

The Royal College of Nursing Wales is grateful for the opportunity to respond to the consultation on the development of an Autism (Wales) Bill. We would like to raise a number of points in relation to the proposals contained in the consultation:

- I. The RCN in Wales commends the proposals outlined in the consultation to raise the profile of the needs of children, young people and adults with autism spectrum conditions, and the aim to meet their needs appropriately and effectively. It is widely accepted that that existing services are not currently meeting the needs of people who autism spectrum conditions as comprehensively as they should, and concerted efforts must be made to improve this. Everyone with autism, at whatever age and from whatever background, should be enabled to meet their full potential.
- II. In that context, and should this proposal proceed, there may be some areas in which the proposed aims of the legislation do not go far enough. For instance, “ensuring that local authorities and health boards publish information on the services they provide for people with autism in their areas”, is an important but partial aspect of ensuring that children young people and adults with autism spectrum disorder receive the right service (including assessment) at the right time in the right place. Consideration could be given to the development of a suite of meaningful outcome measures and assurance mechanisms that capture levels of education, training and learning as well as a range of other important quality measures.
- III. Similarly, there is a focus throughout the document on duties to be placed on health boards and local authorities. However, there are many other key stakeholders at play when it comes to the experiences of people with autism within wider society, such as education, housing, transport and leisure. In the same way that the Welsh Government’s draft dementia strategy ‘Together for a Dementia Friendly Wales’ acknowledges that the whole of society needs to be become more aware, more understanding and more accommodating of the needs and experiences of people living with dementia, the same approach should be taken to those living with autism.

IV. The Royal College of Nursing welcomes that if the proposal progresses, the proposed Bill would ensure that those working with people with autism receive autism training. However, it may be prudent to consider education and learning as well as training. It is also not clear who would be included in the category of “key staff”. The nature and prevalence of autism as a condition means that workers in all public services and many other services, business and settings will have contact with people with ASD, and so more clarity is needed on how the legislation would ensure that there was a true consistency of approach to training and standards across sectors and regions. Again, awareness raising and understanding of autism needs to be promoted across society, not just within specific professions and work places, if genuine and lasting improvements are to be achieved.

V. In considering whether to take the contents of the proposal further, it is important to understand exactly how it will fit in with existing legislation. Whilst it may be that specific legislation for autism would complement existing legislation, it is important that it doesn’t duplicate any of the work already being undertaken. For example, in principle, the Additional Learning Needs (ALN) Bill should cover the needs of those with ASD up to age of 25. Similarly, duties are already being imposed on local authorities and health boards to meet the needs of their local populations through the Social Services & Well-being Act and the Well-being of Future Generations Act. More detail is therefore needed on how the proposed legislation would interact with these pieces of legislation.

VI. The need for robust evidence is key to the development of any primary or secondary legislation. As such, a full and detailed assessment of the effectiveness of the existing Autism Spectrum Disorder Strategic Action Plan (both since its introduction in 2008 and since being refreshed in 2016). Any successes or failings of the current strategy should be fully understood so that they can be addressed and/or replicated as appropriate. Any assessment of effectiveness must include gathering the views and experiences of those for which the strategy has been designed i.e. people with ASD of all ages, their families and carers.

VII. Also essential is for the different terms being used in the proposed legislation to be clearly defined from the outset. This is particularly important when gaining access to support and services can be challenging,

especially those where criteria for access are set e.g. accessing learning disability or mental health services. Having an existing mental health or learning disability diagnosis should not be a barrier in any way to having an assessment or diagnosis of autism. There also needs to be absolute clarity about how people who have autism alongside other co-existing conditions (such as learning disabilities) will be positioned in terms the proposed legislation.

VIII. It should be noted that, whilst any proposals to improve services for those with ASD would of course be welcomed, we understand from some members that concerns have been expressed that, in the current context of diminishing budgets and economic constraint, singling out one aspect of service delivery in this way may mean that individuals with other disabilities are disadvantaged. Absolute assurance that this would not be the case would need to be given, in order for the legislation to have the full support of key stakeholders.

IX. Defining the terms being used in the proposed legislation from the start is also key, as the terminology used will to a certain extent define the scope of the legislation. It is important to understand that autism is a spectrum disorder, and that there is therefore significant variation in the acuteness and presentation of the condition in different individuals; although there are clear sets of criteria involved in diagnosis, the way in which ASD presents itself in different people will vary hugely. Any strategy in place has to appreciate and reflect this, and cannot expect to provide a one-size-fits-all approach. Any draft legislation and accompanying legislation must use the correct terminology and take care not to further stigmatise or 'label' individuals with ASD. For instance, the documentation out for consultation refers at times to "autistic people" whereas possibly "people with autism spectrum conditions" may be preferable.

X. Lastly, whilst the issue of costs is covered in the consultation document with some key areas of potential cost identified, no reference is made to the costs of new services or support which may be required to meet any increase in demand. This is significant since, as we understand from members, many of the existing problems within the system stem from a lack of services. As such it is likely that further service development will be needed if existing and future needs are to be fully met. Without

acknowledgement or assessment of these potential costs, there is a possible danger that expectations are raised and then not met, and this should be avoided.

XI. Whether or not the proposals proceed further, the Royal College of Nursing hopes that all opportunities, such as the ongoing Parliamentary Review of Health & Social Care, can be taken to promote changes to the face of service provision in Wales, so that current issues can be resolved and services improved across the country.