Written submission to the Health, Social Care and Sport Committee

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This response draws primarily upon our evaluation of Wales' first ASD Strategic Action Plan (ASD SAP) (WG, 2016) https://gov.wales/docs/caecd/research/2016/160218-evaluation-autistic-spectrum-disorder-strategic-action-plan-en.pdf   and

the ongoing evaluation of the Integrated Autism Service (IAS) and refreshed autism strategy (WG, 2018) https://gov.wales/statistics-and-research/evaluation-integrated-autism-service-autistic-spectrum-disorder-strategic-action-plan/?lang=en

General principles of the Autism Bill

An autism strategy: Evaluations of the original (WG, 2016) and refreshed autism strategies (WG, 2018) demonstrate that many children and adults with autism (and also their families), have unmet needs, so there is a need for action. Without a national strategy, there is a danger that action to meet those needs will be piecemeal, inadequate and inconsistent. The evaluation of the first autism strategy (WG, 2016) identified widespread support for having a national strategy, and also highlighted how having such a strategy had raised the profile of autism. However, it also identified weaknesses in the original strategy (e.g. a lack of clear prioritisation; and weaknesses in the infrastructure for delivery/implementation of the strategy); weakness which the revised strategy set out to address.

Neither evaluation examined the question of whether there needed to be a legal requirement to publish a strategy, in order to "secure a measure of permanence and sustainability in care and support services of people with autism". (p5 of the Explanatory Memorandum).

Assessment and diagnosis: The evaluation of the original autism strategy (WG, 2014) highlighted the importance of getting a diagnosis to adults with autism and to the parents and carers of children with autism. Diagnosis provides insight and understanding of the difficulties people with autism and their families face and,

particularly for children, can improve access to services[1] and provision. The evaluation of the original strategy (WG, 2016) highlighted improvements in assessment and diagnosis for both children and adults in some areas. However, it also identified considerable inconsistency in practice across Wales, with long waiting lists in some areas; an excessive reliance upon individuals with an interest in and commitment to autism (which contributed to the fragility of services); and, in some areas, a lack of clarity about referral pathways.

The interim evaluation of the Integrated Autism Service (IAS) and refreshed autism strategy (WG, 2018) confirms the need for action to strengthen assessment and diagnosis services as well as enhancing the sustainability of services; minimising inconsistencies in provision across Wales; and establishing clear referral pathways.

Although it is still too early to measure the effectiveness and impact of the IAS, the interim evaluation (ibid.) identifies encouraging evidence that the establishment of an IAS in each region will strengthen services; improve assessment and diagnostic practice for adults[2] (in line with NICE guidelines); reduce inconsistences across Wales and establish clear referral pathways. The evidence for improvement is strongest for adults diagnosed and referred by the IAS, and weaker for those assessed and diagnosed by learning disability or mental health services (the intention is that the IAS will support improvements in these services, but it is too early to assess likely impact). The interim evaluation (ibid.) also identifies that the IAS has increased the profile of assessment and diagnosis within Local Health Boards (and Regional Partnership Boards) and markedly improved accountability for provision for those referred and diagnosed by the IAS. However, the evaluation (ibid) also identifies fears that demand for assessment and diagnosis could exceed the capacity of the new IAS and/or side-line or undermine the other important aspects of the IAS's work, such as post-diagnostic support.

Data collection: The evaluation of the original autism strategy (WG, 2016) evaluated work by the local ASD infrastructure to identify the number of people with

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[1] In contrast, the lack of services for adults, meant the impact of diagnosis upon adults' access to services was much more limited.
[2] The interim report did not consider children's neurodevelopmental services (this will be considered as part of the final report, due in January 2019).

ASD in their area and their needs. The evaluation identified the need to improve understanding of the needs of people with autism. However, it also identified that:

- efforts to create databases of individuals with autism proved extremely difficult, due to the fragmentation of data across multiple databases (e.g. health, education and social services);
- the databases that were created were often incomplete and could rapidly become out of date, as people's needs changed over time; and
- the databases that were created were off limited value to commissioners of services (and little used).

The evaluation (ibid.) considered how data on the numbers of people with autism in a given area could used in the commissioning cycle. It identified that:

- for targeted services, estimates of the numbers of people with autism in a given area, based on a 1% prevalence rate, coupled with existing evidence on the needs of people with autism, would normally be sufficient to inform service planning. For example, detailed data on the numbers of people with autism in a given area would not be required to identify the need to provide information and training and support for people with autism in that area.
- for specialist services, there was a need for rich data on individual people's needs and aspirations (data rarely captured in the databases produced) to inform the commissioning of often bespoke services. Structures such as complex needs panels were felt to be proved reasonably effective in collecting this data (ibid), although other research (see e.g. Holtom and Sophocleous, 2016)[3] suggests that there may be a case for improving data collection and analysis to inform commissioning of these specialist services; and
- for universal, targeted and specialist services, there was a strong case for collecting more qualitative data on the experiences of different groups of people with autism, in order to inform the 'review' phase of commissioning (and service development) (WG, 2016). For example, if information and training and support is provided, it is important to understand how effective it is.

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[3] http://www.wwcp.org.uk/wp-content/uploads/2017/02/complexneedsfinalmps.pdf

As a consequence, the evaluation (ibid). concluded that the only real value in collecting data on the total numbers of people diagnosed with autism in a particular area, was as a measure of the extent to which autism was being recognised and diagnosed in that particular area. It is important to note that this analysis relates to the collection of quantitative data to create databases, and that for example, there is a real value in collecting qualitative and quantitative data on people's expectations and preferences, in order to help develop and design more person centred services.

Holistic services: The evaluation of the original autism strategy (WG, 2016) identified gaps in services for people with autism, particularly for adults who were not eligible for support from mental health or learning disability teams.[4] This lack of services contributed to poor outcomes (e.g. in relation to employment) and poor experiences for adults with autism. In some cases, following transitions from education, the loss of the structure education provided, difficulties finding employment and the absence of support services, meant that their level of disability increased, when, for example, social skills learnt in education were lost as result of withdrawal and social isolation.

The interim evaluation of the IAS (WG, 2018) identifies consistent support from stakeholders for the IAS model as part of the means for filling this gap in services. The IAS is not a panacea though, and cannot and should not seek to address all gaps or weakness in services.

Information: The evaluation of the original autism strategy (WG, 2016) identified how the local 'ASD Infrastructure' (most notably ASD leads and groups) had improved mapping of services and dissemination of this information. However, this remained patchy across Wales; it proved difficult to keep directories up to date; and the evaluation identified that parents and carers consistently reported difficulties identifying support services. To a large degree, this was caused by the absence of services, rather than weakness in service mapping and/or dissemination of information about services. However, there was also widespread frustration with the systems and processes for accessing care and support for children and adults with

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[4] Autism is neither a learning disability noir mental health disorder, and the evaluation also identified weakness in mental health and to a lesser degree, learning disability services. Nevertheless, those able to access support from these services, were generally able to access more support that those who were not eligible or did not need support from mental health or learning disability services.

autism, which were felt to be complex and difficult to understand.[5] Feedback from parents and carers interviewed as part of the ongoing evaluation of the refreshed strategy paints a similar picture.

Parents and carers frequently call for very responsive information and support, most commonly someone with whom to talk through their immediate problems and concerns. Because autism is a lifelong condition and needs can change, as for example, people's circumstances change. Therefore, whilst training and time limited support can help people learn news skills and knowledge, and was valued, people also often want access to support when they needed it (e.g. in a crisis or simply when they encounter a new problem). In the absence of responsive support services, many people rely upon more informal networks (e.g. talking to support groups and/or posting questions on forums) to access information and advice. These informal networks are very much valued, but there are risks that the information and advice given may not be evidence based.

Training: The evaluation of the original autism strategy (WG, 2016) identified the need for training to improve the responsiveness and sensitivity of services and enhance the experiences/wellbeing of people with autism and their parents/carers. It identified the provision of training as a key achievement of the original strategy, but also highlighted the scale of the challenge (e.g. in terms of the numbers of people to be trained). Other research, such as an Assessment of SEN Workforce requirements (WG, 2015)[6], suggests a responsive training and professional development/learning model in which, for example, additional learning is undertaken and/or advice and support is provided when needed, may be required to complement initial training.

The interim evaluation of the IAS (WG, 2018) highlights the important role the IAS is expected to play in providing training and support for services.

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[5] The evaluation identified that "the reasons why people cannot access services and experience such high levels of stress are complex. In part they reflect informational barriers, where carers do not know what services are available, or do not realise they would be entitled to support. However, they also reflect institutional barriers, including the absence of appropriate services, thresholds for eligibility for interventions (rationing access to services), cultural divides between professionals and users and carers, which can lead to misunderstanding and even conflict and a lack of awareness or understanding of ASD" (p 82, WG, 2016).
[6] http://dera.ioe.ac.uk/22888/1/150330-sen-en.pdf

Potential barriers

The evaluation of the original ASD SAP highlighted the failure to allocate resources to achieve many of its objectives as a significant weakness. This appears to apply to the Autism Wales Bill too.

Unintended consequences

Because assessment and diagnosis is perhaps the easiest area to legislate and set clear targets for, there is a danger that the Bill means this area is privileged over other important areas. Although (as outlined above) assessment and diagnosis is important, the evaluation of the original autism strategy (WG, 2016) identified the often limited value of assessment and diagnosis without post-diagnostic support. The evaluation of the IAS (WG, 2018) identified the risk that the IAS could struggle to meet demand for assessment and diagnosis and increasing pressure and accountability around assessment and diagnosis, could means resources intended for post-diagnostic support, are reallocated to assessment and diagnosis.

More broadly, given austerity and increasing demand for services as result of demographic changes and rising expectations (see e.g. Williams, 2014) [7] simply creating new duties in relation to autism without increasing resources, risks stripping or starving other important areas of resources.

Financial implications of the Bill

An autism strategy: In considering the cost of a strategy, it will be important to also consider the costs of evaluating the strategy.

Duty to act: the costs of effective action/support in areas like employment, where the evaluation of the original autism strategy (WG, 2018) suggests there are large gaps in support, are likely to be considerable. The costs of existing projects like Engage to Change may provide some indication of likely costs.

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[7] https://gov.wales/topics/improvingservices/public-service-governance-and-delivery/report/?lang=en

Training: The evaluation of the original ASD SAP highlights the scale of the challenge in relation to training, and the costs here could be considerable, depending on how broadly the definition of "key staff" is drawn.

Data collection: As noted above, the evaluation of the original autism strategy (WG, 2018) highlighted the difficulties of collecting data on the numbers of people with autism, given the fragmentation of this data across different IT systems (e.g. health, education and social services). This suggests that the costs of setting up and populating a database by drawing upon data from different systems/databases, may not be as "minimal" as the Explanatory Memorandum assumes.