Agenda - Health, Social Care and Sport Committee

Meeting Venue:	For further information contact:
Committee Room 3 - Senedd	**Claire Morris**
Meeting date: 25 October 2018	Committee Clerk
Meeting time: 09.15	0300 200 6355
	SeneddHealth@assembly.wales

Informal pre-meeting (09.15 - 09.30)

1 Introductions, apologies, substitutions and declarations of interest

2 Autism (Wales) Bill: Evidence session with the Royal College of Speech and Language Therapists, Royal College of Occupational Therapists and ADHD Connections

(9.30-10.15) (Pages 1 - 37)

Julie Mullis, Autism Consultant, Royal College of Speech and Language Therapists

David Davies, Policy Officer Wales, Royal College of Occupational Therapists

Sally Payne, Professional Adviser, Children, Young People and Families, Royal College of Occupational Therapists

Zoe Piper, Charity Chairperson, ADHD Connections

Paper 1 - Royal College of Speech and Language Therapists

Paper 2 - Royal College of Occupational Therapists

Paper 3 - ADHD Connections

3 Motion under Standing Order 17.42 (vi) to resolve to exclude the public from the meeting for items 4 and 5

(10.15)

4 Autism (Wales) Bill: Engagement work with stakeholders

(11.00-12.30) (Pages 38 - 40)

5 Suicide Prevention: Consideration of draft report

(13.30-14.00) (Pages 41 - 133)

6 Autism (Wales) Bill: Evidence session with the Cabinet Secretary for Health and Social Services

(14.00-15.30) (Pages 134 - 149)

Vaughan Gething, Cabinet Secretary for Health and Social Services

Matthew Jenkins, Deputy Director, Partnerships and Cooperation, Welsh Government

Sarah Tyler, Lawyer, Welsh Government

Paper 4 - Welsh Government

7 Paper(s) to note

(15.30)

7.1 Letter from Chair of Children, Young People and Education Committee to Chair of Health, Social Care and Sport Committee regarding the scrutiny of the Welsh Government Draft Budget 2019-20

(Pages 150 - 151)

7.2 Dentistry in Wales: additional information from Hywel Dda University Health Board

(Pages 152 - 154)

7.3 Dentistry in Wales: additional information from Powys Teaching Health Board

(Page 155)

7.4 Autism (Wales) Bill: additional information from National Autistic Society Cymru

(Pages 156 - 157)

8 Motion under Standing Order 17.42 (vi) to resolve to exclude the public from the remainder of this meeting

(15.30)

9 Autism (Wales) Bill: Consideration of evidence

(15.30)

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

Agenda Item 2

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Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-29-18 Papur 1 / Paper 1

COLEG BRENHINOL
THERAPYDDION
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ROYAL COLLEGE OF
SPEECH & LANGUAGE
THERAPISTS

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

Executive Summary

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

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

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

About the Royal College of Speech and Language Therapists

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

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

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

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

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

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

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

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

- *Education* - The Additional Learning Needs and Education Tribunal (Wales) Act has recently been given Royal Assent and implementation will begin in 2020. It is hoped that the new system will bring tangible benefits to children and young people with ASD by supporting early identification of additional learning needs and effective interventions to support these needs throughout a child and young person's education.

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

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

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

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

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

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

Unintended consequences arising from the Bill;

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

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

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

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

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

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

Further Information

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

[redacted]

References

Education, Lifelong Learning and Culture Committee (2011). Report on Stage 1 of the Autism (Scotland) Bill. Edinburgh: Scottish Parliament

National Audit Office (2009). Supporting People with Autism through adulthood. National Audit Office: London.

National Autism project (2017). The Autism Dividend: reaping the rewards of better investment. London School of Economics and Political Science: London.

National Autistic Society (2014). Push for Action: We need to turn the Autism Act into action. National Autistic Society: London.

National Autistic Society Northern Ireland and Autism NI (2016). Broken Promises. National Autistic Society Northern Ireland and Autism NI: Belfast.

Royal College of Speech and Language Therapists (2018). Children, Young People and Education Committee inquiry into the emotional; and mental health of children and young people – written evidence from the Royal College of Speech and Language Therapists. Available at: http://senedd.assembly.wales/documents/s67508/EMH%2006%20Royal%20College%20of%20Speech%20and%20Language%20Therapists.pdf

Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G (2008). ‘Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample’ in the Journal of the American Academy of Child and Adolescent Psychiatry 2008 Aug;47(8):921-9. doi: 10.1097/CHI.0b013e318179964f.

Welsh NHS Confederation (2017). The Autism (Wales) Bill - Evidence from Welsh NHS Confederation. Available at: http://www.nhsconfed.org/-/media/Confederation/Files/Wales-Confed/Welsh-NHS-Confed-response-to-the-Draft-Autism-Wales-Bill.pdf

Royal College of Occupational Therapists

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

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

Summary of Position

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

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

Background information:

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

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

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

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

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

RCOT's Position:

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

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

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

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

Recommendations

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

References:

Alzheimers Society (2014) Alzheimer's Society view on public health, prevention and dementia. https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/public-health-prevention-dementia (accessed 11.9.18)

Lingam, R; Hunt, L; Golding, J; Jongmans, M; Emond, A; (2009) Prevalence of developmental coordination disorder using the DSM-IV at 7 years of age: a UK population-based study. Pediatrics, 123 (4). e693-700.

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

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

NICE (2018) Attention deficit hyperactivity disorder: diagnosis and management. https://www.nice.org.uk/guidance/ng87/chapter/recommendations (accessed 11.9.18)

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

About the College

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

Contact

For further information on this submission, please contact:

[redacted]
Royal College of Occupational Therapists
[redacted] [redacted]

[redacted]
Royal College of Occupational Therapists
[redacted]

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

I would like to express my concerns over the proposed Autism Bill.

In most counties within Wales ADHD is not a recognised disability and gaining access to any support and services is almost impossible. If you have a diagnosis of Autism as well as ADHD however, you are entitled to a multitude of support services, such as a disability social worker, respite,1-2-1 support and access to specialised holiday clubs to name just a few. As a result, I am finding more and more families are becoming aware that by having an Autism diagnosis, they gain access to this additional help, support and money, therefore they are now trying to get a dual diagnosis on the proviso that the Autism diagnosis carries significantly more weight than just ADHD alone. My concern is that if the bill is passed, it will encourage more families to go down the Autism route in the bid to gain access to the much-needed help and support they fail to receive if they solely receive a ADHD diagnosis.

Whilst I understand the reasons why families and individuals feel they need to go progress down the bill route, as provides them that bit more leverage to ensure things are done, I am worried that the needs of those affected by Autism will become more important when compared to other conditions. I am concerned more money will be invested in providing the required support for Autism, which in turn could then leave the needs and support of other conditions lagging behind. Subsequently, other health conditions may begin to think the only way to get the provisions they need is to try and get their own bill passed, on the basis they have the right level of support to enable them to do this. Autism is fortunate in the sense they have the NAS to voice and drive their concerns and changes, not all health conditions are in a similar position.

Health and Education have spent years trying to devise a new ALN service and new ND teams have been rolled out across each health board. Those two projects alone have cost a considerable amount of time and money. They also do not just limit positive changes to one condition. Would we not be better in waiting to see how those new changes are working first before we try and change things again? Surely, we would be better off trying to make any changes within the new and existing services than scrapping them all and coming up with something completely new.

Yours sincerley

[redacted]

Agenda Item 4

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

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Agenda Item 5

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Welsh Government - Written Evidence to Health, Social Care and Sport Committee – Autism Wales Bill

Summary

1. Since the beginning of the campaign for autism legislation the Welsh Government has carefully considered whether an Autism Act could improve services in Wales. Our conclusion is that there is little evidence to suggest that this Bill will bring any additional benefits to those service improvements that are currently being put in place. The Welsh Government has all the powers we need to deliver improvement to autism services in current legislation in the Social Services and Well-being (Wales Act) 2014, the Additional Learning Needs and Education Tribunal (Wales) Act 2018 and the NHS (Wales) Act 2006.

2. We have closely scrutinised the Bill and considered the evidence presented by other contributors. It has become clear that the Bill raises unrealistic expectations of preferential services for autistic people which will be perceived as unfair, and will disadvantage others who have significant support needs but do not have an autism diagnosis. The possibility to extend the Bill to other neurological conditions is also limited as this is likely to be beyond its purpose. Most worrying is the prospect that the Bill will artificially drive up assessment referrals, as a diagnosis is seen at a golden ticket to access services.

3. We recognise autistic people's real concerns that progress needs to continue at pace. It is vital that we deliver on the commitments we have made and build on the areas where we are making real progress. We will achieve this through issuing a Code of Practice on the Delivery of Autism Services under existing legislation to underpin future delivery. A Code which will have more powers for Welsh Ministers to directly intervene where there is poor service delivery than this Bill currently offers.

Background

4. The Health, Social Care and Sport Committee has invited Welsh Government Ministers to provide written evidence on the merits of the Assembly Member led Autism (Wales) Bill. As requested, this is a joint submission from the Cabinet Secretary for Health and Social Services, the Minister for Children, Older People and Social Care and the Cabinet Secretary for Education. The Cabinet Secretary for Health and Social Services will be attending the Constitutional and Legislative Affairs Committee on 15 October and the Health, Social Care and Sport (HSCS) Committee on 25 October.

5. The evidence responds to written guidance provided by the HSSS Committee and reflects evidence presented by other contributors to the consultations on the Bill or who have provided committee evidence and may be attending Committee in advance of the Cabinet Secretary's attendance.

Introduction

6. The campaign for autism legislation and the introduction of the member led Wales (Autism) Bill has provided a valuable opportunity to debate autism services in Wales. In recent years it is acknowledged that significant progress has been made to address identified gaps in support, however we are all in agreement there is still more work to do. Improvements are being driven by the ASD Strategic Action Plan which was updated in 2016 and delivery is supported by the Social Services and Well-Being (Wales) Act 2014 (SSWBW) and the Additional Learning Needs and Education Tribunal (Act) 2018 (ALNET).

7. This debate has however enabled us to re-examine our plans in relation to what is needed to develop and protect autism services for the future. The ASD Strategic Action plan, backed by £13m, is delivering wide ranging improvement. At its centre is the roll out of the National Integrated Autism Service, which is open in five regions and will be available across Wales this financial year. Also since 2015 we have secured improvements to children's neurodevelopmental services, investing £2m annually. For children and young people we have introduced a 26-week waiting time standard from referral to first diagnostic assessment, in line with other paediatric waiting times. There are published referral pathways for both children and adult assessment services. We are now exploring how we can bring these two services closer together and to take a detailed look at the barriers to reducing waiting times which are complex.

8. To improve educational support for children and young people up to 25, our Additional Learning Needs reform, underpinned by the Additional Learning Needs and Education Tribunal (Wales) Act 2018, introduces a new system focused on ensuring all children and young people that require support, including those with autism, have that support properly planned for and protected, and will have a statutory plan with equal rights of appeal. The Act puts learners at the heart of the decision making process Although it extends to meet the needs of autistic children and young people it does not differentiate between different additional learning needs because it seeks to ensure that all needs are met equitably and comprehensively.

9. We are acting on feedback asking for consistency in services, rolling out the Integrated Autism Service around a national framework, which brings together health and local authority services to work collaboratively to plan and deliver services. As the service matures regions are working together to share practice, and to address continuing gaps in support. We also recognise there is more to do to re-engage with voluntary groups who can provide essential services to support the IAS, and we are exploring what more can be done to provide assistance to enable the voluntary sector to provide much needed additional services.

10. We are also committed to publish a Code of Practice on the delivery of autism Services under the Social Services and Well-being Wales Act 2014 and the NHS Act 2006, which can address all the issues identified in the Bill and can address additional concerns raised by stakeholders. The oral statement on the Updated Delivery Plan and Code of Practice made on 25th September summarises the main provisions in the Code and plans for public consultation commencing in November 2018.

    The main areas for the code correspond to the chapters in the ASD Strategic Action Plan and are:
    a. assessment and diagnosis;
    b. accessing care and support;
    c. staff training;
    d. planning; and
    e. stakeholder engagement in service planning and delivery

11. The Welsh Government has strong delivery mechanisms and a trajectory of improvement. Therefore, on the basis of the evidence presented, including from other parts of the UK which has autism legislation, we do not agree that introducing additional condition specific legislation will add value to the improvements now firmly in train. Our plans to introduce a Code of Practice on the Delivery of Autism Services under existing legislation will ensure that statutory bodies understand their duties to provide services to meet the needs of autistic people. This work will also align with the ALNET Code of Practice which we will shortly consult on and a copy will be laid before the National Assembly for Wales in 2019.

12. Notwithstanding the lack of evidence to support its likely effectiveness, legislation which promises to improve services is attractive for many people who have experienced real struggles to access the support they need. Others may believe that whilst the legislation may not have significant benefits, it will not do any harm, and may therefore be worthy of support. In this evidence paper we seek to explain why condition specific legislation is a retrograde step - it will not bring additional value or more services and is likely

to have unintentional negative impacts both for autistic people and for individuals with other often similar support needs.

13. Our plans for a Code of Practice on the Delivery of Autism services under the Social Services and Well-being (Wales) Act 2014 and the NHS (Wales) Act 2006 is more appropriate and will have more impact. It will direct statutory bodies to act and will enable Welsh Ministers to intervene in service provision directly if necessary.

Comparison with current powers

14. The Bill provides for an autism strategy to be prepared and laid before the assembly (Section 1). It also provides for guidance to be issued to 'relevant bodies' about the exercise of their functions for the purpose of securing the implementation and delivery of the autism strategy and to publish that guidance (section 4). Section 5 sets out that "relevant bodies" must comply with the autism strategy and the guidance.

15. The Bill sets out that the autism strategy must be '*laid before the National Assembly for Wales'* (section 1(4)) but is not required to undergo any Assembly scrutiny processes. There is no requirement for the guidance that is to be prepared under section 4 to be laid before or scrutinised by the Assembly. The Code will therefore undergo a higher level of scrutiny than the guidance which is provided for under the Bill.

16. The SSWBW Act 2014 already gives a power to Welsh Ministers to issue a code in relation to the exercise of social services functions. A code is in the process of being prepared under s.145 of the 2014 Act and the NHS Act 2006.

17. This draft code must be laid before the Assembly for 40 days and must not be issued if the Assembly resolves not to approve it. In accordance with section 145(3) Local Authorities must act in accordance with the relevant requirements within the Code. The Welsh Government has the ability to issue directions to Health Boards. Health Boards are under a duty to comply with directions. Therefore, the Autism Bill does not go any further in terms of placing duties on NHS boards or local authorities.

18. The Autism Bill centres on provision to meet the needs of adults and children with Autism Spectrum Disorder. This is based upon a diagnosis as opposed to a presenting needs basis. In the absence of a specific diagnosis there is a risk that persons who has ASD traits will be unable to access the help and support set out within this legislation.

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

There are three specific regulation making powers contained within the Bill.

- Section 6(6)(j) – provides for The Welsh Ministers to prescribe such other categories of data that NHS bodies must collect to assist them in the diagnosis and provision of services to persons with autism spectrum disorder.

- Section 9 – Interpretation

“autism spectrum disorder” means—

(a) autism spectrum disorder as defined by the World Health Organization International Classification of Diseases from time to time; and

b) for the purpose of this Act, any other neurodevelopmental disorder prescribed by the Welsh Ministers;

“relevant body” (“*corff perthnasol”*) means a local authority, an NHS body and such other bodies as may be prescribed.

19. There would be limitations to how the regulation making power to extend the definition of “autism spectrum disorder” to any other neurodevelopmental disorder as prescribed by the Welsh Ministers could be exercised. The purpose of the Bill is to “*make provision for meeting the needs of children and adults with autism spectrum disorder”*. Therefore, if Welsh Ministers used that regulation making power to then include other neurodevelopmental disorder conditions within the definition, that would not normally have fallen within the definition of autism - this would likely fall outside of the scope of the Bill’s purpose.

Remedies

20. Whereas compliance with the Autism Bill can only be enforced by way of Judicial Review, there are already built in mechanisms within the SSWBW Act for intervention and enforcement of the Local Authority to the Code. Section.150 provides for Welsh Ministers to be able to intervene in the event that Local Authorities fail to comply with a duty that is a social services function, act unreasonably in the exercise of a social services function, or fail to perform a social services function to an adequate standard. There is then provision for a warning notice to be issued and further steps to be taken by Welsh Ministers by way of enforcement against a Local Authority.

21. Similarly, under the NHS (Wales) Act 2006, there is provision to make an intervention order and for further steps to be taken in the event that a local health board is not performing one or more of its functions adequately or at all, or that there are significant failings in the way the body is being run, and the Welsh Ministers are satisfied that it is appropriate for them to intervene

Human Rights and UN Conventions

22. The Autism Bill places a duty on relevant bodies and Welsh Ministers when exercising their functions under the Act to have due regard to the UN principles for older people and the UN convention on the Rights of Persons with disabilities. It also places a duty on relevant bodies to have due regard to the UN Convention on the Rights of the Child.

23. The Additional Learning Needs and Education Tribunal (Wales) Act 2018 ('the 2018 Act') places duties on relevant bodies to have due regard to the United Nations Convention on the Rights of a Child (UNCRC) and the United Nations Convention on the Rights of a Persons with Disabilities (UNCRPD). However, the 2018 Act states that there is no requirement for specific consideration of the conventions on each occasion that a function is exercised. This provision minimises bureaucracy and red tape by ensuring that consideration of the conventions is not required each time a decision is made for an individual. There is no similar provision in the Autism Bill.

24. Furthermore, the requirement in the 2018 Act to have due regard to the conventions is limited to local authorities, schools, further education institutions and NHS bodies who operate on a scale and have sufficient structures in place to effectively carry out these duties. The Autism Bill provides for the Welsh Ministers to be able to prescribe additional bodies within the definition of 'relevant bodies'. This would then mean that these additional bodies would have to also have due regard to the conventions when exercising their functions. This could have the potential of placing significant duties upon bodies that may not have the framework to incorporate this.

25. Both the Autism Bill and the 2018 Act make provision for the guidance (in the Bill) and the Code (in the 2018 Act) to set out what is required to discharge the duty to have due regard, and that the requirement to have due regard should be interpreted in accordance with any provisions in the guidance/code.

26. As the Bill goes further than the 2018 Act, there would be inconsistences as both an Autism Act and the 2018 Act could apply to the same individual. This would create difficulties in interpretation for bodies implementing the Acts.

General Principles of the Bill

27. If the purpose of the Bill is to improve support for autistic people then we share its ambitions. Where we differ is that we already have all the legal powers required to the deliver improvements set out in the Bill and more. We should be building on existing powers in recent legislation to support the improvements that are being put in place.

28. Whilst an Autism Strategy has been in place for some time, we acknowledge that services can still be very difficult to access for some. As Paul Davies AM also acknowledged in his evidence to the Constitutional Affairs Committee, and in the Explanatory Memorandum for the Bill, significant progress has been made in the last 12-18 months. We have considered the views of all the contributors to this debate who all want to see improved services. The overwhelming conclusion to be drawn from the facts is that there is no evidence to support the belief that autism specific legislation will add any value to the improvement we are achieving, nor can it guarantee access to particular services now or in the future.

29. The Bill seeks to make the Autism Strategy statutory, and is seeking to ensure there are diagnostic pathways. We renewed the Strategy in 2016 and in September 2018 published an updated Delivery Plan, which confirmed our commitment to a statutory Code of Practice on the Delivery of Autism Services. The Bill seeks to improve access to social care services, but these are improvements we must achieve for everyone irrespective of their condition or group.

30. We will continue to deliver our autism commitments through existing legislation, notably the SSWBW Act 2014 and the ALNET 2018. We need time for new legislation and services being developed to be rolled out and embedded and we need to learn lessons from the evaluation of their implementation before we consider if any further legislation is required.

31. In written evidence submitted by the Children's Commissioner, she refers to her 2018 *Don't Hold Back Report* noting that there was a strong legislative framework in place to plan for and provide person centred support services, and this extends to autistic people. We agree with her view that existing

legislation could be used more effectively, and that is why we have committed to deliver a Code of Practice.

32. In relation to other duties in the Bill, it seeks to encourage staff training amongst professionals; we are already improving awareness through encouraging the use of the Autism Training Framework for Wales, to assess training needs which will be promoted through the Code of Practice on Autism. The Bill does not mandate professional training.

33. The National ASD Development Team has produced a wide range of highly regarded resources and training materials. For example the *Can You See Me* video aimed at raising awareness amongst health and education professionals. Through partnership working with Cardiff University this resource has been translated in four other European countries – Spain, Italy, Lithuania and Latvia. This and other resources can be found on the dedicated website for delivery of the Autism Strategy. www.asdinfowales.co.uk.

34. The Integrated Autism Service has attracted a wide range of experienced and specialist staff, which offer training to other specialisms such as mental health and learning disability to ensure their expert knowledge is shared. Workforce development is also a critical part of the Additional Learning Needs Transformation Programme. Working with our 5 ALN transformation leads we are delivering an extensive package of training and core skills development for all practitioners, which will include autism training.

Legislation in other parts of the UK

35. In his evidence Paul Davies AM refers to a report by Lemmi, Knappe and Ragan (2017) – the Autism Dividend, stating that without legislation an autism strategy will not have statutory force. The evidence from other UK countries where an Autism Act is in place clearly shows that where legislation in force, even with additional statutory guidance it has not brought the benefits anticipated. It is important to highlight that similar autism legislation made in other parts of the UK was enacted nearly a decade ago, before the introduction of modern legislation which places the individual at the heart of decision making, is person focussed and most significantly requires services to be provided on the basis of need.

36. As other contributors have also demonstrated there is little evidence to show that progress in England nearly a decade after the Autism Act was passed in 2009. The National Autistic Society claims there is a '*national diagnosis crisis*'

as evidence published by Public Health England shows that only 22% of local authorities in England are meeting recommended waiting times. There are reports of waiting times of up to two years in some areas.

37. 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*."

38. The Scottish Parliament considered the need for autism legislation in 2010. It concluded a Bill would not overcome the barriers to service delivery nor satisfy the expectations of people with autism. It stated that passing more legislation is not an appropriate response to the poor implementation of existing legislation and more time was needed to evaluate the impact of other relevant recent legislation. Concerns were also raised about creating 'two tiers' of strategies.

The Impact on Existing Legislation and Welsh Government Policy Development

39. It is our view and that of many other contributors to the debate that we can deliver the improvements to autism services through existing legislation. Paul Davies AM states that the Bill will support and underpin current legislation, however we would strongly argue that diagnosis or condition led law would be directly at odds with the delivery of modern legislation, which bases service provision on the basis of individual assessed need not on a specific diagnosis.

40. The Explanatory Memorandum states a key function of the Bill is to *secure consistent and continued provision of all ASD services across Wales.* As the Children's Commissioner agreed in her evidence, if the aim is to secure permanence to autism services then this will be achieved through plans to issue a Code of Practice on the Delivery of Autism Services under existing legislation.

Information and awareness

41. The Bill raises an important issue in terms of information and awareness raising about existing rights and services. The Welsh Local Government Association National Development Team, has a strong record in raising awareness, as evidenced in their annual report published in June, and is

delivering dedicated awareness programmes this year, with a national autism conference for autistic people next April.

42. In the forthcoming consultation on Code of Practice on the Delivery of Autism we will be asking autistic people and their parents and carers how access to the right information and advice can be improved.

Data Collection

43. Since the introduction of the first ASD Strategy we have considered the value and the benefits of gathering data balanced with the resources required to ensure it is collected consistently and is robust.

44. The detailed person specific data requirement in this Bill does not tell us about the impact of services, only the individual characteristics of those with a diagnosis. As the Community of Practice for Adult Diagnosis and IAS Clinicians points out in their evidence, the level of data required in the Bill is onerous and adds little additional relevant information to both planning and commissioning. It does appear to be collecting for data's sake and there is a need to ensure it will be GDPR compliant.

45. Some of the responses to the consultation on the Bill were uncomfortable about the level of personal information to be collected. Collecting and analysing detailed personal information through an NHS number may be useful for research, but we would question whether it is necessary and would provide the information needed for service planning.

46. The People in Work Unit, which is evaluating our ASD Strategy, in their evidence are of the view that accepted prevalence rates are an adequate measure of the numbers of autistic people. They do state that there is a strong argument for collecting outcome focussed qualitative data about experiences of autism and of using services, and this is an approach that is currently being developed.

47. To give a clearer picture of the numbers of autistic people and to raise awareness of their needs, we are introducing a GP autism register of the numbers of patients diagnosed. Through the Integrated Autism Service and the children's Neurodevelopmental Service we are also working in partnership to establish quality based measures which can provide evidence of distance travelled and the benefits of services to individuals.

48. Under existing duties in the SSWBW Act, we are extending the core themes for Mandatory Population Needs Assessments to include autism as a stand

alone theme. These assessments are undertaken jointly by health and local authorities through Regional Partnership Boards.

49. Establishing new data collections is a complex process to ensure the data is comparable across services, is reliable and consistent. We are currently piloting the 26-week diagnostic waiting time standard and this approach has taken substantial discussion and review to ensure the data being collected is of sufficient quality for publication. As part of the pilot this data will be available on the Stats Wales website if it is of sufficient quality.

Unintended Consequences

50. Our greatest concern is that the Bill continues to raise high expectations that autistic people can expect preferential access to services and the legislation will result in more services becoming available. As the Children's Commissioner stated the Bill may not result in anything more than the current provision.

51. Many may view the prospect of legislation as attractive, but in addition to evidence provided by statutory bodies and the Royal Colleges on its weaknesses, there were also responses from parent groups and autistic people to the consultation on the Bill that were realistic in their views that this Bill will not deliver on its intention.

52. We understand there is frustration amongst Primary Care practitioners that they cannot refer into local authority services, and we will look at how the Integrated Autism Service is bridging this perceived gap between health and social care. It must be emphasised again that an Autism Bill cannot require specific services to be available.

53. Supporters of the Bill believe that legislation is required to compel authorities to deliver the services autistic people and their families want to see. The Constitutional and Legislative Affairs Committee has already heard evidence from Paul Davies AM about remedies under the proposed legislation. There are no specific remedies proposed other than the opportunity to pursue a judicial review, as is the case for other Welsh legislation. We are not aware of any evidence that autism legislation has seen a marked increase in judicial review in England, despite the lack of progress being seen. This is in contrast to the remedies available through a Code of Practice on autism which is stronger as it enables Welsh Ministers to intervene in service delivery. The ALNET Act also brings a right of appeal to education tribunal.

Needs Based Services

54. Another widely held concern we share with many of our delivery partners and practitioners is that the spirit of this legislation is completely at odds with our modern legislative approach as set out in the Social Services and Well-being (Wales) Act 2014 and the Additional Learning Needs and Education Tribunal (Wales) Act 2018. This legislation may undermine our programme of Additional Learning Needs reform, to be rolled out from 2020 which is needs based, by creating an environment where an autism diagnosis could give preferential treatment to support and services.

55. Evidence presented by the NHS Confederation and the Royal Colleges of Psychiatry, Speech and Language Therapy and Occupational Therapists makes the case that a system weighted by diagnosis would drive up referrals and pressure to provide an autism diagnosis, because this is seen as the best gateway to access services. The need for a diagnosis to push for resource is likely to artificially increase diagnosis rates for the wrong reasons. The Children's Commissioner also refers to autism becoming a perceived '*golden ticket'* to accessing services, when in reality other groups of children such as those with mental health needs and learning difficulties can also have challenges in accessing the right services for them.

56. The Bill will undermine the significant progress achieved in the development of neurodevelopmental assessment and diagnostic services. Separating autism from other neurodevelopmental conditions will create barriers to access services for many, it will prevent needs based services, particularly where individuals have co-existing conditions or not easily diagnosable conditions. It will lead to gaps in provision for some people who do not meet the diagnostic criteria. An added unintended consequence of added pressure to diagnose is that this could lead to inappropriate diagnosis, particularly for children, who in later life may not want to carry a diagnosis through their lives if it was not appropriate when made.

57. Feedback from practitioners and evidence from the independent evaluators of the ASD Strategy around the proposed 13-week waiting time targets is that this duty is likely force services to focus limited resources on meeting the duties in the Bill. That is funnelling more people through diagnostic assessment at the expense of providing much needed pre- and post-diagnostic support. The evaluation has found that service providers are already concerned about future capacity to meet demand for diagnosis, this will be exacerbated by legislation focussing services on a single diagnosis.

58. Introducing waiting times targets without a rationale or means to achieve this, will not achieve the desired results. The proposed new duties would require

health boards to signal a child's assessment has started by 13 weeks, however there is no explanation on what this means in practice. It could means as little as the referral being accepted or a letter sent to this effect. We are extending the current evaluation of the autism action plan to investigate the stubborn barriers to reducing diagnostic waiting times, despite the significant additional investment since 2015 and will seek to identify where further action can be taken.

59. The Bill is creating a perception that autistic people will receive preferential services, and this can only mean that resources will be diverted from other services, creating an inequity of support for other individuals who have other substantial support needs, such as people with learning disabilities or sensory impairments. Also within autism services, providers may be forced to divert resources away from evidence based interventions to meet the demands of legislation. In this case resources moved into diagnosis and out of post diagnostic services.

60. We do not accept the argument presented that requiring services for one condition will by default improve services for others. As well as funding concerns there is absence of suitably qualified staff that can be recruited to deliver support. If autism is mandated then that is where services will have to be focused.

61. We also question whether it is possible to extend the Bill to other neurodevelopmental conditions, as is proposed, as explained earlier this is likely to be outside the purposes of the legislation. In his evidence Paul Davies AM is clear that this a Bill for autistic people only. This will immediately disadvantage those with other neurodevelopmental conditions, those who do not fit neatly into diagnostic categories and those who have other significant support needs but do not meet diagnostic criteria.

Regulatory Impact Assessment

62. It is clear that there are very real economic and social costs associated with Autism Spectrum Disorder both to the individual and their parent(s)/carer(s) and to wider society.

63. As with all Regulatory Impact Assessments (RIAs) there is an element of uncertainty in the analysis, but the broad methodological approach appears to be similar to that followed by Welsh Government when developing an RIA. However, there are elements to the RIA which require further explanation to be able to test the robustness of the calculations and areas where additional evidence to support the analysis would be useful.

64. A number of the provisions of the Bill place a duty on Welsh Government to do things that are already being done. For example, Welsh Government already has an autism strategy in place, a Code of Practice is being developed, an awareness raising campaign has already been launched and a training programme is in place for healthcare and education professionals. It is therefore questionable whether the costs identified in the RIA for these activities are additional to the baseline

65. It is difficult to determine what the additional costs and benefits of the Bill will be. The evidence around the potential benefits of the Bill is relatively weak. It is suggested that a 1% reduction in the direct and indirect costs associated with ASD will save £1m per annum but there is little evidence to indicate how the Bill might achieve this saving. Given the estimated direct and indirect cost of ASD in Wales each year is estimated to be £1.1bn, a 1% reduction in this cost would represent an £11m saving and not £1m as reported in the RIA.

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Cynulliad Cenedlaethol Cymru
Y Pwyllgor Plant, Pobl Ifanc ac Addysg

National Assembly for Wales
Children, Young People and Education Committee

Dr Dai Lloyd AM
Chair, Health, Social Care and Sport Committee
National Assembly for Wales
By Email

18 October 2018

Dear Dai,

Scrutiny of the Welsh Government Draft Budget 2019-20

In advance of our respective committees' scrutiny of the Welsh Government's Draft Budget 2019-20, I wanted to write to inform you of the Children, Young People and Education Committee's proposed approach.

I wrote to relevant Welsh Government Cabinet Secretaries and Ministers in August 2018 to request written information to inform our scrutiny. My letter to the Cabinet Secretary for Health and Social Services and the Minister for Children, Older People and Social Care has been published, and may be of interest to you given the overlapping nature of our remits. To avoid any unnecessary duplication of effort, if there are any issues of relevance to children's health and social services that you would like us to cover in our scrutiny of the Welsh Government, please let me know.

I also wanted to draw to your attention that, in light of our recent inquiry into the emotional and mental health of children and young people, and the findings of our Mind over Matter report, one of the areas we are likely to focus on is the funding available for the emotional and mental health of children and young people, including the funding available for children and adolescent mental health services (CAMHS). Again, if there are any particular issues relating to the emotional and mental health of children and young people that you would like us to cover, please get in touch.

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I hope this letter is of use to you, and will enable us to share any relevant information with one another.

Yours sincerely,

Lynne Neagle AM
Chair

Agenda Item 7.2

Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-29-18 Papur 6 / Paper 6

Thank you for your e mail dated 3rd October 2018 regarding the enquiry into Dentistry in Wales being carried out by the Health, Social Care and Sport Committee.

The Health Board procures primary care dental services for Hywel Dda residents by entering into contracts with dental Contractors for the delivery of units of dental activity (treatments). In doing this the Health Board follows a national contracting framework known as the Dental Contract.

If the dental Contractor does not deliver the contracted activity levels (actual units of dental activity delivered are less than the contracted level of activity) then any overpayments that have been made to the dental Contractor during the year will need to be reviewed and recovered if appropriate. This is enacted in accordance with the nationally agreed Dental Contract and demonstrates appropriate governance, value for money, and Contract monitoring.

The Health Board is required under the national Dental Contract to recover money non-recurrently from the Contractor to reflect the fact that they have not met their contractual obligations for a specific financial year. To emphasise the point, this is not a punitive action, but merely reflects the agreed Contractual process and ensures that dental Contractors are paid for the actual activity they deliver in a particular year.
However, in 2015/16, 2016/17 and 2017/18 the Health Board saw an unprecedented level of unplanned underperformance against dental Contracts. In both years a significant proportion of the underperformance (in excess of 80%) related to a specific corporate provider.

The underperformance seen in Hywel Dda Health Board in the financial years 2015/16, 2016/17 and 2017/18 is shown in the table below.

Contractual Underperformance	
	£m
2015/16	0.279
2016/17	1.455
2017/18	0.838

Generally, and with the agreement of the dental Contractor, the Health Board would not seek to recover any small amounts of underperformance from contractors in return for the contractor agreeing to make good the underperformance in the subsequent financial year. However, where underperformance is of the levels seen over the past three financial years, recovery by the Health Board is expected in line with the Contractual process.
Whilst reinvestment of all of the underperformance recovered into Primary Care General Dental Services is always desirable, this is not practically possible in year, as dental Contractors do not always have the workforce capacity to undertake large amounts of non-recurrent General Dental Services activity in any particular financial year. In addition to this the Hywel Dda area is experiencing recruitment and retention issues for existing Practices to either increase capacity within existing contracts or to set up new NHS businesses. As an example the Health Board has tried to attract a new Dental Practice into South Ceredigion on two previous occasions and there have been no expressions of interest received despite increasing the financial value of the contract available to the dental Contractor.

There are other issues that impact on the ability to reinvest funding in a timely manner. Under performance is not normally quantified until the second half of any particular financial year. To reinvest the level of underperformance experienced in Hywel Dda in the years in question there would need to a tender process enacted, in accordance with the SFI and Dental Contract, which can take up to six months. In this sort of time frame it is challenging to re-invest the funding in year and comply with NHS Accounting rules that do not allow the roll forward of resource allocation into subsequent financial years.

In order to mitigate against these occurrences in future, Hywel Dda University Health Board has developed a four year investment plan with the agreement of the Chief Dental Officer for Wales, to cover a period encompassing the years 2017/18 to 2020/21, which ensures that at the end of this period the Health Board will spend the entire ring fenced allocation on sustainable General Dental Services for its population. As stated this plan has been endorsed to by both the Health Board, and Welsh Government through the Chief Dental Officer for Wales.

[redacted]

[redacted]
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Claw back was mainly due to recruitment issues. The majority of Powys contracts are with a Corporate who are currently experiencing recruitment issues which resulted in the clawback.

Powys in an attempt to solve the problem of access has decided to invest in some salaried general dental practitioner posts to complement the general dental service. It has also invested in creating a foundation post to further attract dentists into the area.

Agenda Item 7.4

Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-29-18 Papur 8 / Paper 8

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Hydref 17 October 2018

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Annwyl Dai Lloyd

During our evidence session on the Autism (Wales) Bill, on the 3 October 2018 we mentioned that Wales has around 34,000 autistic people. Your fellow committee member Angela Burns AM asked for a breakdown of the total number of children with autism in Wales.

We are happy to clarify that the figures we currently use on numbers of autistic people in Wales are estimates, based on prevalence research applied to the latest census results. Using those estimates, we would say that there were around 5,000 school aged children on the autism spectrum in Wales. The latest statistics from Welsh Government set out that 7,655 children get extra help in school because of their autism.

In addition, it is also worth highlighting that of those who lodged an appeal with the Education Tribunal during 2015-2016, nearly 40 appeals were identified as having autism as their main special education need (SEN). This was the highest figure of all appeals made by the person's SEN. This shows a particular high level of difficulty in the system in getting the right type of help made available for children with this particular disability and why specific attention needs to be paid to the needs of autistic people.

As the NHS in Wales doesn't currently routinely collect data on autism diagnosis, we don't currently have the clear picture on numbers and needs that we need in order to plan effectively.

Could we also take this opportunity to clarify a point made during the evidence session? Fellow member Dawn Bowden quoted from page 10 of the Autism Dividend report, which said that: ‘Yet nearly a decade on, the needs of autistic people are still unmet and the expected economic dividend never materialised.’

However, it is also incredibly important to note that the report also states that: ‘The existence of autism legislation [in England] at a time when budgets at local level are under increasing pressure has ensured a focus on autism that would not have been possible without the Act.’

And in relation to the Welsh legislation the report goes on to say that: ‘The Welsh Government rejected calls for an Autism Act, believing that other current developments will support autistic people effectively. However, without such legislation, government initiatives lack statutory force resulting in an inability to require local authorities to implement the strategy to the full.’ Far from suggesting that legislation isn’t the answer, the report actually recommends legislation in Wales.

Finally, we were questioned several times around unintended consequences of legislation in terms of potential for over diagnosis and also concerns that a new law on autism in Wales would lead to calls for a law on other conditions. We would like to make it clear that it is not our experience that this has happened in England or Northern Ireland. Moreover, we know that legislation and policy development in Wales is evidenced-based and so we would suggest to the Committee to consider the evidence on whether any of the potential unintended consequences raised as concerns have come to pass in other UK nations as part of its scrutiny.

Yn gywir iawn

[redacted], Rheolwr Materion Allanol / External Affairs Manager
[redacted], Cyfarwyddwr Materion Allanol a Newid Cymdeithasol / Director of External Affairs and Social Change

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Patron: HRH The Countess of Wessex. Chairman: Dr Carol Homden. President: Jane Asher. Chief Executive: Mark Lever. National Autistic Society is a charity registered in England and Wales (269425) and in Scotland (SC039427) and a company limited by guarantee registered in England (No.1205298), registered office 393 City Road, London, EC1V 1NG

Pack Page 173