Cynulliad Cenedlaethol Cymru | National Assembly for Wales
Datblygu Bil Aelod | Development of Member Bill
Y Bil Awtistiaeth (Cymru) - Datblygu'r Bil | The Autism (Wales) Bill - Bill Development
DMB(5) AWB85
Ymateb gan | Evidence from David Malins CertHE, Adult Autistic Representative, Aspie Link

Questions about why we need the Autism (Wales) Bill

1. What do you think about the work that has already happened to improve autism services?

The state of improving Autism Services, is dismally underwhelming: Quite frankly, it seems to only seek views of the same-old providers nationally – even in this consultation, where the main document instead of the ‘easy read’ of which I’m responding in, is aimed at admin clerks of, as it cannot be replied to in a ‘normal’ manner except those who have degree-knowledge and speed-reading abilities, working in large-scale organisations (usually London-based, Carer/Healthcare-centric organisations like the NAS, who have no desire or experience of providing appropriate services, including some disturbing evidence that they actually harm or permit harm to autistic adults of all ability ranges, along with suppressing autistic adult’s journeys of self-empowerment to make them more reliant on said organisations, along with inappropriate placements (e.g. Bristol care setting which led to the death of a vulnerable autistic girl by the hands of a Mental Heath Act applicable patient, despite evidence of the potential harm by placing them in the same inappropriate facilities)). Most council in Wales, have failed to take heed of their legal responsibilities under the much-taunted Social Care and Wellbeing Act, denying Autistic Adults care assessments unless it is on a ‘sliding scale’ like RCT, which is just another form of Triage system to deny access to services because ‘there is no money left’/Forced Austerity – even with the new Intergrated Autism Service, which seems restricted to the whim and agenda of Local Authorities & Healthboards, with NO CONSULTATION with Autistic Adults at all, except to ‘rubber stamp’ bad decisions. A few smaller groups and charities, have had to take-up the slack from the Autistic Adults who have nowhere else to go. ASC Cymru in Cardiff for example is the only facility, providing ‘drop-in’ outreach and various activities that has been substantially helpful to us. However, it has been unable to expand due to a lack of funding of this very helpful resource, meaning that waiting times for appointments, along with expansion to other areas and employing more autistics to be part of the neurodiverse advocacy workforce, is not possible without commitment to guarantee funding. Funding as well into Adult Research that could provide valuble evidence to back-up adult service provision I’ve been shocked to learn (even with the flagship Wales Autism Research Centre at Cardiff University) has been curtailed unless it focuses on areas NOT USEFUL to adults – which also threatens a Neurodiverse workforce's employment, as well as it's leadership – Sue Leekham apparently cannot retire and 'hand the baton' over unless she can find a replacement, which is only possible through a proper, autistic-led research funding system that matches or surpasses in parity with funding to Children and Young People. Adult Autism is so underfunded, that with the ongoing austerity agenda in parallel to further compound the dire situation, threatens (and I don't apologise for calling it what it is) to 'wipe us out in democide': all our hopes, dreams, aspirations, choices, friendships, mobility, skillsets, independence, relationships, volunteering, self-employment & career paths, even our value to society and our ability to 'rise up' against vapid discrimination, intolerance and bigoted criticism of us by those who are not in our shoes. We have been forced into a dependence that takes with one hand as a 'sacrificial offering' to the 'neurotypical gods' as it were for what unacceptably poor service we get (both public, third AND ESPECIALLY private sectors who continue to take and giving very little back in recompense) – or left at worse, to the mercy of societal judgement, impoverisment, loneliness, family procrastination that we're 'not doing enough' and then finally death so slow, painful and so illogical, that many of us (including me – and I'm an eternal optimist naturally!) have contemplated suicide as the only means to escape, despite our ENORMOUS UNTAPPED VALUE AS HUMAN BEINGS – even in public speaking and consulting (on that subject, those of us who have spoken, have not been given the same rates as professionals parallel to us in the 'normal' community – we have been slighted continuously despite our hard work!). Having also heard that the Welsh Government itself, bullies people that disagree with it in it's OWN CABINET (a reason why I personally was reluctant to risk my sefety by stepping foot through the door for the December CPAG in the assembly building at the rear of the Senedd, in case people wished to do me or other vulnerable adults harm!), including those of us asking and begging for an autism act (I bring back MY contribution to that table which I mentioned in the Cross Party Autism Group many moons ago: https://www.youtube.com/watch?v=thjbJWV_HQs) , instead of holding civilised debate with FRESH solutions, only proves that it is still unwilling to listen, be effective for US – it's citizens who SHOULD be among equals, or even take on board some pioneering work provided to it by it's main party's Neurodiverity Manifesto which was consulted on by a leading Autistic Adult Monique Craine, whom I applaud with the work she has undertaken with the Shadow Chancellor. I have recently theorised as a qualified Geographer, that unless things are turned around, we (the Actually Autistic Community) will become part of the statistics of being AMONG the 1/3rd of the overall population (about 22 million, 15 million are already affected, most coming from the wider City Partnership Region surrounding Cardiff & Bristol!) likely to be deprived by austerity & partisan policies in the UK by the end of 2018 – to the point where either we will have to move OUT of Wales and the UK (those of us who can even contemplate being able to make such a disasterous 'transition') or try to self-ghettoise, just to protect our fundamental rights, freedoms and build a community by NOT involving any 'normal' people in that process – which the latter at this moment looks far more practical, but is still 'pie in the sky' and would fly in the face of the wish of Neurodiversity, which I am a very strong proponent of – in other words quoted from Star Trek's "Infinite Diversity in Infinite Combinations". I shouldn't write this long an essay in such a consultation, but I've been left with very little choice in the matter and no other support mechanism to enable expression of this view, which is vehemently sovereign and is my last cry for help – else be left with the words of another pioneer, Patrick Henry, on hearing other representatives calling out for further concessions in what he saw was simple illusion on 'things will get better' when he proclaimed to America's Continental Congress on the eve of a calamety affecting his people: "Give me Liberty, or Give me death!" – Get the job done!

2. Do you think Wales should have a law that says Welsh Government must write an autism strategy?

YES

a. If yes do you think it should say Welsh Government must write guidance about how to follow the plan?

YES

b. If yes do you think it should say local authorities and health services must follow this guidance by law?

YES

3. Do you think that Welsh Government should have to ask people their views about what to put in a plan for autism?

YES

4. Do you think the law should say how often the plan for autism should be checked and updated?

YES

a. If yes how often do you think it should be checked?

Once every quarter, by a fully neurodiverse accessible body that has the authority to force review.

5. Do you have any ideas about how Welsh Government should check how good services are for people with autism?

Face-to-Face meetings with Actually Autistic Adults and Young People in or facing transition from all walks of life (but especially those who are impoverished and do not have the luxury of having social or economic stability like myself!) and renumerated in both travel and time costs as a compulsory condition for participation, so as to overcome pressures and time taken which might otherwise not have been possible. Other accessible methods also need to be utilised, which I will be willing to discuss and advise officially if renumerated for my efforts.

6. Do you have any ideas about what Welsh Government should do if the services are not very good?

LISTEN TO US, PROVIDE THE SERVICES **WE REQUEST AT THE STANDARD WE EXPECT AS EQUAL CITIZENS**, NOT JUST THE STATS THAT ARE RARELY AVAILABLE OR UNRELIABLE OR ARE TAKEN OF US WITHOUT FURTHER ANALYSIS OR BREAKDOWN! IF IN DOUBT, GIVE US THE FUNDING TO DO IT OURSELVES!!!!

Questions about getting a better way to diagnose Autism

1. What do you think about how easy it is to get an autism diagnosis where you live?

Totally inaccessible - requires an impossible foreknowledge of the system, the practitioners involved, the words, the phrases, the rationale, the local authority/healthboard hierarchy, the complaints procedure, others who have been through the same (which can also be very difficult, unlike our parent/advocate counterparts!), along with the ‘sliding scale’ triage used by some to justify NOT providing services or even seeing the individuals who seek diagnosis or better post-diagnostic. Some areas even ‘outsource’ to already struggling bodies to deliver post-diagnostic groups & classes! Seeing a GP in general is impossible, but the referal process is diabolical, if not restricted because of forced privatisation of basic NHS services & of GP consultation which we simply do not have the money for, or only to those who waste hundreds or thousands of pounds to get one privately from often unreliable or profiteering groups!!

2. What are the most difficult things about getting a diagnosis?

THE WHOLE THINGS IS MOST DIFFICULT! WE DON’T KNOW ANYTHING ABOUT IT OR

WHAT THE AIM IS OF IT ANYMORE!!

3. Do you think that the local authorities and health services should have to give out information about how to get an autism diagnosis?

YES

Questions about improving the way people get support services

1. Do you think services at the moment are good enough for people with autism?

NO

2. Do you think the law should say that there must be guidance on how to deliv1seivices for people with autism?

YES

3. I think there should be guidance. I think the guidance should say:

   a. How to organise getting an autism diagnosis
   b. Services cannot turn people with autism away because they have a high IQ
   c. There should be plans for people with autism moving from child to adult services
   d. How to plan for autism services
   e. Who should be in charge of the organisation of autism services?

Do you agree that the guidance should say something about the things listed above?

YES

Is there anything else fhat you think should be in the guidance?

- That all new services (regardless of who provides it) need a minimum of 2 autistic adults (1x of either sex) for oversight (before launch, during operation, along with anytime it may be proposed to shut down a service, but not without signed approval of these representatives, nor without a plan to replace it like-for-like to maintain consistency), whom will be fully renumerated for their time & travel to at least the living minimum wage in a form most useful to them of their choosing.

- That all training has to be at a minimum standard that covers at least 1 week compulsory training on all possible aspects of Autistic Spectrum Conditions (with said training sessions oversighted by a minimum of 2 autistic adults (1x of either sex), whom will be fully renumerated for their time & travel to at least the living minimum wage in a form most useful to them of their choosing.
- That the Welsh Government MUST take-over or fully-replace (with Actually Autistic oversight & leadership) a failing Local Authority/Healthboard service if the wishes of the Actually Autistic Community are not being respected.
- That ANY employment, earnings, resonable expenses from volunteering and community involvement lost by Actually Autistic Adults, due to condition or perception of by the workplace, should be replaced and renumerated, until such times as individuals are able to keep for greater than 6 months sabbatical alternative employment/volunteering that is equal or greater value renumeration for their efforts than their last.
- That all Autistic whilstleblowers in all settings (public, voluntary and private), be protected under the law from harm or retribution by those violating trust and/or abusing autistic adults, regardless of abilty.

4. Do you think local authorities and health seivices should have to collect information about people with autism so they can make better plans for seivices?

YES

6. Do you have any ideas about the best way to collect information about people with autism?

For example, information about how many people have autism and what their support needs are?

Question about autism training for staff

1. Do you have any views about the autism training that staff working with people with autism already get?

2. Do you think the law should say:

a. What the staff who work with people with autism should know and be able to do after their training?

YES

OR

b. That key staff should get autism training. The law would not say la.ihing about what they should know.

Questions about jobs for people with autism

17. Do you have any ideas about what should happen to help more people with autism get jobs?

Firstly, it should appreciate the individuality of the Actually Autistic Community

Questions about the definition of autism

Where do you think the definition should be written? Please tick 1:

a. On the Bill

b. In the plan for autism

c. In the guidance

d. I don't think it should be included