Agenda - Health, Social Care and Sport Committee

Meeting Venue:	For further information contact:
Committee Room 2 - Senedd	**Claire Morris**
Meeting date: 11 October 2018	Committee Clerk
Meeting time: 09.00	0300 200 6355
	SeneddHealth@assembly.wales

Informal pre-meeting (09.00- 09.30)

1 Introductions, apologies, substitutions and declarations of interest

2 Autism (Wales) Bill: Evidence session with representatives of Local Health Boards and the Royal College of General Practitioners

(9.30-10.15) (Pages 15 - 63)

Carol Shillabeer, Chief Executive, Powys Teaching Health Board and the Lead Chief Executive for Mental Health

Dr Mair Hopkin, Joint Chair, Royal College of General Practitioners Wales

Dr Jane Fenton-May, Royal College of General Practitioners Wales

Break (10.15-10.20)

3 Autism (Wales) Bill: Evidence session with Welsh Local Government Association and the Association of Directors of Social Services

(10.20 -11.05) (Pages 64 - 79)

Naomi Alleyne, Director, Social Services and Housing, Welsh Local Government Association

Keith Ingram, Autism Spectrum Disorder Project Lead Officer, Vale of Glamorgan Council

Claire Lister, Head of Adult Services, Conwy County Borough Council

Jo Taylor, Service Manager for Learning Disabilities, Physical Difficulties & Sensory Impaired, Flintshire County Council

Break (11.05-11.10)

4 Autism (Wales) Bill: Evidence session with the Community of Practice for adult diagnosis and Integrated Autism Service practitioners

(11.10-11.55) (Pages 80 - 87)

Dr Nicola Griffiths, Clinical Psychologist, Gwent Integrated Autism Service
Sian Lewis, Service Manager, Gwent Integrated Autism Service
Dr Rona Aldridge, Clinical Psychologist, Clinical Lead for the Integrated Autism Service, Cardiff and the Vale
Wendy Thomas, National Professional Lead for Autism

Break (11.55-12.45)

5 Autism (Wales) Bill: Evidence session with the Royal College of Psychiatrists and the Royal College of Paediatrics and Child Health

(12.45 -13.30) (Pages 88 - 98)

Professor Alka Ahuja, Consultant Child and Adolescent Psychiatrist, Aneurin Bevan Health Board & Royal College of Psychiatrists in Wales
Dr Amani Hassan, Chair, Faculty of Child and Adolescent Psychiatry, Royal College of Psychiatrists in Wales
Dr Catherine Norton, Consultant Community Paediatrician, Royal College of Paediatrics and Child Health
Dr Martin Simmonds Community Paediatrician, Royal College of Paediatrics and Child Health

Break (13.30-13.35)

6 Autism (Wales) Bill: Evidence session with the British Psychological Society and the Association of Educational Psychologists

(13.35 - 14.20) (Pages 99 - 107)

Nigel Atter, Policy Officer, British Psychological Society

Dr Kate Swindon , Educational psychologist, Education Services, Conwy County Borough Council

Andrea Higgins, Academic Director and Programme Coordinator, Doctorate in Educational Psychology , School of Psychology, Cardiff University

7 Papers to note

(14.20)

7.1 Letter from the Cabinet Secretary for Finance to the Chair of the Finance Committee regarding the definition of prevention in relation to spending

(Pages 108 - 109)

7.2 Dentistry in Wales: Additional information from the British Dental Association

(Pages 110 - 117)

8 Motion under Standing Order 17.42 to resolve to exclude the public from the remainder of today's meeting and for the meeting on 17 October, when the Committee will be undertaking engagement work with stakeholders as part of its inquiry on the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers

(14.20)

9 Autism (Wales) Bill: Consideration of evidence

(14.20-14.30)

By virtue of paragraph(s) vi of Standing Order 17.42

Agenda Annex

Document is Restricted

By virtue of paragraph(s) vi of Standing Order 17.42

Agenda Item 2

Document is Restricted

	The Welsh NHS Confederation written response to the Health, Social Care and Sport Committee's scrutiny of the Autism (Wales) Bill.
Contact:	[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.

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.

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

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.

<u>Whether there are any unintended consequences arising from the Bill;</u>

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.

Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-27-18 Papur 3 / Paper 3

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.

ADSS Cymru
Leading Social Services in Wales
Yn arwain Gwasanaethau Cymdeithasol yng Nghymru

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

Authority	[redacted], President
Completed by	[redacted], Policy and Research Lead
Date	3 October 2018

General Comment

1.1 The Association of Directors of Social Services (ADSS Cymru) is the professional and strategic leadership organisation for social services in Wales and is composed of statutory Directors of Social Services and the Heads of Service who support them in delivering social services responsibilities and accountabilities; a group of more than 80 social services leaders across the 22 local authorities in Wales.

1.2 As the national leadership organisation for social services in Wales, the role of ADSS Cymru is to represent the collective, authoritative voice of Directors of Social Services, Heads of Adult Services, Children's Services and Business Services, together with professionals who support vulnerable children and adults, their families and communities, on a range of national and regional issues of social care policy, practice and resourcing. It is the only national body that can articulate the view of those professionals who lead our social care services.

1.3 As a member-led organisation, it is uniquely placed as the professional and strategic leadership organisation for social services in Wales, to lead on national service development initiatives to ensure a consistent efficient and high standard of delivery for people who access care services across Wales.

1.4 ADSS Cymru is committed to using the wealth of its members' experience and expertise, working in partnership with other agencies, to influence important decisions around social care to the benefit of the people it supports and the people who work within care services. Therefore, we welcome the opportunity to comment on the proposals contained in the Autism (Wales) Bill.

1.5 While ADSS Cymru appreciates that the fundamental objectives at heart of the Bill is to ensure that there is consistent and continued provision to meet the needs of the 34,000 autistic people in Wales, we continue to believe that, at this stage, there is not a requirement for specific legislation to address the needs expressed by this particular group, their families or their carers and we will set out the reason for that further in this paper.

1.6 However, it should be noted that the Welsh Government has made strides to strengthen public service provision for people with autism and their families and carers, which has built on its innovative and leading 2008 Autism Spectrum Disorder (ASD) Strategic Action Plan. That plan has been recently reviewed and revised and in addition to the establishment of the All-Age National Integrated Autism Service (IAS) in 2016, there has been increased levels of investment in both national and local structures, all of which has helped raise the profile of the condition, as well as the development of improved services and the establishment of new services.

Current Legislation

2.1 The principle reason why ADSS Cymru is, at this stage, reticent to support new specific legislation, is that there are two fundamental pieces of legislation in place – *the Social Services and Well-being (Wales) Act 2014* (SSWBA) and *the Well-being of Future Generations (Wales) Act 2015* (FGA) – which aim to develop a common understanding of what public services are required in an area and to develop joint working between public bodies, so that local activity and national goals are aligned and centred around the needs of the citizen.

2.2 This needs-based approach is very important, particularly in relation to the SSWBA, as it provides the legal framework for improving the well-being of people who need care and support carers who need support. The SSWBA is transforming the way social services are delivered through an integrated approach that is focused on achieving the outcomes necessary to promote a person's well-being - as an individual, as part of a family and as part of their community; an approach that is person rather than condition specific. This needs-based approach means that resources and support is delivered according to need, not prioritised according to legislation or just linked to receiving an assessment and a diagnosis. One of the fundamental concerns that we have, given that resources in local government are so stretched, is if IAS service managers are being directed under this legislation to focus all their psychology resource to assessment and diagnosis, then this will be to the detriment of post diagnosis support. Our belief is that diagnosis is only a small part of the total input people need but practitioners will not be able to rationalise this with the legislation.

2.3 We should also take into account the recent enactment of the Additional Learning Needs and Education Tribunal (Wales) Act (2018). The needs-based approach is also consistent with this important piece of legislation that has the potential to bring tangible benefits to children and young people with ASD by supporting early identification of additional learning needs and effective interventions to support these needs throughout a child and young person's education.

2.4 The Well Being Plan in the FGA is the overarching strategy for public service activity in an area and therefore, the SSWBA is required to fit in with this broader context for both corporate planning and work across Public Service Boards, as well as being a discreet activity. However, given that there has not been sufficient time to imbed and assess the impact of both pieces of legislation in relation to citizens with ASD, ADSS Cymru believes it would not be prudent at this stage to invest into a resource intensive process to implement additional legislation until that further assessment work has been done.

2.5 Moreover, we are also concern about legislation incompatibility. The legislation is attempting to deal with barriers to people with autism receiving services they need, ensuring that IQ and illness are not reasons to exclude people from services. The SSWBA, if implemented as the Act intends, already determines who has eligible needs and who does not through National Eligibility Criteria. There is a real danger if this legislation is implemented that the two pieces of legislation may be incompatible, which will cause confusion, may raise unnecessary expectation and be unfair to those without a diagnosis of autism who are in similar circumstances.

Guidance

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

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

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

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

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

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

[redacted]
President
ADSS Cymru

[redacted]

[redacted]

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

To the Chair of the Committee

Re: Consultation on the Autism Bill

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

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

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

Please also find enclosed a written response from the CoP.

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

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

Yours faithfully

[redacted]

[redacted]

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

Endorsed by: (PTO)

[redacted]

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

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

- **Strategy**

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

- **Diagnostic waiting times and support**

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

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

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

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

There are considerable difficulties of achieving a target of completing a diagnostic assessment within 13 weeks from referral. We are unclear why 13 weeks has been chosen as a figure as it doesn't align with any other standards for work to commence let alone be completed. To help illustrate the difficulties with a 13 week wait we have outlined the impact for one of the IAS in Wales as follows. The Gwent IAS, as an established service, which launched in September 2017 now have 196 Individuals on a waiting list for diagnosis, which is currently resulting in a 12 month waiting list. They have received 100 appropriate referrals this financial year alone. They have been piloting alternative approaches to diagnostic clinics (still adhering to NICE guidelines and agreed national minimum standards through the Community of Practice), they are therefore confident that they can increase the number of diagnostic clinics going forward. However, best case scenario is that they can reduce the diagnostic waiting time to nine months (this assumes there will be no DNA's, no cancellations due to sickness etc.). The impact of this will be a reduction in the time clinicians have to provide support as around 80% of their time will be committed to diagnostic clinics, MDTs, supervision, CPD, mandatory training etc. However, even with an increased number of diagnostic clinics, they are currently receiving referrals on a weekly basis at a higher rate than they have capacity to meet. If they cleared the waiting list they may just be able to maintain a waiting list of 13 weeks, utilising the majority of their funding to do so. They only have 3 full time equivalent diagnosing clinicians so support staff would need to replace with qualified clinicians to make this possible. There are also issues around the availability of suitable trained and qualifies staff to deliver this if this was the course of action agreed.

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

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

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

Across Wales it is anticipated that moving the focus for IAS services to meet a diagnostic assessment completion target would undermine the action planned commitment for IAS services to organise their services to deliver 60% support and 40% diagnostic assessments. The focus on assessment would undermine their capacity to offer any ongoing support post diagnosis. To meet a 13-week target would require, for example in Gwent, a serious reduction in support staff to recycle the funding to employ additional diagnosing clinicians. So, whilst an assessment of need could be completed the IAS would no longer be in a position to offer anything other than a one appointment, drop-in sessions on a monthly basis and a post diagnostic six-week course. The impact would be similar in all the other IAS services and details can be provided it needed. It would be impossible to resource a keyworker for anyone with ASD let alone everyone with ASD, as the NICE Quality Standards recommend.

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

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

3. An example of feedback from a Mental Health Team professional:
   ‘I wish all of our services were as pleasant and straightforward to deal with……. Replies to email queries and support on offer to patient’s as well as referral process has been invaluable.’

4. Some examples of achievements of people using our service in the last few months include:

   - Two people who have received support from the IAS this quarter are also now attending Radio Platform and several people have said that they are making friends for the first time. This is in part due to their participation in the Socialeyes group.

   - Two people with ASD are now attending university following IAS support to link in the appropriate support services.

- Two people who were not able to leave the house are now leaving the house to attend IAS appointments. Furthermore, one is being supported to use public transport to learn Bee Keeping and the other has gained the confidence to drive again, is going to places independently, and is attending the Allotment group.

- Another person with ASD had wanted to attend a gaming group and had been playing on-line for two years without the confidence to attend in person. Following their attendance in the Socialeyes group, they felt able to join the group.

- A client with significant difficulties engaging in activities and with others now meets regularly with IAS staff for intervention, and also attends the weekly Allotment group. This person has said that this the first time they feel like have had help that meets their needs.

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

> 93% of individuals rated their experience as ‘very good’
> "It was a long wait but worth it"
> “clarity of information was excellent and the support to feel ok about autism”
> "I felt listened to and understood"
> There is a real risk that I we have to meet a 13-week target, then this quality will be compromised.

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

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

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

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

What would be lost by focusing on Diagnostic Assessments?

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

The financial implications

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

The diagnostic assessment is one step in people’s journey with regards to autism services and whilst it is important that people do not have to wait for a significant amount of time for a diagnostic assessment, it must be recognised that this is a very small part of what they will require from services. It is short-sighted for the focus to be on meeting diagnostic waiting times, rather than taking into account all of the other work that is delivered by specialist autism services. The services would need a significant amount of additional money to clear their waiting lists and to keep within the proposed time-scales so that they do not compromise on the other work they deliver. However, simply providing more money will not easily solve the issue with waiting times, because it is also about a lack of suitably qualified diagnosticians. Recruitment to some autism services across Wales is problematic because of a lack of staff with the necessary skills and experience. An additional role of the IASs is about generating interest in working in autism in those who are going through training, working across others services etc. Currently the Cardiff and Vales IAS provide support and advice about how others can develop their skills and offers placement opportunities. Increased pressure on diagnostic waiting times is going to reduce the time that the IASs can offer to students etc. It will also reduce the opportunities to conduct research, which is essential given the lack of research regarding effective interventions for this client group.

- **Data**

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

- **ASD awareness, acceptance and understanding**

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

Community of practice August 2018

Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-27-18 Papur 5 / Paper 5

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].

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.

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

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Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-27-18 Papur 6 / Paper 6

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.

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]
[redacted] [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.
	References
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End.

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

1. Summary

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

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

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

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

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

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

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

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

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

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

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

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

2.3 Clarity is also required on pathways to diagnosis.

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

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

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

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

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

3. Any potential barriers to implementation

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

3.2 A lack of training may create problems in implementation:

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

as the best practice in order to make diagnoses and recommend appropriate interventions, support and provision for CYP with autism.
- More broadly, members highlight that there is a significant amount of effective training currently being supported. It is important to understand what this is and how best to build on it, rather than developing something entirely new.

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

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

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

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

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

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

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

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

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

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

5. The financial implications of the Bill

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

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

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

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

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

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

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

Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref

Llyr Gruffydd AM
Temporary Chair
Finance Committee
National Assembly for Wales
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30 September 2018

Dear Llyr,

Ahead of the forthcoming publication of the outline draft Budget 2019-20, I am writing to update you about the work to establish a shared understanding around a definition of prevention.

When I gave evidence to the Finance Committee during last year's Budget scrutiny, I said discussions were ongoing with our public and third sector partners to define preventative spend.

We have worked with a number of organisations, including Wales Council for Voluntary Action and the Future Generations Commissioner (FGC), to move this important agenda forward. The discussions culminated in a roundtable event in July, organised by the Commissioner's office and attended by Welsh Government officials, the third sector, Public Health Wales, the fire service and academics. It was constructive and has helped to shape our thinking.

We have now agreed a definition of prevention. I hope it will provide a useful framework, which allows an holistic evaluation of government expenditure:

Prevention is working in partnership to co-produce the best outcomes possible, utilising the strengths and assets people and places have to contribute. Breaking down into four levels, each level can reduce demand for the next:

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

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

Pack Page 108

- **Primary prevention** – building resilience – creating the conditions in which problems don't arise in the future. A universal approach.
- **Secondary prevention** – targeting action towards areas where there is a high risk of a problem occurring. A targeted approach which cements the principles of progressive universalism.*
- **Tertiary prevention** – intervening once there is a problem to stop it getting worse and prevent it reoccurring in the future. An intervention approach.
- **Acute spending** – spending, which acts to manage the impact of a strongly negative situation but does little or nothing to prevent problems occurring in the future. A remedial approach.

***Progressive universalism** is a determination to provide support for all, giving everyone and everything a voice and vested interest, but recognises more support will be required by those people or areas with greater needs.

We will use this definition to classify a spending area in each of the six Main Expenditure Groups (MEGs) in this budget round. An analysis of the results, which will be set out in the detailed draft Budget – published on 23 October – will provide a preliminary insight towards the proportion of spend in each category.

These findings will help to inform our thinking further and will provide a useful platform on which we can continue to build on in the future.

I look forward to working with the Finance Committee during its scrutiny of the draft Budget.

Best wishes,

Mark

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

Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-27-18 Papur 10 / Paper 10

Agenda Item 7.2

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

Post-Hearing Note to the Chair

by the BDA Wales

4 October 2018

BDA
Cymru Wales

The BDA

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

Introduction

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

4 October 2018

Dear Dr Lloyd,

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

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

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

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

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

Yours sincerely,

Dr Caroline Seddon

National Director BDA Wales

The BDA Wales Pledge

BDA Wales will undertake to:

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

Trends in Access to NHS Dentistry

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

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

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

March 2012
ITV - 27 March 2012 *Dentistry in Wales still inadequate*
http://www.itv.com/news/wales/2012-03-27/dentists-in-wales-still-inadequate/

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

The Welsh Liberal Democrat survey also revealed that:
More than half of dentists (53%) reported problems with the way the current dental contract operates. 31% believe that the contract needs to change.
It is far easier for patients to access private dentists. 70% of dentists in Wales are currently accepting new patients - almost double the number of practices accepting new NHS patients.

May 2014
BBC - 30 May 2014 NHS dentists: *Nearly half of adults have not been seen*
https://www.bbc.co.uk/news/uk-wales-27626199

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

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

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

September 2018

BBC - 27 September 2018 *NHS dental patients 'face 90-mile trip', union claims*
https://www.bbc.co.uk/news/uk-wales-45660819

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

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

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

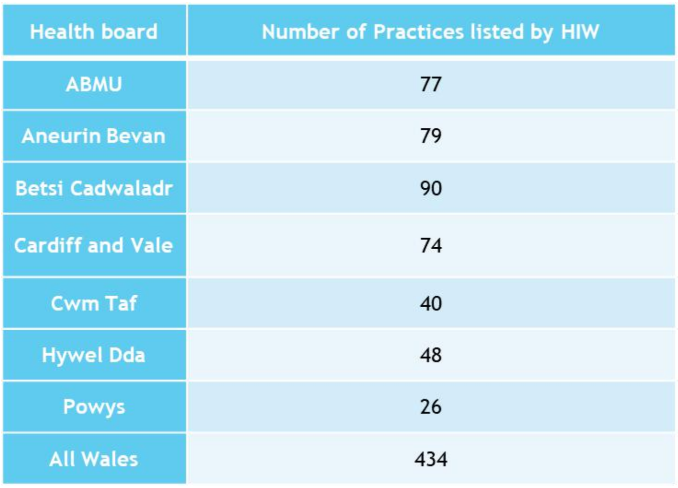
NHS Dentistry Activity Statistics

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

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

Numbers of Practices that solely conduct private work

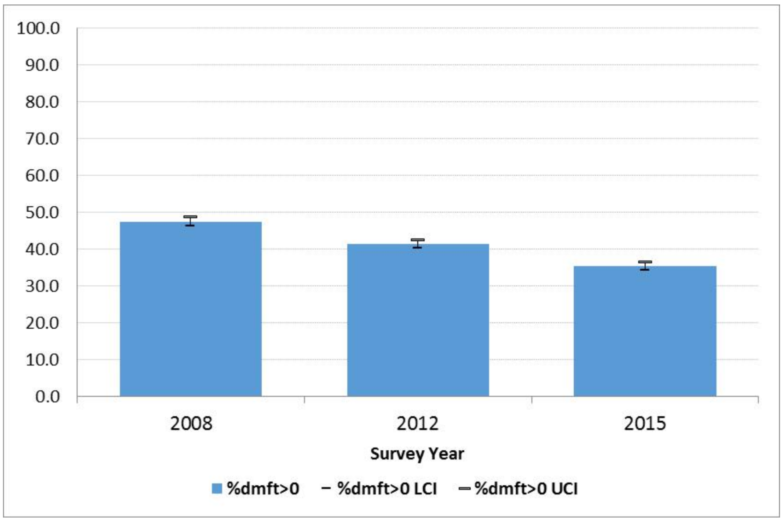
Using figures obtained in 2017 from HIW, below, together with NHS Direct information on services provided by practices, it was calculated that there are 80 practices (18 per cent) in Wales that do only private work and do no NHS work. We believe that number is likely to grow in the next few years as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



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

Designed to Smile

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



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

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

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

References

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

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

Post-Hearing Note to the Chair from the BDA Wales

Submitted on 4 October 2018

Dr Caroline Seddon
National Director BDA Wales
Report Editor

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

https://www.bda.org/bdawales

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