly, while some good work has been done in the development of awareness resources and training, uptake in accessing these has in our view been too slow and is inconsistent across the country. For example, not all local authorities are taking up the 'Learning with Autism' programme for schools. And since the scheme was extended in September 2017, only three secondary schools have achieved the 'Learning with Autism Award.'

We believe that legislation should clearly set out which professionals need what levels of training to ensure that autistic people are supported by professionals who understand them.

Current initiatives recognise the importance of collecting the necessary data to plan future support and services. For example there is a requirement on Regional Partnership Boards to include autism and learning disabilities as a key theme in regional plans. However, this is difficult as very little data on autism is collected in practice and existing plans focus heavily on learning disabilities. Making the data collection mandatory through legislation will make sure that services understand that this is not just a nice to have and give strength to the hand of Regional Partnership Boards and other public services to ask for the data.

In our view, one opportunity in this legislation in ensuring that autistic people's needs are met is by offering an opportunity to embed the necessary training for relevant professionals while obtaining their initial professional qualification and through subsequent continuous professional development. The aim here is not to make things more onerous or difficult for professionals but to provide them with support and clarity, for example, through access to the right training for the right professionals. Professionals we talk to say they want this training and autistic children and adults should at the very minimum expect to be supported by professionals who understand them.

Protecting and promoting the rights of autistic people

As stated on the face of the Bill, this legislation makes provision for meeting the needs of children and adults with autism spectrum disorder in Wales and protecting and promoting their rights. This is consistent with the social model of disability. We believe that this will ensure that societal barriers faced by autistic people are removed. Training and the awareness campaigns are examples of this and we welcome the inclusion of both of these elements in the Bill. Similarly, the Bill makes provision in relation to social issues such as housing and employment. We welcome the ambition in the Bill to look at an autistic person in a holistic way throughout their lifetime as well as the needs of their families and careers.

We note the specific reference in the Bill to have regard to the UN Principles and Conventions. This would bring this piece of legislation in line with the duties on co-existing legislation including most recently the Social Services and Wellbeing Act, and the Additional Learning Needs Act.

We welcome the ambition in the legislation to enable autistic people to live as independently as possible through ensuring that relevant bodies ensure the rights of autistic people to access the provisions listed in section 2 (1) (g). While the list is not limited we particularly welcome the inclusion of social inclusion.

We know from our own research that one of the main barriers facing autistic people in particular is social isolation. For example, nearly four of every five autistic people (79 per cent) who responded to one our surveys said that they felt socially isolated.

We also note the specific mention in the Bill that autistic people should be able to access Welsh Language Services. This combined with the Welsh Government's Active Offer framework strengthens the rights of autistic people to access services in the language they choose.

Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. This Bill will ensure that where autistic people don't fit into current existing structures, local services will be under a duty to make sure there is a pathway for them to get the support they are entitled to, helping create a level playing field for autistic children and adults. Furthermore we welcome the explicit duty in the Bill that adults with autism cannot be denied access to services because of their IQ. This will make it clear to services that the needs of autistic people across the spectrum need to be identified and met.

We recognise that the Bill links to the WHO definition of autism and NICE guidelines and Quality Standards. This means that if and when our understanding of autism improves and develops, any changes made to the WHO definition or NICE guidelines will be reflected in the interpretation of the Bill, and its subsequent guidance and we welcome its inclusion.

We are also pleased that the Bill requires an independent report on the autism strategy, including its ongoing implementation and progress. Furthermore we particularly welcome the requirement to reflect on recommendations made by the independent review. Although the Welsh Government's Action Plan has been evaluated, recommendations have not always been taken on board or implemented in the development of support. This means that many of the issues autistic people face now are exactly the same as they were when the original action plan was first developed in 2008 and which this Bill seeks to address. Examples include getting a timely diagnosis, collecting data for planning services, raising awareness, and training for practitioners.

Barriers and unintended consequences

The Bill is clear that a diagnosis shouldn't prevent support from being made available either for the autistic person themselves or their families and carers, from the point at which their needs first become apparent. Support should be available regardless of a diagnosis.

As currently written, the Bill says that the waiting time from which a referral for diagnostic assessment of autism is made and an initial diagnostic appointment should be no longer than 13 weeks. This is in line with NICE guidelines and has been developed by experts, including clinicians and commissioners, as well as autistic people, and their families.

Welsh Government already base many of their guidelines for autism provision on NICE standards, such as the use of multi-disciplinary teams. This suggests that they are already content with the NICE evidence base. This Bill seeks to ensure full compliance with the NICE recommended timeframe.

This isn't about taking up resources to focus only on diagnosis at the risk of not being able to provide other pre and post diagnostic support. The Bill is clear that a diagnosis shouldn't prevent support from being made available either for the autistic person themselves or their families and carers, from the point at which their needs first become apparent. Support should be available regardless of a diagnosis.

The Welsh Government has had an autism Action Plan in place for the past ten years. There is no evidence to suggest that these provisions have privileged autism above other conditions or are responsible for demands for other condition-specific policy.

Autism legislation already exists in Northern Ireland and in England. There have been specific challenges in implementing the Northern Ireland Act and the suspension of the Assembly and wider political issues have also had an impact on the legislation. In addition, the Act hasn't made as much impact as we would have liked because it didn't result in legally binding duties for local delivery bodies in the same way as the England Act.

Where the England Act has made significant impact has been around making sure that there is a pathway to diagnosis in every area. In 2016, a survey of local authorities found that only three local authorities reported not having an adult diagnostic pathway. This simply wasn't the case before the Act and one of the reasons we argued for it.

Before the Act, our autism services directory could only identify 14 NHS teams/individuals who diagnosed adults in the whole of England. There is also clearer 'infrastructure' at local level in terms of local leadership and local planning, including an autism lead in more than 90 per cent of local authorities.

It is also important to remember that we are not suggesting taking the England Act and the Northern Ireland Act and implementing them in Wales. From the Northern Ireland Act, we learn that we need clear duties on local public services to deliver. In terms of the England Act we want to make sure that the Wales Act is all ages.

Notably, despite the England and NI Act being in force since 2009 and 2011 respectively, there hasn't been a recognised link between this and campaigns for other condition-specific legislation.

As mentioned above we welcome the proposal in the legislation to address the barriers facing autistic adults in accessing services because of their IQ.

Financial implications

The Explanatory Memorandum is clear in where costs would occur. A net initial cost of around £7million is estimated. However, this needs to be measured against the cost effectiveness of current provision, resource and policy. It is also anticipated that there will be longer term savings due to the effective identification and support of individuals with autism.

The Explanatory Memorandum also states that 'There is little information in the public domain to estimate the current provision and future plans with regard to both the administrative costs of providing services to people with ASD… The Welsh Government was unable to provide specific information regarding the cost of the status quo.' It's therefore difficult to estimate the current costs of provision in its entirety due to a lack of reliable data, which is something the Bill seeks to address.

While we recognise that there will be some cost involved in introducing and implementing legislation, we believe that introducing autism legislation will not result in significant burdens. This must also be balanced against the cost of not intervening and the economic impact of having to access acute services.

Economic modelling in England by the National Audit Office showed that identifying and supporting a relatively small number of autistic adults would bring about significant cost savings to the public purse. In their model, they suggested that if just a 14 per cent of the autistic adult population were identified and supported, the savings that could be made would be £5,000 per 1,000 working age population. In Wales, this could mean that a 14 per cent identification and support rate would save £10 million a year to the public purse in Wales. These figures from the NAO are from 2009 and need refreshing and updating for a Welsh context, but do indicate that significant savings can be made from the proper identification and support for autistic adults.

Subordinate legislation

We are content with the affirmative procedures to make subordinate legislation in the three areas listed in Part 2 of the Explanatory Memorandum.

Conclusion

As mentioned above, 10 years of the autism Action Plan hasn't achieved the necessary changes to the lives of autistic people in Wales. We believe that changes that will make a tangible difference are mandatory. Legislation is supported by our members and supporters and the overwhelming majority of the hundreds of responses to both the consultation on both the development and the draft autism bill. The Bill has therefore been shaped by autistic people who will be directly affected by it. We believe that legislation will give autism support parity with other existing support provided to those with learning disabilities and mental health, whilst ensuring better outcomes for autistic children and adults.

In drafting our comments we have done so based on the experience of learning from what works and what hasn't worked so well in other countries that have implemented autism-specific legislation. It's also important to note that this is a Wales bill and should be fit for purpose for the benefits of autistic people in Wales.

A14
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales)Bill
Ymateb gan Goleg Brenhinol Therapyddion Iaith a Lleferydd
Response from Royal College of Speech and Language Therapists

COLEG BRENHINOL THERAPYDDION IAITH A LLEFERYDD
ROYAL COLLEGE OF SPEECH & LANGUAGE THERAPISTS

National Assembly for Wales Health, Social Care and Sport Committee consultation on the general principles of the Autism (Wales) Bill

Executive Summary

- The Royal College of Speech and Language Therapists (RCSLT) Wales welcomes the opportunity to comment on the proposed Autism (Wales) Bill. We have developed our response in consultation with our members who advise on, manage and deliver autism services.
- RCSLT Wales is fully committed to improving outcomes for people with Autism Spectrum Disorder (ASD). The question is whether the proposed bill and whether primary legislation is the most appropriate vehicle to achieve change.
- In scrutinising the proposed legislation, we believe it would be helpful for the committee to consider four main areas, namely:

  - whether the proposed bill could drive a focus on diagnosis rather than need
  - current new developments in relation to ASD services such as the Additional Learning Needs and Educational Tribunal (Wales) Act, the integrated autism service and timeliness of the proposed legislation
  - the potential implications of introducing condition-specific legislation
  - learning from other nations where autism-specific legislation has been enacted.

- We also wish to draw to the attention of the committee the briefings on the bill which we produced jointly with the **Welsh NHS Confederation**, **the Royal College of Psychiatrists, Royal College of Paediatrics and Child Health (RCPCH), and the Royal College of Occupational Therapists (RCOT).**

About the Royal College of Speech and Language Therapists

1. RCSLT is the professional body for speech and language therapists, SLT students and support workers working in the UK. The RCSLT has 17,500 members (650 in Wales) representing approximately 95% of SLTs working in the UK (who are registered with the Health & Care Professions Council). We promote excellence in practice and influence health, education, care and justice policies.

2. Speech and Language Therapists (SLTs) are integral members of the multi-agency teams that provide support to children and adults with ASD and their families and carers. SLTs have a unique role in identifying the social communication characteristics of importance to diagnosis, contributing to differential diagnosis and facilitating identification of retained abilities and co-morbidities. They also have a key role in educating/training others involved in the care of those with ASD, including families, health, education and social care staff.

The general principles of the Autism (Wales) Bill and the extent to which it will makes 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. RCSLT Wales does not object to the general principles of the proposed Autism (Wales) Bill in relation to promoting best practice in diagnosis, strengthening support for families, ensuring that key staff receive appropriate training and strategies are regularly reviewed. The question is whether legislation would be the most appropriate vehicle to achieve the ambitions set out in the purpose of the bill.

4. There are a range of new initiatives for people with ASD currently within the early stages of development in Wales. These initiatives aim to tackle many of the key areas of concern which the legislation proposes to address such as diagnosis, support, data and training. We discuss these changes in more detail here with reference to the key principles of the proposed bill.

- *Prioritisation of ASD* – Under the *Social Services and Well-being (Wales) Act 2014* there is a duty on public bodies to assess and address the needs of individuals. Under the Act, Regional Partnership Boards must ensure that integrated care and support services meet the needs of people in their localities. ASD has been identified as one of the priority areas for integration. The Act also places a legal obligation on Regional Partnership Boards to provide annual progress reports to Welsh Government on their outcomes in relation to the National Integrated Autism Service. We understand that a code of practice on the delivery of Autism services will be published under the Act in 2019.

- *Diagnosis* - Under the *Together for Children and Young People programme,* there has been significant investment in neurodevelopmental services. Nationally agreed neurodevelopmental children and young people's diagnostic pathways and standards are now in place and have been adopted by all health boards. A new 26 week waiting time standard from referral to first assessment appointment has also been introduced.

- *Support* - The National Integrated Autism Service has recently been established with the aim of creating consistent support for people with ASD across Wales. All services are due to be in place by the end of 2018. An independent review of the service will take place in 2019.

- *Education* - The Additional Learning Needs and Education Tribunal (Wales) Act has recently been given Royal Assent and implementation will begin in 2020. It is hoped that the new system will 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.

5. Whilst understanding of the frustrations of people with ASD and their families, given the scale of these changes, we believe that that it may be prudent to assess the impact of the implementation of these new developments prior to the introduction of new legislation.

6. Learning from the enactment of autism specific legislation in other nations (England and Northern Ireland) appears to indicate that legislation is not leading to the envisaged improved outcomes for people with ASD. The National Autistic Society Push for Action report on the implementation of the Autism Act in England in 2014 concluded that whilst the strategy has been successful in putting in place 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' (National Autistic Society, 2014). This is also supported by a recent detailed report by the National Autism Project (a UK wide initiative which aims to provide authoritative recommendations on autism research and practice) which stated that 'nearly a decade on (from the Autism Act) the needs of autistic people are still unmet' (National Autism project, 2017).

7. Similarly in Northern Ireland, the National Autistic Society Northern Ireland and Autism NI 2016 report on progress since the introduction of the Autism Act in 2011 revealed strong evidence that services had stayed the same or worsened since the enactment of legislation. The survey revealed that 75% of respondents felt that services for children had got worse or stayed the same and 56% of adults felt that services had got worse or stayed the same. The report argued that 'in 2011, the Autism Act and resulting Strategy and Action Plan increased the hopes of autistic people and their families for a better future for them and their loved ones. However the reality is that their life is getting more, rather than less, difficult for them and services are failing to deliver' and challenged the Northern Ireland Government on what they saw as 'broken promises' to autistic people and their families (NAS Northern Ireland and Autism NI, 2016).

8. It is our view that learning from other nations suggests that legislation without significant extra funding and detailed consideration of the impact on the workforce will not deliver the ambitions outlined in the general principles of the bill. We would welcome a review of practice in countries where 'autism-specific' legislation is enforced so that assessments can be made of the effectiveness of such measures.

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

9. We believe that a major challenge to the implementation of the bill would be workforce capacity. Our members have told us that neurodevelopmental services are already under significant pressure to provide assessment and support under referral to treatment time targets. In our evidence to the recent Children, Young People and Education Committee inquiry on emotional and mental health, we expressed concern that given the pressures, SLTs' time is often solely focussed on diagnosis with no capacity to support post-diagnostic interventions (RCSLT, 2017). Significant additional resources would be required to meet the specified time targets within the bill and to offer appropriate post-diagnostic support. We are concerned that this would inevitably impact on the ability of the profession to meet the needs of other populations who have similar needs but a different (or no) diagnosis and prioritise those with the greatest needs first. Current prevalence figures suggest that 1% of children and adults have ASD with 7.58% of children affected by developmental language disorder – a disorder that affects the way they understand and express language. Others conditions which may have associated language disorders include learning disabilities, cerebral palsy, brain injury, sensorineural hearing loss and down's syndrome. We strongly believe that policy and legislation should meet the needs of all individuals with neuro developmental (ND) disorders, including those who may not fit the ICD diagnostic criteria for ASD or other ND disorders specified by Welsh Ministers (and therefore not receive a formal diagnosis) but have traits of these conditions that impair their everyday social, psychological and intellectual functioning.

Unintended consequences arising from the Bill;

10. We believe that the proposed bill may have a range of unintended consequences. Throughout the legislative journey thus far, we have raised concerns that autism specific legislation could potentially risk prioritising the needs of people with ASD above the needs of those with other disorders. We understand that this issue has been considered in the proposed bill. However we do not believe the proposed change to include 'any other neurodevelopmental disorder as prescribed by Welsh ministers' will be possible to support given the current lack of shared understanding of this term amongst professional groups and the fast growing body of research in the area of neuro-disabilities, particularly with regard to classification of sub-groups. We foresee such a change to the proposed bill is likely to result in protracted discussions with regards what is included and excluded from the legislation.

11. We strongly believe that protections should be on the basis of need not diagnosis which would be consistent with the ethos of existing legislation such as the Social Services and Wellbeing Act and the Additional Learning Needs and Education Tribunal (Wales) Act. A needs-based approach is particularly important in improving outcomes for this client group given the high prevalence of co-morbidities for individuals with ASD, with evidence suggesting that 70% of young people with ASD live with at least one co-morbid condition (Simonoff et al, 2008).

The development of the all Wales neurodevelopmental pathway has been very helpful in supporting broader thinking around diagnoses. There is currently a move away from tight diagnostic groupings to ensure that people who do not necessarily fulfil the criteria for autism but require intervention have their needs met. We would not wish to see this shift potentially undermined by legislation and for the needs of people with ASD and/ or included other neurodevelopmental conditions to be prioritised above the needs of those with other disorders.

12. We also question whether disability-specific legislation could potentially set a new precedent and could lead other interested parties, patient groups and third sector organisations to call for the introduction of specific legislation for other illnesses and conditions. We concur with the views of the Welsh NHS Confederation in this regard that ‘(while) this does not mean that proposals for an Autism Act are unwarranted, it does mean that the evidence base for the introduction of such legislation must be extremely robust and convincing around improving patient outcomes’ (Welsh NHS Confederation, 2017). As part of scrutiny, we believe it will be key to consider the fit of this legislation with both the Social Services and Wellbeing (Wales) Act 2014 which already legislates for all individuals regardless of the extent of complexity of patient needs and the Additional Learning Needs and Education Tribunal (Wales) Act 2018.

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

13. We recognise the findings of the National Audit Office that if services identified and supported adults with high functioning autism spectrum conditions then the outlay would be cost neutral (National Audit Office, 2009). We believe that improved autism services would bring a number of savings in terms of wellbeing. For example reductions in hospital admittance and early discharge. However we are strongly of the view that in order for the legislation to address the issues the proposal highlights around inconsistencies in services, significant additional funding would be required to support local authorities and local health boards to fulfil their duties. We are mindful that parliamentary scrutiny of the proposed Autism bill in Scotland considered whether the proposed legislation would lead to improvements in services without significant extra funding for staff and resources. This was highlighted as a key issue in the scrutiny committee’s recommendation that the general principles of the bill should not be supported (**Education, Lifelong Learning and Culture Committee Report, 2010)**.

Further Information

1. We would be happy to provide any additional information required to support the Committee’s decision making and scrutiny. For further information, please contact:

[redacted]

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A15

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Gyngor Cymuned Mochdre gyda Phenstrywaid

Response from Mochdre with Penstrowed Community Council

Dear Sirs,

I am writing on behalf of the Council to give its view on the above Bill:

The Council feels that anything which can enable a strategy for meeting the needs of persons in Wales with Autism Spectrum disorder throughout their lives, and also improve the provision of services to such persons has to be good. It views the Bill in a very positive light as something which will facilitate:
a) the diagnosis of Autism Spectrum disorder,
b) the assessment of the care and support needs of such persons,
c) the meeting of those needs.

Best Regards,
[redacted]
Clerk/RFO to Mochdre with Penstrowed Community Council

Comisiynydd Plant Cymru
Children's Commissioner for Wales

Ymateb i Ymgynghoriad / Consultation Response

Date / Dyddiad: **13th September 2018**

Subject / Pwnc: **Autism (Wales) Bill Stage 1 inquiry**

Background information about the Children's Commissioner for Wales

The Children's Commissioner for Wales' principal aim is to safeguard and promote the rights and welfare of children. In exercising their functions, the Commissioner must have regard to the United Nations Convention on the Rights of the Child (UNCRC). The Commissioner's remit covers all areas of the devolved powers of the National Assembly for Wales that affect children's rights and welfare.

The UNCRC is an international human rights treaty that applies to all children and young people up to the age of 18. The Welsh Government has adopted the UNCRC as the basis of all policy making for children and young people and the Rights of Children and Young Persons (Wales) Measure 2011 places a duty on Welsh Ministers, in exercising their functions, to have 'due regard' to the UNCRC.

This response is not confidential.

My response to this Stage 1 inquiry is split into two main sections; the first part discusses the potential disadvantages in introducing a Bill of this kind. I have however also included a second part regarding the merits of the Bill as currently drafted, for further consideration should the Bill proceed beyond stage 1.

At the start of this response, I wish to make it clear that I am convinced that autistic children and adults and those with related autistic spectrum conditions are often failed by our public services. This includes lengthy waiting lists for diagnoses and an inability in some cases to adapt services such as education, therapeutic services and mental health services to meet the needs of those with autism spectrum conditions.

Despite these considerable challenges, I have also been pleased to meet autistic children and young people who say that their diagnosis has been liberating in helping their self-understanding and improving the attitudes of others towards them. They have expressed pride in their uniqueness and state that they are comfortable in not being ‘neurotypical’. There is some indication of a reduction in stigmatisation and a gradual increase in public understanding of autism.

Key questions, however, are whether a specific additional piece of legislation will make a significant positive difference to autistic children, young people and their families’ experiences, and also whether it may serve to unintentionally exclude others without a specific diagnosis.

Potential disadvantages

In my response to the pre-legislative consultation, I noted some of my concerns regarding the introduction of an Autism Bill. These concerns relate to the general policy issues, but are informed by cases that come into my office’s Investigation and Advice service. This is an independent source of advice and support for children and young people, or those who care for or work with them. Often people will contact my team when they feel they have nowhere else to go with a problem and have exhausted all other avenues.

Since my time as Children’s Commissioner we have received a number of contacts related to autistic spectrum conditions. These include but are not limited to: the referral process and length of waiting time for diagnosis by Child and Adolescent Mental Health Teams, the Special Educational Needs process (Additional Learning Needs), availability of school support before and after diagnosis, school exclusion and the appeals process, availability and changes to Social Services including at the point of transition, and the availability of services to support children and families more widely in their day to day lives.

These casework issues also impact negatively on children with other neurodevelopmental conditions and learning disabilities, often without a clear diagnosis even after assessment. It is therefore a matter for debate as to whether what is required is a specific Bill for children and adults living with an autism spectrum condition, or wider measures that ensure that all of our public services are person-centred and aim to remove barriers facing those who are not neuro-typical or who have a learning disability, in order that all citizens are enabled to fulfil their potential.

Many families I speak to tell me about their need to fight to obtain a diagnosis for a child's difficulties, as this is very often seen as the gateway to receiving services and support. This is not unique to autism; it relates to other matters as well such as mental health services and support for a child with learning difficulties. It should not be the case that a diagnosable condition is seen as a 'golden ticket' to receiving a suitable service. An assessment of autism is not always definitive, and another unintended consequence could be a trend towards diagnosing larger numbers of children whose behaviours and experiences of everyday life show some traits associated with autism but where it is not definitive. Some parents that I have met have found that even with a diagnosis, some agencies including CAMHS and schools dispute this, and the diagnosis does not always guarantee access to particular services in any event.

In my response to the *Mind Over Matter* inquiry report I have issued a paper[1] which sets out the importance of providing children with early help, when and where they need it, without needing to be referred to specialist services.

In my 2018 report *Don't Hold Back*[2] I highlighted the 'battles' parents and carers regular speak about to obtain diagnoses and services for their children. The report noted that there is currently a strong legislative framework in place to plan for and provide person centred care and support services. My report highlighted areas where the Social Services and Well-being (Wales) Act 2014 could be used more effectively, and I believe that this could also be the case for services for people with autism. Using the current legislative framework means that children and young people with similar levels of need to young people with autism, but who don't have a diagnosis, should have an equal opportunity to receive assessments and services.

I am aware that similar concerns have been raised in a briefing prepared by the Royal College of Psychiatrists, Royal College of Speech and Language Therapists, Royal College of Paediatrics and Child Health (RCPCH), The Royal College of Occupational Therapists (RCOT) and the Welsh NHS Confederation at the time of the plenary debate introducing the Bill.

The draft Bill

The draft Bill provides much detail for a new statutory Autism Strategy, but crucially it cannot guarantee access to particular services. Section 2(1)(h) requires the strategy to set out how relevant bodies will "make provision so that an appropriate range of services to deliver the autism strategy is available consistently across Wales" but this may not result

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[1] https://www.childcomwales.org.uk/wp-content/uploads/2018/07/Mind-over-matter-position-paper.pdf

[2] https://www.childcomwales.org.uk/wp-content/uploads/2018/07/Dont-Hold-Back.pdf

in anything more than the current provision being available. I am not sure that the draft Bill, despite the best intentions of those who have contributed to it already, will meet the expectations of families.

It is open to the Welsh Government to recognise the criteria set out in Section 2(1) of the draft Bill and commit to incorporating some or all of these into their ongoing work on the existing strategy.

Additionally I would be concerned that the current draft of the Bill will focus a significant proportion of resources into assessments and data collection. This relates to my earlier point about not wanting families to have to pin all of their hopes on a diagnosis, but also means that there may be little resource remaining to actually help and support those assessed as having a need. That would be an unintended consequence of this Bill but it is necessary to highlight this at stage 1. A number of parents have expressed concerns about lack of provision even with a diagnosis of severe need. Parents have also expressed concerns that there may not be any access to services for those who fall “outside” of the Bill but still have a significant support need.

Section 1(7) provides for independent reports every 3 years to review implementation and progress. Related to the points above, I am concerned that this frequency may divert resources and attention away from delivery of services to support people. I understand the intention to ensure that there is independent scrutiny of the Bill but it may not be necessary to have full independent reports every three years. I would suggest perhaps a lesser frequency, and/or incorporating other methods of review such as post legislative scrutiny by Committees of the National Assembly. On a practical note my office has been engaged with work on an evaluation of the Social Services and Well-being (Wales) Act 2014. This is by far a larger piece of legislation, but it has proven complex and time-consuming to evaluate. It will take a number of years to engage with stakeholders to set the terms of the review, to put the work out to tender and to complete the review process itself so it may not even be possible to undertake such regular reviews in this way. On a related point, as that review has not yet concluded, it may be seen as premature to introduce further legislation of this kind at present.

Should the Bill progress, provision will need to be made to take into account the forthcoming Additional Learning Needs and Education Tribunal (Wales) Act 2018. I note that the Bill includes in Section 8(4) a duty of due regard to the UNCRC, drafted in the same terms as the duty contained within the ALN legislation which has now passed. Should this Bill pass through stage 1 I would support section 8 being retained in its current format, as due regard to children’s rights will ensure that individual needs are actively considered when decisions are being made. During the passage of the ALN legislation there was much debate over the impact of such a duty and I provided written and verbal evidence explaining why the duty was a necessary and positive addition to the legislation. This debate does not need to be rehearsed further in this submission as a clear consensus was reached in the committee stages of the ALN legislation, however I would be happy to provide further information as required.

As this is a private members Bill, there is no statutory requirement to undertake a Children's Rights Impact Assessment (CRIA). This is not a critiscim of the Member as I recognise that he would not have a team of civil servants to support him in preparing a CRIA. It does however highlight a potential flaw in the Children's Rights Scheme 2014. The compliance report prepared under the Scheme earlier this year noted that the Scheme is due to be revised, so this may highlight an opportunity to consider this point further as part of that work. There may be a way to introduce a CRIA during stage 1 once the Bill is introduced, as part of the ongoing scrutiny through the stages prior to any Bill being passed.

As Children's Commissioner for Wales it is part of my role to highlight the fact that children and young people are a distinct group of individuals in our society with unique strengths, perspectives and circumstances whilst also being one of the most vulnerable, often with the least powerful voice. As Commissioner I have a statutory role to safeguard and promote the rights and welfare of children and help their voices be heard, however under the UNCRC, all adults have responsibility to do what is in the best interests of children (Article 3).

As is increasingly becoming the case, the Bill provides for a person centred or all age approach. It is important that the particular needs and experiences of children are not lost or diluted within the legislation and guidance. My office, with expert advice from the Wales Observatory on Human Rights of Children and Young People, has published *The Right Way: A Children's Rights Approach in Wales'* (March 2017)[3]. This document provides a principled and practical framework to integrate children's rights into every aspect of decision-making, policy and practice. It is underpinned by 5 principles; embedding Children's Rights, equality and non-discrimination, empowering children, participation, accountability. The application of this children's rights approach in the context of legislation concerning 'people' may also provide opportunities for these principles to be embedded more widely.

Articles 12 and 13 of the UNCRC provide children and young people with a right to express their views in all matters affecting them and to be provided with information. This is both relevant in terms of the Bill's further development and the provisions currently proposed for inclusion. Any guidance introduced under this Bill would need to be produced in consultation with children as well as adults, and be available in a clear and suitable format for all to understand and use.

Submitted by:

[redacted]

Children's Commissioner for Wales

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[3] https://www.childcomwales.org.uk/wp-content/uploads/2017/04/The-Right-Way.pdf

North Wales Integrated Autism Service

Autism (Wales) Bill Consultation response

September, 2018

Background to the North Wales Integrated Autism Service (NWIAS)

The IAS is jointly hosted between health and social care with strong links to education. The Strategic Board is jointly chaired by [redacted] Chief Officer, Social Services in Flintshire County Council and [redacted], Director of Operations and Service Delivery at Betsi Cadwaladr University Health Boards' Mental Health and Learning Disabilities Division.

NW IAS offers continuity of support for Autistic individuals through the various transitions in their lives, and helps people achieve the things that are important to them. The service is for individuals who do not have moderate to severe mental health or learning disability.

NW IAS Comments on areas of the Draft Autism (Wales) Bill

IAS staff and members of the Strategic and Operational groups have contributed to this response.

1. Autism Strategy

The Refreshed Autistic Spectrum Disorder Strategic Action Plan and delivery plan have already been produced with considerable research in to the needs of autistic individuals, their families and carers.

Although through the IAS and other partners, we have been to continue to gather feedback from autistic individuals, 6 months may be a short timescale for the publication of the strategy given the work needed to continue to engage with the autistic community and to develop and implement an consistent national consultation for to identify priority areas. Resources would need to be identified for this process. The North Wales IAS welcomes review of the work against any action plan or strategy as our aim is to continue to improve and develop the services we provide to meet the autistic people of North Wales' needs.

2. Contents of the Autism Strategy

Much of the work described in section 2 is already underway as a result of the development of the IAS, in particular:

(1) The autism strategy must— (a) establish a best practice model or models for the— (i) identification and diagnostic assessment of autism spectrum disorder; (ii) assessment of the care and support needs of persons with autism spectrum disorder; and (iii) planning for and meeting the care and support needs of persons with autism spectrum disorder;	This is now developing with the introduction of the IAS services across Wales. In North Wales, we are in the early stages of rolling out the service across the region. We would hope that ourselves and the IAS provision across Wales would be highlighted as best practice models, although we need to continue to develop the services over time to ensure we gather the baseline evidence. We are already gathering a catalogue of case studies to show the difference the service is making. The figure quoted of £30,037 to develop the strategy seems low given the extent of public engagement needed.
b) make provision for the development of a pathway, that includes access through defined points of referral, to map the services that are available and required for persons with autism spectrum disorder;	Pathways events have been held with colleagues across North Wales and with autistic individuals to discuss and agree pathways in to the service. We continue to respond to feedback on this. The staff are continuing to map the services and support available.
c) provide for diagnostic assessments and any post-diagnostic meetings to be commenced as soon as reasonably practicable following a referral and at least within any timescales set out in the relevant Quality Standard issued by the National Institute for Health and Care Excellence (but this shall not prevent the provision of any other services prior to the commencement of a diagnostic assessment);	The service's diagnostic assessment work will begin in full from November 2018, and will work with colleagues across the Health Board to ensure individuals will not be waiting any additional time. We will also be providing support throughout the diagnostic process. We see this as good practice. There are concerns across the IAS nationally, that the pressure imposed on services to meet the 13 week waiting time from referral to first appointment will have a detrimental effect on the support element we are able to provide. We acknowledge that waiting times are an issue, but this is also linked to a wider workforce issue in that there is a relatively small pool of professionals who can undertake them.

	It is positive that individuals who appear to have been referred inappropriately can be advised of this and possibly redirected to other services by clinicians. We would require more evidence on how the figure quoted of £4,362,563 will meet this requirement across Wales. One of our 'lived experience advisors' has stated that "once there has been a diagnosis, there was a lack of professional support", and that "the diagnosis means nothing without that help and support". 'https://www.youtube.com/watch?v=Lr-vGWyzylc
d) make provision for individual diagnostic assessments to be conducted by a multidisciplinary team of professionals;	The NWIAS has employed Psychologists, SaLT, OT, a Nurse and Social Worker to meet this requirement.
g) outline how the needs of persons with autism spectrum disorder are to be met by relevant bodies in respect of, but not limited to,— (i) access to healthcare services; (ii) access to education; (iii) access to employment; (iv) access to housing; (v) access to Welsh language services; (vi) access to services in other languages; (vii) access to other public services; (viii) social inclusion; and (ix) access to advocacy services;	The NWIAS is making links with a number of services across the region to support them in their practice with autistic individuals. The ASDInfoWales website also has a number of resources aimed at a number of these sectors to ensure they can access information to help them in their work with autistic individuals, and the NWIAS can support the implementation of these alongside the ASD National Team.
(k) place an emphasis on how families and carers of persons with autism spectrum disorder can be supported in meeting the needs of those persons;	An element of the support provided by the NWIAS will be to parents and carers of autistic individuals.
(l) make provision for the wishes of persons with autism spectrum disorder and of their families and carers to be taken into account;	The NWIAS ethos is centred in 'What Matters' to the individual, in line with the Social Services and Wellbeing Act (Wales) 2014.
p) make provision for a campaign to raise awareness and understanding of the needs of persons with autism spectrum disorder	The NWIAS continues to promote the nationally recognised 'Can You See Me' campaign with partners, Elected Members and the community.

q) make provision for the identification of key professionals and provision of appropriate (but not mandatory) training for them in relation to supporting persons with autism spectrum disorder; and	Through the NWIAS mapping of services, we are identifying partners who wish to undertake training, not only to raise awareness, but improve the standard of their practice to meet the needs of autistic individuals. We are also working with partners to identify Autism Champions as part of their service to act as a key point of contact. The IAS staff are being trained to deliver the resources and campaigns available, for free, on the ASDInfoWales site. The NWIAS have committed funding to the role out of ASD training to CMHTs through 'Aspects', alongside other IAS in Wales.

4. Guidance by the Welsh Ministers

We would welcome more information on how the Welsh Ministers will be informed and advised of the changes needed to any future legislation, and by whom. We would seek reassurance that alongside the 'relevant bodies' and those who represent groups of autistic individuals, that a pledge is made nationally to gather the views of those who are more isolated, and more in need of the services offered.

Will the definition of carers (6b) be in line with the definition of carers in the Social Services and Well-being (Wales) Act 2014? For consistency and clarity of services to all carers, we believe this definition should remain.

"A person who provides or intends to provide care for an adult or disabled child."

6. Data on Autism Spectrum Disorder

We welcome the Bill's position in requiring services to record ASD diagnoses. BCUHB has successfully collected and collated such diagnostic information for children over the last 6yrs and is therefore unique in Wales in being able to accurately identify whether or not research-supported internationally recognised prevalence rates are being adhered to, or exceeded or failing to be reached, within each of the 3 constituent areas of BCUHB and over the HB as a whole. These figures are absolutely essential in Wales being able to identify whether diagnoses are being made at appropriate levels.

It is inappropriate for ASD diagnoses to be missed and it is inappropriate for people without ASD to be diagnosed as having ASD. These are real dangers and can only be addressed through accurate data recording and analysis in a constant manner. BCUHB's database, conceived originally by WG, has demonstrated that such data can be efficiently and routinely recorded/analysed.

If diagnoses were to proceed without prevalence levels of comorbid conditions being checked (as the Bill sets out to avoid through the data collection referred to above) then there might be a risk that resources are not allocated appropriately to the correct service users. But the latter risk already exists without the Autism Bill.

7. Awareness Campaign
The NWIAS feel that there is already an awareness campaign in existence through the nationally recognised ‘Can You See Me’? campaign available for free, and bilingually, via the ADInfoWales website. The promotion of this is part of the NWIAS work plan and a change to this may be counterproductive at this stage. However, additional resource to further develop this campaign would be welcome.

In conclusion

Given the work that has already taken place, we feel it is not the time to introduce specific legislation on ASD, and to continue with Option 1 due to the following reasons:

- The Social Services and Wellbeing (Wales) Act MUST continue to be the primary piece of legislation for the wellbeing off ALL citizens in Wales. We must collectively promote new ways of working, person centred thinking and outcome based solutions based on the needs of individuals as part of our daily working practices for ALL people in Wales, regardless of condition. To make specific legislation based around one condition may dilute this work, and the emphasis on any comorbid conditions the individual may have.

- The links to comorbid conditions is not sufficiently referenced or clarified within the Explanatory Memorandum. Although it states this has been included in costings, further information is needed.

- There is a risk that the focus on waiting times will dominate the support element of services. Support functions will ultimately provide better value in the long term and ease pressure on other services, but more importantly give the autistic individuals, their families are carers access to the information, advice and assistance needed to build resilience, preventing crisis. It is important that clinicians can focus half their efforts on supporting families of clients with ASD, rather than be consumed by assessment work. Further information is needed on whether the Bill addresses the need to protect intervention time within services for these clients.

- The Bill and the Explanatory Memorandum make reference to building on that which already exists, such as the ‘Can you see me?’ campaign and Code of Practice. We feel that the existing work is currently meeting much of the requirements of the Bill. We acknowledge that areas need strengthening, and if any additional funding could be channelled in to these areas, improvements will be forthcoming.

- Further information is needed on the details outlined in the Explanatory Memorandum on the finance and where the funding will be sourced from. Will this work be at the expense of existing services?

- Services have often been criticised for the short term view on funding. The IAS across Wales need time to establish and deliver the outcomes they are designed for, and will be able to achieve. The NWIAS was formally launched in June 2018, with diagnostic elements beginning in November. We believe we can achieve great things with the support of our partners, lived experience advisors and staff, but need the time to be able to develop a service that works for the people of North Wales.

Recommendation

We recommend that we continue of the current timescales **(Option 1)** of funding and the review work Welsh Government have already commissioned before any large scale redesign of ASD services are considered.

A18
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Goleg Nyrsio Brenhinol Cymru
Response from Royal College of Nursing Wales

Coleg Nyrsio Brenhinol
Cymru
Royal College of Nursing
Wales

14 September 2018

<u>Response from the Royal College of Nursing Wales to the Health, Social Services & Sport Committee's inquiry into the Autism (Wales) Bill</u>

The Royal College of Nursing Wales is grateful for the opportunity to respond to the consultation on the Autism (Wales) Bill. We would like to raise a number of points in relation to the legislation:

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

I. The Royal College of Nursing remains broadly supportive of the overall aim of the draft legislation and commends the intention to raise the profile of the needs of children, young people and adults with autism spectrum conditions and the aim to meet their needs appropriately and effectively. At present, we are aware of the difficulties of gaining a timely assessment (particularly for adults), and this in turn has a negative impact in terms of timely and appropriate provision of support. There is certainly scope for this legislation to help address this issue.

II. However, the legislation does not necessarily reflect the general trend in moving away from tight diagnoses of specific conditions, and taking a more needs-based approach to supporting people. There is a strong case to be made for the fact that resources and support should be developed and delivered according to the needs of the individual, not according to a diagnosis or piece of legislation. Furthermore, we are aware of concerns that have been expressed that having a condition-specific piece of legislation, may make it *more* challenging for an individual who lives with ASD whilst also experiencing living with other conditions, to access support or be clear where their support is located. For instance, an individual may have moderate learning disabilities as well as ASD, or have ASD alongside mental health problems; there may be a danger that condition-specific legislation creates more issues for with multiple challenges than a needs-based system would.

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

III. At present, access to both assessment and support services for people with ASD appears insufficient. Indeed that is one of the main drivers behind the introduction of this legislation. It follows therefore that without significant additional funding it is difficult to see how the changes proposed can be appropriately and effectively implemented. For example, in order to address existing issues such as the long waiting times for assessment, additional (i.e. not diverted from working in other areas) staff will be required. Furthermore, the

Royal College remain unconvinced that there are sufficient appropriately trained professionals available to fill such posts if they were to be created. The implications for the workforce therefore require careful consideration.

IV. In relation to training and education, we welcome that there is an awareness in the document of the need to make training available to relevant staff and that provision must be made for this. However, consideration needs to be given to what the existing requirements are for mandatory training (which in some cases is extensive), and also whether online training, which increasingly is a preferred method of delivering training, is appropriate means of effecting the changes this legislation requires. For education and training to be effective and to a high standard, additional resource and funding is likely to be required, and this should be taken into account as the legislation is scrutinised.

Whether there are any unintended consequences arising from the Bill

V. There will be a need to very carefully monitor how this Act interfaces with other legislation such as the SSWBA and also with other recent policy statements such as the Improving Lives document setting out the direction of travel in relation to learning disabilities.

VI. We also understand from other colleagues in the sector that there are some concerns that a possible unintended consequence or knock-on effect of linking resource to a particular diagnosis 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.

Further comments

VII. The Royal College is disappointed that Registered Nurses are not explicitly included in the list of ‘key professionals’ in the multi-disciplinary diagnostic assessment team. As highly skilled members of the healthcare team who care for individuals in all healthcare settings, it makes no sense to exclude nurses and health visitors from this list of professionals. In previous written evidence submitted during the development of this Bill, the Royal College of Nursing clearly stated that, in order to be truly person-centred, the list of appropriate professionals would vary from depending on the individual. We also stated however that, if a list is to be included on the face of the Bill, then it should include Registered Nurses, including Children’s Nurses, School Nurses, Health Visitors and Learning Disability Nurses.

Coleg Nyrsio Brenhinol
Cymru
Royal College of Nursing
Wales

About the Royal College of Nursing

The RCN is the world’s largest professional union of nurses, representing over 430,000 nurses, midwives, health visitors and nursing students, including over 25,000 members in Wales. The majority of RCN members work in the NHS with around a quarter working in the independent sector. The RCN works locally, nationally and internationally to promote standards of care and the interests of patients and nurses, and of nursing as a profession. The RCN is a UK-wide organisation, with its own National Boards for Wales, Scotland and Northern Ireland. The RCN is a major contributor to nursing practice, standards of care, and public policy as it affects health and nursing. The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.

A19

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Unigolyn

Response from an individual

Private member's bill to require rapid diagnosis of autism (Ian Davies AM)

As a parent of an autistic person, ex-field professional and activist, could you carefully consider the following:

The proposed legislation has the potential to be seriously counterproductive.

As I understand it the agreed professional approach to diagnosis is cumbersome and time consuming, so the proposed legislation may speed up the start of the process but could not influence the rate of its completion, which is a clinical procedure. Since the legislation makes no provision for additional finance, practitioners required to kick start the process would need to lay aside important supportive work to the detriment of the people concerned and their families.

Families affected by autism usually need immediate input which the proposed legislation may well delay. Service decisions need to be made on the basis of perceived need and not be contingent on diagnosis which is a red herring. I know that there are parents who mistakenly believe that the application of a clinical label via diagnosis will lead to speedier service delivery. However, if implemented, this proposal could do far more harm than good and should not be passed into legislation.

Sincerely yours,

[redacted]

Written evidence submitted by the
Royal College of Psychiatrists in Wales (RCPSych in Wales)
to the Health, Social Care & Sport Committee Consultation
Wales (Autism) Bill
September 2018

The Royal College of Psychiatrists is a professional medical body responsible for supporting psychiatrists throughout their careers, from training through to retirement, and setting and raising standards of psychiatry in the United Kingdom.

The College aims to improve the outcomes of people with mental illness, and the mental health of individuals, their families and communities.

In order to achieve this, the College sets standards and promotes excellence in psychiatry; leads, represents and supports psychiatrists; improves the scientific understanding of mental illness; works with and advocates for patients, carers and their organisations. Nationally and internationally, the College has a vital role in representing the expertise of the psychiatric profession to governments and other agencies.

RCPsych in Wales represents 600 Consultant and Trainee Psychiatrists working in Wales.

For further information please contact:

[redacted]
[redacted]
[redacted].

RC PSYCH
ROYAL COLLEGE OF PSYCHIATRISTS

Introduction

The Royal College of Psychiatrists in Wales (RCPsych in Wales) welcomes the opportunity to provide further written evidence to the National Assembly of Wales' Health, Social Care & Sport Committee.

Autism Spectrum Disorder (ASD) is a complex, co-morbid disorder, that presents differently in different individuals and demographic groups.

ASD and other Neurological Disorders (ND) that will be impacted by the proposed legislation sit across a range of specialisms that accordingly sit across specialist faculties of the College.

RCPsych in Wales have consulted opinion from its own faculties throughout the development of the proposed legislation.

- The Faculty of Child & Adolescent Psychiatry
- The Faculty of Intellectual Disability Psychiatry.

Whilst fully supportive of the need to improve outcomes for people with ASD, RCPsych in Wales members have expressed concerns over whether legislation would be the most appropriate vehicle to achieve the ambitions set out in the purpose of the bill. We would ask the committee to consider the following:

- 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 that
- 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.

RC PSYCH
ROYAL COLLEGE OF PSYCHIATRISTS

Background

In addition to presenting our own view, we have also worked with royal colleges across the sector in considering the proposed legislation. Accordingly, we have co-produced a briefing that outlines our shared position in relation to the proposed legislation alongside:

- Welsh NHS Confederation,
- Royal College of Speech and Language Therapists,
- Royal College of General Practitioners,
- Royal College of Paediatrics and Child Health, and the
- Royal College of Occupational Therapists.

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 feel it important that the committee consider experience from other parts of the UK with regard the introduction of ASD legislation.

Evidence from the Autism Acts in England (2009) and Northern Ireland (2011) suggest that legislation is not leading to improved outcomes for people with ASD. Whilst in Scotland, the Autism (Scotland) Bill fell at the first stage of parliamentary scrutiny (2011).

We would ask the committee to consider the detailed joint briefing produced with the NHS confederation and royal colleges from across the sector that looks specifically at this issue. *Autism (Wales) Bill: A look at autism strategies and legislation in England, Northern Ireland and Scotland*

For ease, we have highlighted a few considerations from this briefing.

- The National Autistic Society report *Push for Action* (2013) 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*".

- In consideration of the Autism Act (2009) in England, The National Autism Project further stated that "*nearly a decade on the needs of autistic people are still unmet and the expected economic dividend has never materialised*".

- 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*"

- 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*". These were highlighted as key issues in the Committee's recommendation that the general principles of the Bill should not be supported.

In Wales, there are currently a number of initiatives aimed to improve services for people with ASD in Wales. We would recommend that these initiatives be assessed as they are at an early stage of development.

- The Social Services and Well-being (Wales) Act 2014 places a duty on public bodies to assess and address the needs of individuals. Regional Partnership Boards established under the Act are responsible for ensuring that there are integrated care and support services to meet the need of people in their area. Autism has been identified as one of their priority areas for integration (Welsh Government, 2016 and Welsh Government, 2018). We understand that a code of practice on the delivery of Autism services will be published under the Social Services and Well-being Act in 2019.

- Under the Together for Children and Young People programme, launched in February 2015, there has been significant investment in neurodevelopmental services. Nationally agreed neurodevelopmental children and young people's diagnostic pathways and standards are now in place and have been adopted by all Health Boards. A new 26 week waiting time standard from referral to first assessment appointment has also been introduced (Welsh Government, 2018).

- The National Integrated Autism Service has recently been established with the aim of creating consistent support for people with ASD across Wales. An interim evaluation report with recommendations has been published and the full evaluation report is scheduled for January 2019 (Dr Duncan Holtom and Dr Sarah Lloyd Jones, 2018).

- The Additional Learning Needs and Education Tribunal (Wales) Act 2018 has recently been given Royal Assent and implementation will begin in 2020. It is hoped that the new system will 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.

Unintended consequences arising from the Bill

As highlighted at introduction, Autism Spectrum Disorder (ASD) is a complex condition that presents differently in different individuals, which is in part why it is difficult to diagnose. No two persons' needs will be the same. Similarly, there are many children with neurodevelopmental differences (ASD like traits, learning disability, ADHD) who may not meet the criteria for a diagnosis, but the sum total of their difficulties is what creates the impairment and affects the quality of life.

We believe support and treatment should be tailored through the needs of the individual through a formulation that is based on a multi factorial understanding of each case, not through their diagnosis and not prescribed through legislation.

We believe Autism legislation will not necessarily drive good practice and could lead to a push for higher diagnosis rates rather than focus on meeting the needs of the individual. The need for diagnosis to push for resource will only artificially increase diagnosis rates for the wrong reasons.

We would agree with the Royal College of Speech and Language Therapists, 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.

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

We are concerned that the financial pressures and significant challenges associated in recruitment and education to enable multi-disciplinary teams to deliver services as envisaged by the Bill would make it difficult to ensure effective implementation. The changes in waiting time targets as envisaged by the proposed legislation, would also have a significant impact on capacity against the current resource for multi-disciplinary teams.

We would also reaffirm the findings of the Parliamentary scrutiny of the proposed Autism Bill in Scotland, which was also introduced as a Members' Bill in 2010. The Committee 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.

Lastly, we are concerned that disability specific legislation could lead to people with other neurodevelopmental disorders and challenges receiving inequitable services. It could also lead to an increase in calls for the introduction of specific legislation for other illnesses and conditions to ensure they also given equal status and provision.

References

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

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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

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

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A21

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Gwasanaethau Cymdeithasol Cyngor Caerdydd

Response from Cardiff Council Social Services

Question 1

Consultation response no:	Do you agree that a definition of 'autism spectrum disorder' should appear on the face of the Bill?
1. 2.	No – the content of the Bill itself will define what is required – autism and ASD are seen as the same. However, if Neurodevelopmental conditions are included, then this may require definition of what this is and will cover. **<u>The</u> <u>act</u> <u>as</u> <u>introduced</u>** added the phrase *(b) for the purpose of this Act,* This has the potential to add to confusion as it implies that an alternative neurodevelopmental condition may be considered as autism only for the purpose of this act and not with respect to other statutory instruments which would be unchanged.

Question 2

Consultation response no:	Do you agree that using the WHO ICD-11 definition in the draft Bill, together with the power for Welsh Ministers to include other neurodevelopmental disorders, is the right approach?
1.	No This approach indicates that the Bill if passed will in future provide challenge for what is and what isn't included. Currently there is a clear notion of what autism does and does not include, and as such, services are designed around these needs to specifically meet those with the condition. Adding in Neurodevelopmental Disorders is a significant change in the list including as well as autism, ADHD, intellectual disability, communication disorders motor disorders, pathological demand avoidance etc. Whilst this is more inclusive, and supports alignment

	of the new ND teams and the IAS, this implies that these two services require legislation to work together across the lifespan. This significantly extends the Bill from its original focus on autism. It also has the potential for further conditions to be added in the future making planning for need based around populations and prevalence very difficult, and could potentially increase legal challenge in the delivery of services, where definitions are not clear. Listing conditions also has the potential to further medicalise an approach that should be seeking to enable children, families and adults to lead fulfilled lives that support wellbeing. For those experiencing other neurodevelopmental disorders, including them within legislation and a more strategic approach is likely to be welcome. However, there are a number of other identified groups which will become excluded who will not welcome the Bill because of preferential set of legal terms which exclude these other groups which in itself is discriminatory. Therefore, a preferred option would be to suggest additions to the SS&WB Act, which could provide a specialist overview for autism, but in its nature is an inclusive legislative all age Act.
2.	**The act as introduced** retained this section providing a power for Welsh ministers to introduce other conditions if necessary. This continues to be a section with the potential to lose the focus and purpose of the proposed Bill turning it into a pan-disability piece of legislation, which is effectively what the Social Services and Well Being Act is.

Question 3

Consultation response no:	Are the “relevant bodies” in section 7 of the draft Bill the appropriate bodies to implement the autism strategy?
1.	No – Noting that the key aspects of the Autism Strategy include: Access to healthcare services; access to education; access to employment; access to housing; access to Welsh language services; access to other public services; social inclusion; and access to advocacy services. Health and local government clearly have key roles to play in implementing the Autism Strategy and, if agreed, an Autism Act, but this is a wide remit covering areas that the LA and NHS will not have jurisdiction to enforce. Other partners, such as Careers Wales and the DWP oversee developments within employment and access to further education and the third sector may also have a role to play to ensure success. If only health and local authority are relevant bodies it is unclear how they would successfully exercise a duty in a non-devolved area such as employment. It is similarly unclear how Welsh ministers would exercise control over the DWP for example with respect to employment.
2.	**The act as introduced** does not change this section and the memorandum of understanding (Explanatory Memorandum) comments *“it is outside the competence of the Assembly to make legislation imposing additional duties on them*”. The outcome is that other than provision of autism training the only aspects that this Act could influence would be those that are delivered by devolved functions.

Question 4

Consultation response no:	Should the duty on relevant bodies to have regard to the autism strategy and guidance be reinforced by providing Welsh Ministers with a power of direction over relevant bodies?
1. 2.	It could be suggested that ‘relevant bodies’ needs to be more prescriptive to include other bodies who should be directed to understand and act to undertake their responsibilities. There is a risk that wider organisations will see that an Autism Act is for local authorities and NHS services to implement, as opposed to a broader context of change as noted within the current strategy. With this in mind, it would need to be made clear to Welsh Ministers who are the relevant bodies that they give direction to, should there be a requirement to exercise power over a relevant body to act. **The act as introduced** changes wording from “*duty to have regard to*” to “*compliance with*”. It is unclear if this indicates a broad power of direction over local authorities and health boards, with respect to compliance with this Bill, if passed. It also unclear whether this has potential to conflict with existing legislation that would lead to confusion.

Question 5

Consultation response no:	Do you have any views about the timing set out in section 1(4) of the draft Bill for the publication of the Autism Strategy?
1.	Yes – the timeframes set out are overly optimistic and carry risk. There will be a requirement for consultation. In addition, there needs to be recognition that local areas will have pre-identified commitments such as preparing for the implementation of the Additional Learning Needs and Education Tribunal (ALNET) Act, which are ongoing and require dedicated resources. Rushing the development of the strategy, and subsequent publication could lead to revisions being required earlier than needed and additional work at a later stage. A measured and realistic timeframe that takes into account the need to implement the ALNET Act, which also allows for engagement and inclusion of those who will be leading the implementation of an ASD strategy, would be more beneficial. This would support wider ownership of the strategy and any action plans that may develop as a result of this.
2.	**The act as introduced** is unchanged in wording it is unclear from the memorandum of understanding how this could be achieved in such a short time scale particularly considering the level of consultation with stakeholders that would be required.

Question 6

Consultation response no:	Do you have any views about the timing set out in section 3(2) for issuing guidance under the Bill?
1. 2.	As above. It would be helpful to reflect on lessons learned from the implementation of the Integrated Autism Service and other time sensitive developments to understand the implications of setting timeframes that are challenging to achieve. Whilst positive change has occurred, there was a significant amount of preparation and planning time, which would have benefitted the development of an integrated service. **<u>The act as introduced</u>** is unchanged the memorandum of understanding envisages that guidance would be developed in parallel with the strategy. Work could therefore begin on the guidance as soon as the Act is passed, which would allow up to nine months for the process. This implies that the guidance can be written before the strategy has been written and consulted on which is poor practice.

Question 7

Consultation response no:	Do you have any views about the timing set out in section 9 for when the Act comes into force?
1.	The information provided implies that an Autism act would come into force prior to the publication of the ASD strategy or guidance. This would prove very challenging to implement as an Autism Act

	would have no purpose and will be challenging to govern without a code or standard as a basis to work undertaken. This could lead to legal challenges and vague expectations from those who may benefit from an Act, but no guidance to work from for those who are supporting these individuals. There would need to be an understanding that an Autism Act may come into force before duties of responsible bodies can be governed. It is therefore difficult to see how these timelines could be adhered to while allowing an appropriate consultation to take place leading to the publication of a strategy and guidance that is a practical and achievable. As the timeline implies that the guidance cannot be finally written until the strategy that informs the guidance has been created, these seem overly optimistic and unrealistic time frames.
2.	**The act as introduced** is unchanged, there are no notes in the memorandum and all concerns previously highlighted remain.

Question 8

Consultation response no:	Do you agree that diagnosis should be completed within timescales in the relevant National Institute for Health and Care Excellence guidelines, as set out in in section 2(1)(c) of the draft Bill?
1.	The NICE guidelines state that a diagnostic assessment for children should be started within the first 3 months. https://www.nice.org.uk/guidance/cg128/chapter/Recommendations#local-pathway-for-recognition-referral-and-diagnostic-assessment-of-possible-autism This does not refer to completion of assessment and confirmation if appropriate of diagnosis. There are no timeframes noted within NICE guidelines for adults for either assessment waiting times, or provision of a diagnosis if appropriate. Within Neurodevelopment Services, the 26-week diagnostic waiting time for children is from referral to first appointment, and the assessment and diagnosis process can take longer and should be bespoke to the needs of the individual but not excessively lengthy.

2.	It would be clearer to outline expectations for waiting times within an act or strategy, but with the acknowledgement of context and complexity of some cases that may require longer to assess to be able to confirm diagnosis. Performance indicators to ensure compliance should include waiting times for governance purposes, but allow for flexibility that accounts for a thorough needs assessment. Simply adding a target will not resolve the issue of waiting times. However, there is no maximum waiting time standard from referral to a final diagnosis of autism. This has been the subject of recent debate in parliament. http://www.normanlamb.org.uk/maximum_waiting_times_for_autism_diagnosis_needed It could be suggested that an Autism Act should refer to a minimum standard waiting time for adults and children, or timescales noted within NICE guidelines, whichever is shorter. **The act as introduced** changes the wording from “completed” to “commenced”. While this is positive and notes in the memorandum acknowledge that the potential complexity of the diagnostic process could make completion within three months challenging, it is doubtful if families and individuals would find this completely satisfactory. Commenced is the start of the diagnostic process and that can be simple steps such as a first telephone call or an initial screening questionnaire. Adding this target is not helpful to families and individuals and will not have the effect of resolving the issue of waiting times. It would be more helpful to define what “commenced” means for the purposes of this Bill as that will give consistency across families and service areas of expected waiting times.

Question 9

Consultation response no:	Do you agree that an assessment of care and support needs should be completed within 2 months of a diagnosis of autism spectrum disorder or any post-diagnostic meeting, as set out in section 2(1)(e)?
1.	No – a proportionate assessment of needs should be carried out post diagnosis, as is consistent with the Social Services and Well Being Act. The timeframe for completion of this proportionate assessment should be consistent with the SS&WB Act within Information, Advice and Assistance services, and where further assistance can only be delivered through the development of a care and support plan, this should also be completed under the principles of the SS&WB Act. The proposed Autism Act suggests a 2-month completion timeframe, whereas the timescale for completion of the assessment within the SS&WB Act is a maximum of 42 working days from the point of referral. This would require alignment to ensure all assessments are prioritised based on needs and not diagnosis. Using the term care and support needs implies that all individuals diagnosed with autism have needs that can only be met through the provision of care and support services. This is simply not the case, with many individuals diagnosed with autism never requiring any further support post diagnosis. There are however a number of individuals who may have care and support needs, which are unrelated to their diagnosis of ASD but need local authority intervention. As within the SS&WB Act it would need to be clear who would have a duty of care to complete assessments. An analysis of current capacity and demand within services would be required to ensure the resource implications for implementing this approach could be fully understood. A diagnosis of ASD should not be a trigger for care and support, but is an appropriate trigger in the requirement to assess and it would be expected that those assessing would be as outlined within the SS&WB Act.
2.	**The act as introduced** changes the time scale from 2 months to 42 working days. The memorandum clarifies that this change provides alignment with social services assessments for children. The memorandum provides some further clarification stating that some people with ASD would not have particular care and support needs, and that there should not be a presumption that a person with ASD would automatically have care and support needs.

	Although the memorandum clarifies that the Bill does not make this assumption it still assumes that an assessment of a person's care and support needs should take place, which may conclude that a person does not have any such needs. This still has resource implications because of current capacity and demand which implementing these additional assessments, albeit with no support needs will require. Under the SS&WB Act, an individual should be assessed at presentation of need for care and support. This Act as introduced has the potential to deny an individual access to assessment until a diagnosis has been made, thereby denying them access to care and service based on need. With this in mind, this piece of legislation will undermine the principles within the SS&WB Act.

Question 10

Consultation response no:	Do you agree that it is useful to include in the draft Bill a list of professionals who may form the multi-disciplinary team for diagnostic assessment?
1. 2.	No – The NICE guidelines outline the key individuals that can support a diagnostic assessment. **The act as introduced** does not change this list the memorandum notes that the list is advisory; there is no intention to set out a prescriptive list of professionals in the Bill, as introduced. Obvious gaps as noted in the memorandum are paediatrician and educational professionals. This section remains unnecessary, as the NICE guidelines should be the standard adhered to for both children and adults.

Question 11

Consultation response no:	If so, are there any other disciplines that you think should be listed as possible members of such a multi-disciplinary team?
1 and 2.	As above (Q10)

Question 12

Consultation response no:	Are there any other factors or individual circumstances which may inappropriately prevent access to services and which should be set out in the Bill?
1.	No - Specific services have eligibility criteria's to enable delivery to vulnerable groups (LD, MH services, Phys Dis etc) There would be resource implications if these services were to include ASD without associated LD, MH.PD etc and these service areas are already delivering to a growing population of eligible citizens. SS&WB Act provides care and support based on need not diagnoses. Equipping services to be able to assess based on need rather than diagnosis to ensure those in need of care and support have access to services that are able to best meet these needs. There should not be an expectation that a diagnosis of ASD is a gateway to services, this should be based on needs of an individual and prioritisation of resources to meet these needs.
2.	**The act as introduced** does not change the wording. The memorandum does note that a lack of staff training in and awareness of, ASD was also said by some respondents to result in barriers to accessing suitable services. This is more relevant and addressable than attempting to fit a person with an ASD diagnosis into an inappropriate team simply because that team happens to exist. Please also refer to response in question 9 regarding access to care and support based on need and not diagnosis.

Question 13

Consultation response no:	Should the draft Bill specify the types of data to be collected by Welsh Ministers to enable them to carry out functions under the Bill?
1.	Any personal data collected must comply with Data protection legislation (GDPR) In order to be consistent the population needs assessment, as identified in the SS&WB Act, should determine what data is collected. Currently ASD data is aggregated within LD and separating that data to clearly delineate the two conditions and the differences between the two population needs would be informative. Lumping autism generally in with LD is incorrect and unhelpful and creates an expectation among families and individuals that will not be fulfilled.
2.	**The act as introduced** has extensive additions in this area saying NHS bodies must collect the following data to assist them in the diagnosis and provision of services to persons with autism spectrum disorder The data requested is only diagnostic in nature and will not inform or assist in the provision of services. It is not consistent with the population needs assessment as identified in the SS&WB Act. The data listed indicates that this Bill is extensively clinical in nature and concentrates on the single event of diagnosis to the detriment of the wider needs of families and individuals.

Question 14

Consultation response no:	If so, do you have any views about the types of data which should be collected? Examples of types of data which should be collected might include: age, age at diagnosis, gender, health board/local authority area, time from assessment to diagnosis, profession(s) of diagnosing staff and service in which based, diagnostic assessment tool(s) used, use of a scored assessment, the diagnosing clinician's estimate of intelligence level[1], communicative development, whether testing for phenylketonuria (PKU) was carried out.
1.	Data gathered should be limited to that necessary in order to satisfy the requirements of data protection and requirements within the Population Needs Assessment to understand regional need. Any other data for 'interest' purposes should be done via research units only. Collecting and processing data should not be to an extent that is significantly beyond that collected for other similar conditions. To do so risks marginalising this population for study purposes. Were this being done for in a research setting it would be accompanied by extensive work around consent and ethics and involve a clear understanding by the individuals as to exactly how the data will be used and processed.
2.	**The act as introduced** has extensive additions to data which is generally of the for 'interest' category. While it may be interesting for the purposes of research to gather extensive data around ASD diagnosis, it is not appropriate to include that in a statutory instrument.

Question 15

Consultation response no:	Should the types of data be specified on the face of the Bill or in guidance?
1. 2.	If at all, in the guidance **The act as introduced** with extensive additions to data should be transferred to the guidance where it can form part of reporting on diagnosis. Having data in guidance, not the Bill allows for additions, deletions and adjustments much more easily than the face of the Bill.

Question 16

Consultation response no:	Do you agree that: - the provision in section 5(2) to allow Welsh Ministers to request anonymised data from relevant bodies is appropriate, and - it should be included on the face of the Bill?
1.	If at all, this should be included in the guidance.
2.	**The act as introduced** with extensive additions to data should be transferred to the guidance. Ministers can then decide based on circumstance and evidence accumulated what data to request much more easily than the face of the Bill.

Question 17

Consultation response no:	Should a campaign to raise understanding and awareness of the needs of persons with autism spectrum disorder be rolled out on a continuous basis, or on a regular (three-year) cycle?
1 and 2. 2.	Both – this is a proven success and should be continue. The campaign should be around awareness and understanding of autism - including those individuals with particular needs. Not all individuals with ASD will see themselves as having needs. The responses based on the Memorandum Of Understanding suggest a continuous campaign. This is not required within an Act but would be better situated within guidance if at all. Each Local Authority area has an ASD lead role who would lead on information and awareness raising, amongst other planned activities.

Question 18

Consultation response no:	Giving reasons for your answer, could any of the proposals in the draft Bill be reformulated so as to increase its positive effects or reduce its possible adverse effects, in relation to: a. the Assembly's official languages (Welsh and English); b. equality, diversity and inclusion; c. the justice system in England and Wales; or d. costs and benefits to you or your organisation
1 and 2	a. Individuals with a diagnosis of autism have impairments in their ability to communicate. Feedback from individuals has indicated that information should be provided in a clear and concise manner. Bilingual documents can be confusing for individuals who already have challenges with communication. Some exceptions within the Welsh Language Act for services to be able to take the individuals lead in language preference which takes into account their communication methods would be helpful.

1 and 2	b. Reduce negative effects by aligning closely with the SS &WB Act to reduce impact on groups not represented within this draft Bill. Other disabling conditions have no Bill to support them, and refer to the new Social Services and Well Being Act, and ALNET Act to support assessment of need and delivery of services. Moving away from the SS&WB Act for a specific group will create an equality issue for those living without autism who will be less well supported, and may lead to an increase in people seeking a diagnosis to access support where previously they did not need to. It would be helpful to see a copy of the Equality Impact Assessment completed on this.
1 and 2	c. Where possible the draft Bill should seek close alignment with existing legislation to reduce cost implications. Where additional responsibilities are outlined, which are not met within current regional strategic action planning these should be resourced accordingly. This would enable regional areas to meet the standards set out which are above and beyond current duties.
1 and 2	d. Where possible the draft Bill should seek close alignment with existing legislation to reduce cost implications. Where additional responsibilities are outlined, which are not met within current regional strategic action planning these should be resourced accordingly. This would enable regional areas to meet the standards set out which are above and beyond current duties.

A22
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Fwrdd Rhaglen Dyfodol Anabledd, Cyngor Caerdydd
Response from Disability Futures Programme Board, Cardiff Council

Question 1

Consultation response no:	Do you agree that a definition of 'autism spectrum disorder' should appear on the face of the Bill?
1. 2.	No – the content of the Bill itself will define what is required – autism and ASD are seen as the same. However, if Neurodevelopmental conditions are included, then this may require definition of what this is and will cover. **<u>The act as introduced</u>** added the phrase *(b) for the purpose of this Act,* This has the potential to add to confusion as it implies that an alternative neurodevelopmental condition may be considered as autism only for the purpose of this act and not with respect to other statutory instruments which would be unchanged.

Question 2

Consultation response no:	Do you agree that using the WHO ICD-11 definition in the draft Bill, together with the power for Welsh Ministers to include other neurodevelopmental disorders, is the right approach?
1.	No This approach indicates that the Bill if passed will in future provide challenge for what is and what isn't included. Currently there is a clear notion of what autism does and does not include, and as such, services are designed around these needs to specifically meet those with the condition. Adding in Neurodevelopmental Disorders is a significant change in the list including as well as autism, ADHD, intellectual disability,

	communication disorders motor disorders, pathological demand avoidance etc. Whilst this is more inclusive, and supports alignment of the new ND teams and the IAS, this implies that these two services require legislation to work together across the lifespan. This significantly extends the Bill from its original focus on autism. It also has the potential for further conditions to be added in the future making planning for need based around populations and prevalence very difficult, and could potentially increase legal challenge in the delivery of services, where definitions are not clear. Listing conditions also has the potential to further medicalise an approach that should be seeking to enable children, families and adults to lead fulfilled lives that support wellbeing.
2.	For those experiencing other neurodevelopmental disorders, including them within legislation and a more strategic approach is likely to be welcome. However, there are a number of other identified groups which will become excluded who will not welcome the Bill because of preferential set of legal terms which exclude these other groups which in itself is discriminatory. Therefore, a preferred option would be to suggest additions to the SS&WB Act, which could provide a specialist overview for autism, but in its nature is an inclusive legislative all age Act. **The act as introduced** retained this section providing a power for Welsh ministers to introduce other conditions if necessary. This continues to be a section with the potential to lose the focus and purpose of the proposed Bill turning it into a pan-disability piece of legislation, which is effectively what the Social Services and Well Being Act is.

Question 3

Consultation response no:	Are the “relevant bodies” in section 7 of the draft Bill the appropriate bodies to implement the autism strategy?
1.	No – Noting that the key aspects of the Autism Strategy include: Access to healthcare services; access to education; access to employment; access to housing; access to Welsh language services; access to other public services; social inclusion; and access to advocacy services. Health and local government clearly have key roles to play in implementing the Autism Strategy and, if agreed, an Autism Act, but this is a wide remit covering areas that the LA and NHS will not have jurisdiction to enforce. Other partners, such as Careers Wales and the DWP oversee developments within employment and access to further education and the third sector may also have a role to play to ensure success. If only health and local authority are relevant bodies it is unclear how they would successfully exercise a duty in a non-devolved area such as employment. It is similarly unclear how Welsh ministers would exercise control over the DWP for example with respect to employment.
2.	**The act as introduced** does not change this section and the memorandum of understanding (Explanatory Memorandum) comments *“it is outside the competence of the Assembly to make legislation imposing additional duties on them*”. The outcome is that other than provision of autism training the only aspects that this Act could influence would be those that are delivered by devolved functions.

Question 4

Consultation response no:	Should the duty on relevant bodies to have regard to the autism strategy and guidance be reinforced by providing Welsh Ministers with a power of direction over relevant bodies?
1.	It could be suggested that 'relevant bodies' needs to be more prescriptive to include other bodies who should be directed to understand and act to undertake their responsibilities. There is a risk that wider organisations will see that an Autism Act is for local authorities and NHS services to implement, as opposed to a broader context of change as noted within the current strategy. With this in mind, it would need to be made clear to Welsh Ministers who are the relevant bodies that they give direction to, should there be a requirement to exercise power over a relevant body to act.
2.	**The act as introduced** changes wording from "*duty to have regard to*" to "*compliance with*". It is unclear if this indicates a broad power of direction over local authorities and health boards, with respect to compliance with this Bill, if passed. It also unclear whether this has potential to conflict with existing legislation that would lead to confusion.

Question 5

Consultation response no:	Do you have any views about the timing set out in section 1(4) of the draft Bill for the publication of the Autism Strategy?
1.	Yes – the timeframes set out are overly optimistic and carry risk. There will be a requirement for consultation. In addition, there needs to be recognition that local areas will have pre-identified commitments such as preparing for the implementation of the Additional Learning Needs and Education Tribunal (ALNET) Act, which are ongoing and require dedicated resources. Rushing the development of the strategy, and subsequent publication could lead to revisions being required earlier than needed and additional work at a later stage. A measured and realistic timeframe that takes into account the need to implement the ALNET Act, which also allows for engagement and inclusion of those who will be leading the implementation of an ASD strategy, would be more beneficial. This would support wider ownership of the strategy and any action plans that may develop as a result of this.
2.	**The act as introduced** is unchanged in wording it is unclear from the memorandum of understanding how this could be achieved in such a short time scale particularly considering the level of consultation with stakeholders that would be required.

Question 6

Consultation response no:	Do you have any views about the timing set out in section 3(2) for issuing guidance under the Bill?
1.	As above. It would be helpful to reflect on lessons learned from the implementation of the Integrated Autism Service and other time sensitive developments to understand the implications of setting timeframes that are challenging to achieve. Whilst positive change has occurred, there was a significant amount of preparation and planning time, which would have benefitted the development of an integrated service.
2.	**The act as introduced** is unchanged the memorandum of understanding envisages that guidance would be developed in parallel with the strategy. Work could therefore begin on the guidance as soon as the Act is passed, which would allow up to nine months for the process. This implies that the guidance can be written before the strategy has been written and consulted on which is poor practice.

Question 7

Consultation response no:	Do you have any views about the timing set out in section 9 for when the Act comes into force?
1.	The information provided implies that an Autism act would come into force prior to the publication of the ASD strategy or guidance. This would prove very challenging to implement as an Autism Act

	would have no purpose and will be challenging to govern without a code or standard as a basis to work undertaken. This could lead to legal challenges and vague expectations from those who may benefit from an Act, but no guidance to work from for those who are supporting these individuals. There would need to be an understanding that an Autism Act may come into force before duties of responsible bodies can be governed. It is therefore difficult to see how these timelines could be adhered to while allowing an appropriate consultation to take place leading to the publication of a strategy and guidance that is a practical and achievable. As the timeline implies that the guidance cannot be finally written until the strategy that informs the guidance has been created, these seem overly optimistic and unrealistic time frames.
2.	**The act as introduced** is unchanged, there are no notes in the memorandum and all concerns previously highlighted remain.

Question 8

Consultation response no:	Do you agree that diagnosis should be completed within timescales in the relevant National Institute for Health and Care Excellence guidelines, as set out in in section 2(1)(c) of the draft Bill?
1.	The NICE guidelines state that a diagnostic assessment for children should be started within the first 3 months. https://www.nice.org.uk/guidance/cg128/chapter/Recommendations#local-pathway-for-recognition-referral-and-diagnostic-assessment-of-possible-autism This does not refer to completion of assessment and confirmation if appropriate of diagnosis. There are no timeframes noted within NICE guidelines for adults for either assessment waiting times, or provision of a diagnosis if appropriate. Within Neurodevelopment Services, the 26-week diagnostic waiting time for children is from referral to first appointment, and the assessment and diagnosis process can take longer and should be bespoke to the needs of the individual but not excessively lengthy.

2.	It would be clearer to outline expectations for waiting times within an act or strategy, but with the acknowledgement of context and complexity of some cases that may require longer to assess to be able to confirm diagnosis. Performance indicators to ensure compliance should include waiting times for governance purposes, but allow for flexibility that accounts for a thorough needs assessment. Simply adding a target will not resolve the issue of waiting times. However, there is no maximum waiting time standard from referral to a final diagnosis of autism. This has been the subject of recent debate in parliament. http://www.normanlamb.org.uk/maximum_waiting_times_for_autism_diagnosis_needed It could be suggested that an Autism Act should refer to a minimum standard waiting time for adults and children, or timescales noted within NICE guidelines, whichever is shorter. **The act as introduced** changes the wording from “completed” to “commenced”. While this is positive and notes in the memorandum acknowledge that the potential complexity of the diagnostic process could make completion within three months challenging, it is doubtful if families and individuals would find this completely satisfactory. Commenced is the start of the diagnostic process and that can be simple steps such as a first telephone call or an initial screening questionnaire. Adding this target is not helpful to families and individuals and will not have the effect of resolving the issue of waiting times. It would be more helpful to define what “commenced” means for the purposes of this Bill as that will give consistency across families and service areas of expected waiting times.

Question 9

Consultation response no:	Do you agree that an assessment of care and support needs should be completed within 2 months of a diagnosis of autism spectrum disorder or any post-diagnostic meeting, as set out in section 2(1)(e)?
1.	No – a proportionate assessment of needs should be carried out post diagnosis, as is consistent with the Social Services and Well Being Act. The timeframe for completion of this proportionate assessment should be consistent with the SS&WB Act within Information, Advice and Assistance services, and where further assistance can only be delivered through the development of a care and support plan, this should also be completed under the principles of the SS&WB Act. The proposed Autism Act suggests a 2-month completion timeframe, whereas the timescale for completion of the assessment within the SS&WB Act is a maximum of 42 working days from the point of referral. This would require alignment to ensure all assessments are prioritised based on needs and not diagnosis. Using the term care and support needs implies that all individuals diagnosed with autism have needs that can only be met through the provision of care and support services. This is simply not the case, with many individuals diagnosed with autism never requiring any further support post diagnosis. There are however a number of individuals who may have care and support needs, which are unrelated to their diagnosis of ASD but need local authority intervention. As within the SS&WB Act it would need to be clear who would have a duty of care to complete assessments. An analysis of current capacity and demand within services would be required to ensure the resource implications for implementing this approach could be fully understood. A diagnosis of ASD should not be a trigger for care and support, but is an appropriate trigger in the requirement to assess and it would be expected that those assessing would be as outlined within the SS&WB Act.
2.	**The act as introduced** changes the time scale from 2 months to 42 working days. The memorandum clarifies that this change provides alignment with social services assessments for children. The memorandum provides some further clarification stating that some people with ASD would not have particular care and support needs, and that there should not be a presumption that a person with ASD would automatically have care and support needs.

	Although the memorandum clarifies that the Bill does not make this assumption it still assumes that an assessment of a person's care and support needs should take place, which may conclude that a person does not have any such needs. This still has resource implications because of current capacity and demand which implementing these additional assessments, albeit with no support needs will require. Under the SS&WB Act, an individual should be assessed at presentation of need for care and support. This Act as introduced has the potential to deny an individual access to assessment until a diagnosis has been made, thereby denying them access to care and service based on need. With this in mind, this piece of legislation will undermine the principles within the SS&WB Act.

Question 10

Consultation response no:	Do you agree that it is useful to include in the draft Bill a list of professionals who may form the multi-disciplinary team for diagnostic assessment?
1. 2.	No – The NICE guidelines outline the key individuals that can support a diagnostic assessment. **The act as introduced** does not change this list the memorandum notes that the list is advisory; there is no intention to set out a prescriptive list of professionals in the Bill, as introduced. Obvious gaps as noted in the memorandum are paediatrician and educational professionals. This section remains unnecessary, as the NICE guidelines should be the standard adhered to for both children and adults.

Question 11

Consultation response no:	If so, are there any other disciplines that you think should be listed as possible members of such a multi-disciplinary team?
1 and 2.	As above (Q10)

Question 12

Consultation response no:	Are there any other factors or individual circumstances which may inappropriately prevent access to services and which should be set out in the Bill?
1.	No - Specific services have eligibility criteria's to enable delivery to vulnerable groups (LD, MH services, Phys Dis etc) There would be resource implications if these services were to include ASD without associated LD, MH.PD etc and these service areas are already delivering to a growing population of eligible citizens. SS&WB Act provides care and support based on need not diagnoses. Equipping services to be able to assess based on need rather than diagnosis to ensure those in need of care and support have access to services that are able to best meet these needs. There should not be an expectation that a diagnosis of ASD is a gateway to services, this should be based on needs of an individual and prioritisation of resources to meet these needs.
2.	**The act as introduced** does not change the wording. The memorandum does note that a lack of staff training in and awareness of, ASD was also said by some respondents to result in barriers to accessing suitable services. This is more relevant and addressable than attempting to fit a person with an ASD diagnosis into an inappropriate team simply because that team happens to exist. Please also refer to response in question 9 regarding access to care and support based on need and not diagnosis.

Question 13

Consultation response no:	Should the draft Bill specify the types of data to be collected by Welsh Ministers to enable them to carry out functions under the Bill?
1.	Any personal data collected must comply with Data protection legislation (GDPR) In order to be consistent the population needs assessment, as identified in the SS&WB Act, should determine what data is collected. Currently ASD data is aggregated within LD and separating that data to clearly delineate the two conditions and the differences between the two population needs would be informative. Lumping autism generally in with LD is incorrect and unhelpful and creates an expectation among families and individuals that will not be fulfilled.
2.	**The act as introduced** has extensive additions in this area saying NHS bodies must collect the following data to assist them in the diagnosis and provision of services to persons with autism spectrum disorder The data requested is only diagnostic in nature and will not inform or assist in the provision of services. It is not consistent with the population needs assessment as identified in the SS&WB Act. The data listed indicates that this Bill is extensively clinical in nature and concentrates on the single event of diagnosis to the detriment of the wider needs of families and individuals.

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1.	Data gathered should be limited to that necessary in order to satisfy the requirements of data protection and requirements within the Population Needs Assessment to understand regional need. Any other data for ‘interest’ purposes should be done via research units only. Collecting and processing data should not be to an extent that is significantly beyond that collected for other similar conditions. To do so risks marginalising this population for study purposes. Were this being done for in a research setting it would be accompanied by extensive work around consent and ethics and involve a clear understanding by the individuals as to exactly how the data will be used and processed.
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1.	If at all, in the guidance
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1 and 2	c. Where possible the draft Bill should seek close alignment with existing legislation to reduce cost implications. Where additional responsibilities are outlined, which are not met within current regional strategic action planning these should be resourced accordingly. This would enable regional areas to meet the standards set out which are above and beyond current duties.
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A23
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Gymdeithas Seicolegol Prydain
Response from British Psychological Society

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:-
[redacted], Policy Advice Administrator (Consultations)
[redacted]

About this Response

The response was led on behalf of the Society by:
[redacted], BPS Policy Advisor

With contributions from:
[redacted], Division of Clinical Psychology
[redacted], Division of Clinical Psychology
[redacted], Division of Clinical Psychology

We hope you find our comments useful.

[redacted]

British Psychological Society response to the National Assembly for Wales

Autism (Wales) Bill

	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;
1.	Comments: 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. 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. 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

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.	Comments: There are long waiting lists for assessment and support – these difficulties will remain unless there are improvements in the workforce and specialist service provision. 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. *Social Work in Health Care, 46*(3), 85–106). Funding to implement the provisions of the Bill should be ring-fenced. 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. 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).
	Whether there are any unintended consequences arising from the Bill;
3.	Comments: The Society has no comment to make.
	The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum);
4.	Comments: The Society has no comment to make.
	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.	Comments: The Society has no comment to make.

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End.

A24
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan GolegauCymru
Response from CollegesWales

ColegauCymru
CollegesWales

National Assembly for Wales: Health, Social Care and Sport Committee

Inquiry into general principles of the Autism (Wales) Bill

14 September 2018

[redacted]

[redacted]

Introduction

ColegauCymru welcomes the opportunity to respond to the National Assembly for Wales' Health, Social Care and Sport Committee on the Autism (Wales) Bill.

ColegauCymru represents the 13 further education (FE) colleges and FE institutions in Wales and exists to promote the public benefit of post compulsory education and learning. This response has been drafted from views from college representatives following a call for views and a working group meeting that included representatives from Coleg Cambria, Bridgend College, Coleg Sir Gar, Pembrokeshire college, The College Merthyr Tydfil and Coleg Gwent.

1. 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

1.1 ColegauCymru welcomes the Autism (Wales) Bill, subject to the observations set out below. We recognise the importance of the work and feel that an Autism Strategy will focus more attention from all services on raising awareness of autism and creating a smooth system from diagnosis to services, thus protecting and promoting the rights of those with autism. This should improve the experiences of those with autism and their families, including within learning environments. The emphasis should be on 'best practice' with an opportunity provided for a review of current systems in order to identify weaknesses and to look for more sensible approaches to identification and diagnosis.

1.2 We welcome the recognition that this Bill seeks to supplement and support, not replace provisions in the Additional Learning Needs and Educational Tribunal (Wales) Act 2018 (ALN Act), thus focussing primarily on health and diagnosis. Speedy diagnosis and identification of needs will assist in ensuring that Individual Development Plans are based on accurate information and assist in the multi-agency approach in working with young people with autism.

1.3 The recognition of the need for the strategy to be for 'people' with autism; to include adults as well as children and young people is vital; improving understanding and responding to the needs of adults in the Strategy should begin to address the difficulties that those with autism frequently face in all areas of their lives. The focus of the Bill is, rightly, about earlier diagnosis and successful individually targeted interventions. This, in the long term, may reduce care needs and increase employment potential for young children currently going through diagnosis process. ColegauCymru welcomes the recognition, in the explanatory notes, of the difficulties that young people and adults currently face in gaining employment. It is hoped that the Strategy will lead to a greater understanding of the difficulties of transition from education into employment. This must include an acknowledgment of the need to focus on specific skills development for employability, as well as resources targeted towards access/supported access to work.

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

2.1 ColegauCymru raised a number of potential barriers in the response made to the previous consultation and it is good to see that most of those have been taken into account and amendments made. This is especially the case in relation to the changes that have been made to timescales, including the period from referral to diagnosis (now to the start of the diagnostic process).

2.2 However, we still have major concerns about the lack of resources and skilled professionals to meet the current demand for services and any additional demand that this Bill will bring. This concern is raised as a result of our current experience in making the way for the implementation of the ALN Act. Many of the problems that are currently experienced – diagnosis, assessment and access to care and support – are not about willingness, but about a lack of resources and skilled professionals. It will take significant time and funding to build the numbers of key professionals required and to ensure that there is consistency of high quality services across Wales, without the need for individuals having to travel large distances to access these provisions. There is potential for Local Authorities, Health Boards and Social Services to be involved in expensive litigation because of difficulties in complying with the legislation if these issues are not addressed adequately and at an early stage.

3. Unintended consequences arising from the Bill;

No additional unintended consequences have been identified at this stage.

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

4.1 The financial implications as set out in Part 2 of the Explanatory Memorandum are not easy to understand and it is difficult to see how the majority of people with autism and their parents and carers would be able to provide an informed response on this.

4.2 The information provided is based on an estimated number of persons with autism in Wales, extrapolated from work carried out for Scotland as no data regarding accurate numbers for Wales currently exists. Likewise, the information in costing the options seems to have proved to be a difficult operation with many costs unknown. However the underlying message would seem to indicate that Wales already spends significant amounts on diagnosis, identification of needs and provision for people with autism. Therefore, the introduction of a Bill could provide benefits in terms of earlier identification of needs and interventions that could make a difference and lead to a possible reduction of costs over a lifetime.

4.3 There are a number of points that need further clarification:

- **Training:** The costs of training include teacher and school staff training, however no specific mention is made of training for teaching and support staff in Further Education. We are very concerned about this and that once again it appears that the important contribution of FE Colleges to the education of post-16 learners has been overlooked or at the least, not fully considered.

  For academic year 2016-17, there were 128,690 learners enrolled in further education institutions (this includes full and part-time study, as well as work-based learning).[1] According to further Welsh Government statistics in February 2018, 1,150 learners who disclosed a diagnosis of autism were enrolled at Further Education Colleges in Wales[2]. Given the difficulties experienced by young people in transition to adulthood and employment, it would seem to be a major oversight if FE staff have not been specifically included in training programmes. These are key professionals and must be fully involved.

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[1] https://statswales.gov.wales/Catalogue/Education-and-Skills/Post-16-Education-and-Training/Further-Education-and-Work-Based-Learning/Learners/Further-Education/uniquelearnersenrolledfurthereducationinstitutions-by-age-modeoflearning-gender [accessed 14-9-18].

[2] https://statswales.gov.wales/Catalogue/Education-and-Skills/Post-16-Education-and-Training/Further-Education-and-Work-Based-Learning/Learners/Further-Education/uniquelearnersenrolledfurthereducationinstitutions-by-primarydisability-gender [accessed 11-9-18].

In addition, the Committee should enquire as to the extent to which apprentices with an ASD diagnosis can be supported under the current contract for Work Based Learning. This provision is currently made on the basis of a framework drawn up under Work Based Learning contract 4 (running 2015-2019) and already requires considerable investment from the Welsh Government to address matters of equality and quality of provision. ColegauCymru would question the extent to which the procurement of vocational education services can be expected to meet the diverse needs of learners particularly those with additional or complex needs such as Autism. ColegauCymru also notes the ALN Act places a statutory duty on FE provided work-based learning to deliver person-centred provision for apprentices with identified additional learning needs. To support the aims of this Bill, the opportunity should be taken to cease the anomaly whereby apprentices with Additional Needs subject to programmes provided by for-profit training providers are not offered the same level of person-centred support as their peers trained via FEIs. An amendment to this Bill should include a provision to amend the Additional Learning Needs (Wales) Act to this effect.

- **Access to employment:** Supported employment schemes are effective but costly. Continued support needs to be in place for those who succeed in gaining employment to ensure that they maintain their jobs and to eliminate potential difficulties within the workplace. ColegauCymru questions whether funding for this been included in the costings.

5. 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).

5.1

- **Additional categories of data to be captured by NHS bodies –** ColegauCymru feel that it is appropriate for Welsh Ministers to prescribe additional categories of data to be captured providing this does not amend the law or confer additional rights in relation to the protection of personal data. It is likely that further categories of data may be required in future years to ensure that the strategy and guidelines remain relevant.

- **Allowing Welsh Ministers to make regulations which include, for the purposes of the Bill only, other neurodevelopmental disorders in addition to the WHO definition of autism spectrum disorder** – Again we feel that this is appropriate and will future proof the Bill for changes and research discoveries. Consultation with relevant bodies and others would be essential before any changes were made.

- **Make regulations that extend the definition of ‘relevant body’ for the purposes of the Bill beyond the local authorities and NHS bodies** – At present, the definition of ‘relevant bodies’ does not include Further Education. Representatives from FE colleges at the working group expressed a strong view that FE should be included, particularly in consultations regarding the preparation and review of the autism strategy and in issuing guidance or revising it. Further Education Colleges are unlikely to be carrying out assessments but have a significant role to play in the delivery of post-16 education services.

5.2 Colleges are already included in the new ALN legislation, and it is likely that this will be sufficient to cover the provision made. However, as there would be implications for administration, resources and funding, it would be essential that further consultation took place if at any time Further Education were to be ‘deemed appropriate’ to be included as a relevant body.

[redacted]

September 2018

[redacted]

A25
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Gymdeithas Llywodraeth Leol Cymru
Response from Welsh Local Government Association

WLGA EVIDENCE TO THE HEALTH, SOCIAL CARE & SPORT COMMITTEE'S INQUIRY INTO THE AUTISM (WALES) BILL

CLlLC • WLGA

September 2018

About Us

The Welsh Local Government Association (WLGA) represents the 22 local authorities in Wales, and the three national park authorities and the three fire and rescue authorities are associate members.

The WLGA is a politically led cross-party organisation, with the leaders from all local authorities determining policy through the Executive Board and the wider WLGA Council. The WLGA also appoints senior members as Spokespersons and Deputy Spokespersons to provide a national lead on policy matters on behalf of local government.

The WLGA works closely with and is often advised by professional advisors and professional associations from local government, however, the WLGA is the representative body for local government and provides the collective, political voice of local government in Wales.

The WLGA, working in partnership with Public Health Wales has hosted a National Autism Spectrum Disorders (ASD) Development Team for a number of years. The team have played a key role in supporting the creation and formation of an Integrated Autism Service (IAS) for Wales and have provided a range of useful resources and advice in supporting public services in better responding to the needs of autistic people. The team are an integral part of the Welsh Government's refreshed Autistic Spectrum Disorder Strategic Action Plan.

Introduction

It is important to acknowledge the progress that has been made since the original ASD action plan was published in 2008, with one of the key achievements being the increased profile and awareness of autism in Wales. There is a wide range of information and resources available to help autistic people and their families and carers, as well as resources for professionals. This progress has been made without the need for legislation. However, we are aware that more can always be done and that some of the improvements and actions will take time to deliver. We all want to see a real difference in the services, care and support available to autistic people, their families and carers and so it is appropriate that we take the time to consider the proposals set out in the Autism (Wales) Bill and whether legislative changes will actually bring about the desired outcomes.

We are clear that any new legislation needs to add value, make a real difference and have an impact, compared to what could be achieved without specific legislation. The reality is that ineffective legislation would only disappoint the high expectations that autistic people and their families and carers have that new and additional legislation will make meaningful changes to the services available to them.

The WLGA previously responded to the consultations on the general concept of a proposed Autism (Wales) Bill and on the draft Autism (Wales) Bill in which we highlighted our fundamental concerns about the approach of creating separate legislation for a particular condition. We believe that legislation such as the Social Services and Well-being (Wales) Act 2014, the Additional Learning Needs and Education Tribunal (Wales) Act 2018, the NHS (Wales) Act 2006 and the Equality Act 2010 should, if they are working correctly, deliver for all our citizens on the basis of need. Given the existing legislative foundations and powers that are already in place in Wales and the fact that we have previously highlighted that many of the aspects of the Bill that have been proposed would better sit within guidance / codes of practice rather than in primary legislation we remain unconvinced of the need to create this separate piece of legislation and would rather build on and use the powers and mechanisms that are already in place to strengthen the services, care and support available to autistic people, their families and carers.

We are therefore not supportive of the need for an Autism (Wales) Bill. We believe that placing a specific autism strategy in statute risks distributing resources inequitably, and without necessarily building a sustainable and strategic longer term solution that addresses the needs of autistic people. In our view, the risk is that the Bill could lead to resources and activity being governed by a narrow set of statutory processes, rather than being directed according to the delivery of improved outcomes. This could lead to particular difficulties for councils in the context of budgets that are already stretched and there is a fear that money could end up being directed away from other support services and that any benefits for autistic people could be at the expense of people with other disabilities. There is also a risk that this Bill will add complexity or duplication, for example in respect of carers.

Serious consideration also needs to be given to the implications of setting such a precedent going forward, as services for autistic people is not the only area where there is a need for service improvement for people with specific conditions. It is essential that we fully identify and consider any unintended consequences of legislating on a particular condition, and that we explore any risk that such legislation may impact on our ability to respond to others on the basis of need.

Progress to date

When considering the need for additional legislation it is vital that we consider the progress that has already been made in Wales under the existing legislative and policy arrangements, along with the planned work that is already underway, to help us weigh up what added value, if any, additional legislation would bring.

Since the development of the Autism Strategy in 2008 and the subsequent Refreshed ASD Strategic Action Plan in 2016, Wales has seen much progress in relation to services and support for autistic people, with awareness increasing, a range of resources being produced and training developed and rolled out. Working closely with Welsh Government (WG), local authorities and health have established, or are in the process of establishing, 7 regional IAS’s. They are funded by WG through the Integrated Care Fund (ICF), based on the Health Board footprints with oversight by the 7 statutory multi agency Regional Partnership Boards focusing on integrating health and social care. The IAS’s collectively contribute to what can be seen as a national service with similar and consistent standards and practice, providing advice, guidance and offering practical solutions to a range of challenges.

During 2017/2018, Cardiff and the Vale, Cwm Taf, Gwent and Powys IAS's were launched in the first phase of development and became operational, while North Wales launched in June 2018. West Wales and Western Bay continue to make progress in readiness of launching later this year and there will be an operational IAS in each region by Autumn 2018. The National ASD Development Team has supported the creation of these IAS's and continues to do so for those areas not yet fully operational.

Part of the National ASD Development Team's role is to develop and provide resources in partnership for the benefit of autistic individuals, parents and carers and professionals. Their website (www.ASDinfoWales.co.uk) is a key part of this offer and is funded by WG as part of the ASD Strategic Action Plan for Wales. It contains a wide range of information, advice and resources for autistic people and those that support them, as well as professionals with an interest and role in autism and to ensure that the needs of autistic people are communicated to key stakeholders. The team continues to raise awareness of autism and develop training, awareness raising and supportive autism resources that can be utilised by the IAS, wider services, autistic people and all those who support them. The National ASD Development Team also support the co-ordination and delivery of training in line with the National Training Framework for Wales. The "Can You See Me?" scheme promotes awareness and acceptance in communities to improve access to community provision for autistic individuals. Specific training is available on the national website for sectors such as sports and leisure providers and housing providers (www.ASDinfoWales.co.uk/leisure-staff and www.ASDinfoWales.co.uk/housing-provider-scheme).

Some of their resources that have been developed are listed below:

Growing with Autism

The Growing with Autism resources are aimed at parents and carers of children and younger adolescents. A range of resources are available, including a guide following diagnosis, advice sheets, child personal profile builder, picture cards to structure a child's daily activities, 5 short films which provide an overview of autism and advice on other common issues including communication planning, coping with changes and visiting health professionals.

Resources to support peers and siblings in understanding autism have also been developed. Teifi and Friends is an animation, voiced by the cast of Stella, which shows young children how to be kind and accepting to those with additional needs. Autism Superheroes is available as a story book and adventure comic strip story designed to develop understanding of autism for children of primary school age.

Learning with Autism

There are a series of resources aimed at educational settings from early years to secondary school and with a further education and work based learning programme currently in development. The Learning with Autism programmes are designed to help staff develop their knowledge and skills to support those with autism. Children and pupils are also encouraged to undertake learning with the Teifi and Friends, Autism Superheroes and Sgilti resources. Once all staff and pupils have undertaken the appropriate training schools can apply to become an Autism Aware setting.

Living with Autism

The Living with Autism resources include a supportive guide containing tips and advice to those that have received a diagnosis of autism. Individuals are also able to search an idiom glossary and can create and download a personal profile to highlight their strengths and difficulties and ways in which others can support them.

Working with Autism

There are resources for those supporting autistic people into employment and for managers and co-workers for those working in HR. Resources to support employers include the Living with Autism film and an e-learning training. To support individuals into employment there is a CV builder, searching for work tool and a skillset builder. For co-workers and managers there is the Positive about Working with Autism scheme which includes a charter to sign, advice and a training scheme for those working in HR.

The National ASD Development Team is also facilitating an adult diagnosis Community of Practice, bringing together health and social care professionals in order to develop consistent assessment, diagnostic and support pathways across Wales. The 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 IAS. The National ASD Development Team further facilitates a network of local authority ASD leads and IAS leads across Wales. The newly established National IAS Leads Network will work collaboratively with the team and WG to finalise reporting ICF templates for the next financial year to ensure that information collected provides information on the outcomes and impact of the services. There will be further work to align data collected in the IAS and that collected in the Neuro Developmental services. These fora are critical to sharing good practice, exchanging knowledge and maintaining a key focus on the needs of autistic individuals, parents, carers and families.

It is also worth noting that WG have already identified that they intend to introduce a Code of Practice on the delivery of autism services which will be published under the Social Services and Well-being (Wales) Act 2014 and the NHS (Wales) Act 2006 next year. This aims to provide clarity on the support autistic people can expect to receive and will provide guidance on how services can adapt their practice to meet the individual needs of autistic people.

The Explanatory Memorandum that sits alongside the Bill makes frequent reference to the fact that the Bill builds on the existing arrangements identified above. For example:

- “build on the gains made by the Strategic Action Plan”
- “build on the current arrangements for data collection, which are currently under development”
- “build on materials already prepared for this Code of Practice [to be developed under the Social Services and Wellbeing (Wales) Act]”
- “the awareness raising campaign for this Bill will build on these existing resources [those already developed by the National ASD Development Team, such as the ‘Can You See Me?’ campaign]”
- “the Bill builds on the ambitions of the Welsh Government’s Autism Spectrum Disorder Strategic Action Plan, which originally established an autism infrastructure in each local authority area, with local co-ordinators and strategies and a Wales national co-ordinator.”

This underlines the fact that much of what the Bill sets out to do is already in train – a lot of progress has already been made and the autism specific legislative proposals being consulted upon highlight the existing rights that already exist and which can be achieved through other routes. However, we also need to recognise that much of the work that has started is still in its formative stage, such as the establishment of the regional IAS’s. Through the Strategic Action Plan and the roll out of the IAS we are now seeing significant improvements in services emerging and a renewed appetite for collaborative working across sectors. We need to focus our attention on delivering the services and support which can make a real difference to the lives of autistic people and their families by supporting the establishment of these services and allowing them time to embed new pathways rather than potentially destabilising or hindering some of this progress. The implementation of the National IAS is currently being independently reviewed, with the outcome of this review due by March 2019 and so we need to await the outcome of this review before looking to make any further changes and considering whether any changes in policy, or indeed legislation are required in order to improve services.

English and Scottish Experiences

It also worth noting the experience in England and whether introducing specific autism legislation actually leads to improvement in services. In England the Autism Act received Royal Assent in November 2009 and placed statutory requirements on the Government to publish an adult autism strategy and associated statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism. A key action from the *Think Autism* strategy was that NHS England would help improve autism diagnostic services, however in the latest Autism Self-Assessment Exercise published by Public Health England only 22% local authorities reported meeting the National Institute for Health and Care Excellence (NICE) recommended waiting times, with some areas in England reporting assessment waiting times of up to two years[1]. The National Autistic Society suggested that the results from the latest progress report exposed "the autism diagnosis crisis" in England despite having legislation in this area.[2] This raises the question of how effective introducing new legislation is in actually improving services for autistic people and whether in fact there is a danger that the development of an Autism Bill at this stage will cut across the work already being undertaken, and in turn cause difficulty in delivery of a consistent approach.

In Scotland the proposed Autism Bill fell at stage 1 in January 2011 after the Scottish Parliament disagreed to the general principles of the Bill. The lead Committee for the Bill was the Education, Lifelong Learning and Culture Committee who concluded that:

> "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."

They also felt that the Bill as introduced would not overcome the barriers to service delivery nor satisfy the expectations of people with autism. They pointed to the fact that there were significant pieces of relevant legislation, similar to the situation in Wales, that had not been in force for a sufficient amount of time to evaluate their impact and so the Committee were not convinced of the need for additional legislation and that **"**resources would be better spent focusing on the implementation of existing legislation and duties".

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[1] https://www.bbc.co.uk/news/uk-england-norfolk-41112597

[2] https://www.autism.org.uk/get-involved/media-centre/news/2017-07-05-autism-support-report-england.aspx

Comments on the proposed Bill

Whilst we have significant reservations about the approach being considered in creating new and additional legislation, below we highlight some specific comments related to the Bill as currently drafted, though overall we believe that the drafting of the Bill would need to be strengthened, with some aspects of the Bill lacking clarity around expectations.

Autism Strategy

Under 1(7) reference is made to the need to commission an “independent” report, whilst we recognise the need to review progress and report on implementation we would question the use of the word “independent”, what is meant by this and whether it needs to be placed on the face of the Bill?

Under 2(1)(a) the Bill identifies that the Autism Strategy must establish a best practice model or models. This seems far too restrictive to prescribe the models that must be established and may hinder innovation in the future, it may be better to highlight pathways rather than models.

Under 2(1)(c) the Bill requires diagnostic assessments be commenced as soon as reasonably practicable following a referral, and at least within any timescales set out in the relevant Quality Standard issued by NICE (currently 13 weeks). This differs to the current Welsh Government guidance, setting a 6 month (26 week) target. The Community of Practice for Adult diagnosis and IAS practitioners’ are responding separately to the inquiry, in their response they highlight this element of the Bill and the challenges and implications involved and we endorse their comments. Whilst it is not ideal to not have any timescales, in reality, the current blanket 26 weeks’ target does not reflect the complexity of many referrals, with a 13-week timescale further challenging this and not reflecting the length of time required to undertake what are often complex assessments. In addition, best practice dictates that diagnosis and assessment should be on a multi-agency basis and therefore, the imposition of timescales might negate or work against such an approach. Work is currently being undertaken by clinicians, practitioners, Welsh Government and the National ASD Development Team to look at diagnosis and assessment timescales as part of the ongoing work around the development of the IAS. It is envisaged that draft guidance will be issued for consultation in the 2018/19 period. While time is a factor in conducting assessments, the quality of the assessment must take priority.

2(1)(g) identifies that the autism strategy must outline how the needs of persons with ASD are to be met by relevant bodies in respect of, but not limited to: access to healthcare services; access to education; access to employment; access to housing; access to Welsh language services; access to services in other languages; access to other public services; social inclusion; and access to advocacy services. Some of these areas are far too general, for example how will access to employment, or access to public services be covered in any meaningful way? Rather than putting these areas on the face of the Bill, they would sit better within guidance.

2(1)(l) states that the autism strategy must, “make provision for the wishes of persons with autism spectrum disorder and of their families and carers to be taken into account”, however under 4(6)(b) reference is made to “persons who are to be classed as carers for the purposes of this Act”. It is not clear what is meant by those who will be classed as carers for the purposes of this Act, how does this fit with the Social Services and Well-being Act and the definition of a carer under that legislation? Are we creating different definitions of carers under different pieces of legislation? This highlights the complexities associated with creating additional legislation for groups that are already covered under existing legislation and the need to be clear on what rights and expectations people have, ensuring that new legislation complements existing laws.

Guidance by the Welsh Ministers

4(2) identifies that guidance must be issued within 3 months of the publication of the strategy. Our previous consultation responses raised concerns with this timescale as the work to develop guidance needs to be progressed collectively and so appropriate time needs to be given to allow for this approach. We therefore still question whether the three-month period set out in the Bill would be sufficient and suggest more time needs to be allowed for.

Under 6(f) the Bill states that “guidance issued under this section must in particular include guidance about local arrangements for leadership in relation to the provision of services”. It is not clear what is meant by this clause, nor what it seeks to achieve and so further clarification is needed.

Data on autism spectrum disorder

Further clarity is needed on what the data will be collected for, how and for what purpose it will be used and why are certain types of data identified but not others? For example, why is gender identified, but not other protected characteristics? It would also be helpful to identify timescales involved and consider how manageable over time some of the expectations will be on the data identified as needing to be collected.

Financial Implications

In our evidence in response to the development of the Social Services and Well-being (Wales) Act we consistently highlighted the resource implications for implementing that piece of legislation and the same is true of this Autism Bill. Many authorities are having to juggle a number of unfunded pressures with unprecedented reductions in funding. We believe that there should be full and early engagement with all stakeholders in the formulation of legislation and that the financial impacts should not be assessed in isolation but part of the whole programme. It is vital that any new duties and burdens created are identified and fully funded. Any legislation that is enacted also needs to be assessed after it has been implemented independently of government. The reality is that if the true costs of implementing this proposed legislation and guidance are not identified, then its introduction could result in resources being directed away from other support services in order to provide the relevant services for autistic people.

The Explanatory Memorandum identifies additional costs of over £7 million, this is a significant resource requirement that would need to be fully funded and supported, with ongoing monitoring of these costs to ensure that the additional responsibilities continue to be fully funded. Whilst the Memorandum argues that there is evidence that the Bill will result in considerable benefits, both direct and indirect, it fails to identify what these are, stating that, “these are not possible to quantify and hence unknown.” The biggest costs attributed to the Bill are in relation to the cost of meeting the additional demand of the 13 week waiting time. As identified by the Community of Practice for Adult diagnosis and IAS practitioners’ response the diagnostic assessment is just one step in people’s journey in relation to autism services and whilst it is important that people are not just left waiting for a diagnostic assessment this is a very small part of what they will require from services. The focus should not just be on meeting waiting times, but has to take into account all of the other work that is delivered by specialist autism services. Significant amounts of additional funding are needed to be able to clear existing waiting lists and to then be able to keep within the proposed time-scales so that they do not compromise on the other work they deliver. There is also a need to ensure that there is appropriate post diagnostic support available, which also requires additional investment in order to be able to meet the extra demands being placed on services.

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, with recruitment to some autism services across Wales being problematic because of a lack of staff with the necessary skills and experience.

Conclusion

Significant progress has been made in Wales in recent years in improving services and support for autistic people, with awareness increasing and a range of resources being produced and rolled out. This progress has been made without the need for additional legislation. Existing legislation in Wales such as the Social Services and Well-being (Wales) Act, the Additional Learning Needs and Education Tribunal (Wales) Act 2018, the NHS (Wales) Act 2006 and the Equalities Act 2010 are already in place and provide existing rights to autistic people, which if working correctly will deliver for all of our citizens on the basis of need and can be used to meet the ambitions of the proposed Bill. There are also implications of setting such a precedent going forward of introducing condition-specific legislation which could lead to other calls for the introduction of specific legislation for other illnesses and conditions without robust evidence being available.

There is evidence to suggest that where autism specific legislation has been introduced, such as in England, it has not led to improved outcomes for autistic people and has not brought about the benefits originally envisaged. We firmly believe that the focus in Wales should be on using the resources available to focus on the implementation of existing legislation and duties, concentrating on the work that is already in train, which the Bill seeks to build on, focussing our attention on delivering the services and support already in development which can make a real difference to the lives of autistic people, their families and carers.

A26

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Dr Dawn Wimpory

Response from Dr Dawn Wimpory

Autism Bill Consultation response from Dr Dawn Wimpory, Consultant Clinical Psychologist – Lead for ASD (BCUHB) and Lecturer (Bangor University)

I have held an autism-specific clinical and research joint post for the last 3 decades and have been invited to present evidence to the scrutiny committee for this bill on 3.10.18. (I was also asked by the Division of Clinical Psychology, for the British Psychological Society, to represent them in their response to this bill but had to decline as I shall be abroad on the date that my presence was required for that.)

1) <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>

I think the general principles of the bill are sound and that they will help Wales to meet the needs of children and adults with ASDs, and achieve the aim of protecting and promoting their rights, more than previous strategies have been able to do. I was on the original strategic group for the first ASD action plan and have seen the level of impact of this and subsequent action plans over the last decade; as a result I think it is appropriate to bring in legislation to address the issues of concern.

2) <u>Any potential barriers to the implementation of the provisions and whether the Bill takes account of them</u>

I think that staffing and their organisation may represent potential barriers to the implementation of the provisions in the Bill in relation to waiting list times. Specifically this may include initial difficulty with commencing ASD assessments within 3 months of referral. However, I think it is inappropriate that Wales should have guidance of 26wk maximum Waiting List (WL) time (e.g. for children) whilst NICE guidelines from England specify 3months for adults and children. It seems appropriate that any ASD legislation for Wales at least matches NICE-issued guidelines. I think it is positive that individuals who appear inappropriate referrals can be advised of this promptly and possibly redirected to other services by clinicians.

I am concerned that discussions of the this Bill have been erroneously representing the 13 wks until *commencement* of assessment as 13 wks until a *diagnosis* should be made (this appeared to be how it was represented by the new WLGA national ASD Lead at a recent regional IAS strategic meeting and subsequent written communication reflected this misunderstanding). These are very different in terms of the implications/resources required for each and

I would be very disappointed if confusion around this issue influences receptiveness to the bill on a larger scale.

Currently, waiting lists, e.g. in children's ND services, are being clogged by inappropriate referrals that tend to be held there for too long. After such cases have waited for an unreasonable amount of time, there is a tendency to feel that they are 'owed' an ASD assessment even when other indicators show that this is not the most appropriate use of resources. I think that removing such cases from ASD WLs early on, as advocated in the bill, will ultimately reduce pressure on WLs and therefore proved helpful. Of course additional resources may well be necessary, especially initially, in order to assist in this reorganisation of how services/WLs are organised.

I also think it is important that clinicians can focus half their efforts on supporting families of clients with ASD, rather than be consumed by assessment work - I am not yet certain that the bill addresses the need to protect intervention time within services for these clients.

I welcome the bill's position in requiring services to record ASD diagnoses. Under my own direction, BCUHB has successfully collected and collated such diagnostic information for children over the last 6yrs and is therefore unique in Wales in being able to identify accurately whether or not research-supported internationally-recognised prevalence rates are being adhered to, or exceeded or failing to be reached. BCUHB’s Autism Module enables examination of such figures within each of the 3 constituent areas of BCUHB and over the HB as a whole. Such figures are absolutely essential in Wales being able to identify whether diagnoses are being made at appropriate levels.

It is both inappropriate for ASD diagnoses to be missed and for people without ASD to be erroneously diagnosed as having ASD. These are real dangers and can only be addressed through accurate data recording and analysis in a constant manner. BCUHB's database, conceived originally by WG, as a pilot for the whole of Wales, has demonstrated that such data can be efficiently and routinely recorded/analysed. I understand concerns from other services that this may be an impossible task but 6yr's experience with our ASD database proves otherwise. Software for this database, via CCH2000’s database system of electronic records, already exists throughout NHS Wales. CCH2000 is currently migrating to an upgraded system, CYPRIS. ABHB are the first Health Board to use the Autism Database Module on CYPRIS.

3) Whether there are any unintended consequences arising from the Bill

My experience of successive ASD all-Wales strategies is that they have not drawn attention away from, eg, ADHD, so I do not envisage this as an unintended consequence of the Autism Bill. However, IF diagnoses of ASD were to proceed without prevalence levels being checked (as the Bill sets out to avoid through the data collection referred to above) then there might be a risk that resources are not allocated appropriately to the correct service users. But the latter risk already exists without the Autism Bill anyway.

It would seem essential that the bill is applied to private services as well as to statutory services so that the former adhere to standards required of the latter; this is particularly important to help address any over-diagnosis of ASD in private provision, possibly through less thorough assessment strategies.

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

My understanding of the bill is that it has been supported through appropriate research and reviewing of available information, including financial elements; I particularly welcome the involvement of Professor Martin Knapp at LSE as appropriate international expert in this aspect of ASD. The data collection/analysis elements of the bill are based on experience of 6yrs piloting an ASD Database Module that was piloted by WG in anticipation of All Wales roll out.

5 **)** 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)

Unlike NICE guidelines that advocate both ICD-10 and DSM5, the Bill employs just DSM5, this seems regrettable as there have been some criticism of this system (e.g. that it may be too influenced by insurance issues in US). It seems surprising, and perhaps too bold, that ministers will be able to extend the client group to whom the Autism Bill applies, in addition to ASD in the future.

I welcome a bill that identifies the unique difficulties and challenges presented by autism to services and their uses. It seems too wide that ministers might expand the neuro-developmental conception of service users to whom the bill might apply in the future. As a related example, the current strategic inclusion of ADHD child referrals along with those for ASD has been not been helpful in my experience. This is because approximately half of those children with diagnosed with ADHD have an emotional or environmental basis for their diagnosis (as outlined by Dr. Elspeth Webb, Consultant Paediatrician, ND national presentation), whereas this is not the basis of ASD. Clinicians working with each group of children therefore require a different skill set and, in my experience, services for children with ASD can be slowed down by the contrasting needs and challenges presented by those with ADHD.

Hopefully ministers would not be defining the boundaries of ASD. Instead it seems appropriate that research-informed leaders of the ASD clinical field should take that responsibility, with research-evidenced prevalence figures in mind. As a disability, even in high functioning individuals, ASD should only be diagnosed (through the NHS or private services) where there is a level of impairment that warrants clinical recognition.

Dr Dawn Wimpory
Consultant Clinical Psychologist – Lead for ASD (BCUHB) and Lecturer
([redacted]) ([redacted])

A27

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Rheolwyr y Gwasanaethau Anableddau a Phobl Agored i Niwed, Adran Gofal Cymdeithasol Conwy

Response from Managers of the Disabilities and Vulnerable People Services, Conwy Social Care Department

Good afternoon,

Please find enclosed within this email, responses from the Conwy Social Care Department, in particular from Managers of the Disabilities and Vulnerable People Services.

- 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; **The Bill is not clear on general principles as is for example: the Additional Learning Needs and Education Tribunal (Wales) Act (2018), the Social Services and Wellbeing (Wales) Act (2014) and the Wellbeing of Future Generations (Wales) Act 2015. I would argue that the principles of the SS& Wellbeing Act (Wales) 2014 are relevant and are focussed on protecting people's rights irrespective of diagnosis. I am aware that the Bill is intended to complement the ALN, & SS&WB Acts, but it is very much focussed on provision of services rather than on individual wellbeing outcomes.**
- Any potential barriers to the implementation of the provisions and whether the Bill takes account of them; **Capacity to undertake a proper and holistic diagnosis. Impact of Brexit on the NHS and ability to respond. Impact on Wales of the Brexit in terms of support staff. The interface between rights of the individual set out in this Bill and those enshrined elsewhere especially within the SS&WB Act.**
- Whether there are any unintended consequences arising from the Bill; **- This would create a two tier system where the rights of people with Autism to access diagnosis within a specified period could impact on the rights of other people with disabilities to have access to diagnosis.**
- **Capacity within Organisations to respond to timescales would drive the focus of services and delivery. Diagnosis is an output and not an outcome, this Bill is contrary to the SS&WB Act which is focussed not on diagnosis but on rights, wellbeing and outcomes. It is interesting that a focus of the Bill is diagnosis, yet the Neurodevelopmental Pathway work is very much focussed on outcomes for the child. We understand that families want a diagnosis as this enables them to understand their child's world better, but there are also often expectations that with a diagnosis comes access to services. We need to switch the thinking and culture towards outcomes in line with the SS&WB Act. This Bill is a retrograde step from the aspirational SS&WB Act (move from service led to focus on the person). The memorandum states that it is complementary, but it interferes with the guiding principles of the SS&WB Act for a specific group of people.**
- **Introducing a 42 day timescale for assessment of need may be appropriate for children and in line with SS&WB Act but is not so for adults and would result in an inequitable approach. Currently there are locally agreed PI's but not national ones on timescale for assessment. Which would be the primary diagnosis for someone with and a Learning Disability and ASD?**
- **We feel strongly that the Bill, if it is to proceed should not stray in to areas already covered by the SS&WB Act and ALN Act. That if it is to proceed; the Bill should only focus on areas that are not covered by other legislation.**
- The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum); -
- 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 regulation-making powers in this section allow the Welsh Ministers to make regulations, 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’. – that could include Learning Disability and a whole other range of Neurodevelopmental conditions such as dyslexia, dyspraxia, ADHD etc.

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.

A29

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Dr Elin Walker-Jones

Response from Dr Elin Walker-Jones

Evidence for the Autism Bill

General principles

Generally speaking an Autism Bill to enshrine the rights of individuals with Autism is long overdue: England and Northern Ireland already have such legislation. We need a consistent, Wales-wide strategy to ensure that individuals can access a timely and reliable diagnosis if they need so, as well as access to appropriate services and support. The Bill in its essence is therefore to be welcomed. However, there are a range of issues that need to be addressed in order to achieve this overall aim, and obstacles to be overcome.

1. Background

Autism or Autism Spectrum Disorder (ASD) is currently defined as:

"Persistent deficits in social communication and social interaction across multiple contexts...and restricted, repetitive patterns of behaviour, interests, or activities"

(DSM-5, 2013)

The National Autistic Society's (NAS) prevalence rates (NAS, 2018) indicate that more than 1 in 100 individuals in the UK are likely to be on the spectrum (e.g. Baird et al.,2006; Brugha et al., 2009), demonstrating that a significant number of the population are likely to be on the spectrum.

We know that ASD can cause persistent behavioural and management difficulties in children (Totsika & Hastings, 2009). These researchers found that typically parents report higher levels of stress when they have a child with autism than for example, other developmental disorders. We know that individuals with ASD have an increased susceptibility to challenging behaviours across the lifespan (Matson, Sipes, Fodstad & Fitzgerald, 2011, McClintock, Hall & Oliver, 2003), parental stress (Hastings & Brown, 2002, Estes et al, 2009) as well as being associated with mental health difficulties, more often with higher functioning individuals (Mazzone, Ruta & Reale, 2012) and indeed there is evidence to suggest that there is an increased likelihood that in-patients in psychiatric settings will have a diagnosis of ASD (Tromans, Chester, Kiani, Alexander & Brugha, 2018). Thus, any attempt by government to meet the needs of individuals with ASD and their families is to be welcomed.

2. Diagnosis

A timely diagnosis is acknowledged to be important so individuals with autism can make of their difficulties, access appropriate services and apply suitable strategies / learn techniques *to manage any issues that can cause difficulties in their daily lives. The same issues are relevant for families accessing a diagnosis for their child. Welsh Government have released funds to increase capacity for services to assess individuals and applied waiting times. However it appears that such investment has not necessarily reduced waiting times in the way expected; availability of assessment has increased expectations of ASD assessment and so often, the diagnosis of Autism is seen as a golden ticket, providing access to services and an explanation of any unusual behaviours. Services are thus under pressure to provide a diagnosis, and to complete assessments quickly, leading to possible concerns regarding taking shortcuts which could affect diagnostic validity. Families sometimes reject the notion of no diagnosis. There is a common perception that there is only one diagnosis (ASD) and that it is only a diagnosis of ASD that can explain developmental or behavioural difficulties, at the expense of other diagnoses, e.g. learning disability. ASD is seen as the diagnosis du jour. Parents seek answers to explain their child's behaviour, and sometimes seek a second opinion if they are not satisfied with the results of the assessment. Time spent conducting a second opinion assessment potenatilly increases waiting times, leads to additional costs if the second opinion is sought by a private agency and paid for by the NHS, and can cause a loss of confidence in diagnosis by public sector services, deskilling practitioners.*

We know that ASD is a complex spectrum, and that prevalence is increasing although the reasons for this are not fully understaood as yet. Clearly we need diagnostic services and a better understanding of the needs of individuals on the spectrum. Despite this, this should not be at the expense of intervention and support services. We need cost-effective services that can provide ASD assessment and other neurodevelopmental conditions, learning disabilities etc, and there is an equal need for individual and family support services, providing cost effective interventions to improve the quality of life of those individuals on the spectrum and their families. The improvements in diagnostic services have led to an increased demand for diagnosis which could lead to questions about the value of a diagnosis, and how to manage demand. Should we prioritise building resilience in the population as a whole rather than labelling individuals?

3. Support

The need for social support is paramount. Many of our families lack the necessary resources to cope without additional support. Indeed research demonstrates that marital and family breakdown may be correlated with rearing a child with autism, and the stress and strains that can accompany such developmental difficulties (Totiska & Hastings, 2009)

The Incredible Years parent programmes (IY) (e.g. Webster-Stratton, 2013) have been very successful in teaching parents how to apply behavioural strategies to manage their children and develop play and early learning skills. It's a 12 week parenting programme, and it is common for parents of children with conduct disorders to be referred to the group. There is significant evidence for the effectiveness of the programme.

The IY programme has expanded in its range of applications (e.g. see the Dinosaur school, etc., e.g. Webster-Stratton, 1991) to include a programme which applies to the parents of children with Autism and Language delays. This focuses on building desirable skills and some sessions on learning to manage challenging behaviours. The emphasis is on creating and maintaining a positive group atmosphere which reflects a positive context for the relationship between the parent and the child.

This programme has been evaluated in North Wales (Hutchings et al., 2016). As such, it is recommended that IY ASD parent programmes continue to be evaluated to refine their relevance and efficacy with such families, and are also routinely made available as one aspect of interventions available to parents, alongside others such as PACT ((Parent-mediated social communication therapy for young children with autism (Pickles et al. 2016), Early Bird (NAS), etc.

4. *Other Interventions*

Early Intensive Behavioural Intervention (EIBI) is a programme of intervention that has produced promising results; decreasing challenging behaviours and increasing prosocial, pre-academic and play skills in young children with Autism. Original studies were conducted by Lovaas (1987) however since those early days psychological treatments have developed and moved on, becoming more refined and allowing more naturalistic teaching. There is local and international evidence to suggest that behaviour analytic approaches continue to have a significant effect on the development and behaviour of autistic individuals (e.g. Kovshoff et al., 2011; Eldevik et al., 2009) since those early days.

In the US, state-wide interventions are routinely provided to young children with autism however EIBI have not yet become routinely available in many countries in Europe to the same degree (Keenan et al., 2014). In the UK, the growth of EIBI has been mainly within the private sector, with increasing numbers of affluent, educated and vocal parents accessing such approaches, particularly in the South East of England. Similar services in Wales tend to have been related to University-led provision (e.g. clinic provision at the University of South Wales), or state-run educational establishment provision, which tends to be less intensive, but with promising results (Grindle et al., 2012; Foran et al., 2015; Jones & Hoerger, 2011).

Recent studies have demonstrated continued effectiveness, and long term outcomes are particularly promising when parents are included in the delivery of such programmes (Kovshoff et al., 2011). There is wealth of evidence to demonstrate the effectiveness and justification in terms of cost of delivering an EIBI programme to young children with Autism (e.g. Chasson et al., 2007).

It is recommended that health, social care services and education collaborate to support the use of early interventions to support parents to manage their children, teaching them play skills, prosocial and pre-academic skills, as part of a package, whilst also learning to manage challenging behaviours. There is world-wide evidence to suggest that early interventions are *crucial and highly effective when applied with a high degree of fidelity, by trained, well-supervised individuals.*

In addition, currently behavioural specialists are a vital component of Neurodevelopmental teams however often practitioners do not have specific qualifications although Positive Behaviour Support (PBS) and Active Support (AS: Jones et al, 1999) are approaches that are already well established in adult learning disability services.

It is recommended that behavioural specialists seek a qualification in, for example, Applied Behaviour Analysis (ABA) so that service quality can be measured. Behaviour analysis is not recognised as a discrete profession in the UK at present. There exists an international qualification, the BCBA (Board Certified Behaviour Analyst) which denotes accredited Behaviour Analysts. There needs to a structure in place to ensure effective regulation as this is important for public protection. It is recommended that the HCPC (Health Care Professions Council) takes responsibility for regulation of behavioural practitioners as a profession. This would need to be achieved in conjunction with the other nations of the UK. The UK-SBA (UK Society for Behaviour Analysis) is already working on this.

5. *Education*

Any attempts for joint working to provide seamless services are to be welcomed. Too often there are examples, evidence, anecdotes that families find themselves turned away from services due to ineligibility and lack of co-ordination, or they appear not to be anyone's responsibility. The Bill states that the Autism Bill would "complement" the work of the ALN Act. This is to be welcomed.

6. *Welsh Language services*

The Autism Bill refers to Welsh Language provision (5.8, explanatory memorandum). Specifically, the Bill refers to the 'Active Offer' and the need for public services to recognise and respond to language need as an integral element of care without the need for service users having to ask for Welsh language services. The Welsh Language Commissioner has cited examples of barriers to appropriate Welsh medium service provision, e.g. poor workforce planning and lack of linguistically appropriate testing resources as have others responding to the consultation.

The situation in Conwy & Denbighshire: Betsi Cadwaladr University Health Board Central area in my experience as a practitioner.

BCU has appointed a Welsh language tutor. The needs of the service will inevitably exceed the tutor's capacity, so an analysis of service need may help to target key areas for intervention (in this case, Welsh lessons).

ASD is a social communication disorder. It would be reasonable to suggest that therefore staff need to have competencies in the languages that the child /family use. In Wales we are required for services to provide Welsh and English services, according to need, providing an

Active Offer (Welsh Government, 2012). In the case of any additional languages, the NHS provides an interpretation service.

There is even a suggestion that as social-communicative behaviours are culturally-bound, and high functioning autism may be linked to cultural competencies and that therefore to diagnose reliably one would need an understanding of the linguistic and cultural context of that individual (Gillberg & Gillberg, 1996).

Currently in Central BCU (Conwy & Denbighshire), there are three possible routes to an ASD assessment. The Neurodevelopmental team undertakes assessments for children and young people without intellectual disabilities aged between 5-18 years across both counties. Conwy Social-Communication Panel undertakes ASD assessments for all children aged between 0-5 years and for children and young people aged between 5-18 years. Denbighshire Social-Communication panel also undertakes ASD assessments for all children aged between 0-5 years and children and young people aged between 5-18 years with an intellectual disability. The plan is for there to be a SPOA (single point of access) for an ASD assessment in due course.

A limited number of fluent Welsh speaking staff currently work into the three services. In addition, it is commonly thought that recruiting Welsh speakers into the service is very difficult.

An audit was conducted of team members' Welsh language skills, collated with ASD assessment skills. Team members about their Welsh language skills: as follows:

- *I am a Welsh speaker,*
- *I understand Welsh but cannot speak it,*
- *I can speak a bit of Welsh, say with young children,*
- *I can understand Welsh well enough to write words when spoken,*
- *none.*

It was demonstrated that some team members had some Welsh Language skills, appropriate for possibly assessing young children particularly non verbal children. In addition, it was found that some team members had receptive Welsh Language skills, suitable for undertaking school observations.

Such an undertaking makes possible the pairing of staff competencies with service needs and also identifies targets for up skilling the workforce. This level of analysis could be generalised to help with every aspect of service delivery and could also help with workforce planning.

ASD assessment typically includes a validated direct assessment of communicative and interactive skills such as the ADOS (Autism Diagnostic Observation Schedule, Lord & Rutter, 1989), which provides a semi structured context to evaluate an individual's social-communication and language skills as well as potential for eliciting repetitive behaviours, following the DSM diagnostic criteria for ASDs. I have managed a project to translate the

ADOS into Welsh. Validation of this assessment needs to be completed and it also needs further funding.

We are also in the process of organising Welsh lessons with the BCU Welsh language tutor specifically to address the needs of those practitioners who have some Welsh and therefore could upskill to undertake ADOS assessments, especially with young children with limited language abilities.

With regards to other aspects of assessment, typically a practitioner does not follow a structured protocol for school observations and thus there are no validated assessments currently available, although there are local guidelines.

In terms of the developmental history interview, the gold standard for such an interview is commonly agreed to be the ADI-R (Autism Diagnostic Interview – Revised, e.g. Rutter et al, 1994). However NICE guidelines do not require this assessment to be used in every case, and rather, have published a set of guidelines as to the required content of such an interview. Therefore practitioners undertake this interview using the NICE guidelines and /or locally used instruments as well as the ADI-R. A Comprehensive lsit can be provided if necessary.

In this respect the delivery of the interview can be in Welsh by an appropriately linguistically skilled clinician however at present to my knowledge there is no structured, validated DHI available in the medium of Welsh.

The situation for intellectual assessment in Welsh is dire: there are no validated Welsh language versions of any intellectual assessments such as the Wechsler Adult Intelligence Scale (WAIS), Wechsler Intelligence Scale for Children (WISC), and so on. This means that there is no reliable and valid method for identifying the intellectual capacities of Welsh speakers in Wales. Any undertaking to validate such instruments would need to consider the bilingual nature of individuals' language skills, as well as the long term nature and costs of such an undertaking. It is recommended that a Centre for Validation of Assessment and Psychological Therapy is set up as a centre of excellence, based at Bangor University. This university already has long and respected history in pioneering in Welsh medium / bilingual research and developments, (e.g. The Centre for Bilingualism, Canolfan Bedwyr and Uned Technoleg Iaith). The costs to the public sector could be mediated by grant funding. Such a Centre would allow cross-cultural collaboration with speakers of other minority languages, and could become a world leader in research in this field.

7. *Raising Awareness*

Raising Awareness of the needs of individuals with ASD is useful. There are excellent resources on the Welsh Government ASDinfoWales website.

8. *Equality and human rights impact: Individuals with a Learning Disability*

Contrary to what is stated in the Equality and human rights impacts (section 10.2) the identification of ASD and provision of services specifically for individuals with ASD does not necessarily make "a significantly positive contribution in relation to people with a disability" (p.135) as it potentially creates a disability hierarchy. The needs of other individuals with a range of other disabilities could possibly be ignored as a result of this Bill. The needs of those individuals with learning disabilities have traditionally and historically been disregarded, and thus, concerns regarding increasing the invisibility of people with learning disabilities need to be monitored carefully, and provision should be made to ensure that this vulnerable group are not left behind.
The needs of the general learning disability population are not within the scope of this Bill but the case of a disability hierarchy must be addressed. – not just neurodevelopmental disorders but any others with disabilities.

9. *Data Collection*

Clearly the effect of any legislative change needs to be monitored to evaluate its impact on vulnerable individuals, services, demand, and costs. Data collection regarding prevalence rates needs to be rigorous and consistent across the geographical regions of Wales, an across services. Staff training and ongoing monitoring need to be carried out to avoid procedural drift and to iron out any anomalies and differences in diagnostic rates.

10. *Service User Consultation*

This is paramount. It is crucial that service users consider themselves essential members in this process, and that this population feels that those who are responsible for developing and providing services are listening what they have to say. Empowerment should be a key aspect of this process.

Author details

My evidence is presented as an experienced bilingual clinician /academic in the field of Autism Spectrum Disorders. This includes my expertise in Applied Behaviour Analysis / Positive Behaviour Support, as well as reference to the clinical work, research and consultation regarding service users' Welsh language needs.

I am employed as a Consultant Clinical Psychologist working for Betsi Cadwaladr University Health Board, working into and leading a small team of clinical psychologists in Children's Learning Disability services in the Central (Conwy & Denbighshire counties) area of North Wales. Clinically at present I work with mostly Welsh speaking families, as I am the only fluent Welsh speaking clinical psychologist in the Central area working in Child LD. I have worked within NHS services mostly with children and adults with learning disabilities, and autistic individuals for over thirty years. I have been contributed to Welsh Government strategic groups to enhance the experience of Welsh speaking individuals using NHS services.

I have recently resigned from my University post due to work pressures. My post at the University was that of a lecturer on the Master's course in Applied Behaviour Analysis /Positive Behaviour Support, teaching the academic coursework requirements of postgraduates wishing to qualify as behaviour analysts (Board Certified Behaviour Analysts). I have contributed to developing Welsh medium teaching, vocabulary and services within the field of Applied Behaviour Analysis.

I have confined myself to referring to examples regarding the services to which I contribute rather than citing BCU-wide/North Wales examples: that would be beyond the bounds of my responsibilities as I am not the lead clinician for services Autism Spectrum Disorders for BCUHB.

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A29

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Dr Elin Walker-Jones

Response from Dr Elin Walker-Jones

Tystiolaeth ar gyfer y Bil Awtistiaeth

Egwyddorion cyffredinol

Yn gyffredinol, mae angen Bil Awtistiaeth i sicrhau hawliau unigolion gydag Awtistiaeth ers tro: mae gan Loegr a Gogledd Iwerddon ddeddfwriaeth o'r fath yn barod. Mae gennym angen am strategaeth Gymru-gyfan, gyson i sicrhau y gall unigolion ag Awtistiaeth gael diagnosis dibynadwy ac amserol os oes angen, a mynediad i gefnogaeth ac amrediad o wasanaethau priodol. Croesawir y Bil yn ei hanfod felly. Serch hynny, mae angen cyfarch ystod o faterion er mwyn cyrraedd y nod cyffredinol hwn, ac mae rhwystrau i'w goresgyn hefyd.

1. Cefndir

Yn gyfredol, diffinir Awtistiaeth neu Anhwylder Sbectrwm Awtistiaeth (ASD) fel a ganlyn:

"*Persistent deficits in social communication and social interaction across multiple contexts...and restricted, repetitive patterns of behaviour, interests, or activities".*

(DSM-5, 2013)

Dengys ffigyrau'r Gymdeithas Awtistaidd Genedlaethol (*National Autistic Society*: NAS, 2018) fod mwy nag 1 mewn 100 o unigolion yn debygol o fod ar y sbectrwm Awtistaidd ym Mhrydain (e.e. Baird et al.,2006; Brugha et al., 2009). Felly mae cyfran sylweddol o'r boblogaeth yn debygol o fod ar y sbectrwm.

Gwyddom y gall ASD achosi anawsterau ymddygiad parhaus ymysg plant (e.e. Totsika & Hastings, 2009). Darganfuwyd fod rhieni plant ag ASD yn fwy tebygol na rhieni plant ag anableddau datblygiadol eraill o adrodd lefelau uwch o straen. Gwyddom fod unigolion ag ASD â thebygolrwydd uwch o ymddygiadau heriol gydol oes (e.e. Matson, Sipes, Fodstad & Fitzgerald, 2011; McClintock, Hall & Oliver, 2003); straen mewn rhieni (e.e. Hastings & Brown, 2002; Estes et al, 2009). Yn ogystal, mae ASD wedi ei gysylltu gyda phroblemau iechyd meddwl, yn enwedig mewn unigolion sydd ag ASD uwch weithredol (e.e. Mazzone, Ruta & Reale, 2012). Mae tystiolaeth hefyd fod cleifion preswyl mewn lleoliadau seiciatrig yn fwy tebygol o fod â diagnosis o ASD (e.e. Tromans, Chester, Kiani, Alexander & Brugha, 2018). Felly, mae unrhyw ymgais gan lywodraeth i gyfarch anghenion unigolion ag ASD a'u teuluoedd i'w groesawi.

2. Diagnosis

Cydnabyddir fod diagnosis amserol yn bwysig i sicrhau fod unigolion ag ASD yn gallu gwneud synnwyr o'u hanawsterau, cael mynediad i wasanaethau priodol, a dysgu defnyddio technegau i ymdopi gydag anawsterau sy’n codi yn eu bywydau bob dydd. Mae’r un ffactorau yn bwysig i deuluoedd. Mae Llywodraeth Cymru wedi rhyddhau cyllid i gynyddu capasiti gwasanaethau i asesu unigolion ac hefyd wedi gosod terfynnau amseoedd aros. Serch hynny, ymddengys nad yw’r buddsoddiad wedi gostwng rhestrau aros o reidrwydd yn y modd a obeithiwyd; mae argaeledd asesu wedi cynyddu disgwyliadau, ac yn aml, gwelir diagnosis o ASD fel y tocyn aur sy’n ddrws i wasanaethau, a sy’n eglurhad am unrhyw ymddygiadau anarferol. Mae pwysau felly ar wasnaethau i roi diagnosis, ac i’w roi yn gyflym, gan achosi perygl o dorri ar ddilysrwydd yr asesiad er mwyn ei gwblhau’n gyflym. Mae teuluoedd weithiau’n gwrthod canlyniad sy’n atal diagnosis, a mae canfyddiad aml mai diagnosis ASD ydi’r unig diagnosis, a’r unig eglurhad o ymddygiad neu ddiffyg sgiliau, ar draul diagnosis o anableddau dysgu yn enwedig. Mae rhieni yn chwilio am atebion i egluro anawsterau eu plentyn, ac felly’n galw am ail farn os nad ydynt yn hapus gyda chanlyniad yr asesiad (hy dim diagnosis ASD). Mae treulio amser yn cynnal ail asesiad yn cynyddu’r rhestr aros, neu’n gallu bod yn gostus os mai’r GIG sy’n talu am farn breifat, ac yn achosi colli hyder yn y farn wreiddiol a roddwyd, ac yn tynnu oddi ar yr hyder yn y tîm, a sgiliau ymarferwyr.

Gwyddom fod ASD yn sbectrwm cymhleth a’r niferoedd ar gynydd heb i ni ddeall yn iawn pam fod hyn yn digwydd. Yn amlwg mae angen gwasnaethau diagnosis, ac angen am well dealltwriaeth o anghenion unigolion ar y sbectrwm. Serch hynny, ni ddylai hyn fod ar draul gwasnaethau ymyrraeth a chefnogaeth. Mae angen am wasanaethau cost-effeithiol sy’n gallu asesu am ASD a chyflyrau niwroddatblygiadol eraill, anableddau dysgu ac ati, ac hefyd mae llawn cymaint o angen am wasanaethau sy’n cefnogi unigolion a theuuoedd, ac yn darparu ymyrraethau cost-effeithiol i wella ansawdd bywyd unigolion ar y sbectrwm a’u teuluoedd. Mae gwella gwasanaethau diagnosis wedi cynyddu’r galw am ddiagnosis, sy’n codi cwestiwn am werth diagnosis, a sut mae rheoli’r galw. A ddylen ni fod yn rhoi pwyslais ar adeiladu gwytnwch yn gyffredinol yn hytrach na cheisio rhoi label ar unigolion?

3. Cefnogaeth

Mae’r angen am gefnogaeth gymdeithasol yn flaenoriaeth. Mae nifer o’n teuluedd yn methu ymdopi heb gefnogaeth ychwanegol. Dengys ymchwil fod posibilrwydd fod perthynas rhwng magu plentyn ag ASD â thor-priodas, neu deulu yn torri lawr yn llwyr hyd yn oed, oherwydd y straen sy’n gallu bod yn rhan o fywyd teulu lle mae plentyn ag anawsterau datblygiadol o’r fath. Ymddygiadau heriol yw’r broblem fawr, ac mae tebygolrwydd uwch o ymddygiadau heriol gydag ASD (Totiska & Hastings, 2009).

Mae gwaith y Blynyddoedd Rhyfeddol (e.e. Webster-Stratton, 2013) yn llwyddiannus iawn yn dysgu rhieni i ddefnyddio strategaethau ymddygiadol gyda’i plant, i reoli ymddygiad annerbyniol ac i adeiladu ar sgiliau chwarae a chyn-ysgol. Mae’n gwrs 12 wythnos gyda grŵp o rieni, ac yn aml, cyfeirir rhieni plant ag anhwylderau ymddygiad i’r grŵp. Mae tystiolaeth helaeth o effeithlonrwydd yr ymyrraeth.

Mae'r rhaglen Blynyddoedd Rhyfeddol wedi ehangu i ddarparu rhaglenni a ellir eu gweithredu o fewn ysgol (e.e. Rhaglen Dinosôr, Webster-Stratton, 1991) ymysg eraill, ac erbyn hyn, mae gan y gyfres raglen ar gyfer rhieni plant ag Awtistiaeth ac Oediad Iaith. Mae hwn yn canolbwyntio ar adeiladu ar ymddygiadau dymunol, ac yn cynnwys rhai sesiynnau hefyd ar reoli ymddygiad heriol. Mae'n creu a chynnal naws cadarnhaol i'r rhaglen, sy'n cael ei adlewyrchu wedyn ym mherthynas y rhiant a'r plentyn.

Gwerthuswyd y rhaglen Blynyddoedd Rhyfeddol ar gyfer Plant ag Awtistiaeth ac Oediad Iaith yng Ngogledd Cymru (Hutchings et al., 2016) ac mae'r gwerthuso yn mynd yn ei flaen o hyd. Argymhellir fod rhaglenni rhieni Blynyddoedd Rhyfeddol ar gyfer ASD yn cario mlaen i gael eu gwerthuso, i fireinio eu perthnasedd a'u effeithlonrwydd gyda theuluoedd o'r fath. Dylid sicrhau fod y rhaglen ar gael yn arferol fel un agwedd o ymyrraethau ar gyfer rhieni, ochr yn ochr ag ymyrraethau eraill fel PACT (*Parent-mediated social communication therapy for young children with autism*, Pickles et al. 2016), Early Bird (NAS) ac ati.

4. Ymyrraethau eraill

Mae Ymyrraeth Ymddygiadol Dwys Gynnar (*Early Intensive Behavioural Intervention*: EIBI) yn raglen o ymyrraeth sydd wedi cynhyrchu canlyniadau addawol; gan leihau ymddygiadau heriol a chynyddu ymddygiadau cymdetihasol, sgiliau cyn-ysgol a chwarae mewn plant ifanc ag Awtistiaeth. Cwblhawyd yr astudiaethau cynnar gan Lovaas (1987) ond ers y dyddiau cynnar hynny mae triniaethau seicolegol wedi datblygu a symud ymlaen, gan gael eu mireinio a chan ganiatau addysgu mwy naturiol. Mae tystiolaeth lleol a rhyngwladol sy'n awgrymu fod triniaethau dadansoddi ymddygiad yn cael effaith gadarnhaol ar ddatblygiad ac ymddygiad unigolion gydag Awtistiaeth (e.e. Kovshoff et al., 2011; Eldevik et al., 2009).

Yn yr UDA, cynigir ymyrraethau ar draws y taleithiau fel rheol i blant ag Awtistiaeth ond nid yw mor hawdd cael mynediad i EIBI mewn sawl gwlad yn Ewrop yn yr un modd (Keenan et al., 2014). Yn y DG, mae tyfiant EIBI wedi bod yn y sector breifat gan fwyaf, gyda chynnydd mewn darpariaeth ar gyfer plant sydd a rhieni addysgiedig, cyfoethog, sy'n gallu bod yn eiriol dros eu plant, a rheini yn Ne Ddwyrain Lloegr. Mae gwasanaethau tebyg yng Nghymru yn tueddi bod yn gysylltiedig â phrifysgolion (e.e. darpariaeth clinig ym Mhrifysgol De Cymru) neu mewn ysgolion. Mae darpariaeth ysgol yn tueddi bod yn llai dwys, ond eto mae'r canlyniadau yn addawol (e.e. Grindle et al., 2012; Foran et al., 2015; Jones & Hoerger, 2011).   Mae cyfoeth o dystiolaeth i ddangos effeithlonrwydd rhaglenni EIBI (e.e. Eldevik et al., 2009) ac mae'r canlyniadau tymor hir yn arbennig o addawol pan fod rhieni yn cael eu cynnwys yn y rhaglen (e.e. Kovshoff, 2011). Mae modd cyfiawnhau costau darparu rhaglen EIBI i blant bach ag Awtistiaeth (e.e. Chasson et al., 2007).

Argymhellir fod iechyd, gwasanaethau gofal Cymdeithasol ac addysg yn cydweithio i gefnogi defnyddio ymyrraethau cynnar i helpu rheini i ddysgu sgiliau chwarae iddynt, sgiliau cymdeithasol a chyn-ysgol, a chan reoli ymddygaid heriol eu plant, fel rhan o becyn cynhwysfawr. Mae tystiolaeth ryngwladol i awgrymu fod ymyraethau cynnar yn allweddol ac yn effeithiol dros ben pan gânt eu defnyddio gan unigolion sydd wedi eu hyfforddi ac sy'n cael eu goruchwylio'n dda, a sy'n cynnig ymyrraethau sy'n gywir a ffyddlon i raglen (*treatment fidelity*).

Yn ogystal, mae arbenigwyr ymddygiad yn aelodau creiddiol o dimoedd Niwroddatblygiadol. Serch hynny, nid oes angen am gymhwysterau penodol, er fod triniaethau Cefnogaeth Ymddygiadol Gadarnhaol (*Positive Behaviour Support*: PBS) a Chefnogaeth Weithredol (*Active Support*: AS) (e.e. Jones et al, 1999) yn driniaethau sydd wedi gwreddio yn niwylliant gwaith gydag oedolion gydag anableddau dysgu.

Argymhellir fod arbenigwyr ymddygiad yn cyrchu cymhwyster penodol, er enghraifft mewn Dadanosddi Ymddygiad Cymhwysol (ABA), fel bod modd mesur ansawdd gwasanaethau. Nid yw Dadansoddi Ymddygiad yn cael eu gydnabod fel proffesiwn ar wahan yn y DG ar hyn o bryd, er fod yr UK-SBA (*UK-Society for Behaviour Analysis*) yn gweithio arno. Mae cymhwyster rhyngwladol ar gael, sef y BCBA (*Board Certified Behaviour Analyst*) sy'n dynodi dadansoddwyr ymddygiad ardystiedig. Rhaid cael strwythur mewn lle i sicrhau rheoleiddio effeithiol sy'n bwysig i warchod y cyhoedd. Argymhellir y gallai Cyngor y Proffesiynnau Iechyd a Gofal (HCPC: *Health Care Professions Council*) gymryd cyfrifoldeb am reoleiddio ymarferwyr ymddygiadol fel proffesiwn. Byddai'n rhaid cydweithio gyda chenhedloedd eraill y DG. Mae'r UK-SBA yn barod yn gweithio ar hyn hefyd.

5. Addysg

Croesawir unrhyw ymgais i gydweithio i greu gwasanaethau didor. Yn llawer rhy aml, mae enghreiffitiau, tystiolaeth ac anecdotau am deuluoedd yn cael eu gwrthod oherwydd nad ydynt yn cyrraedd meini prawf rhyw wasanaeth, neu oherwydd diffyg cydgordio, ac mae pobl yn darganfod nad oes neb yn fodlon cymryd cyfrifoldeb am gynnig dim iddynt. Mae'r Bil yn datgan y byddai'r Bil Awtistiaeth yn "ychwanegu" at waith y Ddeddf ADY. Mae hyn i'w groesawi.

6. Gwasanaethau cyfrwng Cymraeg

Mae'r Bil Awtistiaeth yn cyfeirio tuag at y ddarpariaeth cyfrwng Cymraeg (5.8, Memorandwm Esboniadol). Yn benodol, mae'r Bil yn cyfeirio at 'Y Cynnig Rhagweithiol', a'r angen i wasanaethau cyhoeddus adnabod ac ymateb i angen iaith fel elfen greiddiol o ofal, heb i'r defnyddiwr gwasanaeth ei hun orfod gofyn am wasanaethau Cymraeg. Mae Comisiynydd y Gymraeg wedi dyfynnu enghreifftiau o rwystrau i wasanaethau cyfrwng Cymraeg priodol, e.e. cynllunio gweithlu gwael a'r difyg adnoddau asesu ieithyddol-briodol, fel y gwnaeth eraill a ymatebodd i'r ymgynghoriad.

Y sefyllfa yng Nghonwy a Sir Ddinbych: ardal Ganol Bwrdd Iechyd Prifysgol Betsi Cadwaladr yn fy mhrofiad i fel ymarferydd.

Mae'r Bwrdd Iechyd wedi cyflogi tiwtor Cymraeg. Mae'n debygol y bydd y galw am wasanaeth y tiwtor yn fwy na'r capasiti fydd ganddi, ac felly gallai dadansoddiad o elfennau gwasanaeth helpu i dargedu agweddau allweddol ar gyfer ymyrraeth (gwersi Cymraeg yn yr achos hwn).

Mae ASD yn anhwylder cyfathrebu Cymdeithasol. Byddai'n rhesymol felly awgrymu fod angen i staff sy'n asesu feddi ar alluoedd yn yr iaith / ieithoedd sy'n cael eu defnyddio gan y plentyn a'i deulu, fel mater o flaenoriaeth. Yng Nghymru, mae'n ofynnol i ni ddarparu gwasnaethau Cymraeg a Saesneg yn ôl y galw, gan ddarparu'r Cynnig Rhagweithiol, heb i'r claf orfod wneud cais drosto ef /hi ei hun (Llywodraeth Cymru, 2012). Mewn achos o unrhyw iaith /ieithoedd eraill, mae'r GIG yn darparu cyfieithwyr.

Mae hyd yn oed awgrymiad gan fod ymddygiadau cyfathrebu cymdeithasol yn digwydd mewn cyd destun diwylliannol, y gallai ASD uwch weithredol fod yn gysylltiedig â chymwyseddau diwylliannol, ac felly er mwyn rhoi diagnosis dibynadwy mi fyddai angen am ddealltwriaeth o gyd destun ieithyddol a diwylliannol yr unigolyn (Gillberg & Gillberg, 1996).

Ar hyn o bryd yn y BI Betsi (Canol) mae tri llwybr at asesu ar gyfer ASD. Mae'r tîm Niwroddatblygiadol yn ymgymeryd ag asesiadau ar gyfer plant a phobl ifanc 5-18 oed sydd heb anableddau dysgu ar draws y ddwy sir. Mae Panel Cyfathrebu Cymdeithasol Conwy yn ymgymeryd ag asesiadau ASD pob plentyn 0-5 oed, ac asesiadau plant 5-18 oed ag anableddau dysgu. Mae Panel Cyfathrebu Cymdetihasol Sir Ddinbych yn ymgymeryd ag asesiadau ASD pob plentyn 0-5 oed, ac asesiadau plant 5-18 oed ag anableddau dysgu. Mae cynlluniau i greu SPOA (*single point of access*) cyffredinol ar gyfer pob plentyn 0-18 oed, a gwneud i ffwrdd â'r rhaniadau ond dydi hyn ddim wedi digwydd hyd yma.

Nifer fach o staff sy'n siarad Cymraeg yn rhugl sy'n gweithio yn y tri gwasanaeth. Mae'n ganfyddiad cyffredin hefyd fod recriwtio siaradwyr Cymraeg bron yn amhosib.

Cynhaliwyd awdit o sgiliau Cymraeg aelodau o'r timoedd, gan goladu'r sgiliau Cymraeg gyda sgiliau asesu ASD. Gofynwyd i'r staff am eu sgiliau Cymraeg, fel a ganlyn:

- Rydw i'r siarad Cymraeg,
- Rwyf yn deall ond dydw i ddim yn siarad Cymraeg,
- Gallaf siarad ychydig bach o Gymraeg, er enghraifft, gyda phlentyn bach,
- Gallaf ddeall Cymraeg yn ddigon da i ysgrifennu geiriau pan dwi'n clywed nhw,
- Dim sgiliau Cymraeg.

Dangoswyd fod gan rai aelodau o'r tîm sgiliau Cymraeg, yn briodol efallai ar gyfer asesu plant bach yn enwedig plant bach nad oedd yn siarad llawer. Dangoswyd hefyd fod gan rai aelodau o'r tîm ddigon o ddealltwriaeth o'r Gymraeg i'w galluogi i ymgymeryd ag arsylwi ysgol.

Roedd cwblhau'r awdit yn galluogi'r gwasanaeth i baru cymhwysedd Cymraeg staff gydag anghenion gwasanaeth, ac hefyd yn ffordd o adnabod targedau ar gyfer uwchsgilio'r gweithlu. Gallai'r lefel yma o ddadansoddiad gael ei gyffredinoli i helpu pob agwedd o ddarpariaeth gwasanaeth a gallai helpu gyda chynllunio gweithu.

Mae asesu ar gyfer ASD fel arfer yn cynnwys asesu uniongyrchol o sgiliau cyfathrebu a rhyngweithio gan ddenfyddio asesiad wedi ei ddilysu fel yr ADOS (*Autism Diagnostic Observation Schedule*, Lord & Rutter, 1989). Mae'r asesiad hwn yn darparu cyd destun wedi ei led-strwythuro i werthuso sgiliau cyfathrebu Cymdeithasol ac iaith unigolyn, ac yn rhoi cyfle hefyd i ennyn ymddygiadau ailadroddus, gan ddilyn meini prawf y DSM (*Diagnostic and Statistical Manual of Disorders*, e.e. DSM-5. 2013) ar gyfer ASD. Rwyf wedi rheoli prosiect i gyfieithu'r ADOS i'r Gymraeg. Mae angen dilysu'r gwaith ac angen am ragor o gyllid er mwyn cwblhau'r gwaith.

Rydym hefyd yn y broses o drefnu gwersi Cymraeg gyda thiwtor Cymraeg Betsi, yn benodol ar gyfer cyfarch anghenion ymarferwyr sydd yn siarad neu'n deall peth Cymraeg ac felly â'r gallu i uwchsgilio i ddarparu asesiadau ADOS, yn enwedig gyda phlant bach heb lawer o sgiliau iaith.

O ran agweddau eraill o asesu, nid yw ymarferydd yn arfer dilyn protocol wedi ei strwythuro ar gyfer arsylwi yn yr ysgol, ac felly nid oes asesiadau wedi eu dilysu ar gael ar hyn o bryd, er fod canllawiau lleol.

Yr ADI-R (*Autism Diagnostic Interview-Revised*, Rutter et al., 1994) ydi'r safon aur o ran y cyfweliad hanes datblygiad. Serch hynny, nid yw'r ADI-R yn ofynnol gan NICE (*National Institute of Clinical Excellence*). Yn hytrach, mae NICE wedi cyhoeddi canllawiau ar gyfer cynnwys cyfweliad o'r fath. Felly mae ymarferwyr yn arferol yn ymgymeryd â'r cyfweliad hwn gan ddefnyddio canllawiau NICE neu gyfweliadau sy'n cael eu defnyddio yn lleol, yn ogystal a'r ADI-R. Gellir darparu rhestr os oes angen.

Yn y modd yma, gall y cyfweliad gael ei gynnal gan unrhyw ymarferydd sy'n rhugl yn y Gymraeg sydd â'r sgiliau asesu perthnasol ond hyd y gwn i, does dim cyfweliad hanes datblygiad strwythuredig wedi ei ddilysu ar gael yn Gymraeg ar hyn o bryd.

Mae'r sefyllfa ar gyfer asesu gwybyddol yn arswydus: does dim asesiadau cyfrwng Cymraeg wedi eu dilysu ar gael o gwbl (e.e. *Wechsler Adult Intelligence Scale (WAIS), Wechsler Intelligence Scale for Children (WISC)*, ac ati). Golyga hyn nad oes modd dilys a dibynadwy o asesu sgiliau gwybyddol siaradwyr Cymrage yng Nghymru. Byddai rhaid i unrhyw waith i ddilysu'r math yma o asesiadau fod yn barhaus, gan ystyried natur ddwyieithog sgiliau iaith unigolion, yn ogystal â natur hir-dymor y gwaith a'r costau ynghlwm. Argymhellir fod angen sefydlu Canolfan Ragoriaeth ar gyfer Dilysu Asesiadau a Therapi, ac y byddai Prifysgol Bangor yn ddewis amlwg, oherwydd hanes a thraddodiad y Brifysgol yn arloesi mewn ymchwil ac addysgu, a datblygiadau cyfrwng Cymraeg a dwyieithog yn barod (e.e. Y Ganolfan Ddwyieithrwydd, Canolfan Bedwyr a'r Uned Technoleg Iaith). Gallai'r costau i'r sector gyhoeddus gael eu lleihau drwy ymgeisio am grantiau. Byddai modd i Ganolfan o'r fath gydweithio efo ymchwilwyr o ddiwylliannau eraill, gyda siaradwyr ieithoedd lleiafrifol eraill, a gallai'r Ganolfan arloesi yn fyd-eang mewn ymchwil yn y maes.

7. Codi Ymwybyddiaeth

Mae codi ymwybyddiaeth o anghenion unigolion gydag ASD yn ddefnyddiol. Mae adnoddau penigamp ar wefan ASDinfoCymru Llywodraeth Cymru.

8. Yr effeithiau ar gydraddoldeb a hawliau dynol: Unigolion gydag Anableddau Dysgu

Yn groes i'r hyn sy'n cael ei ddatgan o dan Adran 10.2: Yr effeithiau ar gydraddoldeb a hawliau dynol, nid yw adnabod ASD a darparu gwasanaethau yn benodol ar gyfer unigolion ag ASD o reidrwydd yn cynnig cyfraniad cadarnhaol sylweddol mewn perthynas a phobl ag anabledd (tud.153) gan fod posib fod y ddeddfwriaeth yn creu hierarchaeth anabledd. Gallai'r ddeddfwriaeth greu sefyllfa lle'r anwybyddir unigolion ag anableddau heblaw ASD. Mae anghenion unigolion ag anableddau dysgu yn draddodiadol ac yn hanesyddol wedi eu hesgeuluso, ac felly, mae angen monitro gofalus o bryderon am anweladwyedd pobl ag anableddau dysgu, a dylid darparu i sicrhau nad yw'r grŵp bregus hwn yn cael ei adael ar ôl.

Nid yw anghenion pobl ag anableddau dysgu cyffredinol yn dod o dan y Bil hwn, ond rhaid cyfarch mater yr hierarchaeth anabledd – nid dim ond anawsterau niwroddatblygiadol ond unrhyw rai eraill ag anabledd.

9. Casglu Data

Yn amlwg mae angen monitro effaith unrhyw newid mewn deddfwriaeth er mwyn gwerthuso effaith ar unigolion bregus, gwasanaethau, y gofyn, a chostau. Dylid sicrhau fod cysondeb wrth gasglu data ynglŷn â niferoedd, a bod y dulliau yn fanwl gywir ar draws ardaloedd gwahanol Cymru, ac ar draws gwasanaethau. Rhaid cynnal hyfforddiant staff a monitro parhaus er mwyn osgoi drifftio trefniadol, ac i gysoni unrhyw wahaniaethau ac anghysonderau rhwng graddfeydd diagnostig.

10. Ymgynghori â Defnyddwyr Gwasanaeth

Mae hyn yn greiddiol. Mae'n allweddol fod defnyddwyr gwasnanaeth yn ystyried eu hunain yn ran annatod o'r broses, a bod y boblogaeth hon yn teimlo fod y rhai sy'n gyfrifol am ddatblygu a chynnig gwasanaethau yn gwrando ar yr hyn sydd ganddynt i'w ddwedu. Dylai ymbweru fod yn allweddol i'r broses.

Manylion yr awdur

Cynigir fy nhystiolaeth fel ymarferydd dwyieithog profiadol / academydd ym maes Awtistiaeth. Mae hyn yn cynnwys fy arbenigedd mewn Dadanosddi Ymddygiad Cymhwysol / Cefnogaeth Ymddygiadol Gadarnhaol, ac yn cyfeirio hefyd at fy ngwaith clinigol, ymchwil a gwaith ymgynghorol ar anghenion iaith Gymraeg defnyddwyr gwasnaeth.

Rwyf yn gweithio fel Seicolegydd Clinigol Ymgynghorol i Fwrdd Iechyd Prifysgol Betsi Cadwaladr, gan weithio mewn i wasanaethau plant ag anableddau dysgu, ac chan arwain tîm bach o seicolegwyr ar draws y ddwy sir (Conwy a Sir Ddinbych, sef ardal Ganol BI Betsi). Rwy'n gwetithio'n glinigol gan fwyaf gyda siaradwyr Cymraeg gan mai fi yw'r unig seicolegydd rhugl ei Chymraeg yn y gwasanaeth yn y Canol. Rwyf wedi gweithio i'r GIG ers dros 30 mlynedd, mewn gwasanaethau plant ac oedolion gydag anabledd dysgu, ac awtistiaeth gan fwyaf. Rwyf wedi cyfrannu i grwpiau stratgeol Llywodraeth Cymru i wella gwasanaethau ar gyfer siaradwyr Cymraeg sy'n defnyddio'r GIG.

Rwyf yn ddiweddar wedi rhoi'r gorau i'm swydd fel darlithydd ar gwrs Meistr Dadanosddi Ymddygiad Cymhwysol Prifysgol Bangor oherwydd pwysau gwaith, ond yn dal â chysylltiadau fel tiwtor lleoliad i rai o'r myfyrwyr. Mae'r cwrs yn darparu'r gwaith academaidd angenrheidiol i'r rhai sy'n dymuno ennill cymhwyster fel Dadansoddwr Ymddygiad (BCBA). Rwyf wedi cyfrannu i ddatblygu addysgu cyfrwng Cymraeg, geirfa a gwasanaethau Cymraeg o fewn y maes.

Rwyf wedi sôn am enghreifftiau o bethau o fewn y gwasanaeth rwyf yn gweithio ynddo yn hytrach na sôn am bethau sy'n berthnasol i Ogledd Cymru / ar draws BI Betsi: ni fyddai hynny'n briodol gan nad fi sy'n arwain ar Awtistiaeth ar ran BI Betsi.

Dr Elin Walker Jones, D.Clin.Psy, BCBA-D

Seicolegydd Clinigol Ymgynghorol, Bwrdd Iechyd Prifysgol Betsi Cadwaladr
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A30

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Gymdeithas Siartredig Ffisiotherapi

Response from Chartered Society of Physiotherapy

CHARTERED SOCIETY
OF PHYSIOTHERAPY
CYMDEITHAS SIARTREDIG
FFISIOTHERAPI

[redacted]

[redacted]

Dr Dai Lloyd AM
Chair of the Health, Social Care and Sport Committee
National Assembly for Wales
Cardiff Bay
Cardiff CF99 1NA

[redacted]

Dear Chair and Committee Members

Consultation on the Autism (Wales) Bill – response from the Chartered Society of Physiotherapy

The Chartered Society of Physiotherapy (CSP) welcomes the opportunity to provide comment on the proposed Autism (Wales) Bill. Physiotherapists, whilst not a key professional working with children and adults with Autism Spectrum Disorders (ASD) or Neurodevelopmental Disorders (ND) specifically, will see people with both in relation to any physical disability they may also have that requires physiotherapy input.

Feedback from CSP members in Wales suggests that appropriate intervention should not be based on diagnosis. CSP members raised concerns (also expressed by others such as the Royal College of Speech and Language Therapists and the Royal College of Occupational Therapists) that proposed legislation would lead to a focus on diagnosis rather than on their needs and outcomes. CSP members considered that services for children and adults with ASD and ND must be **needs driven and outcomes focussed**.

CSP members suggested that condition specific legislation might push individuals or families to believe that the only/best way to ensure access to services would be by obtaining a diagnosis. They commented that the current best practice approach relies on early access to therapies and intervention to address specific clinical needs and this is of greater importance than on trying to ascertain a particular diagnosis.

CSP members raised concerns that if there is to be a condition specific piece of legislation then this could potentially lead to the call for other condition specific pieces of legislation. Such as approach would lead to a highly complex situation in relation to service delivery. The 'knock-on' effects could be detrimental to service provision.

The CSP welcomes the developments which have already been brought forward by Welsh Government for children and adults with ASD and ND and acknowledges that a profile must be retained to ensure services continue to develop across the sectors. It is the view, however, of physiotherapy members in Wales that autism specific legislation is not required at this time. A focus on needs and not on diagnosis is the way forward.

The CSP hopes the members of the Health, Social Care and Sport Committee will find this response useful.

Yours sincerely

[redacted]

[redacted]
Public Affairs and Policy Manager for Wales
[redacted]

In association with:
CSP Welsh Board
All Wales Children and Young People's Physiotherapy Service Managers
Welsh Physiotherapy Leaders Advisory Group

A31

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Goleg Brenhinol y Therapyddion Galwedigaethol

Response from Royal College of Occupational Therapists

Evidence to the Health, Social Care and Sport Committee's inquiry into the general principles of the Autism (Wales) Bill

Produced by [redacted], Professional Adviser for Children, Young People and Families, and [redacted], Policy Officer for Wales on behalf of the Royal College of Occupational Therapists, the professional body for occupational therapists across the UK.

Summary of Position

RCOT supports the need to improve outcomes for people with autism but is concerned that the proposed legislation will not achieve the desired aim.

The College believe that equality of access to occupational therapy should be a guiding principle for everyone, and that access to occupational therapy should be person-centred and based on occupational need rather than diagnosis. Occupational therapists have the skills and expertise to enable people with autism to lead healthy and productive lives. Occupational therapy is however a limited resource and focusing on one population will mean that others miss out.

Background information:

There are 1900 registered occupational therapists in Wales (August 2018) working across health, social care, education, the voluntary sector and in other specialist areas.

Occupational therapy is a science-based, person-centered profession, concerned with promoting health and well-being through occupation. Occupational therapists work with people of all ages who are experiencing difficulties through injury, illness or disability or a major life change. Occupational therapists consider the relationship between what a person does every day (their **occupations**), how illness or disability impacts upon the **person** and how a person's **environment** supports or hinders their activity. The primary goal of occupational therapy is to enable people to participate in the activities they want, need or are expected to engage in, including work, social activities and maintaining roles and responsibilities.

Occupational therapists are uniquely trained to address mental health and physical health which means we are able to work with people in a more streamlined way.

NICE (2016) identifies occupational therapists as key members of specialist autism teams for adults and recommends that children should have access to an occupational therapist if one is not included as a core member of their local autism team (NICE 2017).

As members of these teams, occupational therapists contribute to the early identification, diagnosis (where appropriate) and participation of people with autism in activities that are important to them. We enable people's participation and occupational performance by working directly with individuals and indirectly through consultation and collaboration with family members, communities, teachers, employers and other professionals. Occupational therapists identify individual's strengths and abilities as well as the needs and challenges that hinder their participation in meaningful activities. Occupational therapists choose the most appropriate setting in which to work with people with autism, for example at home, in their workplace, at school/nursery/college, in residential settings and at diagnostic/assessment centres. In Wales, occupational therapists meet people with autism through their role as members of a children's occupational therapy team, as independent practitioners and as members of an Integrated Autism Service.

RCOT's Position:

- **Access to occupational therapy should be based on need, rather than diagnosis.** Occupational therapists focus on health and well-being: "*Occupational therapists are active health enablers, focused on what matters to the person so that they can help them to participate in the occupations they need, want or are expected to do."* (RCOT, 2016). Occupational therapists do not try to fix or cure the problem, but endeavour to fix 'what matters to the person'. RCOT recognises that people often present with complex needs and occupational therapists rarely work with individuals who fit into neat diagnostic categories. Some people with autism manage very well, while others who don't reach the threshold for diagnosis have great difficulty participating in daily life activities and benefit from occupational therapy. RCOT is concerned that condition-specific legislation may prevent some people from accessing the services, support and resources they need to live happy, healthy and productive lives.

- **Occupational therapy is a limited resource. Focusing the workforce on services for people with autism will mean that others are disadvantaged.** People with a wide range of neurodevelopmental difficulties benefit from occupational therapy including people with developmental coordination disorder (which affects around 5% of the population, Lingam et al 2009), ADHD (which affects around 5% of the population, NICE 2018) and autism (which affects around 1% of the population, NICE 2017). Recruitment to specialist occupational therapy posts (including those for children) can be difficult. If services for people with autism (which represent 1% of the population) are prioritised by legislation, occupational therapists will be diverted from other areas of practice (particularly CAMHS) to the detriment of other populations who would benefit from occupational therapy.

- **Demand for diagnostic assessments will increase.** Diagnosis can provide an explanation for a person's difficulties and is useful in identifying appropriate support and resources. There is a risk however, of individuals and families regarding a diagnosis of autism as a 'passport to services', leading to increased demand for assessments and an artificial increase in diagnostic rates. Clinicians may be required to prioritise assessments rather than intervention, meaning that individuals do not receive the post-diagnostic support they need to live healthy and productive lives. Individuals/parents may also be reluctant to accept an alternative, more appropriate diagnosis and may seek alternative assessments which do not meet the same quality standards as those offered by Integrated Autism Services. RCOT is concerned that an unintended consequence of diagnosis-specific legislation will be increased demand for diagnosis and increased risk of inappropriate diagnosis.

- **An increase in the number of people diagnosed with autism will mean increased demand and expectations for post-diagnostic occupational therapy support**. Diagnosis-specific legislation increases the expectation of individuals and family members that they will receive post-diagnostic support, yet prioritising assessments means fewer occupational therapy resources will be available for intervention. This has been the case for people with dementia in Wales. Despite diagnosis of dementia being identified as a priority, diagnosis rates in Wales lag significantly behind those of the other nations and many people struggle to access support when they need it (Alzheimers Society, 2014). RCOT is concerned that without additional funding and resources, the proposed legislation will not lead to improvements in services for people with autism and their families.

Recommendations

RCOT recommends that services should be commissioned to meet the needs of people with autism and their families, and not driven by legislation or linked to diagnosis. We share the concerns outlined in the joint briefing prepared with the Royal Colleges and the Welsh NHS Confederation that the proposed legislation may not achieve the desired outcome of improving services for people with autism. Instead we recommend that services are commissioned to address local needs, drawing on existing resources and partnerships to ensure that delivery is sustainable and contextually relevant. Further examples of how occupational therapists work as agents of change to improve outcomes across health, education, social care, employment and voluntary sectors are included in our Improving Lives Saving Money campaign reports which can be found here.

References:

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NICE (2016) Autism spectrum disorder in adults: diagnosis and management https://www.nice.org.uk/guidance/CG142 (accessed 11.9.18)

NICE (2017) Autism spectrum disorder in under 19s: support and management https://www.nice.org.uk/Guidance/CG170 (accessed 11.9.18)

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Royal College of Occupational Therapists (2016) Reducing the pressure on hospitals: A report on the value of occupational therapy in Wales. Pub: RCOT, London.

About the College

The Royal College of Occupational Therapists is the UK Professional Body and Trade Union for over 33,000 occupational therapists, support workers, managers and students. Occupational therapy enables people of all ages to participate in daily life to improve health and wellbeing. They are the only Allied Health Profession trained at a pre-registration level to work within both physical and mental health.

Contact

For further information on this submission, please contact:

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Royal College of Occupational Therapists
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[redacted]

Darperir cyfieithiad at ddefnydd yr Aelodau yn unig l Translation provided for Members' use only

Autism (Wales) Bill

September 2018

UCAC - The union that protects Welsh teachers and lecturers

Autism (Wales) Bill

UCAC welcomes this opportunity to respond to the Health, Social Care and Sport Committee's consultation on the latest version of the Autism (Wales) Bill.

UCAC is a union that represents teachers, school leaders, tutors and lecturers in all education sectors across Wales.

1.1. UCAC is fully supportive of the Bill and its general principles. We believe that the Bill has the potential to improve the services that are provided to people of all ages with autistic spectrum disorder in Wales, and thus to improve the quality of their lives and the lives of their families.

1.2. However, we are still concerned about one aspect of the Bill in particular, namely the lack of provision on the face of the Bill in relation to the Welsh language.

1.3. Like others, including the Welsh Language Commissioner, UCAC has noted in previous consultations the difficulties involved in obtaining specialist services and provision through the medium of Welsh, including diagnostic assessments.

1.4. As we have emphasised in previous consultations, remaining silent or indeterminate on the issue of Welsh leads to ambiguity and uncertainty in the provision of services. We cannot rely upon other pieces of legislation (e.g. the Welsh Language Standards under the Welsh Language (Wales) Measure 2011, or the Additional Learning Needs and Education Tribunal (Wales) Act 2018) as they will not apply to all aspects of this Bill, nor to all aspects of the proposed Autism Strategy. We must be very specific about the responsibilities.

1.5. There is an opportunity in the Bill to set a higher standard, and to ensure future progress, for the benefit of people with autistic spectrum disorder; we would not want to miss that opportunity.

1.6. We do not feel that the provision in clause 2(1)(g)(v) adequately addresses these concerns and difficulties, as it is too general.

1.7. We feel very strongly that the face of the Bill needs to make reference(s) to duties regarding the Welsh language in relation to the implementation of the Autism Strategy itself. Those references could be made in one or more of the following places:

- 2(1)(i) which relates to the accessibility of services for each person who needs them
- 2(1)(l) which relates to the wishes of persons with autistic spectrum disorder and of their families and carers

1.8. In addition, we urge you to consider including a reference to the Welsh language in Section 6: Data on autism spectrum disorder. In order to obtain a full picture of the situation facing people with autistic spectrum disorder, and in order to achieve future improvements, we believe that data should be collected on:

- linguistic needs and/or choices in relation to the Welsh language
- any relevant data regarding the impact of those needs/choices on the provision of services; for example, were they provided through the medium of Welsh in line with the deadlines set out in the Strategy and/or in guidelines, or were there any delays or difficulties?

1.9. Aside from a lack of recognised diagnostic testing in Welsh, the lack of workforce planning from the perspective of Welsh-language skills has been a systematic, long-term problem. Above all else, this creates barriers to accessible, appropriate and timely services for Welsh speakers with autistic spectrum disorder. Ensuring that reference is made to that in the Bill could be transformative. The Additional Learning Needs and Education Tribunal (Wales) Act 2018 could be viewed as an example of how this issue could be addressed in a way that takes the current situation into account but also sets the direction for future improvement.

1.10. If the references cited above were to be made on the face of the Bill, there would be certainty that any subordinate legislation would expand on them.

1.11. UCAC is convinced that making provision on the face of the Bill is the only way to ensure that linguistic needs are treated as an essential element of care, and to ensure the creation of conditions that will facilitate the 'proactive offer' that ought to be expected.

1.12. We draw your attention to paragraph 552 in the Explanatory Memorandum:

552. As such, it is believed that the provisions of the Bill will not have a positive impact in relation to Welsh language speakers, particularly in terms of facilitating services and diagnosis provided through the Welsh language.

We assume that this is a mistake (in both the Welsh and English versions) – though it may not be far from the fact if action is not taken regarding our concerns outlined above.

Credwch mewn plant
Believe in children
Barnardo's
Cymru

Barnardo's Cymru Consultation Response

Stage one scrutiny of the Autism (Wales) Bill

21st September 2018

[redacted]

[redacted]

www.barnardos.org.uk/what_we_do/who_we_are/wales/wales_policy

- **This response may be made public**
- **This response is on behalf of Barnardo's Cymru**

Barnardo’s Cymru introduction

Barnardo’s Cymru has been working with children, young people and families in Wales for over 100 years and is one of the largest children’s charities working in the country. We currently run around 90 diverse services across Wales, working in partnership with 16 of the 22 local authorities.

Every one of our services is different, but each believes that every child and young person deserves the best start in life, no matter who they are, what they have done or what they have been through. We use the knowledge gained from our direct work with children to campaign for better child and social care policy and to champion for the rights of every child. We believe that with the right help, committed support and a little belief, even the most vulnerable children can turn their lives around. We aim to secure better wellbeing outcomes for more children by providing the support needed to ensure stronger families, safer childhoods and positive futures.

Barnardo’s Cymru, Autism and the Bill

For the purposes of this response when using the term ASD we include other neurodevelopmental conditions.

Barnardo’s Cymru supports some autistic children and young adults; we also support some parents who may be autistic through our family support services. While it could be argued that Barnardo’s Cymru do not provide any autism specific support, services we provide for disabled children and families with one or more disabled child are experiencing a significant increase in the volume of referrals with ASD as an issue. Barnardo’s Cymru may also have contact with families affected by ASD through young carer, substance misuse, Child Sexual Exploitation, Emotional Health and Wellbeing, Child Sexual Abuse, Harmful Sexual Behaviour, Care and Leaving Care services.

We are aware of the consultation response submitted by the National Autistic Society Cymru and both support their response and recognise their specific expertise.

Having contributed to the consultation on the previous draft Barnardo’s Cymru remains supportive of the Bill believing the experiences of people and families affected by ASD should be improved by placing services within a statutory accountable framework.

Response overview

Barnardo’s Cymru does not support the development of legislation without clear need and feel the case for this legislation is well made. The passing of this bill would not however achieve all of the change required and we would therefore advocate for additional provisions be considered through amendment to the Social Services and Well-being (Wales) Act.

Barnardo’s Cymru recognises the progress made in the decade since the first Autism Strategy and more latterly the Integrated Autism Service. It appears to Barnardo’s Cymru that it is possible more progress could have been made if both strategic and service developments had been made within a clearer statutory framework. As such Barnardo’s Cymru suggests that the aim of the Bill would be better served if there was a clear expectation of positive change for autistic people on the face of the bill.

While Barnardo’s Cymru recognise the progress made, the lack of an accountability framework with clear outcome expectations of local provisions will promote ‘postcode’ variation, not necessarily in the nature of provision but in the outcomes experienced.

In a recent consultation in one local authority Barnardo’s Cymru were surprised by the frequency that families affected by ASD said they avoided Social Service contact afraid that they would be seen as not coping and putting their families at risk. While there is no evidence to support this belief or that it is as pronounced in other areas, a legislative framework may go some way in addressing this issue.

Autism definition

Barnardo’s Cymru welcomes the inclusion of a definition of autism on the face of the Bill. Further we recognise the benefit of utilising the WHO definition.

Rights

Barnardo’s Cymru is pleased to see the inclusion at Section 8 of the duty of due regard to the UNCRC, UNCRDP and the UN Principles for Older Persons. While this inclusion gives strength to the promotion and protection of Human Rights Barnardo’s Cymru argue that this could be further strengthened in the style and wording of the Bill, for example in section 2 the need for the inclusion of the person with ASD and their families and carers taking account of their goals and aspirations could be more explicit than 2 (l).

Section 2 could also require consideration of advocacy for each party and further recognise the role of familiar known workers in supporting engagement.

Relevant bodies

In recognising the life long experience of autism and therefore the changing nature of particular care needs, should this list also include, in some form, regulated social care and residential services, such as elderly and nursing care and secure accommodation?

We are aware of significant representation in the secure estate, whether for welfare or justice issues, of people with autism whether diagnosed or not. This is a situation that would benefit from appropriate early intervention and diagnosis.

Timescales

Whilst Barnardo’s Cymru will always advocate for reductions in the periods of waiting for assessment and service, we recognise the value in the pragmatic nature of setting achievable timescales and would agree with the suggested use of the NICE guidelines.

However, Barnardo’s Cymru suggest in legislating for diagnosis the Bill might unwittingly promote diagnosis as a threshold for other services or support. We recognise that the wording around this suggests that assessment of or provision of care and support should not be delayed by the need for diagnosis but feel it would be better if this was more explicit if possible.

Multi-disciplinary team

Barnardo’s Cymru suggest that the role of independent advocacy for each party, and, due to the nature of Autistic Spectrum Disorder, the role of any worker already supporting the individual and known to them could be considered at 4 (6)(d).

Inclusion of this nature would be more in keeping with a rights approach and co productive in nature.

Data collection

Barnardo’s Cymru agree with the requirement to gather data; however, while recognising the catch all statement at 6 (6)(j) we would suggest that further data sets should be listed as well as a duty on bodies other than NHS such as local authorities should be considered. We would argue more usable data would be obtained if we included data such as:

- Age now
- Age at first indication
- Numbers waiting for diagnostic assessment
- Waiting times for diagnostic assessment
- Period undiagnosed
- Family role, parent/carer etc
- Numbers of families known with ASD indicating behaviours not referred, refusing or not seeking diagnostic assessment.

Given the focus on reducing ACEs and early intervention this data could prove invaluable.

Equity of access

Article 9 of the UNCRDP outlines state party responsibilities in relation to accessibility and the equality objectives include:

> *"5. Tackle barriers and support disabled people so that they can live independently and exercise choice and control in their daily lives."*

Barnardo's Cymru are aware of the experiences of some autistic people having difficulties in accessing appropriate support services because of a lack of evident disability and the presence of a normal to high IQ. We should expect that this will be eradicated in relation to statutory or social care services; however, it may prove more difficult to address in the provision of wider commercial services which points to the need for comprehensive **awareness raising campaigns** to challenge understanding.

Barnardo's Cymru supports the provision in the Bill requiring the provision of awareness and understanding campaigns. This also features as an obligation in article 8 of the UNCRDP.

Conclusion

There has undoubtedly been improvements in the provision and experience of services for and received by autistic people. It remains the case that further improvements are required to continue the drive towards equity of opportunity and experience for autistic people. It is also evident that we are experiencing the most challenging financial climate whilst seeking to increase the quality and volume of support against a rising identification of need.

Within this environment Barnardo's Cymru welcomes the development of this bill seeing it as an opportunity to clarify the national aim as well as the framework of delivery and accountability for services to autistic people.

Barnardo’s Cymru welcomes the inclusion of specific rights duties and hope for further development in the provision of advocacy and requirements to enable individual engagement where possible.

In closing Barnardo’s Cymru welcomes the development of the Autism Bill and see this as a necessary progressive step in the provision of improved services to people with or affected by Autistic Spectrum Disorders.

[redacted]
Barnardo’s Cymru
September 2018

A34
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Dr Duncan Holtom
Response from Dr Duncan Holtom

Written submission to the Health, Social Care and Sport Committee

Dr Duncan Holtom, Head of Research, People and Work

This response draws primarily upon our evaluation of Wales' first ASD Strategic Action Plan (ASD SAP) (WG, 2016) https://gov.wales/docs/caecd/research/2016/160218-evaluation-autistic-spectrum-disorder-strategic-action-plan-en.pdf and

the ongoing evaluation of the Integrated Autism Service (IAS) and refreshed autism strategy (WG, 2018) https://gov.wales/statistics-and-research/evaluation-integrated-autism-service-autistic-spectrum-disorder-strategic-action-plan/?lang=en

General principles of the Autism Bill

An autism strategy: Evaluations of the original (WG, 2016) and refreshed autism strategies (WG, 2018) demonstrate that many children and adults with autism (and also their families), have unmet needs, so there is a need for action. Without a national strategy, there is a danger that action to meet those needs will be piecemeal, inadequate and inconsistent. The evaluation of the first autism strategy (WG, 2016) identified widespread support for having a national strategy, and also highlighted how having such a strategy had raised the profile of autism. However, it also identified weaknesses in the original strategy (e.g. a lack of clear prioritisation; and weaknesses in the infrastructure for delivery/implementation of the strategy); weakness which the revised strategy set out to address.

Neither evaluation examined the question of whether there needed to be a legal requirement to publish a strategy, in order to "secure a measure of permanence and sustainability in care and support services of people with autism". (p5 of the Explanatory Memorandum).

Assessment and diagnosis: The evaluation of the original autism strategy (WG, 2014) highlighted the importance of getting a diagnosis to adults with autism and to the parents and carers of children with autism. Diagnosis provides insight and understanding of the difficulties people with autism and their families face and, particularly for children, can improve access to services[1] and provision. The evaluation of the original strategy (WG, 2016) highlighted improvements in assessment and diagnosis for both children and adults in some areas. However, it also identified considerable inconsistency in practice across Wales, with long waiting lists in some areas; an excessive reliance upon individuals with an interest in and commitment to autism (which contributed to the fragility of services); and, in some areas, a lack of clarity about referral pathways.

The interim evaluation of the Integrated Autism Service (IAS) and refreshed autism strategy (WG, 2018) confirms the need for action to strengthen assessment and diagnosis services as well as enhancing the sustainability of services; minimising inconsistencies in provision across Wales; and establishing clear referral pathways.

Although it is still too early to measure the effectiveness and impact of the IAS, the interim evaluation (ibid.) identifies encouraging evidence that the establishment of an IAS in each region will strengthen services; improve assessment and diagnostic practice for adults[2] (in line with NICE guidelines); reduce inconsistences across Wales and establish clear referral pathways. The evidence for improvement is strongest for adults diagnosed and referred by the IAS, and weaker for those assessed and diagnosed by learning disability or mental health services (the intention is that the IAS will support improvements in these services, but it is too early to assess likely impact). The interim evaluation (ibid.) also identifies that the IAS has increased the profile of assessment and diagnosis within Local Health Boards (and Regional Partnership Boards) and markedly improved accountability for provision for those referred and diagnosed by the IAS. However, the evaluation (ibid) also identifies fears that demand for assessment and diagnosis could exceed the capacity of the new IAS and/or side-line or undermine the other important aspects of the IAS's work, such as post-diagnostic support.

Data collection: The evaluation of the original autism strategy (WG, 2016) evaluated work by the local ASD infrastructure to identify the number of people with

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[1] In contrast, the lack of services for adults, meant the impact of diagnosis upon adults' access to services was much more limited.

[2] The interim report did not consider children's neurodevelopmental services (this will be considered as part of the final report, due in January 2019).

ASD in their area and their needs. The evaluation identified the need to improve understanding of the needs of people with autism. However, it also identified that:

- efforts to create databases of individuals with autism proved extremely difficult, due to the fragmentation of data across multiple databases (e.g. health, education and social services);
- the databases that were created were often incomplete and could rapidly become out of date, as people's needs changed over time; and
- the databases that were created were off limited value to commissioners of services (and little used).

The evaluation (ibid.) considered how data on the numbers of people with autism in a given area could used in the commissioning cycle. It identified that:

- for targeted services, estimates of the numbers of people with autism in a given area, based on a 1% prevalence rate, coupled with existing evidence on the needs of people with autism, would normally be sufficient to inform service planning. For example, detailed data on the numbers of people with autism in a given area would not be required to identify the need to provide information and training and support for people with autism in that area.
- for specialist services, there was a need for rich data on individual people's needs and aspirations (data rarely captured in the databases produced) to inform the commissioning of often bespoke services. Structures such as complex needs panels were felt to be proved reasonably effective in collecting this data (ibid), although other research (see e.g. Holtom and Sophocleous, 2016)[3] suggests that there may be a case for improving data collection and analysis to inform commissioning of these specialist services; and
- for universal, targeted and specialist services, there was a strong case for collecting more qualitative data on the experiences of different groups of people with autism, in order to inform the 'review' phase of commissioning (and service development) (WG, 2016). For example, if information and training and support is provided, it is important to understand how effective it is.

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[3] http://www.wwcp.org.uk/wp-content/uploads/2017/02/complexneedsfinalmps.pdf

As a consequence, the evaluation (ibid). concluded that the only real value in collecting data on the total numbers of people diagnosed with autism in a particular area, was as a measure of the extent to which autism was being recognised and diagnosed in that particular area. It is important to note that this analysis relates to the collection of quantitative data to create databases, and that for example, there is a real value in collecting qualitative and quantitative data on people's expectations and preferences, in order to help develop and design more person centred services.

Holistic services: The evaluation of the original autism strategy (WG, 2016) identified gaps in services for people with autism, particularly for adults who were not eligible for support from mental health or learning disability teams.[4] This lack of services contributed to poor outcomes (e.g. in relation to employment) and poor experiences for adults with autism. In some cases, following transitions from education, the loss of the structure education provided, difficulties finding employment and the absence of support services, meant that their level of disability increased, when, for example, social skills learnt in education were lost as result of withdrawal and social isolation.

The interim evaluation of the IAS (WG, 2018) identifies consistent support from stakeholders for the IAS model as part of the means for filling this gap in services. The IAS is not a panacea though, and cannot and should not seek to address all gaps or weakness in services.

Information: The evaluation of the original autism strategy (WG, 2016) identified how the local 'ASD Infrastructure' (most notably ASD leads and groups) had improved mapping of services and dissemination of this information. However, this remained patchy across Wales; it proved difficult to keep directories up to date; and the evaluation identified that parents and carers consistently reported difficulties identifying support services. To a large degree, this was caused by the absence of services, rather than weakness in service mapping and/or dissemination of information about services. However, there was also widespread frustration with the systems and processes for accessing care and support for children and adults with

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[4] Autism is neither a learning disability noir mental health disorder, and the evaluation also identified weakness in mental health and to a lesser degree, learning disability services. Nevertheless, those able to access support from these services, were generally able to access more support that those who were not eligible or did not need support from mental health or learning disability services.

autism, which were felt to be complex and difficult to understand.[5] Feedback from parents and carers interviewed as part of the ongoing evaluation of the refreshed strategy paints a similar picture.

Parents and carers frequently call for very responsive information and support, most commonly someone with whom to talk through their immediate problems and concerns. Because autism is a lifelong condition and needs can change, as for example, people's circumstances change. Therefore, whilst training and time limited support can help people learn news skills and knowledge, and was valued, people also often want access to support when they needed it (e.g. in a crisis or simply when they encounter a new problem). In the absence of responsive support services, many people rely upon more informal networks (e.g. talking to support groups and/or posting questions on forums) to access information and advice. These informal networks are very much valued, but there are risks that the information and advice given may not be evidence based.

Training: The evaluation of the original autism strategy (WG, 2016) identified the need for training to improve the responsiveness and sensitivity of services and enhance the experiences/wellbeing of people with autism and their parents/carers. It identified the provision of training as a key achievement of the original strategy, but also highlighted the scale of the challenge (e.g. in terms of the numbers of people to be trained). Other research, such as an Assessment of SEN Workforce requirements (WG, 2015)[6], suggests a responsive training and professional development/learning model in which, for example, additional learning is undertaken and/or advice and support is provided when needed, may be required to complement initial training.

The interim evaluation of the IAS (WG, 2018) highlights the important role the IAS is expected to play in providing training and support for services.

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[5] The evaluation identified that "the reasons why people cannot access services and experience such high levels of stress are complex. In part they reflect informational barriers, where carers do not know what services are available, or do not realise they would be entitled to support. However, they also reflect institutional barriers, including the absence of appropriate services, thresholds for eligibility for interventions (rationing access to services), cultural divides between professionals and users and carers, which can lead to misunderstanding and even conflict and a lack of awareness or understanding of ASD" (p 82, WG, 2016).

[6] http://dera.ioe.ac.uk/22888/1/150330-sen-en.pdf

Potential barriers

The evaluation of the original ASD SAP highlighted the failure to allocate resources to achieve many of its objectives as a significant weakness. This appears to apply to the Autism Wales Bill too.

Unintended consequences

Because assessment and diagnosis is perhaps the easiest area to legislate and set clear targets for, there is a danger that the Bill means this area is privileged over other important areas. Although (as outlined above) assessment and diagnosis is important, the evaluation of the original autism strategy (WG, 2016) identified the often limited value of assessment and diagnosis without post-diagnostic support. The evaluation of the IAS (WG, 2018) identified the risk that the IAS could struggle to meet demand for assessment and diagnosis and increasing pressure and accountability around assessment and diagnosis, could means resources intended for post-diagnostic support, are reallocated to assessment and diagnosis.

More broadly, given austerity and increasing demand for services as result of demographic changes and rising expectations (see e.g. Williams, 2014) [7] simply creating new duties in relation to autism without increasing resources, risks stripping or starving other important areas of resources.

Financial implications of the Bill

An autism strategy: In considering the cost of a strategy, it will be important to also consider the costs of evaluating the strategy.

Duty to act: the costs of effective action/support in areas like employment, where the evaluation of the original autism strategy (WG, 2018) suggests there are large gaps in support, are likely to be considerable. The costs of existing projects like Engage to Change may provide some indication of likely costs.

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[7] https://gov.wales/topics/improvingservices/public-service-governance-and-delivery/report/?lang=en

Training: The evaluation of the original ASD SAP highlights the scale of the challenge in relation to training, and the costs here could be considerable, depending on how broadly the definition of “key staff” is drawn.

Data collection: As noted above, the evaluation of the original autism strategy (WG, 2018) highlighted the difficulties of collecting data on the numbers of people with autism, given the fragmentation of this data across different IT systems (e.g. health, education and social services). This suggests that the costs of setting up and populating a database by drawing upon data from different systems/databases, may not be as “minimal” as the Explanatory Memorandum assumes.

Ymatebion i’r Ymgynghoriad yn y Gymraeg

Consultation Responses in the Welsh Language

A12
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Ludlow Street Healthcare
Response from Ludlow Street Healthcare

Y Bil Awtistiaeth (Cymru)

Ymateb i'r ymgynghoriad 12/09/2018

LUDLOW STREET
HEALTHCARE

Y Tîm Adolygu

- Mae Ludlow Street Healthcare yn darparugwasanaethau i boblâ chyflyrau Asperger cymhleth achyflyraucymhleth ar y Sbectrwm Awtistig yng Nghymru, yn benodol:
  - Coleg Beechwood yn Sili; cyfleuster addysgol sy'ncynnig gwasanaethau preswyl a gwasanaethau diwrnod i oedolion ifanc rhwng 16 a 25 oed
  - Ocean Community Services; sy'n darparu gofal pontio a thymor hir mewn unedau preswylbach yn ygymuned
- Mae ein timau amlddisgyblaethclinigol ac addysgol wedi adolygu'r Bil drafft, ac mae'r canlynol yn grynodeb o'u sylwadau

[redacted]

www.lshealthcare.co.uk

LUDLOW STREET
HEALTHCARE

Adran 2

- Sut bydd y Bil Awtistiaeth (Cymru) yn cysylltu â’r Ddeddf Anghenion Dysgu Ychwanegol, a sut byddant yn gweithio gyda'i gilydd i wella’r ddarpariaeth i oedolion ac i blant yng Nghymru? O ranasesu a chefnogi, sut bydd y darpariaethau hyn yn cysylltu â'r Cynlluniau Datblygu Unigol?
- Wrth fapio gwasanaethau, sut bydd darparwyr annibynnol yn cael eu hintegreiddio i’r rhwydwaith gwasanaethau? Pa ystyriaeth fydd yn cael ei chynnwys yn y broses dethol gwasanaethauar gyfer dewis rhieni?
- Beth yw hawliau’r person ifanc a/neu deuluoedd o ran prosesau apelio os ydynt yn anghytunoâ'r diagnosis, a chydnabyddiaeth o unrhyw asesiadau annibynnol sy’n cael eu cynnal?
- Sut bydd y Bil yn sicrhau bodyr holl wasanaethausy’n ymwneud â diagnosis yn cyd-fynd â’i gilydd? Pwy fydd yn gallu cyfrannu at y broses gwneud diagnosis (ee teuluoedd, lleoliadau gofal preswyl, darparwyr addysg ayb),ac a fyddpob partisy’n gysylltiedig â’r defnyddiwr gwasanaethau yn gallucyfrannu?Sut bydd y Bil yn sicrhau bod pawb sy’n defnyddio gwasanaethau cefnogi yn cael y ddarpariaeth briodol ar y lefel briodol?

LUDLOW STREET
HEALTHCARE

Adran 2

- Mae'n hollbwysig sicrhau bod gwasanaethau'n parhau wrth i unigolion dyfu o fod yn blant i fod yn oedolion. Rhaid i'r Bil sicrhau bod y newidiadau i gyllid addysgac AnghenionDysgu Ychwanegol, gyda'r cyfrifoldeb dros gyllid yn symud olywodraeth ganolog iawdurdodau lleol, yn cael ystyriaeth lawn a bod protocolau rheoli priodol yn cael eu cynnwys.A fydd y Bil yn caniatáu darparu gwasanaethau y tu hwnt i'r cynnig a'r ardal leol?
- Darpariaeth addysg – a yw hynyn cynnwys darparwyr annibynnol ac addysg ôl-orfodol?
- Sut gall darparwyr addysg ddisgwyl caelcefnogaeth gan y cyrff sy'n cael eu hamlinellu yn 2.1g – ee adnoddau a gwasanaethau cyfrwng Cymraeg?
- Parhad gwasanaethauwrth dyfuo blant ioedolion – hollbwysig bod hynyn eglur yn enwedig oran y newidiadau i gyllid addysg ac Anghenion Dysgu Ychwanegol, gyda'r cyfrifoldeb yn symud o lywodraeth ganolog i awdurdodau lleol. A fyddant yn edrych y tu hwnt i'r cynnig a'r ardal leol?
- O ran hyfforddiant i weithwyrproffesiynol, pa broses fydd yno ar gyfer darparwyr annibynnol i sicrhau eu bod yn cael digon o hyfforddiant?

Adran 6

- O ran casglu data –sut bydd darparwyr annibynnolyn gorfodcyflwyno data a pha reolau data fydd ynrhaid iddynt eu dilyn?
- A fydd y gofynion data ddim ond yn cynnwys pobl oGymru sy'n defnyddio gwasanaethau yng Nghymru, neua fyddantyn cynnwys pobl o Loegr sy'n defnyddiogwasanaethau yng Nghymru a phobl o Gymru sy'n defnyddio gwasanaethau yn Lloegr?

Sylwadau Cyffredinol

- Mae egwyddorion cyffredinol yBil yn dda, ond mae'n bwysig fod y Bil yn cynnwys yr ystod lawn o wasanaethau sydd ar gael, fel darparwyr annibynnol, er mwyn sicrhau dull cynhwysfawr ar gyfer darparu gwasanaethau Awtistiaeth.
- Rhaid i'rBil hefydwneud yn siŵr bod hawliau defnyddwyr gwasanaethaua'u rhieni/teuluoedd i gyfrannu at y broseso ddewis eu gwasanaethau yn cael eu cydnabod a'u diogelu.
- Rhaid ystyried yn llawn sut bydd y Bil Awtistiaeth yn cysylltu â'r Ddeddf Anghenion Dysgu Ychwanegol a'r targedau/darpariaethau sy'n cael eu hamlinellu ibobl ifanc drwy ddarparu Cynlluniau Datblygu Unigol.
- Un o fethiannau'r ddarpariaeth gwasanaethau bresennol yw diffyg integreiddio rhwng comisiynwyr gwasanaethau a darparwyr gwasanaethau; byddai cynnwys argymhellion ar gyfer gwella'r cyfathrebu rhwng asiantaethau yn cryfhau'r broses o ganfod yr atebionmwyaf llwyddiannus i ddefnyddwyr gwasanaethau.

A20
Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill
Ymateb gan Goleg Brenhinol y Seiciatryddion
Response from Royal College of Psychiatrists

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.

- Cyfadran seiciatreg glasoed
- Cyfadran seiciatreg anabledd 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 deddfwriaeth 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 deddfwriaeth sy'n benodol i awtistiaeth; A bod
- ar hyn o bryd, nid oes digon o dystiolaeth i ddangos y byddai deddfwriaeth 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 disgwyliedig 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 argymell 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 lansiwyd 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 ddiagnosio. 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 amlffactorol o bob achos, nid drwy ei ddiagnosis 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 ddiagnosis i wthio am adnoddau ond yn cynyddu cyfraddau diagnosis 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 reidrwydd 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 ngham 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.

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

CLlLC • 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 polisïau drwy’r Bwrdd Gweithredol a’r Cyngor WLGA ehangach. Mae’r WLGA hefyd yn penodi uwch aelodau fel Llefarwyr ac Is-lefarwyr 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 Sbectrwm 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 Sbectrwm Awtistiaeth sydd wedi’i ddiweddaru.

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 ddosbarthu 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 gofalwyr 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 bwyso 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 (LlC), mae awdurdodau lleol ac iechyd wedi sefydlu, neu maent yn y broses o sefydlu, 7 GAI rhanbarthol. Fe'u hariennir gan LlC 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, lansiwyd 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 gofalwyr a gweithwyr proffesiynol. Mae eu gwefan (www.ASDinfoWales.co.uk) yn rhan allweddol o'r cynnig hwn ac fe'i hariennir gan LlC 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 chyngor 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 chwiorydd 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 chyngor 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 diagnosio 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 LlC 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 LlC 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 chydlynydd 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 chyrff 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 ddeddfwriaeth 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 ddeddfwriaeth 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 sbectrwm awtistiaeth a theulu a gofalwyr y personau hynny", fodd bynnag, o dan 4(6)(b) cyfeirir at "bersonau 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 Sbectrwm 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 gwarchodedig 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 ddeddfwriaeth 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.

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Bil Awtistiaeth (Cymru)

Medi 2018

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Bil Awtistiaeth (Cymru)

Croesawa UCAC y cyfle hwn i ymateb i ymgynghoriad Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon ar y fersiwn diweddaraf o Fil Awtistiaeth (Cymru).

Mae UCAC yn undeb sy'n cynrychioli athrawon, arweinwyr ysgol, tiwtoriaid a darlithwyr ym mhob sector addysg ledled Cymru.

1.1. Mae UCAC yn llwyr gefnogol i'r Bil ac i'w egwyddorion cyffredinol. Credwn fod gan y Bil y potensial i wella'r gwasanaethau a ddarperir i bobl o bob oedran ag anhwylder sbectrwm awtistiaeth yng Nghymru, ac felly i wella ansawdd eu bywydau nhw a'u teuluoedd.

1.2. Fodd bynnag, rydym yn dal i fod yn bryderus ynghylch un agwedd yn benodol, sef y diffyg darpariaeth ar wyneb y Bil mewn perthynas â'r Gymraeg.

1.3. Mae UCAC, fel y mae eraill, gan gynnwys Comisiynydd y Gymraeg, wedi nodi mewn ymgynghoriadau blaenorol yr anawsterau o ran cael gwasanaethau a darpariaeth arbenigol, gan gynnwys asesiadau diagnostig, trwy gyfrwng y Gymraeg.

1.4. Fel yr ydym wedi pwysleisio mewn ymgynghoriadau blaenorol, mae aros yn fud neu'n benagored ar fater y Gymraeg yn arwain at amwysedd ac ansicrwydd o ran darparu gwasanaethau. Ni ellid dibynnu ar ddeddfwriaeth arall (e.e. Safonau'r Gymraeg dan Fesur y Gymraeg (Cymru) 2011, neu Ddeddf Anghenion Dysgu Ychwanegol a'r Tribiwnlys Addysg (Cymru) 2018) gan na fyddant yn berthnasol i bob agwedd o'r Bil hwn nac i bob agwedd o'r Strategaeth Awtistiaeth arfaethedig. Rhaid bod yn gwbl benodol ynghylch y cyfrifoldebau.

1.5. Mae cyfle yn y Bil i osod y safon yn uwch, ac i sicrhau cynnydd at y dyfodol, er budd pobl ag anhwylder sbectrwm awtistiaeth, ac ni fyddem am weld colli'r cyfle hwnnw.

1.6. Ni theimlwn fod y ddarpariaeth yng nghymal 2(1)(g)(v) yn ddigonol i fynd i'r afael â'r pryderon a'r anawsterau hyn, gan ei fod yn rhy gyffredinol.

1.7. Teimlwn yn gryf iawn bod angen cyfeiriad(au) ar wyneb y Bil at ddyletswyddau o ran y Gymraeg mewn perthynas â gweithrediad y Strategaeth Awtistiaeth ei hun. Gallai'r cyfeiriadau hynny ddod yn un neu fwy o'r mannau canlynol:

- 2(1)(i) sy'n ymwneud â hygyrchedd i bob person y mae angen y gwasanaethau arnynt
- 2(1)(l) sy'n ymwneud â dymuniadau personau ag anhwylder sbectrwm awtistiaeth a theuluoedd a gofalwyr y personau hynny

1.8. Yn ogystal, pwyswn arnoch chi i ystyried cynnwys cyfeiriad at y Gymraeg yn Adran 6: Data ar anhwylder sbectrwm awtistiaeth. Er mwyn cael darlun cyflawn o'r sefyllfa sy'n wynebu pobl ag anhwylder sbectrwm awtistiaeth, ac er mwyn sicrhau gwelliannau ar gyfer y dyfodol, credwn y dylid casglu data ynghylch:

- anghenion a/neu ddewisiadau ieithyddol mewn perthynas â'r Gymraeg
- unrhyw ddata perthnasol ynghylch effaith yr anghenion/dewisiadau hynny ar ddarpariaeth gwasanaethau, er enghraifft, a ddarparwyd yn y Gymraeg yn unol â'r terfynau amser sydd wedi'u nodi yn y Strategaeth a/neu mewn canllawiau, neu a fu oedi neu anawsterau?

1.9. Heblaw am ddiffyg profion diagnostig cydnabyddedig yn y Gymraeg, mae diffyg cynllunio'r gweithlu, o safbwynt sgiliau ieithyddol yn y Gymraeg, wedi bod yn broblem systemig, hirdymor. Hynny, yn anad dim, sy'n creu rhwystrau i wasanaethau hygyrch, addas ac amserol i siaradwyr Cymraeg ag anhwylder sbectrwm awtistiaeth. Byddai sicrhau cyfeiriad at hynny yn y Bil yn gallu bod yn drawsnewidiol. Gellid edrych ar Ddeddf Anghenion Dysgu Ychwanegol a'r Tribiwnlys Addysg (Cymru) 2018 i weld enghraifft o sut medrir ymdrin â'r mater mewn ffordd sy'n cymryd y sefyllfa bresennol i ystyriaeth ond gan osod y cyfeiriad ar gyfer gwelliant yn y dyfodol.

1.10. O wneud y cyfeiriadau uchod ar wyneb y Bil, mi fyddai sicrwydd y byddai unrhyw is-ddeddfwriaeth yn ymhelaethu arnynt.

1.11. Mae UCAC yn argyhoeddedig mai dim ond trwy wneud darpariaeth ar wyneb y Bil y gellir sicrhau yr ymdrinnir ag anghenion ieithyddol fel elfen hanfodol o ofal, ac y gellir creu’r amodau fydd yn caniatáu’r ‘cynnig rhagweithiol’ sydd i fod yn ddisgwyliedig.

1.12. Tynnwn sylw at baragraff 552 yn y Memorandwm Esboniadol:

> **552. O'r herwydd, credir na fydd darpariaethau'r Bil yn cael effaith gadarnhaol mewn perthynas â siaradwyr Cymraeg, yn enwedig o ran hwyluso gwasanaethau a diagnosis a ddarperir trwy gyfrwng y Gymraeg.**

Cymrwn mai camgymeriad yw hynny (yn y fersiynau Cymraeg a Saesneg fel ei gilydd) – ond efallai nad yw’n bell o’r gwirionedd os na weithredir ar sail ein pryderon uchod.

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Credwch mewn plant
Believe in children
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Ymateb i'r Ymgynghoriad gan Barnardo's Cymru

Gwaith craffu cyfnod un Bil Awtistiaeth (Cymru)

21 Medi 2018

[redacted]

[redacted]

www.barnardos.org.uk/what_we_do/who_we_are/wales/wales_policy

- **Gellir gwneud yr ymateb hwn yn gyhoeddus**
- **Mae'r ymateb hwn ar ran Barnardo's Cymru**

Cyflwyniad Barnardo’s Cymru

Mae Barnardo’s Cymru wedi bod yn gweithio gyda phlant, pobl ifanc a theuluoedd yng Nghymru am dros 100 mlynedd ac mae'n un o’r elusennau plant mwyaf sy’n gweithio yn y wlad. Ar hyn o bryd rydym yn cynnal tua 90 o wahanol wasanaethau drwy Gymru, gan weithio mewn partneriaeth ag 16 o’r 22 awdurdod lleol.

Mae pob un o’n gwasanaethau’n wahanol, ond mae pob un ohonynt yn credu bod pob plentyn a pherson ifanc yn haeddu’r dechrau gorau mewn bywyd, waeth pwy ydyn nhw, beth maen nhw wedi’i wneud neu beth maen nhw wedi bod drwyddo. Rydym yn defnyddio’r wybodaeth a geir o’n gwaith uniongyrchol gyda phlant i ymgyrchu am bolisi plant a gofal cymdeithasol gwell ac er mwyn amddiffyn hawliau pob plentyn. Rydym yn credu, gyda’r help cywir, cefnogaeth ymroddedig ac ychydig o ymddiriedaeth, gall hyd yn oed y plant mwyaf bregus gael trefn ar eu bywydau. Rydym yn anelu at sicrhau gwell canlyniadau ar gyfer mwy o blant trwy gynnig y gefnogaeth sydd ei hangen arnynt i sicrhau teuluoedd cryfach, plentyndod mwy diogel a dyfodol cadarnhaol.

Barnardo’s Cymru, Awtistiaeth a’r Bil

I bwrpas yr ymateb hwn pan ddefnyddir y term anhwylder ar y sbectrwm awtistig (ASA) rydym yn cynnwys cyflyrau niwroddatblygiadol eraill.

Mae Barnardo’s Cymru’n cefnogi rhai plant ac oedolion ifanc awtistig; rydym hefyd yn cefnogi rhai rhieni a allai fod yn awtistig trwy ein gwasanaethau cymorth teuluoedd. Er y gellid dadlau nad yw Barnardo’s Cymru’n darparu unrhyw gefnogaeth benodol ar gyfer awtistiaeth, mae’r gwasanaethau yr ydym yn eu darparu ar gyfer plant a theuluoedd anabl gydag un neu fwy o blant anabl yn gweld cynnydd sylweddol yn nifer yr atgyfeiriadau lle mae ASA yn broblem. Gall Barnardo’s Cymru hefyd gael cyswllt â theuluoedd sy’n cael eu heffeithio gan ASA drwy wasanaethau gofalwr ifanc, camddefnyddio sylweddau, Cam-fanteisio’n Rhywiol ar Blant, Iechyd a Lles Emosiynol, Cam-drin Plant yn Rhywiol, Ymddygiad Rhywiol Niweidiol, Gofal a Gadael Gofal.

Rydym yn ymwybodol o’r ymateb i’r ymgynghoriad a gyflwynwyd gan Gymdeithas Genedlaethol Awtistiaeth Cymru ac rydym yn cefnogi eu hymateb ac yn cydnabod eu harbenigedd penodol.

Cyfrannodd Barnardo’s Cymru at yr ymgynghoriad ar y fersiwn drafft blaenorol, ac mae’n dal i gefnogi’r Bil ac yn credu y dylid gwella profiadau pobl a theuluoedd sy’n cael eu heffeithio gan ASA trwy osod gwasanaethau o fewn fframwaith atebol statudol.

Trosolwg o’r ymateb

Nid yw Barnardo’s Cymru’n gefnogol i ddatblygu deddfwriaeth heb fod angen clir ac mae'n teimlo bod achos da wedi’i gyflwyno ar gyfer y ddeddfwriaeth hon. Fodd bynnag, ni fyddai pasio’r bil hwn yn sicrhau’r holl newid sydd ei angen ac felly byddem yn dadlau dros ystyried darpariaethau ychwanegol trwy ddiwygio’r Ddeddf Gwasanaethau Cymdeithasol a Lles (Cymru).

Mae Barnardo’s Cymru’n cydnabod y cynnydd a wnaed yn y degawd ers y Strategaeth Awtistiaeth gyntaf ac yn fwy diweddar, y Gwasanaeth Awtistiaeth Integredig. Mae'n ymddangos i Barnardo’s Cymru ei fod yn bosibl y gellid bod wedi gwneud mwy o gynnydd pe byddai datblygiadau strategol a gwasanaeth wedi’i gwneud o fewn fframwaith statudol cliriach. Felly mae Barnardo’s Cymru’n awgrymu y byddai nod y Bil wedi bod yn well pe byddai disgwyliad clir o newid positif i bobl awtistig yn amlwg ynddo.

Tra bod Barnardo’s Cymru’n cydnabod y cynnydd a wnaed, bydd diffyg fframwaith atebolrwydd gyda disgwyliadau clir o ran canlyniadau lleol yn hybu gwahaniaeth rhwng ‘codau post’, nid o anghenraid yn natur y ddarpariaeth ond yn y canlyniadau a welir.

Mewn ymgynghoriad diweddar yn un awdurdod lleol roedd Barnardo’s Cymru wedi’u synnu pa mor aml yr oedd teuluoedd oedd wedi’u heffeithio gan ASA yn dweud eu bod yn osgoi cysylltu â Gwasanaethau Cymdeithasol gan fod ofn arnynt y byddai’r gwasanaeth yn ystyried nad oedden nhw’n ymdopi a’u bod yn gosod eu teuluoedd mewn risg. Er nad oes tystiolaeth i gefnogi’r gred hon neu ei bod mor amlwg mewn ardaloedd eraill, gallai fframwaith deddfwriaethol fynd beth o’r ffordd i roi sylw i’r mater hwn.

Diffiniad o awtistiaeth

Mae Barnardo’s Cymru’n croesawu cynnwys diffiniad o awtistiaeth yn y Bil. Hefyd rydym yn cydnabod y budd o ddefnyddio diffiniad Sefydliad Iechyd y Byd.

Hawliau

Mae Barnardo’s Cymru’n falch o weld bod Adran 8 yn cynnwys sylw dyledus i CCUHP, Confensiwn y Cenhedloedd Unedig ar Hawliau Pobl ag Anableddau ac Egwyddorion yr UC ar gyfer Pobl Hŷn. Tra bod cynnwys hyn yn atgyfnerthu, yn hybu a diogelu Hawliau Dynol mae Barnardo’s Cymru’n dadlau y gellid cryfhau hyn ymhellach yn arddull a geiriad y Bil, er enghraifft yn adran 2 gallai’r angen i gynnwys yr unigolyn ag ASA a’u teuluoedd a’u gofalwyr gan ystyried eu nodau a’u dyheadau fod yn gliriach na 2 (l).

Yn Adran 2 gellid hefyd ystyried eiriolaeth ar gyfer bob parti a chydnabod ymhellach rôl gweithwyr cyfarwydd i gefnogi ymgysylltiad.

Cyrff perthnasol

I gydnabod profiad gydol oes awtistiaeth ac felly natur newidiol anghenion gofal penodol, oni ddylai’r rhestr hon hefyd gynnwys, ar ryw ffurf, wasanaethau gofal cymdeithasol a phreswyl wedi’u rheoleiddio, fel gofal nyrsio a’r henoed a llety diogel?

Rydym yn ymwybodol fod cynrychiolaeth sylweddol yn ystâd ddiogel, boed ar gyfer materion lles neu gyfiawnder, pobl ag awtistiaeth boed wedi cael diagnosis ai peidio. Byddai’r sefyllfa hon yn elwa ar ymyrraeth a diagnosis cynnar priodol.

Amserlenni

Tra bydd Barnardo’s Cymru bob amser yn dadlau dros leihau’r cyfnodau aros i gael asesiad a gwasanaeth, rydym yn cydnabod gwerth natur bragmatig gosod amserlenni y gellir eu cyflawni a byddem yn cytuno â’r awgrym o ddefnyddio canllawiau NICE.

Fodd bynnag, mae Barnardo’s Cymru’n awgrymu wrth ddeddfu ar gyfer diagnosis y gallai’r Bil yn ddiarwybod hybu diagnosis fel trothwy ar gyfer gwasanaethau neu gefnogaeth arall. Rydym yn cydnabod bod y geiriad yma’n awgrymu na ddylai asesu neu ddarparu gofal a chefnogaeth gael ei ohirio yn sgil yr angen am ddiagnosis ond rydym yn teimlo y byddai’n well pe byddai hyn yn gliriach os yw’n bosibl.

Tîm amlddisgyblaethol

Mae Barnardo’s Cymru’n awgrymu y gallai rôl eiriolwr annibynnol ar gyfer bob parti, ac, oherwydd natur yr Anhwylder ar y Sbectrwm Awtistig, rôl unrhyw weithiwr sydd eisoes yn cefnogi’r unigolyn ac yn hysbys iddynt gael ei ystyried yn 4 (6)(d).

Byddai ei gynnwys fel hyn yn fwy cydnaws â dull hawliau a chyd-baratoi.

Casglu data

Mae Barnardo’s Cymru’n cytuno â’r gofyniad i gasglu data; fodd bynnag, tra ein bod yn cydnabod y datganiad hollgynhwysol yn (6)(j) byddem yn awgrymu y dylid ystyried rhestru setiau data pellach yn ogystal â dyletswydd ar gyrff ar wahân i'r GIG fel awdurdodau lleol. Buasem yn dadlau y byddai data mwy defnyddiol yn cael ei gasglu pe buasem yn cynnwys data fel:

- Oed nawr
- Oed pan gafwyd yr arwyddion cynharaf
- Niferoedd sy'n disgwyl am asesiad diagnostig
- Amseroedd aros am asesiad diagnostig
- Cyfnod heb ddiagnosis
- Rôl y teulu, rhiant/gofalwr ayb
- Nifer teuluoedd lle mae'n hysbys bod ymddygiad sy'n amlygu ASA ond sydd heb eu hatgyfeirio, sy'n gwrthod neu ddim yn ceisio asesiad diagnostig.

O ystyried y ffocws ar leihau profiad niweidiol yn ystod plentyndod. Ac ymyrraeth gynnar gallai'r data hwn fod yn amhrisiadwy.

Mynediad cyfartal

Mae Erthygl 9 o Gonfensiwn y Cenhedloedd Unedig ar Hawliau Pobl ag Anableddau yn amlinellu cyfrifoldebau gwladol mewn perthynas â hygyrchedd ac mae'r amcanion cydraddoldeb yn cynnwys:

> *"5. Mynd i'r afael â rhwystrau a chefnogi pobl anabl er mwyn iddynt allu byw'n annibynnol a chael dewis a rheolaeth yn eu bywydau bob dydd."*

Mae Barnardo's Cymru'n ymwybodol o brofiadau rhai pobl awtistig sy'n cael anhawster i gael mynediad at wasanaethau cefnogi priodol oherwydd diffyg anabledd amlwg ac IQ normal i uchel. Dylem ddisgwyl y bydd hyn yn cael ei ddileu mewn perthynas â gwasanaethau statudol neu ofal cymdeithasol; fodd bynnag, gallai fod yn anos rhoi sylw i hyn wrth ddarparu gwasanaethau masnachol ehangach sy'n dangos bod angen **ymgyrchoedd codi ymwybyddiaeth** cynhwysfawr i herio deallusrwydd.

Mae Barnardo's Cymru'n cefnogi'r ddarpariaeth yn y Bil sy'n gofyn am ddarparu ymgyrchoedd ymwybyddiaeth a deallusrwydd. Mae hyn yn cael ei gynnwys hefyd fel ymrwymiad yn erthygl 8 o Gonfensiwn y Cenhedloedd Unedig ar Hawliau Pobl ag Anableddau.

Casgliad

Heb os bu gwelliannau o ran darpariaeth a phrofiad o wasanaethau ar gyfer pobl awtistig, ac a dderbynnir ganddynt. Mae'n dal yn wir fod angen gwelliannau pellach i barhau i sicrhau cyfle a phrofiad cyfartal i bobl awtistig. Mae hefyd yn amlwg ein bod yn wynebu'r hinsawdd ariannol fwyaf heriol wrth geisio gwella ansawdd a chael mwy o gefnogaeth yn erbyn angen cynyddol a nodwyd.

O fewn yr amgylchedd hwn mae Barnardo’s Cymru’n croesawu datblygiad y bil hwn ac yn ei ystyried yn gyfle i ddatgan yn glir beth yw’r nod cenedlaethol yn ogystal â’r fframwaith darparu ac atebolrwydd ar gyfer gwasanaeth i bobl awtistig.

Mae Barnardo’s Cymru’n croesawu’r cam o gynnwys dyletswyddau hawliau penodol ac mae’n gobeithio y bydd datblygiadau pellach o ran darparu eiriolaeth a gofynion i hwyluso ymgysylltiad unigol lle y bo’n bosibl.

Wrth gloi mae Barnardo’s Cymru’n croesawu datblygiad y Bil Awtistiaeth ac yn ei ystyried fel cam blaengar angenrheidiol wrth ddarparu gwell gwasanaethau i bobl sy’n dioddef neu sydd wedi’i heffeithio gan Anhwylderau’r Sbectrwm Awtistig.

[redacted]
Barnardo’s Cymru
Medi 2018

Eitem 3

Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-26-18 Papur 2 / Paper 2

Written submission to the Health, Social Care and Sport Committee

Dr Duncan Holtom, Head of Research, People and Work

This response draws primarily upon our evaluation of Wales' first ASD Strategic Action Plan (ASD SAP) (WG, 2016) https://gov.wales/docs/caecd/research/2016/160218-evaluation-autistic-spectrum-disorder-strategic-action-plan-en.pdf and

the ongoing evaluation of the Integrated Autism Service (IAS) and refreshed autism strategy (WG, 2018) https://gov.wales/statistics-and-research/evaluation-integrated-autism-service-autistic-spectrum-disorder-strategic-action-plan/?lang=en

General principles of the Autism Bill

An autism strategy: Evaluations of the original (WG, 2016) and refreshed autism strategies (WG, 2018) demonstrate that many children and adults with autism (and also their families), have unmet needs, so there is a need for action. Without a national strategy, there is a danger that action to meet those needs will be piecemeal, inadequate and inconsistent. The evaluation of the first autism strategy (WG, 2016) identified widespread support for having a national strategy, and also highlighted how having such a strategy had raised the profile of autism. However, it also identified weaknesses in the original strategy (e.g. a lack of clear prioritisation; and weaknesses in the infrastructure for delivery/implementation of the strategy); weakness which the revised strategy set out to address.

Neither evaluation examined the question of whether there needed to be a legal requirement to publish a strategy, in order to "secure a measure of permanence and sustainability in care and support services of people with autism". (p5 of the Explanatory Memorandum).

Assessment and diagnosis: The evaluation of the original autism strategy (WG, 2014) highlighted the importance of getting a diagnosis to adults with autism and to the parents and carers of children with autism. Diagnosis provides insight and understanding of the difficulties people with autism and their families face and, particularly for children, can improve access to services[1] and provision. The evaluation of the original strategy (WG, 2016) highlighted improvements in assessment and diagnosis for both children and adults in some areas. However, it also identified considerable inconsistency in practice across Wales, with long waiting lists in some areas; an excessive reliance upon individuals with an interest in and commitment to autism (which contributed to the fragility of services); and, in some areas, a lack of clarity about referral pathways.

The interim evaluation of the Integrated Autism Service (IAS) and refreshed autism strategy (WG, 2018) confirms the need for action to strengthen assessment and diagnosis services as well as enhancing the sustainability of services; minimising inconsistencies in provision across Wales; and establishing clear referral pathways.

Although it is still too early to measure the effectiveness and impact of the IAS, the interim evaluation (ibid.) identifies encouraging evidence that the establishment of an IAS in each region will strengthen services; improve assessment and diagnostic practice for adults[2] (in line with NICE guidelines); reduce inconsistences across Wales and establish clear referral pathways. The evidence for improvement is strongest for adults diagnosed and referred by the IAS, and weaker for those assessed and diagnosed by learning disability or mental health services (the intention is that the IAS will support improvements in these services, but it is too early to assess likely impact). The interim evaluation (ibid.) also identifies that the IAS has increased the profile of assessment and diagnosis within Local Health Boards (and Regional Partnership Boards) and markedly improved accountability for provision for those referred and diagnosed by the IAS. However, the evaluation (ibid) also identifies fears that demand for assessment and diagnosis could exceed the capacity of the new IAS and/or side-line or undermine the other important aspects of the IAS's work, such as post-diagnostic support.

Data collection: The evaluation of the original autism strategy (WG, 2016) evaluated work by the local ASD infrastructure to identify the number of people with

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[1] In contrast, the lack of services for adults, meant the impact of diagnosis upon adults' access to services was much more limited.

[2] The interim report did not consider children's neurodevelopmental services (this will be considered as part of the final report, due in January 2019).

ASD in their area and their needs. The evaluation identified the need to improve understanding of the needs of people with autism. However, it also identified that:

- efforts to create databases of individuals with autism proved extremely difficult, due to the fragmentation of data across multiple databases (e.g. health, education and social services);
- the databases that were created were often incomplete and could rapidly become out of date, as people's needs changed over time; and
- the databases that were created were off limited value to commissioners of services (and little used).

The evaluation (ibid.) considered how data on the numbers of people with autism in a given area could used in the commissioning cycle. It identified that:

- for targeted services, estimates of the numbers of people with autism in a given area, based on a 1% prevalence rate, coupled with existing evidence on the needs of people with autism, would normally be sufficient to inform service planning. For example, detailed data on the numbers of people with autism in a given area would not be required to identify the need to provide information and training and support for people with autism in that area.
- for specialist services, there was a need for rich data on individual people's needs and aspirations (data rarely captured in the databases produced) to inform the commissioning of often bespoke services. Structures such as complex needs panels were felt to be proved reasonably effective in collecting this data (ibid), although other research (see e.g. Holtom and Sophocleous, 2016)[3] suggests that there may be a case for improving data collection and analysis to inform commissioning of these specialist services; and
- for universal, targeted and specialist services, there was a strong case for collecting more qualitative data on the experiences of different groups of people with autism, in order to inform the 'review' phase of commissioning (and service development) (WG, 2016). For example, if information and training and support is provided, it is important to understand how effective it is.

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[3] http://www.wwcp.org.uk/wp-content/uploads/2017/02/complexneedsfinalmps.pdf

As a consequence, the evaluation (ibid). concluded that the only real value in collecting data on the total numbers of people diagnosed with autism in a particular area, was as a measure of the extent to which autism was being recognised and diagnosed in that particular area. It is important to note that this analysis relates to the collection of quantitative data to create databases, and that for example, there is a real value in collecting qualitative and quantitative data on people's expectations and preferences, in order to help develop and design more person centred services.

Holistic services: The evaluation of the original autism strategy (WG, 2016) identified gaps in services for people with autism, particularly for adults who were not eligible for support from mental health or learning disability teams.[4] This lack of services contributed to poor outcomes (e.g. in relation to employment) and poor experiences for adults with autism. In some cases, following transitions from education, the loss of the structure education provided, difficulties finding employment and the absence of support services, meant that their level of disability increased, when, for example, social skills learnt in education were lost as result of withdrawal and social isolation.

The interim evaluation of the IAS (WG, 2018) identifies consistent support from stakeholders for the IAS model as part of the means for filling this gap in services. The IAS is not a panacea though, and cannot and should not seek to address all gaps or weakness in services.

Information: The evaluation of the original autism strategy (WG, 2016) identified how the local 'ASD Infrastructure' (most notably ASD leads and groups) had improved mapping of services and dissemination of this information. However, this remained patchy across Wales; it proved difficult to keep directories up to date; and the evaluation identified that parents and carers consistently reported difficulties identifying support services. To a large degree, this was caused by the absence of services, rather than weakness in service mapping and/or dissemination of information about services. However, there was also widespread frustration with the systems and processes for accessing care and support for children and adults with

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[4] Autism is neither a learning disability noir mental health disorder, and the evaluation also identified weakness in mental health and to a lesser degree, learning disability services. Nevertheless, those able to access support from these services, were generally able to access more support that those who were not eligible or did not need support from mental health or learning disability services.

autism, which were felt to be complex and difficult to understand.[5] Feedback from parents and carers interviewed as part of the ongoing evaluation of the refreshed strategy paints a similar picture.

Parents and carers frequently call for very responsive information and support, most commonly someone with whom to talk through their immediate problems and concerns. Because autism is a lifelong condition and needs can change, as for example, people's circumstances change. Therefore, whilst training and time limited support can help people learn news skills and knowledge, and was valued, people also often want access to support when they needed it (e.g. in a crisis or simply when they encounter a new problem). In the absence of responsive support services, many people rely upon more informal networks (e.g. talking to support groups and/or posting questions on forums) to access information and advice. These informal networks are very much valued, but there are risks that the information and advice given may not be evidence based.

Training: The evaluation of the original autism strategy (WG, 2016) identified the need for training to improve the responsiveness and sensitivity of services and enhance the experiences/wellbeing of people with autism and their parents/carers. It identified the provision of training as a key achievement of the original strategy, but also highlighted the scale of the challenge (e.g. in terms of the numbers of people to be trained). Other research, such as an Assessment of SEN Workforce requirements (WG, 2015)[6], suggests a responsive training and professional development/learning model in which, for example, additional learning is undertaken and/or advice and support is provided when needed, may be required to complement initial training.

The interim evaluation of the IAS (WG, 2018) highlights the important role the IAS is expected to play in providing training and support for services.

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[5] The evaluation identified that "the reasons why people cannot access services and experience such high levels of stress are complex. In part they reflect informational barriers, where carers do not know what services are available, or do not realise they would be entitled to support. However, they also reflect institutional barriers, including the absence of appropriate services, thresholds for eligibility for interventions (rationing access to services), cultural divides between professionals and users and carers, which can lead to misunderstanding and even conflict and a lack of awareness or understanding of ASD" (p 82, WG, 2016).

[6] http://dera.ioe.ac.uk/22888/1/150330-sen-en.pdf

Potential barriers

The evaluation of the original ASD SAP highlighted the failure to allocate resources to achieve many of its objectives as a significant weakness. This appears to apply to the Autism Wales Bill too.

Unintended consequences

Because assessment and diagnosis is perhaps the easiest area to legislate and set clear targets for, there is a danger that the Bill means this area is privileged over other important areas. Although (as outlined above) assessment and diagnosis is important, the evaluation of the original autism strategy (WG, 2016) identified the often limited value of assessment and diagnosis without post-diagnostic support. The evaluation of the IAS (WG, 2018) identified the risk that the IAS could struggle to meet demand for assessment and diagnosis and increasing pressure and accountability around assessment and diagnosis, could means resources intended for post-diagnostic support, are reallocated to assessment and diagnosis.

More broadly, given austerity and increasing demand for services as result of demographic changes and rising expectations (see e.g. Williams, 2014) [7] simply creating new duties in relation to autism without increasing resources, risks stripping or starving other important areas of resources.

Financial implications of the Bill

An autism strategy: In considering the cost of a strategy, it will be important to also consider the costs of evaluating the strategy.

Duty to act: the costs of effective action/support in areas like employment, where the evaluation of the original autism strategy (WG, 2018) suggests there are large gaps in support, are likely to be considerable. The costs of existing projects like Engage to Change may provide some indication of likely costs.

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[7] https://gov.wales/topics/improvingservices/public-service-governance-and-delivery/report/?lang=en

Training: The evaluation of the original ASD SAP highlights the scale of the challenge in relation to training, and the costs here could be considerable, depending on how broadly the definition of “key staff” is drawn.

Data collection: As noted above, the evaluation of the original autism strategy (WG, 2018) highlighted the difficulties of collecting data on the numbers of people with autism, given the fragmentation of this data across different IT systems (e.g. health, education and social services). This suggests that the costs of setting up and populating a database by drawing upon data from different systems/databases, may not be as “minimal” as the Explanatory Memorandum assumes.

Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon

Health, Social Care and Sport Committee

HSCS(5)-26-18 Papur 3 / Paper 3

Autism Bill Consultation response from Dr Dawn Wimpory, Consultant Clinical Psychologist – Lead for ASD (BCUHB) and Lecturer (Bangor University)

I have held an autism-specific clinical and research joint post for the last 3 decades and have been invited to present evidence to the scrutiny committee for this bill on 3.10.18. (I was also asked by the Division of Clinical Psychology, for the British Psychological Society, to represent them in their response to this bill but had to decline as I shall be abroad on the date that my presence was required for that.)

1) 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

I think the general principles of the bill are sound and that they will help Wales to meet the needs of children and adults with ASDs, and achieve the aim of protecting and promoting their rights, more than previous strategies have been able to do. I was on the original strategic group for the first ASD action plan and have seen the level of impact of this and subsequent action plans over the last decade; as a result I think it is appropriate to bring in legislation to address the issues of concern.

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

I think that staffing and their organisation may represent potential barriers to the implementation of the provisions in the Bill in relation to waiting list times. Specifically this may include initial difficulty with commencing ASD assessments within 3 months of referral. However, I think it is inappropriate that Wales should have guidance of 26wk maximum Waiting List (WL) time (e.g. for children) whilst NICE guidelines from England specify 3months for adults and children. It seems appropriate that any ASD legislation for Wales at least matches NICE-issued guidelines. I think it is positive that individuals who appear inappropriate referrals can be advised of this promptly and possibly redirected to other services by clinicians.

I am concerned that discussions of the this Bill have been erroneously representing the 13 wks until *commencement* of assessment as 13 wks until a *diagnosis* should be made (this appeared to be how it was represented by the new WLGA national ASD Lead at a recent regional IAS strategic meeting and subsequent written communication reflected this misunderstanding). These are very different in terms of the implications/resources required for each and

I would be very disappointed if confusion around this issue influences receptiveness to the bill on a larger scale.

Currently, waiting lists, e.g. in children's ND services, are being clogged by inappropriate referrals that tend to be held there for too long. After such cases have waited for an unreasonable amount of time, there is a tendency to feel that they are 'owed' an ASD assessment even when other indicators show that this is not the most appropriate use of resources. I think that removing such cases from ASD WLs early on, as advocated in the bill, will ultimately reduce pressure on WLs and therefore proved helpful. Of course additional resources may well be necessary, especially initially, in order to assist in this reorganisation of how services/WLs are organised.

I also think it is important that clinicians can focus half their efforts on supporting families of clients with ASD, rather than be consumed by assessment work - I am not yet certain that the bill addresses the need to protect intervention time within services for these clients.

I welcome the bill's position in requiring services to record ASD diagnoses. Under my own direction, BCUHB has successfully collected and collated such diagnostic information for children over the last 6yrs and is therefore unique in Wales in being able to identify accurately whether or not research-supported internationally-recognised prevalence rates are being adhered to, or exceeded or failing to be reached. BCUHB’s Autism Module enables examination of such figures within each of the 3 constituent areas of BCUHB and over the HB as a whole. Such figures are absolutely essential in Wales being able to identify whether diagnoses are being made at appropriate levels.

It is both inappropriate for ASD diagnoses to be missed and for people without ASD to be erroneously diagnosed as having ASD. These are real dangers and can only be addressed through accurate data recording and analysis in a constant manner. BCUHB's database, conceived originally by WG, as a pilot for the whole of Wales, has demonstrated that such data can be efficiently and routinely recorded/analysed. I understand concerns from other services that this may be an impossible task but 6yr's experience with our ASD database proves otherwise. Software for this database, via CCH2000’s database system of electronic records, already exists throughout NHS Wales. CCH2000 is currently migrating to an upgraded system, CYPRIS. ABHB are the first Health Board to use the Autism Database Module on CYPRIS.

3) <u>Whether there are any unintended consequences arising from the Bill</u>

My experience of successive ASD all-Wales strategies is that they have not drawn attention away from, eg, ADHD, so I do not envisage this as an unintended consequence of the Autism Bill. However, IF diagnoses of ASD were to proceed without prevalence levels being checked (as the Bill sets out to avoid through the data collection referred to above) then there might be a risk that resources are not allocated appropriately to the correct service users. But the latter risk already exists without the Autism Bill anyway.

It would seem essential that the bill is applied to private services as well as to statutory services so that the former adhere to standards required of the latter; this is particularly important to help address any over-diagnosis of ASD in private provision, possibly through less thorough assessment strategies.

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

My understanding of the bill is that it has been supported through appropriate research and reviewing of available information, including financial elements; I particularly welcome the involvement of Professor Martin Knapp at LSE as appropriate international expert in this aspect of ASD. The data collection/analysis elements of the bill are based on experience of 6yrs piloting an ASD Database Module that was piloted by WG in anticipation of All Wales roll out.

5 **)** 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)

Unlike NICE guidelines that advocate both ICD-10 and DSM5, the Bill employs just DSM5, this seems regrettable as there have been some criticism of this system (e.g. that it may be too influenced by insurance issues in US). It seems surprising, and perhaps too bold, that ministers will be able to extend the client group to whom the Autism Bill applies, in addition to ASD in the future.

I welcome a bill that identifies the unique difficulties and challenges presented by autism to services and their uses. It seems too wide that ministers might expand the neuro-developmental conception of service users to whom the bill might apply in the future. As a related example, the current strategic inclusion of ADHD child referrals along with those for ASD has been not been helpful in my experience. This is because approximately half of those children with diagnosed with ADHD have an emotional or environmental basis for their diagnosis (as outlined by Dr. Elspeth Webb, Consultant Paediatrician, ND national presentation), whereas this is not the basis of ASD. Clinicians working with each group of children therefore require a different skill set and, in my experience, services for children with ASD can be slowed down by the contrasting needs and challenges presented by those with ADHD.

Hopefully ministers would not be defining the boundaries of ASD. Instead it seems appropriate that research-informed leaders of the ASD clinical field should take that responsibility, with research-evidenced prevalence figures in mind. As a disability, even in high functioning individuals, ASD should only be diagnosed (through the NHS or private services) where there is a level of impairment that warrants clinical recognition.

Dr Dawn Wimpory
Consultant Clinical Psychologist – Lead for ASD (BCUHB) and Lecturer
([redacted]) ([redacted])

Tystiolaeth ar gyfer y Bil Awtistiaeth

Egwyddorion cyffredinol

Yn gyffredinol, mae angen Bil Awtistiaeth i sicrhau hawliau unigolion gydag Awtistiaeth ers tro: mae gan Loegr a Gogledd Iwerddon ddeddfwriaeth o'r fath yn barod. Mae gennym angen am strategaeth Gymru-gyfan, gyson i sicrhau y gall unigolion ag Awtistiaeth gael diagnosis dibynadwy ac amserol os oes angen, a mynediad i gefnogaeth ac amrediad o wasanaethau priodol. Croesawir y Bil yn ei hanfod felly. Serch hynny, mae angen cyfarch ystod o faterion er mwyn cyrraedd y nod cyffredinol hwn, ac mae rhwystrau i'w goresgyn hefyd.

1. Cefndir

Yn gyfredol, diffinir Awtistiaeth neu Anhwylder Sbectrwm Awtistiaeth (ASD) fel a ganlyn:

"*Persistent deficits in social communication and social interaction across multiple contexts...and restricted, repetitive patterns of behaviour, interests, or activities*".

(DSM-5, 2013)

Dengys ffigyrau'r Gymdeithas Awtistaidd Genedlaethol (*National Autistic Society*: NAS, 2018) fod mwy nag 1 mewn 100 o unigolion yn debygol o fod ar y sbectrwm Awtistaidd ym Mhrydain (e.e. Baird et al.,2006; Brugha et al., 2009). Felly mae cyfran sylweddol o'r boblogaeth yn debygol o fod ar y sbectrwm.

Gwyddom y gall ASD achosi anawsterau ymddygiad parhaus ymysg plant (e.e. Totsika & Hastings, 2009). Darganfuwyd fod rhieni plant ag ASD yn fwy tebygol na rhieni plant ag anableddau datblygiadol eraill o adrodd lefelau uwch o straen. Gwyddom fod unigolion ag ASD â thebygolrwydd uwch o ymddygiadau heriol gydol oes (e.e. Matson, Sipes, Fodstad & Fitzgerald, 2011; McClintock, Hall & Oliver, 2003); straen mewn rhieni (e.e. Hastings & Brown, 2002; Estes et al, 2009). Yn ogystal, mae ASD wedi ei gysylltu gyda phroblemau iechyd meddwl, yn enwedig mewn unigolion sydd ag ASD uwch weithredol (e.e. Mazzone, Ruta & Reale, 2012). Mae tystiolaeth hefyd fod cleifion preswyl mewn lleoliadau seiciatrig yn fwy tebygol o fod â diagnosis o ASD (e.e. Tromans, Chester, Kiani, Alexander & Brugha, 2018). Felly, mae unrhyw ymgais gan lywodraeth i gyfarch anghenion unigolion ag ASD a'u teuluoedd i'w groesawi.

2. Diagnosis

Cydnabyddir fod diagnosis amserol yn bwysig i sicrhau fod unigolion ag ASD yn gallu gwneud synnwyr o'u hanawsterau, cael mynediad i wasanaethau priodol, a dysgu defnyddio technegau i ymdopi gydag anawsterau sy'n codi yn eu bywydau bob dydd. Mae'r un ffactorau yn bwysig i deuluoedd. Mae Llywodraeth Cymru wedi rhyddhau cyllid i gynyddu capasiti gwasanaethau i asesu unigolion ac hefyd wedi gosod terfynnau amseoedd aros. Serch hynny, ymddengys nad yw'r buddsoddiad wedi gostwng rhestrau aros o reidrwydd yn y modd a obeithiwyd; mae argaeledd asesu wedi cynyddu disgwyliadau, ac yn aml, gwelir diagnosis o ASD fel y tocyn aur sy'n ddrws i wasanaethau, a sy'n eglurhad am unrhyw ymddygiadau anarferol. Mae pwysau felly ar wasnaethau i roi diagnosis, ac i'w roi yn gyflym, gan achosi perygl o dorri ar ddilysrwydd yr asesiad er mwyn ei gwblhau'n gyflym. Mae teuluoedd weithiau'n gwrthod canlyniad sy'n atal diagnosis, a mae canfyddiad aml mai diagnosis ASD ydi'r unig diagnosis, a'r unig eglurhad o ymddygiad neu ddiffyg sgiliau, ar draul diagnosis o anableddau dysgu yn enwedig. Mae rhieni yn chwilio am atebion i egluro anawsterau eu plentyn, ac felly'n galw am ail farn os nad ydynt yn hapus gyda chanlyniad yr asesiad (hy dim diagnosis ASD). Mae treulio amser yn cynnal ail asesiad yn cynyddu'r rhestr aros, neu'n gallu bod yn gostus os mai'r GIG sy'n talu am farn breifat, ac yn achosi colli hyder yn y farn wreiddiol a roddwyd, ac yn tynnu oddi ar yr hyder yn y tîm, a sgiliau ymarferwyr.

Gwyddom fod ASD yn sbectrwm cymhleth a'r niferoedd ar gynydd heb i ni ddeall yn iawn pam fod hyn yn digwydd. Yn amlwg mae angen gwasnaethau diagnosis, ac angen am well dealltwriaeth o anghenion unigolion ar y sbectrwm. Serch hynny, ni ddylai hyn fod ar draul gwasnaethau ymyrraeth a chefnogaeth. Mae angen am wasanaethau cost-effeithiol sy'n gallu asesu am ASD a chyflyrau niwroddatblygiadol eraill, anableddau dysgu ac ati, ac hefyd mae llawn cymaint o angen am wasanaethau sy'n cefnogi unigolion a theuuoedd, ac yn darparu ymyrraethau cost-effeithiol i wella ansawdd bywyd unigolion ar y sbectrwm a'u teuluoedd. Mae gwella gwasanaethau diagnosis wedi cynyddu'r galw am ddiagnosis, sy'n codi cwestiwn am werth diagnosis, a sut mae rheoli'r galw. A ddylen ni fod yn rhoi pwyslais ar adeiladu gwytnwch yn gyffredinol yn hytrach na cheisio rhoi label ar unigolion?

3. Cefnogaeth

Mae'r angen am gefnogaeth gymdeithasol yn flaenoriaeth. Mae nifer o'n teuluedd yn methu ymdopi heb gefnogaeth ychwanegol. Dengys ymchwil fod posibilrwydd fod perthynas rhwng magu plentyn ag ASD â thor-priodas, neu deulu yn torri lawr yn llwyr hyd yn oed, oherwydd y straen sy'n gallu bod yn rhan o fywyd teulu lle mae plentyn ag anawsterau datblygiadol o'r fath. Ymddygiadau heriol yw'r broblem fawr, ac mae tebygolrwydd uwch o ymddygiadau heriol gydag ASD (Totiska & Hastings, 2009).

Mae gwaith y Blynyddoedd Rhyfeddol (e.e. Webster-Stratton, 2013) yn llwyddiannus iawn yn dysgu rhieni i ddefnyddio strategaethau ymddygiadol gyda'i plant, i reoli ymddygiad annerbyniol ac i adeiladu ar sgiliau chwarae a chyn-ysgol. Mae'n gwrs 12 wythnos gyda grŵp o rieni, ac yn aml, cyfeirir rhieni plant ag anhwylderau ymddygiad i'r grŵp. Mae tystiolaeth helaeth o effeithlonrwydd yr ymyrraeth.

Mae'r rhaglen Blynyddoedd Rhyfeddol wedi ehangu i ddarparu rhaglenni a ellir eu gweithredu o fewn ysgol (e.e. Rhaglen Dinosôr, Webster-Stratton, 1991) ymysg eraill, ac erbyn hyn, mae gan y gyfres raglen ar gyfer rhieni plant ag Awtistiaeth ac Oediad Iaith. Mae hwn yn canolbwyntio ar adeiladu ar ymddygiadau dymunol, ac yn cynnwys rhai sesiynnau hefyd ar reoli ymddygiad heriol. Mae'n creu a chynnal naws cadarnhaol i'r rhaglen, sy'n cael ei adlewyrchu wedyn ym mherthynas y rhiant a'r plentyn.

Gwerthuswyd y rhaglen Blynyddoedd Rhyfeddol ar gyfer Plant ag Awtistiaeth ac Oediad Iaith yng Ngogledd Cymru (Hutchings et al., 2016) ac mae'r gwerthuso yn mynd yn ei flaen o hyd. Argymhellir fod rhaglenni rhieni Blynyddoedd Rhyfeddol ar gyfer ASD yn cario mlaen i gael eu gwerthuso, i fireinio eu perthnasedd a'u effeithlonrwydd gyda theuluoedd o'r fath. Dylid sicrhau fod y rhaglen ar gael yn arferol fel un agwedd o ymyrraethau ar gyfer rhieni, ochr yn ochr ag ymyrraethau eraill fel PACT (*Parent-mediated social communication therapy for young children with autism*, Pickles et al. 2016), Early Bird (NAS) ac ati.

4. Ymyrraethau eraill

Mae Ymyrraeth Ymddygiadol Dwys Gynnar (*Early Intensive Behavioural Intervention*: EIBI) yn raglen o ymyrraeth sydd wedi cynhyrchu canlyniadau addawol; gan leihau ymddygiadau heriol a chynyddu ymddygiadau cymdetihasol, sgiliau cyn-ysgol a chwarae mewn plant ifanc ag Awtistiaeth. Cwblhawyd yr astudiaethau cynnar gan Lovaas (1987) ond ers y dyddiau cynnar hynny mae triniaethau seicolegol wedi datblygu a symud ymlaen, gan gael eu mireinio a chan ganiatau addysgu mwy naturiol. Mae tystiolaeth lleol a rhyngwladol sy'n awgrymu fod triniaethau dadansoddi ymddygiad yn cael effaith gadarnhaol ar ddatblygiad ac ymddygiad unigolion gydag Awtistiaeth (e.e. Kovshoff et al., 2011; Eldevik et al., 2009).

Yn yr UDA, cynigir ymyrraethau ar draws y taleithiau fel rheol i blant ag Awtistiaeth ond nid yw mor hawdd cael mynediad i EIBI mewn sawl gwlad yn Ewrop yn yr un modd (Keenan et al., 2014). Yn y DG, mae tyfiant EIBI wedi bod yn y sector breifat gan fwyaf, gyda chynnydd mewn darpariaeth ar gyfer plant sydd a rhieni addysgiedig, cyfoethog, sy'n gallu bod yn eiriol dros eu plant, a rheini yn Ne Ddwyrain Lloegr. Mae gwasanaethau tebyg yng Nghymru yn tueddi bod yn gysylltiedig â phrisfysgolion (e.e. darpariaeth clinig ym Mhrifysgol De Cymru) neu mewn ysgolion. Mae darpariaeth ysgol yn tueddi bod yn llai dwys, ond eto mae'r canlyniadau yn addawol (e.e. Grindle et al., 2012; Foran et al., 2015; Jones & Hoerger, 2011).   Mae cyfoeth o dystiolaeth i ddangos effeithlonrwydd rhaglenni EIBI (e.e. Eldevik et al., 2009) ac mae'r canlyniadau tymor hir yn arbennig o addawol pan fod rhieni yn cael eu cynnwys yn y rhaglen (e.e. Kovshoff, 2011). Mae modd cyfiawnhau costau darparu rhaglen EIBI i blant bach ag Awtistiaeth (e.e. Chasson et al., 2007).

Argymhellir fod iechyd, gwasanaethau gofal Cymdeithasol ac addysg yn cydweithio i gefnogi defnyddio ymyrraethau cynnar i helpu rheini i ddysgu sgiliau chwarae iddynt, sgiliau cymdeithasol a chyn-ysgol, a chan reoli ymddygaid heriol eu plant, fel rhan o becyn cynhwysfawr. Mae tystiolaeth ryngwladol i awgrymu fod ymyraethau cynnar yn allweddol ac yn effeithiol dros ben pan gânt eu defnyddio gan unigolion sydd wedi eu hyfforddi ac sy'n cael eu goruchwylio'n dda, a sy'n cynnig ymyrraethau sy'n gywir a ffyddlon i raglen (*treatment fidelity*).

Yn ogystal, mae arbenigwyr ymddygiad yn aelodau creiddiol o dimoedd Niwroddatblygiadol. Serch hynny, nid oes angen am gymhwysterau penodol, er fod triniaethau Cefnogaeth Ymddygiadol Gadarnhaol (*Positive Behaviour Support*: PBS) a Chefnogaeth Weithredol (*Active Support*: AS) (e.e. Jones et al, 1999) yn driniaethau sydd wedi gwreddio yn niwylliant gwaith gydag oedolion gydag anableddau dysgu.

Argymhellir fod arbenigwyr ymddygiad yn cyrchu cymhwyster penodol, er enghraifft mewn Dadanosddi Ymddygiad Cymhwysol (ABA), fel bod modd mesur ansawdd gwasanaethau. Nid yw Dadansoddi Ymddygiad yn cael eu gydnabod fel proffesiwn ar wahan yn y DG ar hyn o bryd, er fod yr UK-SBA (*UK-Society for Behaviour Analysis*) yn gweithio arno. Mae cymhwyster rhyngwladol ar gael, sef y BCBA (*Board Certified Behaviour Analyst*) sy'n dynodi dadansoddwyr ymddygiad ardystiedig. Rhaid cael strwythur mewn lle i sicrhau rheoleiddio effeithiol sy'n bwysig i warchod y cyhoedd. Argymhellir y gallai Cyngor y Proffesiynnau Iechyd a Gofal (HCPC: *Health Care Professions Council*) gymryd cyfrifoldeb am reoleiddio ymarferwyr ymddygiadol fel proffesiwn. Byddai'n rhaid cydweithio gyda chenhedloedd eraill y DG. Mae'r UK-SBA yn barod yn gweithio ar hyn hefyd.

5. Addysg

Croesawir unrhyw ymgais i gydweithio i greu gwasanaethau didor. Yn llawer rhy aml, mae enghreiffitiau, tystiolaeth ac anecdotau am deuluoedd yn cael eu gwrthod oherwydd nad ydynt yn cyrraedd meini prawf rhyw wasanaeth, neu oherwydd diffyg cydgordio, ac mae pobl yn darganfod nad oes neb yn fodlon cymryd cyfrifoldeb am gynnig dim iddynt. Mae'r Bil yn datgan y byddai'r Bil Awtistiaeth yn “ychwanegu” at waith y Ddeddf ADY. Mae hyn i'w groesawi.

6. Gwasanaethau cyfrwng Cymraeg

Mae'r Bil Awtistiaeth yn cyfeirio tuag at y ddarpariaeth cyfrwng Cymraeg (5.8, Memorandwm Esboniadol). Yn benodol, mae'r Bil yn cyfeirio at ‘Y Cynnig Rhagweithiol’, a'r angen i wasanaethau cyhoeddus adnabod ac ymateb i angen iaith fel elfen greiddiol o ofal, heb i'r defnyddiwr gwasanaeth ei hun orfod gofyn am wasanaethau Cymraeg. Mae Comisiynydd y Gymraeg wedi dyfynnu enghreifftiau o rwystrau i wasanaethau cyfrwng Cymraeg priodol, e.e. cynllunio gweithlu gwael a'r difyg adnoddau asesu ieithyddol-briodol, fel y gwnaeth eraill a ymatebodd i'r ymgynghoriad.

Y sefyllfa yng Nghonwy a Sir Ddinbych: ardal Ganol Bwrdd Iechyd Prifysgol Betsi Cadwaladr yn fy mhrofiad i fel ymarferydd.

Mae'r Bwrdd Iechyd wedi cyflogi tiwtor Cymraeg. Mae'n debygol y bydd y galw am wasanaeth y tiwtor yn fwy na'r capasiti fydd ganddi, ac felly gallai dadansoddiad o elfennau gwasanaeth helpu i dargedu agweddau allweddol ar gyfer ymyrraeth (gwersi Cymraeg yn yr achos hwn).

Mae ASD yn anhwylder cyfathrebu Cymdeithasol. Byddai'n rhesymol felly awgrymu fod angen i staff sy'n asesu feddi ar alluoedd yn yr iaith / ieithoedd sy'n cael eu defnyddio gan y plentyn a'i deulu, fel mater o flaenoriaeth. Yng Nghymru, mae'n ofynnol i ni ddarparu gwasnaethau Cymraeg a Saesneg yn ôl y galw, gan ddarparu'r Cynnig Rhagweithiol, heb i'r claf orfod wneud cais drosto ef /hi ei hun (Llywodraeth Cymru, 2012). Mewn achos o unrhyw iaith /ieithoedd eraill, mae'r GIG yn darparu cyfieithwyr.

Mae hyd yn oed awgrymiad gan fod ymddygiadau cyfathrebu cymdeithasol yn digwydd mewn cyd destun diwylliannol, y gallai ASD uwch weithredol fod yn gysylltiedig â chymwyseddau diwylliannol, ac felly er mwyn rhoi diagnosis dibynadwy mi fyddai angen am ddealltwriaeth o gyd destun ieithyddol a diwylliannol yr unigolyn (Gillberg & Gillberg, 1996).

Ar hyn o bryd yn y BI Betsi (Canol) mae tri llwybr at asesu ar gyfer ASD. Mae'r tîm Niwroddatblygiadol yn ymgymeryd ag asesiadau ar gyfer plant a phobl ifanc 5-18 oed sydd heb anableddau dysgu ar draws y ddwy sir. Mae Panel Cyfathrebu Cymdeithasol Conwy yn ymgymeryd ag asesiadau ASD pob plentyn 0-5 oed, ac asesiadau plant 5-18 oed ag anableddau dysgu. Mae Panel Cyfathrebu Cymdetihasol Sir Ddinbych yn ymgymeryd ag asesiadau ASD pob plentyn 0-5 oed, ac asesiadau plant 5-18 oed ag anableddau dysgu. Mae cynlluniau i greu SPOA (*single point of access*) cyffredinol ar gyfer pob plentyn 0-18 oed, a gwneud i ffwrdd â'r rhaniadau ond dydi hyn ddim wedi digwydd hyd yma.

Nifer fach o staff sy'n siarad Cymraeg yn rhugl sy'n gweithio yn y tri gwasanaeth. Mae'n ganfyddiad cyffredin hefyd fod recriwtio siaradwyr Cymraeg bron yn amhosib.

Cynhaliwyd awdit o sgiliau Cymraeg aelodau o'r timoedd, gan goladu'r sgiliau Cymraeg gyda sgiliau asesu ASD. Gofynwyd i'r staff am eu sgiliau Cymraeg, fel a ganlyn:

- Rydw i'r siarad Cymraeg,
- Rwyf yn deall ond dydw i ddim yn siarad Cymraeg,
- Gallaf siarad ychydig bach o Gymraeg, er enghraifft, gyda phlentyn bach,
- Gallaf ddeall Cymraeg yn ddigon da i ysgrifennu geiriau pan dwi'n clywed nhw,
- Dim sgiliau Cymraeg.

Dangoswyd fod gan rai aelodau o'r tîm sgiliau Cymraeg, yn briodol efallai ar gyfer asesu plant bach yn enwedig plant bach nad oedd yn siarad llawer. Dangoswyd hefyd fod gan rai aelodau o'r tîm ddigon o ddealltwriaeth o'r Gymraeg i'w galluogi i ymgymeryd ag arsylwi ysgol.

Roedd cwblhau'r awdit yn galluogi'r gwasanaeth i baru cymhwysedd Cymraeg staff gydag anghenion gwasanaeth, ac hefyd yn ffordd o adnabod targedau ar gyfer uwchsgilio'r gweithlu. Gallai'r lefel yma o ddadansoddiad gael ei gyffredinoli i helpu pob agwedd o ddarpariaeth gwasanaeth a gallai helpu gyda chynllunio gweithu.

Mae asesu ar gyfer ASD fel arfer yn cynnwys asesu uniongyrchol o sgiliau cyfathrebu a rhyngweithio gan ddenfyddio asesiad wedi ei ddilysu fel yr ADOS (*Autism Diagnostic Observation Schedule*, Lord & Rutter, 1989). Mae'r asesiad hwn yn darparu cyd destun wedi ei led-strwythuro i werthuso sgiliau cyfathrebu Cymdeithasol ac iaith unigolyn, ac yn rhoi cyfle hefyd i ennyn ymddygiadau ailadroddus, gan ddilyn meini prawf y DSM (*Diagnostic and Statistical Manual of Disorders*, e.e. DSM-5. 2013) ar gyfer ASD. Rwyf wedi rheoli prosiect i gyfieithu'r ADOS i'r Gymraeg. Mae angen dilysu'r gwaith ac angen am ragor o gyllid er mwyn cwblhau'r gwaith.

Rydym hefyd yn y broses o drefnu gwersi Cymraeg gyda thiwtor Cymraeg Betsi, yn benodol ar gyfer cyfarch anghenion ymarferwyr sydd yn siarad neu'n deall peth Cymraeg ac felly â'r gallu i uwchsgilio i ddarparu asesiadau ADOS, yn enwedig gyda phlant bach heb lawer o sgiliau iaith.

O ran agweddau eraill o asesu, nid yw ymarferydd yn arfer dilyn protocol wedi ei strwythuro ar gyfer arsylwi yn yr ysgol, ac felly nid oes asesiadau wedi eu dilysu ar gael ar hyn o bryd, er fod canllawiau lleol.

Yr ADI-R (*Autism Diagnostic Interview-Revised*, Rutter et al., 1994) ydi'r safon aur o ran y cyfweliad hanes datblygiad. Serch hynny, nid yw'r ADI-R yn ofynnol gan NICE (*National Institute of Clinical Excellence*). Yn hytrach, mae NICE wedi cyhoeddi canllawiau ar gyfer cynnwys cyfweliad o'r fath. Felly mae ymarferwyr yn arferol yn ymgymeryd â'r cyfweliad hwn gan ddefnyddio canllawiau NICE neu gyfweliadau sy'n cael eu defnyddio yn lleol, yn ogystal a'r ADI-R. Gellir darparu rhestr os oes angen.

Yn y modd yma, gall y cyfweliad gael ei gynnal gan unrhyw ymarferydd sy'n rhugl yn y Gymraeg sydd â'r sgiliau asesu perthnasol ond hyd y gwn i, does dim cyfweliad hanes datblygiad strwythuredig wedi ei ddilysu ar gael yn Gymraeg ar hyn o bryd.

Mae'r sefyllfa ar gyfer asesu gwybyddol yn arswydus: does dim asesiadau cyfrwng Cymraeg wedi eu dilysu ar gael o gwbl (e.e. *Wechsler Adult Intelligence Scale (WAIS), Wechsler Intelligence Scale for Children (WISC)*, ac ati). Golyga hyn nad oes modd dilys a dibynadwy o asesu sgiliau gwybyddol siaradwyr Cymrage yng Nghymru. Byddai rhaid i unrhyw waith i ddilysu'r math yma o asesiadau fod yn barhaus, gan ystyried natur ddwyieithog sgiliau iaith unigolion, yn ogystal â natur hir-dymor y gwaith a'r costau ynghlwm. Argymhellir fod angen sefydlu Canolfan Ragoriaeth ar gyfer Dilysu Asesiadau a Therapi, ac y byddai Prifysgol Bangor yn ddewis amlwg, oherwydd hanes a thraddodiad y Brifysgol yn arloesi mewn ymchwil ac addysgu, a datblygiadau cyfrwng Cymraeg a dwyieithog yn barod (e.e. Y Ganolfan Ddwyieithrwydd, Canolfan Bedwyr a'r Uned Technoleg Iaith). Gallai'r costau i'r sector gyhoeddus gael eu lleihau drwy ymgeisio am grantiau. Byddai modd i Ganolfan o'r fath gydweithio efo ymchwilwyr o ddiwylliannau eraill, gyda siaradwyr ieithoedd lleiafrifol eraill, a gallai'r Ganolfan arloesi yn fyd-eang mewn ymchwil yn y maes.

7. Codi Ymwybyddiaeth

Mae codi ymwybyddiaeth o anghenion unigolion gydag ASD yn ddefnyddiol. Mae adnoddau penigamp ar wefan ASDinfoCymru Llywodraeth Cymru.

8. Yr effeithiau ar gydraddoldeb a hawliau dynol: Unigolion gydag Anableddau Dysgu

Yn groes i'r hyn sy'n cael ei ddatgan o dan Adran 10.2: Yr effeithiau ar gydraddoldeb a hawliau dynol, nid yw adnabod ASD a darparu gwasanaethau yn benodol ar gyfer unigolion ag ASD o reidrwydd yn cynnig cyfraniad cadarnhaol sylweddol mewn perthynas a phobl ag anabledd (tud.153) gan fod posib fod y ddeddfwriaeth yn creu hierarchaeth anabledd. Gallai'r ddeddfwriaeth greu sefyllfa lle'r anwybyddir unigolion ag anableddau heblaw ASD. Mae anghenion unigolion ag anableddau dysgu yn draddodiadol ac yn hanesyddol wedi eu hesgeuluso, ac felly, mae angen monitro gofalus o bryderon am anweladwyedd pobl ag anableddau dysgu, a dylid darparu i sicrhau nad yw'r grŵp bregus hwn yn cael ei adael ar ôl.

Nid yw anghenion pobl ag anableddau dysgu cyffredinol yn dod o dan y Bil hwn, ond rhaid cyfarch mater yr hierarchaeth anabledd – nid dim ond anawsterau niwroddatblygiadol ond unrhyw rai eraill ag anabledd.

9. Casglu Data

Yn amlwg mae angen monitro effaith unrhyw newid mewn deddfwriaeth er mwyn gwerthuso effaith ar unigolion bregus, gwasanaethau, y gofyn, a chostau. Dylid sicrhau fod cysondeb wrth gasglu data ynglŷn â niferoedd, a bod y dulliau yn fanwl gywir ar draws ardaloedd gwahanol Cymru, ac ar draws gwasanaethau. Rhaid cynnal hyfforddiant staff a monitro parhaus er mwyn osgoi drifftio trefniadol, ac i gysoni unrhyw wahaniaethau ac anghysonderau rhwng graddfeydd diagnostig.

10. Ymgynghori â Defnyddwyr Gwasanaeth

Mae hyn yn greiddiol. Mae'n allweddol fod defnyddwyr gwasnanaeth yn ystyried eu hunain yn ran annatod o'r broses, a bod y boblogaeth hon yn teimlo fod y rhai sy'n gyfrifol am ddatblygu a chynnig gwasanaethau yn gwrando ar yr hyn sydd ganddynt i'w ddwedu. Dylai ymbweru fod yn allweddol i'r broses.

Manylion yr awdur

Cynigir fy nhystiolaeth fel ymarferydd dwyieithog profiadol / academydd ym maes Awtistiaeth. Mae hyn yn cynnwys fy arbenigedd mewn Dadanosddi Ymddygiad Cymhwysol / Cefnogaeth Ymddygiadol Gadarnhaol, ac yn cyfeirio hefyd at fy ngwaith clinigol, ymchwil a gwaith ymgynghorol ar anghenion iaith Gymraeg defnyddwyr gwasnaeth.

Rwyf yn gweithio fel Seicolegydd Clinigol Ymgynghorol i Fwrdd Iechyd Prifysgol Betsi Cadwaladr, gan weithio mewn i wasanaethau plant ag anableddau dysgu, ac chan arwain tîm bach o seicolegwyr ar draws y ddwy sir (Conwy a Sir Ddinbych, sef ardal Ganol BI Betsi). Rwy'n gwetithio'n glinigol gan fwyaf gyda siaradwyr Cymraeg gan mai fi yw'r unig seicolegydd rhugl ei Chymraeg yn y gwasanaeth yn y Canol. Rwyf wedi gweithio i'r GIG ers dros 30 mlynedd, mewn gwasanaethau plant ac oedolion gydag anabledd dysgu, ac awtistiaeth gan fwyaf. Rwyf wedi cyfrannu i grwpiau stratgeol Llywodraeth Cymru i wella gwasanaethau ar gyfer siaradwyr Cymraeg sy'n defnyddio'r GIG.

Rwyf yn ddiweddar wedi rhoi'r gorau i'm swydd fel darlithydd ar gwrs Meistr Dadanosddi Ymddygiad Cymhwysol Prifysgol Bangor oherwydd pwysau gwaith, ond yn dal â chysylltiadau fel tiwtor lleoliad i rai o'r myfyrwyr. Mae'r cwrs yn darparu'r gwaith academaidd angenrheidiol i'r rhai sy'n dymuno ennill cymhwyster fel Dadansoddwr Ymddygiad (BCBA). Rwyf wedi cyfrannu i ddatblygu addysgu cyfrwng Cymraeg, geirfa a gwasanaethau Cymraeg o fewn y maes.

Rwyf wedi sôn am enghreifftiau o bethau o fewn y gwasanaeth rwyf yn gweithio ynddo yn hytrach na sôn am bethau sy'n berthnasol i Ogledd Cymru / ar draws BI Betsi: ni fyddai hynny'n briodol gan nad fi sy'n arwain ar Awtistiaeth ar ran BI Betsi.

Dr Elin Walker Jones, D.Clin.Psy, BCBA-D

Seicolegydd Clinigol Ymgynghorol, Bwrdd Iechyd Prifysgol Betsi Cadwaladr
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Mae cyfyngiadau ar y ddogfen hon