

## Aspergers Network

We as an ASD Charity have watched the passage of the Autism Bill over this past year; and have had growing concerns over its content, and construction as it has passed along; and it must be mentioned at this stage, we cannot give it our backing or support One of the biggest deficits in this past year has been the severe lack any of detail about the Services for any Parent/Carer, or any individual having been mentioned; and in particular the lack of clarity as to whether this Bill will produce any intervention. This Bill has caused huge divisions; and not only with Autism families; but also within the disability world. Any individual or Charity who speaks against the Bill leaves themselves open to verbal attack.

We acknowledge how genuinely hard our politicians have strived to get things improved for those with Autism, and their families.

Our fears are based in numerous areas.

Given the fact that over twenty Charities in Northern Ireland do deliver services to different degrees for Autism, it speaks volumes that essentially one main Charity has been the driver behind its passage.

We hope to give brevity to this submission, and instead of providing all documents in a range we will only attach the required documents to help you in your considerations.

The Disability Discrimination (Northern Ireland) Order 2005 was correctly and rightly given out to

(A) Public Consultation (700 Consulted)

(B) Financial Effects of the Order

(C) Human Rights Compatible

(D) Impact Assessed

(E) Section 75 Assessed

(F) Equality Commission Involved as to Review and Advice. Major deficits are apparent.

See attachment 1

The Autism Bill does not appear to have any of these same safe guards in place.

On the 7<sup>th</sup> December Mr D Bradley MLA said “More recently, in March and April 2010, consultation on the proposed legislation was conducted across statutory and voluntary agencies, resulting in a 70% to 80% positive rating for legislation. We held follow-up meetings with the Equality Commission, the Children’s Commissioner and Disability Action. Autism touches the lives of a staggering 68,000-plus people”.

There was no public Consultation whatsoever, and considering this Bill will affect quote “a possible 68,000 people” why no public Consultation; and why was there such a ineffectual and unprofessional Consultation carried out for such an important subject.

Also a full Public Consultation should be over a twelve week period as required by the Governments own Code of Practice i.e., Sedley Requirement; Equality Commission Guidelines; when and if it comes.

As far as the Consultation that was carried out was concerned; eleven Autism related Charities were sent the Consultation and only three responded.

Again from the three leading Equality and Human Rights groups in Northern Ireland i.e., Human Rights Commission Equality Commission, and Pils; all three declined to respond; which gives us great cause for concern

This is a Consultation which claimed a 70% return; but in fact four Autism Branches were added, plus two Anon; **which were not on the list of Consultees**; and this skewed the figures. How did six Responses appear when they were not consulted? The correct figures should have stated a 50% return.

**The fact that Autism NI, PAL, and four Branches of Autism NI were all included in the responses list this gave Autism NI Six Votes which allowed them a block vote of 25% of all Respondents to the Consultation.**

The resulting figures of 70 to 80% positive rating; which Mr Bradley eluded to; **does not stand up**; taking into account the way the figures were presented, and given that 25% came from one source Autism NI. If the figures were downsized by this 25%; then the positive rating for the Legislation in the consultation would only be 45 to 55%.

Another question; why did the other fifteen branches not take part in the Consultation?

Another important factor is that the true response figure for **Autism Related Charities was 20%**. **The vast majority 80% did not respond. At least 45% of Autism related Charities** did not even receive a Consultation Document.

Whilst we have no difficulty with Autism NI; we do have a major difficulty with allowing this Consultation to influence anyone without the knowledge that the figures are not in any way a credible reflection of the Autism community. Nor are the percentages in any way correct as presented.

No Financial effects are available, and considering the Bill requires public servants, who deal with the public are to be trained; at what cost. Will these costs be removed from the recent increase in Trust services for families? Or would there be a decrease in the new Autism related jobs within Trusts?

There has been no Equality Impact Assessment been carried out.

Also Regulations and orders to be made under the act would they be made without the views and needs sought from the 68,000 individuals affected by any future changes.

Also the All Party Assembly Group Stated that under the Consultation that they required a minimisation of duplication of resource allocation; yet we have a RADS Strategy ongoing this past two years then why is this Bill appearing to go down the same pathway of duplicating, and recollecting the same information that has been already scoped. The APAGA also stated about training yet we have spent many millions on Middletown's training, along side Dept of Education, and Voluntaries, which runs into hundreds. The SIGN Guidelines document was imbedded into RADS; many months ago; and yet the APAGA document is still talking about training functions across all sectors

It is also obvious that some Trusts have already spotted the fact that this Legislation is supportive only of one Disability; and the fact that their scarce resources and time may be diverted to defending Legal challenges. This would be under Section 75, showing an inequality which Trusts would have to try and defend, and they would all be liable.

I think the Equality Commissions Remit must be looked at in this affair. See Attachment 2 Their duties are wide and varied, and make recommendations to government on ways in which they can be improved, but in the case of the Autism Bill they have not made those

recommendations. Also these duties on public authorities include the production and review of Equality Schemes, conducting equality impact assessments and including consultation as an integral part of the policy-making process. One of their priorities for Legislative reform in Northern Ireland is to keep the DDA 1995 under review; and also includes Section 75.

To change the Main Elements of the DDA's general definition, by describing and detailing Physical or Mental impairment may weaken the legal status of the DDA completely, as this has generally been its strength. This is the advice from the Equality Commission. To quantify and qualify the condition we could find that some individuals may fall outside these impairments. Taking part in Social activities may exclude some, or their social exclusion may not fit in other cases. To be social, or retain friendship; or even be a member of a social group may even work against our individuals. To redefine the DDA would actually eliminate many on the Spectrum. The many complexities of this condition cannot be prescriptive, or it will exclude some. The Law was set to include all with the Diagnosis of Autism, Aspergers Syndrome and not exclude individuals; which could be the case in the future. No amendment over this last fifteen years has redefined any condition, for this reason. See Attachment 3.

The knock on effect would also be to DLA applications; of which we have successfully won every case at Tribunal on Aspergers Syndrome. The DLA cases can and are fought on the effects of the condition its self, and the Law as it stands at the moment. If we change it we think it will be to the detriment of the individual's rights that now exist. The question number 8 in the consultation document on DLA in the Consultation was misleading: as it are the impairments on the individual and their Care Needs those gains a DLA award; and not their Disability.

As far as the Autism strategy is concerned there has been RADSNI for coming up on two years now; and this includes the Reference Group. Autism NI sits on this group, as do many of her members; and also many PAL members including their Vice Chairman.

The thing that is very important about the Reference Group is that in its make up there are thirty Parent/Careers and individuals with Autism, plus service users; and they are working on the full range of services. These cover, to name a few, Health Visiting at two years old to Children and Adult Pathways, and also Transitions, assessment criteria, training, and interventions. Also they are involved in service design and delivery.

There is also the factor that RADSNI works under Personal and Public Involvement; whereby the Department's commitment to strengthening the voice of those who use the services and ensuring the public has a stronger voice in priority setting and decisions is a new Statutory Duty. See Attachment 4

We don't think **removing** those Legal rights would be the thing to do, as these individuals are competent and have a professional attitude towards improving the Autism services in Northern Ireland. To remove their voices in Autism matters would be a retrograde step.

The lack of any particular clause regarding co-morbid conditions; or what we would describe as dual diagnosis is concerned; is so low on the radar that these multiplicities of conditions are nowhere to be seen on the Bill. So by changing a DDA and Writing an already written Strategy, surely the question is how where and when do we address these other conditions. Nearly every one of our individuals with ASD, suffer from some add on condition. It can be, ADHD, ADD, ODD, OCD, Epilepsy, Downs Syndrome Diabetes, Sensory Difficulties, Anxiety etc., See Attachment 5.

We cannot attempt to address Autism services in isolation; as they come under the bigger umbrella of Disability. An Autism Commissioner would not be the answer; but consideration should be given to establishing a Disability Commissioner; who no doubt could cover the Autistic

Spectrum, and the complexities of all their add on conditions. Plus the Commissioner could work with the Equality Commission to amend the required laws. What we don't need is to promulgate a Hierarchy of Disabilities when Autism is separate to all other Disabilities. In the very near future we will face major cuts in Budgets in the welfare budgets and we will require as many friends as possible. See attachment 6. We feel that the Equality Commission must be heard at the HSSPS Committee, as Mr. Wells suggested in December 2010.

A quote from Mr. Jim Wells on the 7<sup>th</sup> December 2010

“As with any Bill, the Committee will take evidence from key stakeholders who are involved in providing services to children and adults with autism and from organisations that may be affected by the Bill. The Committee recognises that complex issues are in play and that there are different opinions on the various aspects of the Bill. We will listen carefully to all views and come to our decisions on the basis of the evidence that is put before us”.

We would ask the Committee for an Oral Hearing, as we are as passionate as the Committee to get these issues correct; and to ensure we definitely do not get it wrong.