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Mick Antoniw AM
Chair, Constitutional and Legislative Affairs Committee
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Annwyl Mick,

I noted with interest the evidence provided to the Committee from the Cabinet Secretary for Health and Social Services, Vaughan Gething AM, on the Autism (Wales) Bill, on 15 October.

On behalf of our members and supporters, I would like to extend our gratitude for the work that the Committee is undertaking to ensure that, if passed, the Autism (Wales) Bill will be as strong and effective as possible and make a significant difference to the lives of autistic people across Wales.

In this spirit, I hope the Committee will allow me to address a number of comments made during the evidence session on the 15 October.

Remedy

It was noted by the Cabinet Secretary that the only remedy option, where it appears duties within the Bill aren't adhered to, is Judicial Review. Similar is ultimately true of a whole range of legislation. Suzy Davies AM pointed out that this could be said of the Social Services and Well Being Act, under which the proposed code of practice will be published. As you will know public services have their own complaint resolution mechanisms that aim to resolve concerns at an early stage.

In this context we would urge the Committee to consider the role that legislation has on behaviour change. We very much view the Bill as a driver that will lead to improvements in service delivery and support. Autistic people and their families will have their rights strengthened and made clearer through this legislation. In our view, this could lead to less cause for remedial action, or remedy at an early stage.



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It is worth noting that the main vehicle through which the strategy, as proposed by the Bill, will be monitored is through independent evaluation, with a duty to reflect any recommendations made. The Bill also includes the power for the Welsh Minister to make regulations, if approved by the Assembly.

Diagnosis

In his evidence the Cabinet Secretary said that Bill provided for services and support to be made available only once ‘over the gate’ in terms of diagnosis, and that this was a fundamental concern about the Bill. This, we feel, is an unfair summation of the Bill. The Bill clearly states in section 2.1(c): “this shall not prevent the provision of other services prior to diagnosis assessment”.

We agree with the Cabinet Secretary when he says that services should take into account the needs of the individual and ensure services are put in place to meet those needs. However, this assumes that professionals understand and can accommodate these needs without the benefit of a diagnostic assessment. This is where autistic people are failed by the current system.

A timely diagnosis is of fundamental importance in fully understanding the needs of an autistic person and shapes and informs any subsequent support. As Dai Lloyd AM said, ‘on the ground’ a diagnosis is key. It is also crucial in enabling autistic people to better understand themselves.

The current Welsh Government waiting time standard for children and adults is 26 weeks from referral to first assessment. The Bill proposes that the wait between a referral and first assessment should be determined by NICE guidelines and quality standards. This is currently 13 weeks. However, it is important to note that this timescale is not on the face of the Bill, and as clinical best practice changes, as determined by NICE, this can be reflected in the requirements of the Bill.

Examples of other UK Autism-specific legislation

The Cabinet Secretary said that he disagreed with the principle of condition-specific legislation and suggested that autism legislation in England and Northern Ireland had not led to ‘visible improvements’. There are many examples of where clear and tangible duties included in those Acts have led to clear and tangible outcomes for autistic people. One clear example, to take the England Act, is that, prior to the 2009 Act, only 14 areas of England had an established adult Autism diagnostic pathway. As a result of the Act, only three areas do not have a diagnostic pathway.

There is also no evidence to support the Cabinet Secretary’s concern that the Bill will lead to more condition specific legislation. This simply hasn’t been the case elsewhere.



The status of a Bill, Code or Action Plan

The Cabinet Secretary has committed to consulting on a code of practice in November 2018. Our chief concern is the confusion that this may cause to our members and supporters who feel that they have already given their views on the improvements they would like to see and the vehicle through which they think these improvements should occur, through the three consultations already held in relation to the Autism Bill

In our evidence to the Health, Social Care and Sport Committee, we suggested that it may be helpful for the Committee to have sight of the proposed code so that they could assess it alongside the Bill. We would encourage the Constitutional and Legislative Affairs Committee to also consider this course of action. From our initial understanding we feel that the scope, permanence and enforcement of any such code would be limited in comparison to the Bill.

I hope you find this information useful to your consideration of the legislation. I would of course be happy to provide the Committee with any further information as required.

Cofion cynnes,

Meleri Thomas
External Affairs Manager



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