Cynulliad Cenedlaethol Cymru Bil Awtistiaeth (Cymru) drafft Arolwg Ar-lein DAB130 Ymateb gan Cyfrannog ar-lein 130 National Assembly for Wales Draft Autism (Wales) Bill Online Survey DAB130 Evidence from Online Participant 130

Please refer to questions in the Online Survey.

Question	Answer
01	Yes This is an 'Autism Bill', it should therefore specify what is meant by ASD within the constraints of the paper. By all means, it should enable support for other Neurodevelopmental disorders where appropriate, but if you're not going to define Autism, the bill should be renamed.
02	Yes
03	Yes
04	Yes Support for those with an ASD in the NHS and LAs is spotty at best, often dependent on the knowledge, experience and understanding of the individual(s) involved: some clinicians are brilliant with my daughter (who also has complex medical needs, but is in
05	It's certainly not 'too much' time. I would abstractedly question if it's not enough time, but only the final strategy would effectively answer that.
08	Wales is generally so woefully far behind the NICE guidelines that heeding them can only be a good thing. I can't see NICE increasing the amount of time for diagnosis when ASDs are recognised as having a huge impact on a persons quality of life and access to education and support.
09	Not sure I think that's dependent on the impact and extent of a person's ASD. There is no additional support having a formal diagnosis will bring my daughter, so an assessment within 2 months makes no difference in cases like hers. For other children, where they are less 'high-functioning', an assessment within 2 months could be absolutely vital.
10	Yes The bill should stipulate how a diagnosis should be made and who should be involved to reinforce the NICE guidelines that already specify a multi-faceted, MDT approach to ASD diagnosis. Girls in particular are much less-likely to be

	accurately diagnosed where there is a narrower approach with a smaller pool of experienced professionals. Years ago I had social workers telling me that smearing behaviours are 'ageappropriate' in a six year old. Professionals on a team should need to have proven, specific training and experience with ASDS as a prerequisite to joining a diagnostic team.
11	Specialist Health Visitors should not be discounted.
12	Degree of ASD. My daughter is intellectually capable and confirmed as academically excellent in certain areas, far exceeding the ability of a 10 year old, but socially and emotionally functioning akin to a 5 year old in many areas. Because of this, and her ability like many girls on the spectrum to 'mask' her degree of difficulty, she is often perceived as high-functioning: there is nothing high-functioning about a 9 year old bolting into traffic if a fire-alarm goes off, or not being competently able to go out wearing underwear or weather-appropriate clothing without being prompted and encouraged. There is currently no specialist educational provision anywhere in Wales that can meet her needs because she's deemed as 'not autistic enough' (that's a direct quote), yet some days she barely functions in mainstream schooling and for four months last academic year was a frequent school refused directly because of her ASD and subsequent perception of the world around her.
13	Yes
14	Age Gender Age at Diagnosis Length of wait for diagnosis from referral Healthboard AND Local Authority area How they were diagnosed How long diagnosis took e.g from first diagnostic assessment to final diagnosis If there are other immediate, biological fa
15	It should be written on the Bill. Numbers can be less easily 'fudged' if the bill itself stipulates the information that legally must be gathered. Organisations can be held far more readily to account.
16	Yes
	Yes, but they shouldn't have to.
17	It should happen all the time.
18	I'd like to think good, but having read the draft bill, I currently fail to see it making real and meaningful difference in practical

	application for many with an ASD. All people with ASDs and their families/carers want is timely, accurate diagnosis, appropriate support and provision of specialist help and environments regardless of the perceived degree of severity. Bilingualism is supposed to be a given in Wales, people on the spectrum are treated so unfairly that anything to improve that even slightly has to be good.
19	NAS Cymru only reach so far and are not always considered 'good' support - some chapters are poorly organised to the point that you sign up to mailing lists and only get one email a year, don't answer queries or direct emails, yet you then find out they'r