

## Introduction

1. The Welsh Local Government Association (WLGA) is a membership organisation that represents all 22 local authorities in Wales, the 3 fire and rescue authorities and the 3 national park authorities as associate members.
2. The WLGA represents the interests of local government and promotes local democracy in Wales. Its primary purposes are to promote better local government, to promote its reputation and to support authorities in the development of policies and priorities which will improve public service and democracy.
3. The WLGA has hosted the National Autism Spectrum Disorders (ASD) Development Team for over 7 years. The team have been leading developments in relation to autism and are an integral part of the Welsh Government's refreshed Autistic Spectrum Disorder Strategic Action Plan. The National ASD Development Team are currently supporting and coordinating the development of an Integrated Autism Service for Wales.
4. It is important to acknowledge the progress that has been made since the original ASD action plan in 2008. One of the key achievements has been the increased profile and awareness of autism. There is a wide range of information and resources available to help autistic people and their families and carers, as well as resources for professionals. However, we are aware that more can always be done and that some of the improvements and actions will take time to deliver. We all want to see a real difference in the services, care and support available to autistic people and so it is appropriate that we take the time to consider the proposals for the development of an Autism Bill in Wales and the issues outlined in the consultation paper.

## Response

5. The consultation paper recognises that much work has been undertaken in recent years to improve the services and support for people with autism

spectrum conditions, their families and carers. The Welsh Government's Autism Spectrum Disorder Strategic Action Plan, published in 2008, established an infrastructure to address autism in each local authority area, with local co-ordinators and development of local strategies, and a Wales national co-ordinator. The plan expanded research capacity, raised awareness of autism spectrum conditions and made available a range of information and resources for both autistic people, their families and professionals.

6. The Strategic Action Plan also recognised the need for better diagnostic services for children and adults with autism spectrum conditions. Awareness raising led to an increase in demand for diagnosis.
7. A Refreshed Strategic Action Plan 2016–20 is introducing further reforms, including improvements to diagnostic services (which should lead to shorter waiting times), the development of a National Integrated Autism Service, and measures to improve education and employment opportunities for people with autism spectrum conditions.
8. As part of the refresh of the ASD Strategic Action Plan for Wales, scoping work was undertaken by the WLGA National ASD Development Team and included both consultation on the needs of over 1,000 autistic individuals in Wales and a review of existing services, both in and outside of Wales.
9. From the consultation work, the most frequently reported areas of unmet need were:
  - support for lower level emotional / behavioural difficulties
  - support to access social and leisure opportunities
  - support for ASD specific issues / life skills.
10. It was also identified that in order to meet the needs of those affected by autism, a service would need to be:
  - age wide (to avoid service transition points)
  - responsive to need
  - integrated between health and social care
  - linked with education and employment services
  - flexible
  - easily accessible

11. A summary of the consultation activity can be found [here](#):
12. The evidence and learning from the exercise was incorporated into a proposal for an Integrated Autism Service (IAS). In March 2017 this proposal was accepted by Welsh Government with the Minister for Social Services and Public Health announcing additional investment in the development of an Integrated Autism Service for Wales. The National ASD Development Team, based in the WLGA are currently supporting and coordinating the development of the service – an ambitious plan that will provide support for autistic individuals across the age range, and their families/carers.
13. The National Integrated Autism service aims to address the gaps in service provision that autistic people are experiencing including:
  - diagnostic assessment for adults
  - support and advice for parents and carers
  - Support and advice for autistic adults
14. And aims to do this by:
  - Linking existing services for autistic people
  - Providing a direct support service
  - Bridging the gap between child and adult services
  - Develop existing services in terms of capacity and skills
15. Evidence tells us that a single, supported approach will help deliver the outcomes individuals need. This needs commitment from all to drive the work forward, and varying approaches and distractions, such as the development of new autism specific legislation, might be detrimental to the existing work being undertaken.
16. There is a danger of seeing legislation as the “answer” to tackling autism across Wales. 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 have demonstrable effectiveness in benefiting autistic people and their communities) found that “nearly a decade on [from the Autism Act] the needs of autistic people are still unmet”, Their report “The Autism Dividend: Reaping the Rewards of Better Investment” sets out a range of challenges which must be placed at the heart of this debate. These include: –

- The need for public bodies and service providers to participate in good quality effectiveness research into services and programmes currently commissioned for autistic adults and/or children and their families.
- The need for commissioners to consider to what extent the claims of service providers are borne out by objective research evidence which considers the benefits or otherwise that services actually have on the lives of autistic people.
- Endorsement of the importance of person-centred models of support in work with autistic people.
- Recognising the additional barriers faced by autistic people in accessing appropriate care and support compared to the general population. The report points out “autistic people generally have more health problems than other people, and a higher risk of premature death”.
- The cost-effectiveness of early and preventive support.
- The need to overcome ‘silo budgeting’ which fails to invest in effective interventions in one sector (e.g. social care) which reduce costs in another sector (e.g. health). The report does not propose systemic changes or service integration, but rather “proportionate coordination – creating the means by which different organisations and the professionals within them can work together to find pragmatic solutions for individual autistic people”.
- The need to recognise the impact of environmental stressors, uncertainty and anxiety on behaviour which causes concern and to invest in community support if any long-term progress is to result from the Transforming Care agenda to reduce the number of people in institutional settings.
- The importance of good transitions, including the need to prevent foreseeable crises (such as the eventual death of a parent primary carer) “by ensuring that a full assessment of needs is in place”. The report points out that, despite the Care Act in England, “there is a widespread lack of implementation” of social care assessments which actually recognise and set out the full needs of an adult, whilst most of those needs are still being met by an informal carer.

17. The progress report<sup>1</sup> on England's updated strategy for adults with autism which was developed to deliver the aims of the Autism Act shows limited progress as a result of the Act, and we understand central coordination has now been decreased there. Informal discussions with practitioners in England have led us to be concerned about the increased number of complaints and FOI requests that have been submitted since the Act, and the amount of staff time these are now taking up.
18. In Wales the development of a National Integrated Autism Service is in its infancy, and whilst we are yet to evaluate the benefits of this, the ASD National Development Team have procured software which will act as a National database for individuals with autism. The data gathered will be key to ensuring any further approaches to autism are based on evidence of need and not opinion.
19. There is a danger that the development of an Autism Bill at this stage could cut across the work being undertaken, and in turn cause difficulty in the delivery of a consistent approach. We would ask the National Assembly to reflect on this in their considerations of a possible Bill. Indeed, barriers to the sharing and support of the work being undertaken are already being experienced due to this issue. We believe that the current approach will make the difference needed and we would urge a single approach to this.
20. It should also be noted that many of the suggested issues to be addressed by the Bill are already being addressed through the ongoing work within the ASD Strategic Action Plan and Together for Young People Framework, alongside the Social Services and Wellbeing (Wales) Act and proposed ALN Bill. For example, a National Autism Training Framework for Wales has already been developed.
21. The Social Services and Well-being (Wales) Act provides a new legislative framework for care and support in Wales. It is aimed at improving the wellbeing of people who need care and support, and carers who need support, and for transforming the way in which services are commissioned and delivered. The Act is all age, as opposed to England's Autism Act which covers adults only, and whilst it covers all care and support needs it does

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<sup>1</sup> Progress Report on Think Autism: the updated strategy for adults with autism England, HM Government (2016)

place a special focus on autism. We need to recognise that it is still early days in the implementation of the Social Services and Well-being (Wales) Act and given the scale, scope and ambition of the Act it will take time for all of the aspects of the Act to become fully embedded within practice, however many of the ambitions that the proposed Autism Bill aims to achieve are already achievable under the Act.

22. In particular, the Social Services and Well-being (Wales) Act already places a duty on both health boards and social services to assess the needs for care and support services in their areas and identify the range and level of services required to meet them. One of the core themes of these population assessments is learning disability/autism. All regions are currently working towards the development of their population area plans, following the publication of their regional population assessments. These area plans will set out the range and level of services proposed to be provided or arranged in response to the care and support needs, including the support needs of carers, identified in the population assessment reports and they must include services for people with autism.
23. In addition, the Social Services and Well-being (Wales) Act also places a statutory duty on local authorities to establish information, advice and assistance services, including to autistic people, their families and carers.

## Conclusion

24. At this stage we have reservations about the approach of legislating for a particular condition, as we believe that legislation such as the Social Services and Well-being (Wales) Act 2014 and the ALN Bill currently going through the Assembly should, if they are working correctly, deliver for all our citizens on the basis of need. Consideration also needs to be given to the implications of setting such a precedent going forward, as services for autistic people is not the only area where there is a need for service improvement. It is essential that we fully consider any unintended consequences of legislating on a particular condition, and that we explore any risk that such legislation may impact on our ability to respond to others on the basis of need.