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Ysgrifennydd y Cabinet dros Iechyd a Gwasanaethau
Cymdeithasol
Cabinet Secretary for Health and Social Services



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref MA L VG 0696 18

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

19 November 2018

Dear Dai,

Thank you for your letter of 26 October seeking further information on the evidence I presented to Committee on the Autism (Wales) Bill on 25th October. As requested I am pleased to provide you with information on current waiting times and a confidential draft of the consultation document for the Code of Practice on the Delivery of Autism Services. This has also been mapped against the duties in the Autism (Wales) Bill. The consultation document will be finalised and published before the end of November. I also set out below my response to the other queries the committee raised.

Current Diagnostic Waiting Times

Performance statistics in relation to the neurodevelopment target will be published on Stats Wales from April 2019. After completion of the Welsh Informatics Standards Board (WISB) process, in October 2017 all health boards began reporting the number of referrals they had accepted that month into the neurodevelopment service. The new data specifies the number of people who had been waiting less than 26 weeks, 26-35 weeks, 36-51 weeks, and over 52 weeks. This data is still in a 'pilot' stage and is not currently public until next spring. Piloting is required so that health boards can ensure their services are working to the ways set out in the Data Standard Change Notice (DSCN). It also provides opportunity to test the robustness of the data.

However, for transparency I can report confidentially to the HSCS Committee that the pilot data suggests Betsi Cadwaladr and Hywel Dda are the lowest end of achieving against the target. However, they are also the two health boards with the highest numbers of referrals. Cardiff and Vale and Powys are the top end of achievement against the target.

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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.

Condition Specific Code of Practice

The Code of Practice on the Delivery of Autism Services will be made under the Social Services and Well-being (Wales) Act 2014 and the NHS (Wales) Act 2006. The purpose of the Code is to re-inforce existing duties to provide services and support. The Code will help to ensure that autistic people and their carers have the access to needs-based assessment and services on a basis that is comparable to citizens with other health or social care support needs. The Code will raise awareness of autism and what reasonable adjustments public services and employers should make to enable autistic people to maximise their potential. This will help to create the level playing field which supporters of the Bill are seeking. However, it will not exclude individuals with similar needs but without an autism diagnosis from accessing certain services which will be a negative consequence of the Bill should it pass into legislation.

As evidence you have received from other contributors including the Children's Commissioner, the NHS Confederation and the Royal Colleges of General Practitioners, Occupational Therapists, Speech and Language Therapists, Paediatrics and Child Health and Psychiatrists has stated, if strong existing needs based legislation is not working for some individuals, the answer cannot be to introduce yet more legislation. The right approach is to take steps to strengthen autism services including by ensuring statutory services fully understand their existing responsibilities to support autistic people and their carers.

I also reiterate my considerable concern that the Bill is not compatible with and will adversely cut across modern needs based legislation seen in the SSWBW Act 2014, the Additional Learning Needs and Education Tribunal Act 2018 and the Future Generations Act 2015. There is also the prospect of autistic people having conflicting rights and entitlements across differing legislation which will cause confusion amongst front line staff.

Needs based services and support

The Committee has raised the important issue of ensuring there is holistic support for autistic people. It is first important to note that the Bill as drafted is completely silent on this other than to say a range of bodies to have 'due regard'. This signifies that this is a very difficult area in which to legislate, particularly as many services will be outside the Welsh Government's scope to regulate. Our existing needs based legislation looks at an individual in the round, works with them to determine their own well-being outcomes and establishes a route for them to access a range of services and support to achieve these outcomes. Many of the services they may want to access in the areas you mention particularly employment and inclusion may be outside statutory services, for example, participating in volunteering.

In my written evidence to Committee, I also sought to demonstrate that there are already a number of initiatives within the framework of existing legislation, which are contributing significantly to promoting services in education, employment, housing and social inclusion for autistic people.

Through the ASD Strategic Action Plan, the National ASD Development Team are delivering much needed resources and support for autistic people to assist them in their daily lives. I attach the Team's annual work plan and resources leaflet to demonstrate the breadth of work being undertaken. I would particularly like to draw your attention to the work they are undertaking to develop autism housing guidance.

You have also heard other evidence of direct support being provided to individuals through the National Integrated Autism Service. I understand the Welsh Local Government Association will be providing further evidence including case studies to illustrate how the service is providing specialist expertise. The full range of resources available include development programmes for schools and other settings, advice for health and social care settings, post diagnostic guidance for parents, children and for adults. These can be accessed on their website www.asdinfowales.co.uk,

In education, our Additional Learning Needs reform, underpinned by the Additional Learning Needs and Education Tribunal (Wales) Act 2018, will provide significant support to those who require additional educational support needs. It introduces a new system focussed on ensuring all children and young people, including those with autism are able to access support and that it is properly planned for and protected. Children and young people will have a statutory plan with equal rights of appeal. In addition the Mental Health Act 1997 and 2008 will support those with additional mental health needs.

The ALNET Act contains a chapter devoted to transition between schools, which can often be distressing to those on the autism spectrum. The ALNET code, in the section devoted to multi-agency working, will explicitly reference the Integrated Autism Service and other support available. This code will impose a requirement on local authorities and governing bodies to use the appropriate standard form of an Individual Development Plan.

The National ASD Development Team is also supporting those on the autism spectrum throughout their progress through the education system through the development of training resources within its Learning with Autism (LwA) programme. In the Secondary School sphere, 1562 teachers have completed the LwA teachers' scheme and 6951 pupils have undertaken the Sgilti lesson and signed the pledge, all since 4th September 2018. Additionally, 7 Secondary Schools across Wales have received their Learning with Autism School award, and on the 28th September, the LwA strategy was presented to the ADEW ALN/ Inclusion & School Improvement Group.

In Further Education, work has already started with Colegau Cymru. The Team are promoting understanding of autism to the general student body through educational materials, providing training for direct work staff, and resources are being compiled for autistic students to support their passage through further education. Work Based Learning will also be supported through LwA, with forums, advice sheets and handbooks being prepared.

For employment, the ASD strategy sets out our 'Working with Autism' programme, this has led to the development of a 'Working with Autism' app, a CV builder, personal skills builder, searching for work tool, master skills dictionary and an e-learning programme. Further, the programme highlights the Big Lottery Funded – Getting Ahead Project, specifically aimed at improving employment opportunities for young people with learning disabilities and autism.

Responsibility for benefits and statutory employment support is largely non-devolved, but we are working with JobCentre Plus to encourage increased knowledge and awareness of autism amongst support staff. Our Integrated Autism Service can also provide individual advice and sign posting in relation to employment needs.

On housing, we are taking action through the ASD Strategy, working across government and with partners to develop guidance for housing providers to provide tailored support for autistic people. The National Autism Development Team has also produced The 'Housing e-learning scheme' for housing staff, to raise awareness and understanding of the difficulties and needs that autistic people may have in housing.

In relation to social inclusion we understand that many autistic people find social relationships difficult, but they want to engage with their community. Through the ASD Strategy, the National Autism Development Team has developed services and support. The Living with Autism programme provides support, and the Integrated Autism Service has been specifically designed to help individuals who are having difficulties with daily living. The social inclusion of those on the autism spectrum can also be encouraged by increasing awareness of autism. In Wales, the 'Can You See Me' campaign celebrates the differences of those with autism, and gives autistic people the choice to identify themselves to others with a band or smart phone logo. It also educates those in retail and leisure services on how to be more responsive to autistic customers.

The Code will make it clear how social inclusion for different groups of people on the autism spectrum will require different strategies from service providers. Specifically it will make reference to BAME individuals, and also on how gender and gender dysphoria affects the social inclusion of those with autism. The Welsh Government has recognised the need to improve gender identity services in Wales and have established the All-Wales Gender Identify Partnership Group to provide advice. A Wales Gender Team is being created which will operate from the University Hospital of Wales.

Wider than this the Welsh Government recognises that loneliness and isolation can have a devastating impact on individual well-being of many individuals. We are developing a loneliness and isolation strategy and published a public consultation document on 22 October 2018.

IQ and eligibility for services

National eligibility criteria for care and support under the Social Services and Well-being (Wales) Act 2014 makes no reference to IQ. This should not therefore be a factor in the assessment process.

If there is concrete evidence about how the SSWBW Act is not working then this must be addressed holistically for all citizens. This is also set out in Chapter 3 section 17 of the Autism Spectrum Disorder Strategic Action Plan. It states that 'The Welsh Assembly Government has made clear to authorities that access to health and social care services for adults must not be based on IQ related criterion.'

The Code will make specific reference to supporting all autistic people to access social care assessments. Whilst IQ must not contribute to assessment, there may be some on the autism spectrum whose needs mean that, once assessed, a social care package is not deemed appropriate. The Code will provide guidance on referral to appropriate services for

autistic people such as the Integrated Autism Service which has been specifically designed with this group of autistic people in mind. It is there to provide support for those who may not be eligible for social care services but still have support needs, and may previously have been falling through gaps in support.

Health Bodies duty to act under the Code

I can confirm that the Code will require health bodies to act on the same basis as local authorities, requiring them to comply with the requirements in the Code. The Social Services Wellbeing (Wales) Act 2014 already gives a power to Welsh Ministers to issue a code in relation to the exercise of social services functions. The code will also be issued under s.145 of the 2014 Act and the NHS Act 2006. This draft code must be laid before the Assembly. In accordance with section 145(3) local authorities must act in accordance with the relevant requirements within the Code. Welsh Ministers will issue directions to Health Boards and place requirements on them to comply with the Code.

As I have set out in my written evidence to committee, compliance with autism legislation can only be enforced by way of Judicial Review, whereas there are already built in mechanisms within the SSWBW Act for enforcement. S150 of the Code provides for Welsh Ministers to intervene in the event local authorities fail to exercise a social services function, act unreasonably or fail to perform a social services function to an adequate standard. Similarly, under the NHS (Wales) Act, there is provision to make an intervention order and for further steps to be taken where a local health board is not performing their functions adequately or if there are significant failings in the way the body is being run.

Accessible formats

All information about our services is provided bilingually. Further, in accordance with the Equality Act 2010 (Statutory Duties) (Wales) Regulations 2011, Welsh Government is committed to responding to individual requests for alternative methods of communication of its services. In this way, we are dedicated to ensuring that all persons are able to access and understand any information related to them. Provision of 'easy read' documents is an example of this. If there are specific examples where families have experienced difficulties then I would be keen to receive further information so the situation can be remedied.

Stakeholder involvement

I have also recently met with autism groups in Aberavon and Ynys Mon to discuss policy priorities including plans for the autism code. I listened to the very real struggles experienced by families and learned how they felt services needed to improve to meet individuals' needs. The main themes emerging were around difficulties in accessing support at school and additional services such as respite care. I heard that some families thought legislation could place direct duties on schools to provide support, and I was asked what remedies were currently available so that decisions in schools could be challenged.

It was clear that families did not think that the current system was working for them, and hoped that condition specific legislation would help them to access support they are urgently seeking. There is nothing in the Bill which would enable these concerns to be

addressed and I remain concerned that the progress of the Bill is raising unrealistic expectations.

The most effective route to improve services must be to increase the pace of improvement to ensure the current needs based system is working properly. This improvement will be delivered through the autism Code of Practice and the Additional Learning Need reforms which are being rolled out from 2020. My evidence which is supported by many professional bodies has demonstrated that we need time for existing needs based legislation to be rolled out and embedded and not take forward an additional layer of confusing and contradictory legislation.

You will also be aware that I have recently given evidence at Finance Committee. I have concerns that the Regulatory Impact Assessment for the Bill underestimates the costs of introducing it and is silent on its disbenefits. I will shortly be providing the Finance Committee with further information about this.

Yours sincerely,

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive style with a large initial 'V' and a distinct 'G'.

Vaughan Gething AC/AM

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