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Aelod Y Ceidwadwyr Cymreig dros Preseli Penfro
Conservative Member for Preseli Pembrokeshire

Llyr Gruffydd AM
Chair, Finance Committee
National Assembly for Wales

16 November 2018

Dear Llyr,

Autism (Wales) Bill

Further to the Cabinet Secretary for Health and Social Services' appearance before the Finance Committee to give evidence on the Autism (Wales) Bill, I would like to respond to some of the issues raised during the session and the views expressed by the Cabinet Secretary.

Costs provided in the Regulatory Impact Assessment

In relation to costs outlined in the Regulatory Impact Assessment (RIA), you will be aware that the Cabinet Secretary did not provide me with important financial information I requested relating to the current costs of Autism Spectrum Disorder (ASD) services. Throughout I have sought to make every possible effort to provide comprehensive financial data in the impact assessment and, notwithstanding the lack of data from the government, respectfully submit that the financial analysis set out in the impact assessment is a fair reflection of the costs and savings.

I note the Cabinet Secretary's suggestion of engaging a health economist to assist in this process. It is clear from my evidence that I sought robust expert advice on the available data. It is concerning to note the difficulties the Cabinet Secretary outlined to you in apportioning ASD specific spend from wider spend on neurological development conditions, as one would expect the government to be capturing this data as part of its existing ASD activities. Further, if this information is not readily available, I'm unsure as to how a health economist could have assisted in this instance.

Despite the lack of information available to me, the RIA sets out the best estimates of the cost impact of the options. To help inform detailed costings I engaged with a number of health economists, academics and organisations delivering services. As has been discussed in scrutiny of this Bill in the Health, Social Care and Sport Committee, there is still no data published on ASD waiting times, so I performed my own research by contacting local health boards directly for waiting times data, Dr Dawn Wimpory at Betsi Cadwaladr University Health Board and her colleagues at Bangor University who manage a current database for detailed discussions on how a data collection system could work and what it could cost (as well as information on the current processes) and validation of our methodology.

In the absence of any data on number of people with ASD diagnosis, services provided or the wider impact on carers, Professor Tommy MacKay and his team of experts, from the University of Strathclyde and London School of Economics, who worked on the The Microsegmentation of the Autism Spectrum: Economic and research implications for Scotland report, helped me with my approach to estimating the costs of ASD in Wales. I am grateful for figures that ASD Info Wales provided when I approached them for information on ASD specific training developed and provided in Wales.

The official supporting the Cabinet Secretary at the Finance Committee session acknowledged that the methodology used in estimating costs under option 1 followed the same approach as would have been adopted by the Welsh Government. However, the official reported there were points of detail around some “fundamental flaws”. As an example, the official cited the costs outlined on page 57 of the RIA and Table 5, querying whether these were 2013–14 or 2017–18 prices. Table 5 sets out an extract from the report, ‘The Microsegmentation of the Autism Strategy’, which are in 2013–14 prices. However, paragraph 299 of the Explanatory Memorandum notes the resulting costs were discounted back to the present value (PV) using the discount rate of 3.5%, which is the HM Treasury’s central rate (to which paragraph 245 of the Explanatory Memorandum refers).

Diagnosis focused approach

I would like to refute the view continuously expressed by the Cabinet Secretary that the sole focus of the legislation is to achieve a diagnosis of ASD. As I explained in my evidence to the Health, Social Care and Sport Committee, the claim that the Bill is overly focused on diagnosis is misleading. The Bill is not solely concerned with diagnosis, but instead puts forward an overarching regime that

seeks to address all the needs of a person with ASD, both pre and post diagnosis. It is concerned with the range of services which people with ASD may access, including healthcare, education, employment, housing, Welsh language, and advocacy.

The Cabinet Secretary has asserted his belief that resources would be diverted from support services in order to meet the demands of an increase in demand for diagnosis. I would like to emphasise that is not the intention of this Bill. I have identified that additional resources will be needed to achieve the 3 month timescale, including staffing resources, and I have set this out in the Explanatory Memorandum. Introducing timescales will have the effect of concentrating effort, but if the necessary resources are put in place there should be no detrimental effect on other service areas. Further, I have received considerable evidence that giving children and adults an earlier diagnosis and having trained staff to deliver services appropriate to their needs will result in better outcomes, including longer term savings.

As noted at paragraph 411 of the Explanatory Memorandum, there is a growing body of evidence to suggest that early intervention programmes can improve overall functioning, social communication, language, cognition and adaptive behaviour in children with ASD. Examples of the benefits of timely diagnostic assessment of children and adults are set out at paragraph 422. These note that supported employment can be both effective and (strongly) cost-effective from a societal perspective, and has important economic benefits for people with ASD. The National Institute for Health and Care Excellence (NICE) reports¹:

A systematic review (11 studies, n= 67,251) examined the costs, benefits and the cost-benefit ratio of employing adults with ASD, from a societal perspective and from the perspective of employers. The results indicated that enhancing the opportunities for adults with ASD to join the workforce is beneficial from a societal perspective, not only from an inclusiveness viewpoint, but also from a strict economic standpoint.

¹ 4 year surveillance (2016) Autism in Adults (2012) NICE guideline CG142. National Institute for Health and Care Excellence. Available at <https://www.nice.org.uk/guidance/cg142/evidence/appendix-a-decision-matrix-pdf-2600145326>

In its clinical guidance in respect of children and young people², NICE states ‘there are benefits in establishing the nature of any developmental or behavioural disorder. Many families and carers find the process helpful, and early recognition can avoid delayed diagnosis’. It also states:

No evidence was identified that addressed the cost effectiveness of recognising signs and symptoms of autism.... If it was decided that the child did not have autism but another differential diagnosis, the initial referral could still lead to earlier identification of the child’s other developmental or communication needs, which is likely to be a cost-effective use of resources ...The additional benefit of correctly identifying and referring on children with autism needs to be weighed up against the added cost to the NHS and stress to the family of over-assessing children and young people who do not have the condition. There was no data to help the GDG [the Guideline Development Group] in making its considerations, but the GDG consensus was that the benefits would outweigh the costs.

The Welsh Government has chosen to pursue a specific strategy for ASD, based on diagnosis, and has also indicated that the proposed code seeks to cover much of what the Bill does, so clearly it thinks that such an approach can work symbiotically with the existing legislation. The Refreshed [*Autistic Spectrum Disorder Strategic Action Plan*](#) has assessment and diagnosis as one its three key priority areas. It states:

Timely access to assessment services is vital for families so that each child’s needs are understood and appropriate services are put in place to support them to lead fulfilling lives. An early diagnosis will also enable parents to understand their child’s needs and to seek appropriate support in their caring role. Some adults with autism are not identified or diagnosed during childhood but may be helped by having access to assessment services as adults. (p9)

The lack of information on the services that are currently provided makes it difficult to make precise estimates of the additional costs for support services and the cost and other savings in terms of having an understanding of a person’s needs earlier and the preventative benefits of providing appropriate rather than potentially inappropriate needs to people with ASD and their carers. Paragraph 422

² Autism: recognition, referral and diagnosis of children and young people on the autism spectrum, National Collaborating Centre for Women’s and Children’s Health, Commissioned by the National Institute for Health and Care Excellence, September 2011. Available at <https://www.nice.org.uk/guidance/cg128/evidence/full-guideline-pdf-183228447>

of the Explanatory Memorandum provides further details on benefits of timely diagnosis. My approach was to look at the costs of supporting people with ASD and their carers as a whole in Wales. This was based on the latest in-depth research provided in the Microsegmentation report, which was applied to Wales and the methodology checked with the authors of that report.

Increase in demand

I note that the Welsh Government official also commented to you that the RIA is “silent” on costs beyond eradicating the diagnosis “waiting list”, and on the increased demand on services. He cited Northern Ireland, which had seen an increase in demand and pressure on diagnosis as a result of increasing awareness.

Wales also experienced an increase in demand for diagnosis following the introduction of the Autistic Spectrum Disorder Strategic Action Plan (ASD SAP). In February 2016, the Welsh Government published the outcome of the external evaluation of the ASD SAP, which had been undertaken by the People and Work Unit³. This reported that the original ASD SAP, which had been published by the Welsh Government in April 2008, and the implementation of national and local infrastructure have ‘helped raise the policy profile of ASD, empowered individuals to develop and improve services and provided a focus for developments across Wales’⁴. It noted the outcome:

Increased awareness of ASD has contributed to increased rates of identification. This in turn has contributed to sharply increased rates of diagnosis among school age pupils in Wales, from approximately 0.2 per cent in 2003/2004 to 1 per cent by 2012/13 (Holtom et al., forthcoming).

This increased rate of diagnosis is broadly consistent with the most accurate prevalence estimates available. As noted at paragraph 291 of the Explanatory Memorandum, these are based on the Microsegmentation report’s recommendation that 103.5 per 10,000 population be used. Paragraph 366

³ Outcome evaluation of the Autism Spectrum Disorder Strategic Action Plan, Welsh Government, February 2016. Available at <https://gov.wales/statistics-and-research/outcome-evaluation-autism-spectrum-disorder-strategic-action-plan/?lang=en>

⁴ Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Executive Summary, Welsh Government. Available at <https://gov.wales/docs/caecd/research/2016/160218-evaluation-autistic-spectrum-disorder-strategic-action-plan-summary-en.pdf>

demonstrates that we have assumed diagnoses will be above the prevalence rate to allow for some growth in demand. As highlighted in Dr Dawn Wimpory's evidence to the Health, Social Care and Sport Committee, better training should lead to better referrals and reduced incidence of repeat GP visits for people with undiagnosed ASD.

The significantly lower diagnosis rate prior to the ASD SAP suggests there were high levels of unmet need. It is important that people with ASD are identified and provided with any support they may need, and it is not a sustainable or acceptable position to take the view that persons with ASD should go undiagnosed. To support this, the provisions in the Bill for data collection would facilitate a comparison of diagnostic rates for each local health board in Wales against the expected prevalence.

Workforce capacity

I am aware of the workforce pressures that exist in ASD services, and indeed across wider health and social care services, and I acknowledge that workforce issues need to be addressed in order that ASD services can be improved. The Royal colleges responded to my consultations on the Bill and highlighted the workforce pressures ASD services face. While it would not be appropriate to include detailed workforce provisions in an autism Bill, I have taken account of staffing resources in the cost estimates. Paragraphs 393 and 394 of the Explanatory Memorandum detail how these costs have been estimated.

I accept that increasing workforce capacity will not happen overnight but it is an issue which needs to be addressed if we are serious about improving services for people with ASD. The Explanatory Memorandum does highlight additional funding needed to implement this Bill. The Impact Assessment also suggests that investment will be needed over a number of years to reflect the time needed to identify resources to reduce waiting times and provide training to relevant staffing. The Bill does not seek to duplicate or conflict with organisations current staff and resource planning, such as the current 3 year NHS planning regime. It would be expected that public organisations would include plans to implement this Bill into their current workforce planning.

Welsh Government proposed code of practice

Throughout the Stage 1 process, the Cabinet Secretary has referred to the ASD code of practice which he proposes to issue, as being able to do everything my Bill

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sets out to achieve. Whilst it is difficult to comment on the proposed code without seeing it, it is possible to highlight a number of important differences between the code and the Bill. The code for example, will not:

- Introduce a waiting time target from referral to start of diagnosis in line with the NICE Quality Standard (currently 3 months);
- Require NHS bodies to collect data to enable them to improve the planning and delivery of services.

These are two of the areas of the Bill where I have undertaken the most detailed research, in conjunction with leading academics and health economists to provide cost estimates for the RIA.

The Cabinet Secretary told you that the code had already been budgeted for and that the Welsh Government is investing £13 million to underpin the delivery of the ASD strategy.

It is perhaps worth noting that many of the issues the Welsh Government is planning to address in the code are the same as those in the Bill (e.g. assessment and diagnosis; accessing care and support; staff training; planning, and stakeholder engagement in service planning and delivery).

I note that the Cabinet Secretary has agreed to provide you with approximate costs for the development and implementation of the code. This suggests that the Cabinet Secretary does have access to specific ASD data, rather than general unsegmented neurodevelopmental data. If this is not the case, then one has to ask how the government can properly plan for and cost its ASD related activities, and this further strengthens the need for the collection of valid data, such as that proposed under section 6 of my Bill.

Working with the Welsh Government

I note that the Cabinet Secretary told you that he had offered me the opportunity to be involved in the development of the code, but that I decided to pursue my Bill. I would like to make it absolutely clear that I have sought to work with the Welsh Government from the outset, and indicated early on that I would consider withdrawing my Bill, subject to specified improvements to ASD services being achieved across Wales. Early in the process I proactively provided Milestones to the Welsh Government, setting out where I believed gaps that exist in services and

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support for autistic children and adults in Wales could be filled but, after some delay, received responses which did not provide sufficient detail or assurance that these Milestones would be met. Thereafter, I was given sight of early proposals for a code but I did not believe that these would achieve the objectives I set for my Bill. As I have still not had sight of the content of the code, despite indications that it would be available before introduction of my Bill, it is difficult to judge whether it will meet the aims of my Bill, and it would not have been appropriate to withhold introduction of the Bill on that basis.

Finally may I express my thanks in advance for your consideration of this further evidence, and I hope you will find the information I have provided useful. I am copying this letter to the Chair of the Health, Social Care and Sport Committee.

Yours sincerely,

A handwritten signature in blue ink that reads "Paul Davies". The signature is written in a cursive style with a large initial 'P' and a long, sweeping underline.

Paul Davies AM
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Leader of the Welsh Conservative Assembly Group