

Cynulliad Cenedlaethol Cymru Bil Awtistiaeth (Cymru) drafft Arolwg Ar-lein DAB120 Ymateb gan Cyfrannog ar-lein 120	National Assembly for Wales Draft Autism (Wales) Bill Online Survey DAB120 Evidence from Online Participant 120
---	---

Please refer to questions in the [Online Survey](#).

Question	Answer
01	<p>Yes</p> <p>However, it would be a bold statement to those living with autism if you adopted the phrase Autistic Spectrum Condition rather than Disorder. Many people living with autism do not view themselves as having a disorder. It is a difference rather than a disability and should be seen as such. The disabling factors often come more from lack of support, lack of awareness, lack of understanding and lack of acceptance which lead to additional disabling conditions such as anxiety, depression, OCD's. There needs to be mention of the co-occurring conditions as well. There are many including epilepsy, ADHD, dyslexia, hyperlexia, dyscalculia, dyspraxia, and sensory issues. These need to be acknowledged and defined as well.</p>
02	<p>Yes</p> <p>See my previous response</p>
03	<p>Not sure</p> <p>I feel that the support needs to be driven locally but I wonder whether Local Authorities and the NHS are the right organisations to have overall responsibility. I wonder whether an overarching team should hold overall responsibility for ensuring that Local Authorities and the NHS follow the strategy and guidance that will be stipulated within the ACT and accompanying Code.</p>
04	<p>Yes</p> <p>Or, as said previously, a body that has the power to challenge. Such as an Autism Commissioner as with other Acts.</p>
05	<p>Yes. The strategy needs to include the voices of those living with autism, parents, carers and professionals to ensure it adequately meets the needs of the people it will be representing.</p>
06	<p>Yes. Again, this needs to include consultation with people who will be most affected by this Bill.</p>
07	<p>I feel this would be a fantastic timescale for the people who it</p>

	will support as many have been left without adequate support with little right to challenge. However, I wonder whether Local Authorities and NHS will need time to prepare.
08	This should be a target rather than a rule but with limits on what would be acceptable outside of this target. 2 months would be fantastic but currently the waiting lists are often vast. In my experience, people are willing to wait if they know the wait is not too long and that they will receive the answers they need, and the support they need to move forward.
09	<p>Yes</p> <p>Services must not stop providing support at the point of diagnosis. There must be a next steps stage built into the diagnosis in that people are automatically referred to services that offer the support the person needs to manage their condition effectively. Single person assessments must stop and there must be a joint assessment process from services including SALT, OT, CAMHS, Paediatricians (if appropriate) and anyone else deemed necessary to provide an holistic assessment so that the diagnosis is not just about providing a label but actually a tool that identifies strengths and challenges and pathways to support these strengths and challenges. A book or a series of leaflets for what support is available, is not good enough. It has to include actual referrals to the appropriate services and a continuation of care from the bodies conducting the diagnosis not a closed door with a vague offer of support at some point in the future which is what so often accompanies a diagnosis.</p>
10	<p>Yes</p> <p>The examples above are the right types of people but the number of people will depend on the person. Some may not require all of these professionals but the team should be flexible to fit the needs of the person but also to be called in at a later date if necessary.</p> <p>Assessments MUST NOT be completed by a single practitioner as is often the case. It HAS to be a team assessment. The diagnosis should end with an assessment of the strengths and challenges and a pathway for support (such as automatic referrals to the appropriate services (even if this is at a post diagnosis meeting)). This would mean that everyone going through a diagnostic assessment receives support regardless of whether they meet the criteria for a diagnostic label.</p>
11	I think it will depend on the person. It could include educational professionals, professionals who can assess the person's level of independent living skills. It should be free to call in additional professionals as required

12	<p>The person's levels of communication. Their understanding of when they need to ask for help. Some have an assumption that those around them know what they are thinking (theory of mind issues) and so do not understand that they need to ask or tell. In my experience communication needs are more important an assessment than IQ which is often misrepresentative because of the person's communication needs. Non-verbal does not mean that they do not understand but is often viewed as meaning the person has low IQ.</p>
13	Yes
14	Any information which is pertinent to ensuring that there is an understanding of what kind of services are needed in any given area.
15	<p>It should be written on the Bill.</p> <p>But the guidance should stipulate that additional information should also be recorded when and where necessary to evidence the type of support that is required in an area. This helps to ensure that funding is allocated accordingly and there is less waste.</p>
16	<p>Yes</p> <p>But only where anonymity and confidentiality is assured</p>
17	<p>It should happen all the time.</p> <p>It is not enough to provide awareness, alongside this needs to be acceptance. Awareness only goes so far. There needs to be an acceptance of autism across all services which accept the challenges that can be faced by those living with autism but also acknowledges that there can be huge strengths as well. It would be good to build on the employability of those living with autism, and ensuring that the educational needs are managed well to allow everyone who lives with autism to reach their "FULL" potential. This includes early identification, early diagnosis, appropriate support in schools including additional communicative resources where appropriate, assessment of skills as well as needs, and campaigning to help employers recognise the advantages of employing those with autism</p>
18	<p>It will be good for everyone. As said, if assessment pathways are standardised and made to fit the multi-disciplinary assessment model which is stipulated in the NiCE guidance, and assessments are based on strengths and Challenges then everyone entering the system benefits from an automatic referral system for additional support, be that therapeutic support, medical support, social support or family support. Ensuring that employers understand the benefits of employing</p>

	<p>people with autism, builds our economy by allowing more people to be in work.</p> <p>Helping people as early as possible ensures that needs are met earlier and therefore reduces the risks of people becoming involved in the criminal justice system.</p> <p>It will provide a great deal of help to those living with autism including those with a diagnosis, those without, families, carers, professionals etc. but more than this it shows the autistic community in Wales that the Welsh Government cares enough to enshrine their rights in law.</p>
19	<p>My main points have been covered. It is vital that you communicate with those living with autism when writing the strategy and guidance that will run alongside this Bill. This is the only way that the Act will work to meet the needs of those living with</p>