

A03

Ymchwiliad i Fil Awtistiaeth (Cymru) / Inquiry into the Autism (Wales) Bill

Ymateb gan Unigolyn

Response from an individual

I am writing to you in a personal capacity. My son, who is now 26, was diagnosed with autism at the age of 5. He then attended a local special school and currently lives with us in the family home. It might seem to a casual observer that an autism bill would be good news for my son and I but this is simply not true. I honestly feel that if you make this law it will be harmful to my son and the wider family.

Excerpt The autism strategy must—

(a) establish a best practice model or models for the—

(i) identification and diagnostic assessment of autism spectrum disorder;

(ii) assessment of the care and support needs of persons with autism spectrum disorder; and

(iii) planning for and meeting the care and support needs of persons with autism spectrum disorder;

(b) make provision for the development of a pathway, that includes access through defined points of referral, to map the services that are available and required for persons with autism spectrum disorder;

(c) provide for diagnostic assessments and any post-diagnostic meetings to be commenced as soon as reasonably practicable following a referral and at least within any timescales set out in the relevant Quality Standard issued by the National Institute for Health and Care Excellence (but this shall not prevent the provision of any other services prior to the commencement of a diagnostic assessment);

(d) make provision for individual diagnostic assessments to be conducted by a multidisciplinary team of professionals;

(e) provide for an assessment of care and support needs to be completed as soon as reasonably practicable and in any event within 42 working days of a diagnosis of autism spectrum disorder or any post-diagnostic meeting, whichever is the later;

(f) make provision to ensure that persons are not denied access to services on the grounds of IQ or receipt of services for other medical conditions;

(g) outline how the needs of persons with autism spectrum disorder are to be met by relevant bodies in respect of, but not limited to,—

(i) access to healthcare services;

- (ii) access to education;
- (iii) access to employment;
- (iv) access to housing;
- (v) access to Welsh language services;
- (vi) access to services in other languages;
- (vii) access to other public services;
- (viii) social inclusion; and
- (ix) access to advocacy services;

The autism bill as presented places a huge emphasis on diagnosis. I understand the reasons behind a Pembrokeshire AM placing this emphasis as there is a long standing local situation of parent's waiting an extended period for a diagnosis. Yes this should be addressed in Pembrokeshire but not at the expense of everything else. You can't make a national change in a misguided attempt to solve a local problem.

The Welsh Government formally adopted the Social Model of disability in 2002. The Social Model of Disability makes the important difference between 'impairment' and 'disability'. It recognises that people with impairments are disabled by the barriers that commonly exist in a society. In simple terms, it is not the inability to walk that prevents a person entering a building unaided but the existence of stairs that are inaccessible to a wheelchair-user. In other words, 'disability' is socially constructed. The Social Model of Disability requires society to remove the barriers in order that all people have equality. (Welsh Government, 2013) This return to diagnosis seems to drive a coach and horses through this long established policy and indicates a return to the archaic medical model.

Diagnosis is just one short moment in a person's life and by no means the most important. If it takes say 1 year to gain a diagnosis out of a 70 year life span how can such a disproportionate amount of resource be directed in that direction compared to more general assistance. In terms of adults the bill therefore has the potential to cause more harm than good. There are new services being set up that provide diagnosis for adults and then a range of activities etc after that event. The bill is seeking to reduce the diagnosis time to 3 months which is mind blowing. This could mean that a disproportionate amount of resource will have to be diverted to achieve this artificial target. Getting a diagnosis is good but a piece of paper from a doctor saying you have autism doesn't actually help you progress anywhere in life. My personal experience is that having a diagnosis has become less and less relevant to my son as the years have gone by. It's the people he has met along the way, the support assistants, the teachers the employment coaches they are the ones who've made the difference. He hasn't seen a clinician other than his GP in many years. Being able to access other things around employment or social opportunities these are actually helpful but if everything goes into diagnosis those things simply won't be there.

The bill goes on to assume that every person following a diagnosis should then be referred to social services for an assessment of need. Leaving aside the sheer folly of diverting that amount of clearly limited social worker resources to one specific group what on earth gives you right to say my son must be referred to social services. If his needs ever escalate to a point that he and we as a family can't cope we might consider social services but we have managed well for the last 20 years. He is very proud of every step he takes towards being an independent contributing member of our society. These steps may be small like learning to cook a meal or catch a train, but he makes them.

He does not need or want to be taken into care or institutionalised he just wants to live his life. What on earth does the writer of this bill think autistic people are like !! It indicates a horribly skewed view of people with autism. It even implies that despite his high IQ (a-levels and university maths) he must still need a care and support plan. Some people with autism do need a lot of help some, like my son a bit less and some really none at all. This cavalier assumption that the next step after a diagnosis is to get social services involved because such people simply can't cope is horribly insulting. It implies that people with autism are incapable of looking after themselves and perhaps should be shut away somewhere, I thought, hoped that society had moved on from such archaic notions.

The other major concern I have is the sheer volume of personal data the act thinks it is appropriate to collect. Would it just make it easier if I sewed a yellow star on his jacket !!! It is outrageous to think that this level of intrusion is appropriate. My son is an active contributing member of our society. Yes, he has a condition but he makes the best of his life as we all do. He volunteers for a charity and has recently begun actual work 3 mornings a week. It is ridiculous to think that it is OK just because he has a disability to gather data on him as if he is some kind of a lab specimen.

I urge you not to pass this bill

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