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) AWB16
Ymateb gan Di-enw | Evidence from Anonymous

I am writing to you in response to your request for feedback on your proposed Autism for Wales Bill. I should firstly state that I am an autistic adult individual and what many people would consider a highly successful individual, being a director and part owner of a very successful Welsh business.

I was diagnosed in 2009 after, I feel, a significant failing by the NHS to diagnose me during 2007/2008. Since diagnosis I have had very little support other than what I have recently gained privately. This lack of support has lead to a number of relationship breakdowns, repeated misunderstandings in my personal and work life, and apparently a long history (but also in recent years) of moderate to severe depression and persistent suicidal thoughts.

It just goes to show that success and happiness are not synonymous and that even autistic individuals who are "lucky" enough to go largely unnoticed in society really may not be coping as well as they are perceived. For this reason I would really like to do what I can to help others like myself or to better still prevent them falling into the same trap as me.

a) What are your views on the effectiveness of the current arrangements for improving autism services in Wales?

I can't really comment on current effectiveness. I was failed by the NHS in this areas many years ago and have not since had the courage to attempt to re-engage - what I can do is highlight the significant impact that not getting this right can have on an individual's life

b) Do you believe Wales should have legislation requiring the Welsh Government to publish a national autism strategy for children and adults and issue guidance to local authorities and NHS bodies on implementing the strategy?

Absolutely, I feel that without this public awareness and particularly awareness for professionals assisting and diagnosing people with autism, and adequate methods for them to deal with it, will simply not be developed.

c) To what degree of detail do you think the content of a national autism strategy should be defined in legislation?

I agree that the bill should focus on creating an adequate strategy, that putting too much content regarding how it should take place and the definition of autism will simply limit individuals getting the support they need as has happened so often in the past.

d) What (if any) consultation do you think the Welsh Government should be required in legislation to undertake, when developing, reviewing and updating a national autism strategy?

They should be required to consult with those who support autistic individuals but most importantly autistic individuals themselves – **absolutely nothing** should be decided without consulting us!!

e) Do you believe that legislation should define how often a national autism strategy should be reviewed and updated? If so, how often should it be reviewed and updated?

Yes – once it is developed it should be reviewed ideally annually or at least every other year. It should only be updated as necessary per the review.

f) Do you have any views on how Welsh Government should monitor what progress is being made and how public services should be held accountable for how they support autistic people and their families?

Ask autistic people, their families and people who support them – with particular emphasis on autistic people, this is the only way to be certain that you are meeting their needs.

g) What are your views on how easy it is to access a diagnostic assessment where you live?

I can't give recent experience but when I sought diagnosis in 2007/2008 the GP that I saw (it's not easy to see the same doctor at my surgery) did not take me seriously, if I recall in fact he gave a surprised chuckle when I asked about it (I don't feel he was malicious, simply lacked awareness) and I insisted that he refer me on. He did so and I eventually saw a locally based Occupational Therapist who didn't have a clue what Asperger's Syndrome was and so diagnosed me with stress – I agreed with her on this but equally pointed out that diagnosing the symptom does not resolve the underlying issues. She would take it no further and so I simply exited the system from that point onward for a diagnosis and any further future support that I may need. I eventually had to travel to Surrey 18 months later and having spent this time saving up so that I could finally receive a diagnosis through private means.

In a nutshell, based on my personal experience and ignoring the length of time since my diagnosis I feel it is extremely difficult to get a diagnosis and support. I recognise that it may be easier now and that it may be easier for individuals who have more severe symptoms of autism.

h) What key challenges around how the diagnostic process works would you like legislation to address?

Awareness and education are the two single biggest factors that must be addressed. General public awareness is important but this will come in time, the key target should be professionals assisting autistic people, including those who may have a hand in diagnosis.

i) Do you believe that Local Health Boards and Local Authorities in Wales should be required to publish information on the pathway to diagnosis for children and adults living in their areas?

Absolutely – unless this is taken serious through the entire chain then it will not be successful and autistic people will continue to be failed.

j) What are your views on the sufficiency of services currently provided to meet the needs of people with autism spectrum conditions in Wales?

As already mentioned I cannot really comment on current provision of services. Certainly if there are sufficient services currently available I am not aware of them so awareness spreading schemes are definitely not efficient. If I need support I do not know where to go to get publicly available help, only the means to seek this privately – I would also still likely not go to my local surgery for assistance due to previous experiences. Based on this I would say that they are insufficient.

k) The legislation I am proposing would require the Welsh Government to issue statutory guidance that would put duties on local authorities and Local Health Boards on how they should be delivering services for autistic children and adults and their families. Do you agree that legislation should require statutory guidance?

Yes, absolutely – without this guidance this will be implemented in an inconsistent and potentially haphazard way, likely negatively impacting individuals.

If so, I would like to know your views on which requirements the guidance should place on local authorities and Local Health Boards. The following is a list of the areas which I believe should be included in the statutory guidance for local authorities and Local Health Boards. Please indicate:

whether you agree that these should be included, and,

Yes I absolutely agree with all of these areas.

any other areas that should be included.

I strongly believe that autistic individuals should not be treated as though there is something wrong with them and that they need to fixed, simply due to them being autistic. Whist I understand that the needs of autistic individuals varies to to it being a spectrum disorder and that some individuals have further learning and mental disorders, but if the public were to change its view (a big ask, I know) and make it easier for these individuals (and other individuals with other disorders) to be treated as another type of normal then they would much more easily be able to fit in to society and not be or feel like a burden or that they are different. How this would be achieved I have no idea other than generally raising awareness and encouraging society to be positive, understanding, caring and helpful.

l) Do you believe that Local Health Boards and Local Authorities in Wales should be required to establish and maintain new data collection practices around the numbers and needs of children and adults with autism spectrum conditions so that local areas can plan services accordingly?

Yes – without this it will be difficult to truly understand the breadth of autism and the success (or not) of any initiatives. This information should be used appropriately and individuals' data **MUST** be kept extremely confidential and only used according to the consent that they or their guardians provide.

m) Do you have a view on how data can most effectively be gathered, on the numbers and needs of children and adults with autism spectrum conditions in different Local Health Board and Local Authority areas in Wales?

Some sort of census that assures anonymity – I know that I myself have been very guarded over the years because of my reticence due to fears of how I may be treated; for instance since my poor experience with my diagnosis there is no NHS medical record of my diagnosis therefore I would not appear with any statistic that does not receive input directly from myself.

n) Do you have a view on the current scope and effectiveness of training in Wales for key staff working with people with autism spectrum conditions?

No.

o) Do you believe that legislation should specify outcomes that training should achieve, thereby providing greater flexibility around the delivery of such training? An alternative approach would be for legislation to specify that key staff working with people with autism spectrum conditions should undertake autism training

Anyone that may need to support someone that does have or could have autism needs training - this could be teachers, teaching assistance, head teachers, GP's, nurses, psychologists, therapists etc. Anybody who may need to identify that someone needs further assistance or diagnosis **MUST** have this training or else individuals **will** (continue to) be failed. There should be at the very least a base level of training across all of these people, and further training for those who must work directly with/support autistic individuals.

p) Do you have any suggestions for additional action that could be taken through legislation to improve the rates of employment of people with autism spectrum conditions (bearing in mind that the National Assembly for Wales does not have the power to make changes to employment law)?

Don't try to force employers to employ autistic people - this will not be successful as employers and their employees will resent it and autistic people will end up being put into roles that they should not be in which will be destructive to them. Do educate employers on autism and the many strengths of autistic individuals, encourage them to see that the skills that they can offer and help to reduce their fear of the "cost" of supporting these individuals - they need to focus on the benefits (which can be immense!); this is the absolute key! Most people are not the "normal" that people perceive as being normal, the real normal is that everyone has different aspects that they struggle with and other aspects where they excel - putting in place measures to assist autistic people will also help other individuals to be the best that they can be and give the most that they can give, so this will help employers beyond just their (potential) autistic employees.

q) Do you believe that a definition of autistic spectrum disorder should:

- be included on the face of legislation (which makes it more difficult to change in the future);
- be included in an autism strategy;
- be included in guidance;
- not be stated at all?

It may be best to not state at all and simply leave this down to the medical profession, otherwise I believe it is better to state this in the strategy as enshrining into legislation could make this inflexible, as you state.

r) Can you identify any possible unintended consequences which could arise as a result of this legislation? If so, what steps could be taken to deal with them?

My biggest concern would be how employers may perceive any changes that they feel are thrust upon them and which they are not equipped to manage, whether putting in to practice or financially, or maybe both. This may be minimal or it may be significant depending on the eventual legislation (and this includes not just private organisation but public ones that are really struggling under the current government). I address this in question p).

s) Do you believe that the proposals in this consultation would give rise to any substantial costs, in addition to the cost-areas already noted in this consultation? How can such costs best be mitigated?

Yes, it's clear that the provision of additional services, training, research, reviews, monitoring and auditing will increase the cost of public bodies in implementing this legislation. I am not sure how this would be accepted in the current climate, my fear is that it would not happen. All I can offer is that if autistic people are better supported and welcomed in to public life and employment they can at least make some positive contribution to society which could save cost or possibly even make monumental positive impacts on society which could simply enrich society (financially and developmentally).

t) What would the impact or costs be in terms of:

i. producing a national autism strategy;
See above.

ii. placing duties on local authorities and NHS bodies to act under guidance;
See above.

iii. creating and maintaining data collection practices on the numbers and needs of adults and children with autism spectrum conditions; and,
See above.

iv. providing training for key staff?
See above.

u) Do you envisage any other additional administrative and regulatory costs as a result of this legislation and if so, how can any such impacts be mitigated?

I don't feel I am able to answer this.

v) What factors should be measured to determine the cost-benefit analysis of this legislation should it become law?

Current financial cost of supporting autistic people, current negative social impact of not supporting autistic people adequately, future cost of the new legislation, future saving of the future legislation and future social positive impact of supporting autistic people.

w) Do you have any views on how savings that might arise from this legislation can most effectively be identified and calculated?

Clearly you have to be recording the current cost of supporting individuals; I would suggest that it is also important to keep in mind that there are likely a large number of individuals who have not been correctly diagnosed and how are therefore receiving support that is not getting attributed to the support of autistic individuals. Finally there is then the cost to society of those individuals who are not receiving any support, and this may be through other benefits or the harder to calculate impacts such as homelessness and suicide. I don't know how but there must be some way to estimate and assess this impact. We must then calculate how much of this can be saved through positively impacting people's lives to reduce (significantly, I hope) these negative impacts through hopefully lower cost support. If at least it is cost neutral and improving people's lives then we have won!

x) Do you wish to make any other comments on my proposals?

I just want to say I wish you all the best in your endeavour and thank you on behalf of all autistic people for doing what you (and I) feel what is right to support us and correct the current failings of our Government and society.