

Cynulliad Cenedlaethol Cymru
Bil Awtistiaeth (Cymru) drafft
Llythyr Ymgynghori DAB24
Ymateb gan Pobl yn Gyntaf Cymru

National Assembly for Wales
Draft Autism (Wales) Bill
Consultation Letter DAB24
Evidence from All Wales People First

Please refer to questions in the [Consultation Letter](#).

Question	Answer
01	<p>In principle, yes. Having a definition in law is important in terms of providing clarity and empowering people to be able to hold service providers to account.</p> <p>However, using the term 'autism spectrum disorder' is not reflective of the Social Model of disability. 'autism spectrum condition' is a better fit.</p> <p>As the National Director of All Wales People First, my extensive interactions with the organisation's members qualifies me to confirm that the general consensus among young people and adults with autism spectrum conditions is that 'autism spectrum condition' is a preferred term when referring to autism.</p>
02	<p>In principle, yes. Mirroring the definition will allow greater flexibility for legislation to adapt more smoothly to developments in the medical arena.</p> <p>Providing power to Welsh Ministers to include other neurodevelopment disorders will also provide a similar flexibility for the Act to retain its relevancy in line with research and developments.</p>
03	<p>Yes, it seems logical that Local Authorities and NHS bodies should implement the strategy.</p> <p>Since the Act is heavily focussed on services, this should provide an accessible structure for users of services to hold providers to account.</p> <p>It is also important that government funded agencies such as the CSSIW and HIW play an important role in ensuring that services are fulfilling their duties in the Act. It is imperative therefore that inspectors have a good understanding of autism spectrum conditions and the unique difficulties in communication and understanding if they are to ensure that autism services are working in a truly person-centred way.</p>
04	<p>In light of the likely challenges that implementing the strategy will bring, it is important that Welsh Government retains a strong</p>

	<p>jurisdiction over implementation.</p> <p>All Wales People First's members' pan Wales perspective of the support they currently have access to and/or receive, is suggestive of a Postcode Lottery.</p> <p>It is thus clear that any changes to the status quo will require the extra powers of Welsh Government to be enshrined in the Act. This should provide the required teeth to the proposed legislation, so that the strategy can deliver meaningful outcomes to people with autism spectrum conditions, rather than statistical hoops for implementation bodies to jump through.</p>
05	6 Months seems reasonable in terms of allowing time to produce a quality piece of work, which will more likely produce real outcomes for people with autism spectrum conditions.
06	3 months seems reasonable so that any issues or challenges presented by the strategy can be addressed before the guidance is issued.
07	3 Months from the date of being passed seems reasonable.
08	Yes, this provides consistency, and transparency, both of which are conducive to managing people's expectations, health and wellbeing.
09	Yes, however it should be ensured that 'post-diagnostic meetings' do not provide a caveat for delaying assessments for care and support needs.
10	Yes
11	<p>Whilst it is important to include a list of professionals, the value of people with autism spectrum conditions, their family members, key workers, friends and advocates should be enshrined in the spirit of this proposed legislation.</p> <p>This is not only reflective of the Social Services and Wellbeing (Wales) Act, it places a value on the input of the person being assessed, and the input of people who have a lived experience of familiarity with the person being assessed.</p> <p>Ultimately it is crucial that the person being assessed is empowered to be part of the diagnostic process where they have some capacity to do so.</p>

	<p>Our members with learning disabilities and/or autism spectrum conditions are capable self-advocates and are clear about having a voice and control about decisions and issues which affect them.</p>
<p>12</p>	<p>It is important that individuals with autism spectrum conditions are not denied access to other services on account of them receiving a diagnosis, or an account of being 'signed up' with another service. For example, some support services for mental health may preclude people with autism spectrum conditions if they are already receiving an autism related support service.</p> <p>Issues for consideration with a wider scope are as follows:</p> <p>Cuts to services -</p> <p>In my experience of liaising with our members, cuts to services are currently presenting enormous barriers to choice and independence, and to people with autism spectrum conditions being able to live meaningful lives.</p> <p>For example -</p> <p>Public transport barriers:</p> <p>Due to inaccessible information such as timetables and announcements, unreliable services, inaccessible buses and trains, and a lack of transport services in some areas.</p> <p>Feeling safe:</p> <p>Cuts to street lighting and Policing services in some areas mean that people with autism spectrum conditions do not always feel safe going out on their own.</p> <p>Although these are issues which affect disabled people more widely, they do present particular barriers to people with autism spectrum conditions who experience sensory issues and anxiety about going out.</p> <p>It is also important that those with a history of challenging behaviour are not denied services. People of all needs should be supported in the bill/ act.</p>
<p>13</p>	<p>Yes, where the data is collected in the interests of safeguarding and identifying the best support.</p> <p>Collecting and holding the right data can be helpful in providing consistency of transition between children and adult services.</p>

14	<p>A person's age, if they are male or female, the age they were when they got diagnosed, how long it took them to get a diagnosis, how they were diagnosed, the job titles of the people who diagnosed them, if other tests were done.</p> <p>Where diagnosis is made early, this sort of data could provide join up between Part 6 of the Social Services and Wellbeing (Wales) Act, and transition to adult services.</p> <p>It is also important that it is recorded if a person has a history of mental health difficulties. This could be essential for safeguarding and smooth transition within services. Especially where communication is a significant barrier.</p>
15	<p>On the face of the bill so that consistency is ensured.</p> <p>Guidance can provide caveats for omission, and regional inconsistencies.</p>
16	<p>a) Yes</p> <p>b) Yes</p>
17	<p>Continually, and with the help of other organisations, which are funded by Welsh Government.</p> <p>For example, third sector, charitable organisations and the CSIW and HIW.</p>
18A	No
18B	<p>It is important that the greater emphasis (where possible) is placed on community participation and supporting people with autism to have meaningful lives. This is essential for mental health and well-being.</p> <p>Social interaction and visibility is also important to help inclusion and integration into society and for people with autism to play an active part in challenging negative perceptions/ stereotypes about them. It is important that we do not view services as purely medically based interventions. Services must be gift centred not deficit centred and need to be measured on meaningful outcomes</p>
18C	No
18D	Through looking more widely at, and investing in the merits of self-advocacy as a key preventative measure to reducing medically based

	<p>service interventions, the potential benefits of an Autism (Wales) Act to All Wales People First's members could be significant.</p> <p>These sorts of changes bolstered by an Autism (Wales) Act, could be fundamental to driving the changes which our members tell us are needed to empower them to play active roles as citizens in Welsh society, to play an active part in designing their own services, and to fulfilling their own well-being outcomes.</p> <p>If the scope of the Act can provide more than medically based service interventions, All Wales People First recognises its potential to provide a fundamental step in developing self-advocacy in Wales.</p>
19	<p>Whilst services are important in the interests of supporting condition specific needs, my own personal lived experience of receiving services as a man with an autism spectrum condition demonstrates how services can also present barriers to achieving choice, independence and to living a meaningful life.</p> <p>Where service providers by default benefit financially through meeting targets and providing their service, there will always be a danger that their financial interest may outweigh what is actually important to individuals. This is perhaps an issue to be addressed through the commissioning of services, and the relationship between Local Authorities/ NHS Bodies, and the contractors they appoint to deliver support services.</p> <p>My personal lived experience is well documented and relevant for the purposes of highlighting learning points for moving forward with delivering real life-choices which people with autism spectrum conditions can be empowered to make for themselves if they wish.</p> <p>At the age of twenty in 1996 I was placed in a residential care facility. I was diagnosed by professionals as having complex needs, and the focus of the system at the time was to provide services to manage my behaviour. I was not empowered to grow life skills or to make my own choices.</p> <p>Whilst services are certainly crucial to varying extents in order that people with autism spectrum conditions can live meaningful lives, my experience of support in to early adulthood is that I felt institutionalized, and a victim of the profit and loss ledger of the service provider.</p> <p>Having battled with the support of others to escape an institutionalised setting, I was able to grow my confidence, and in turn to develop my life skills, such that I now live independently, have an honours degree, a real paid job, and a wide social circle - people who are not paid to interact with me. I am living proof that there is</p>

	<p>more to the lives of people with autism spectrum conditions than services alone.</p> <p>Whilst the right services, guided by individuals themselves are crucial to empowering people with autism spectrum conditions, developing skills and confidence through self-advocacy is not only a preventative measure to reducing high support costs, it can promote opportunities for building meaningful friendships, reduces loneliness and isolation, and is conducive to good mental health and wellbeing.</p> <p>It is important that legislation and the strategies and guidance which follow are conducive to facilitating real choices for people with autism spectrum conditions; choices around education opportunities, real opportunities to find meaningful jobs, and access to appropriate housing. Our members tell us that these are integral components to tackling social isolation. They provide the essential blocks to building social circles which promote their health and sense of wellbeing.</p>
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All Wales People First is an organisation for and led by men and women with a learning disability and/or autism spectrum conditions. It is unique in Wales in that it is the only national member-led organisation that represents the voice of men and women with a learning disability and/or autism spectrum conditions.