Cynulliad Cenedlaethol Cymru Bil Awtistiaeth (Cymru) drafft Arolwg Ar-lein DAB81 Ymateb gan Cyfrannog ar-lein 81	National Assembly for Wales Draft Autism (Wales) Bill Online Survey DAB81 Evidence from Online Participant 81

Please refer to questions in the Online Survey.

Question	Answer
01	Yes I agree that the bill should define autism as whatever the WHO says is means.
02	No It seems that existing legislation should ensure appropriate support for adults and children with autism, but does not do so because their needs can be difficult to recognise, or can be outside of the remit of existing support provisions; hence the need f
03	Yes The Act needs to place a duty upon voluntary organisations, housing providers and employers as well.
04	Not sure I would like to answer 'yes', although I am aware this has resource implications. Also there are sometimes situations when a need for support has been assessed and funding agreed, but there is no provision available. If the power to tell local authorities
05	The Welsh Government has a strategy, which has just been refreshed following extensive consultation and influence, particularly of the NAS. Its seems appropriate to allow 6 months to ensure that the existing strategy is aligned with the autism act. Welsh
08	It is inevitable that sometimes diagnosis will be a difficult and complex process and I am uncomfortable with placing time limits upon it. There is no point in getting a decision within 6 months for example if that decision is flawed because it has not been possible to seek the opinion of expert clinicians. What is important is that people should not be placed on a waiting list and left there with no advice, intervention of support while they wait for the diagnostic assessment. There should be a time limit between being referred and being seen by a member of the diagnostic assessment team for a pre-diagnostic screening interview. This would mean that people inappropriately referred would not sit on a waiting list only to be told that they are not autistic. There should be staff in the

	neurodevelopmental service and adults diagnostic teams who are responsible for providing a level of on-going pre-diagnostic support.
09	Not sure It depends what sort of assessment and obviously whether the diagnosed person wants to have an assessment. I do not think there should be an assumption that every diagnosed person will need some kind of support but I am also aware that many people diagnosed as adults only get one short post diagnostic counselling session. Several autistic people have told me that this amounts to nothing more than an informal chat and they found it inadequate. It is usual for people to need some time to adjust, someone to talk to about the diagnosis and to understand the pros and cons of this major change in their lives. For many people a basic NAET assessment following diagnosis would be helpful and this could be part of an enhanced for of post diagnostic support - perhaps a series of 5 or 6 meetings rather than just one, with more efficient and individualised signposting and advice. This should probably be part of the WG guidance rather than part of the Act
10	Yes Yes. The bill should be aligned to NICE guidance, which also sets out the range of professionals who should be in the team. In spite of NICE guidance some adults with autism are not diagnosed by a team composed of a range of therapeutic and clinical specialists, and the diagnosis is limited in terms of the number of sessions, observations, use of video on personal/family history. If the bill can result in a robust, detailed and diligent diagnostic assessment service across Wales, individual experiences of the diagnostic process will improve, post diagnostic advice will be improved and outcomes for those diagnosed might be more positive. The bill could specify the minimum number of people who should be in involved in an individual diagnosis, and the minimum hours of observation and interview, but it would be more appropriate for this to be included in WG guidance.
11	-
12	Some individuals are unsupported by services in adult life because they do not want to acknowledge their diagnosis, or have assistance from local authority social care services. Local authorities are sometimes criticised for this, but I believe it is very important that the new bill upholds the rights of each individual on the autism spectrum to determine how they want

	to live their own life and to respect their decisions. The bill should make it clear that when an autistic person has physical or mental ill health, all the conditions should be treated and supported by the appropriate professionals in different teams and services working together.
13	Yes
14	All of the above, plus what services they are using, information about their accommodation and family support, whether they are in paid or voluntary employment, whether they have other physical and mental health conditions.
15	It should be written in the guidance. Because it will also be necessary to have some guidance about who collects the information, how the information is collected and how an individual's rights can be protected if, for example, their parents and carers want to share the information whilst they might not.
16	Not sure
17	Not sure I am aware that the Welsh Government has been raising awareness since 2008 and that considerable time and money has been spent on this. Other organisations, notably the NAS but increasingly also parent groups and people on the spectrum are also raising awareness. I agree that there is more to be done, but I am not convinced it is the Welsh Government's role to do it directly. Raising awareness is one of the roles of the National ASD team and their work plan clearly states the intention to continue this. The act should probably say that WG should continue to fund/support the National ASD team and monitor the work it does and the resources it produces to raise awareness.
18	I do not think the bill will make a difference to people wanting to speak English or Welsh, as other legislation already reinforces their rights in respect of language. I think the bill will be positive for people with autism but I do not think it will be good in terms of things being fair for everyone; It might lead to other vulnerable groups feeling disadvantaged. It might lead to an increase in inappropriate requests for autism diagnosis if the 'label' of autism is perceived to be advantageous. Looking at the draft bill I am finding it hard to see that it will make any difference in the criminal justice system. I hope the bill will resolve the difficulty my services experiences in getting appropriate understanding and support for people

	who have autism and mental ill health, PTSD, or misuse substances such as drugs and alcohol. Working with autistic people everyday, priorities should be to develop a range of different types of autism friendly housing, a wider range of different types of support, more opportunities for supported or mentored paid employment (with incentives for employers) and above all, adjustments to the DWP benefits system, particularly the application process and the decision making process. The difficulties experienced by autistic people are not recognised or identified in the ESA or PIP application process, the specialist support to assist them is often not available and when it is, the process is time consuming and stressful for both applicant and supporting professional and a considerable drain on local authority resources. In addition, although autism is a life long condition, this process has to be endured again and again.
19	Looking at the draft bill, it seems that if enacted it will have the power to place obligations upon local authorities and the NHS. I think that the real challenge is to introduce a bill that can have a wider impact and improve outcomes in the benefits sy