Cynulliad Cenedlaethol Cymru Bil Awtistiaeth (Cymru) drafft Arolwg Ar-lein DAB43 Ymateb gan Cyfrannog ar-lein 43 National Assembly for Wales Draft Autism (Wales) Bill Online Survey DAB43 Evidence from Online Participant 43

Please refer to questions in the Online Survey.

Question	Answer
01	Not sure
02	Yes
03	No
	Local authorities (LEAs in particular) have proved themselves incapable of doing what is best for autistic children in their charge, fighting SEN tribunals to prevent autistic children going into autistic special schools.
	There are also concerns with the NHS - they prescribe using methods such as Positive Behaviour Support which are considered almost abusive by the a significant part of the autistic community, and a recent "gold standard" trial has proved to be ineffective (see https://www.ncbi.nlm.nih.gov/pubmed/29436314) and is also
	based on discredited ABA therapy.
	Could I suggest looking at the #actuallyautistic hashtag on twitter (https://twitter.com/hashtag/actuallyautistic) to hear the voice of people who are autistic but are able to communicate well. The reason I suggest this is to give autistic people a voice rather than neuro-typical people (myself included) deciding what is best for them.
04	Yes
05	It is important to get it right, so 6 months seems fair.
06	If it takes 3 months to write the guidance, the perhaps the bill is too complicated ?
09	Yes
10	Yes
	It should also give clear guidance on who they are employed by - for example, Educational Psychologists employed by the local education authority have a clear conflict of interest. If the person being assessed has autism, there are clear cost implications for said authorities. An element of independence is necessary.
11	Parents
	Teaching staff who have worked with and know the person

	being assessed
	Someone independent who can keep the assessment team "honest".
12	A person with autism may have other socially uncomfortable behavior - they may be loud, clumsy, heavy handed, have vocal or bodily tics or they may "stim" ( see https://en.wikipedia.org/wiki/Stimming ), or may not respect others' social boundaries. They may react unusually or excessively to for example an unexpected hand on their shoulder. Strong smells or noise or other things can cause sensory overload, which is why having "quiet rooms" at places like hospital waiting rooms are a good idea. These can all cause problems with accessing services.  One thing to note - sometimes services are excellent at dealing with these problems, but parents or carers may perceive that they are not. Ability to provide service for people with autism should be advertised, such as some cinemas having showings specially for children with autism or some superstores having a
	designated quiet time.
13	Yes
14	Things that were done well (some people in authority really do go above and beyond the call of duty and this should be recognized and celebrated)  Things that were not done well (having to fight for diagnoses, can't get into appropriate school)  Did assista
15	It should be written on the Bill.
	If it is not written in the bill it will not be done. An example of this is the SEN code of practice which was parts which are largely ignored.
16	Yes
17	It should happen all the time.
	Awareness & *acceptance* should be promoted.
18	My son has had, and still has, a difficult life. At times authorities (local and NHS) have made his life significantly more difficult. Support has always had to be fought for, and unless you have a good network of friends and contacts, you don't always know what support is possible, because the authorities will not offer it to you unless you ask for it.  Things become worse once the autistic child becomes the autistic adult. And if your view as a parent is different that that of the authorities, things are even worse. One of the lowest moments we had of parents was a senior psychologist more or

	less bullying us to get his way, threatening to "section" our son if we did not agree to exactly what he said, saying that it would be the outcome if we tried to look at the legal position for our son in his particular situation. This is far from an isolated incident.  In short, anything that will make my son's life easier is welcome, and I hope that this bill will help.
19	A clear method of who parents / carers can go to if it is clear that instructions in this bill are not being carried out. Please keep in mind that a lot of parents with children who have special needs are not very confident themselves, so it needs to be