



Autism NI Credentials

Length of service to the ASD Community in Northern Ireland (NI).

The Charity celebrated its 20th anniversary this year (2010). It was established in 1990 as NI's indigenous Autism charity.

In 1992, only six children in NI had a diagnosis of ASD. In 1992, the Library Service only had one title on ASD, so Autism NI donated supplies of the second title.

N.B. Autism NI (PAPA) – the only NI ASD charity to be regularly evaluated over 20 years.

Mandate.

Autism NI supports a network of over 30 groups and Branches across NI involved in local activities and run by local families living with ASD. Each group supports between 10 and 100 families at a range of events.

Autism NI also has a membership base currently totalling over 800 families and agencies.

The charity also supports an active Parent lobby for improved services and required legislation (PAL). PAL is run by parents for parents. It is the parent political voice of the charity.

Research.

Autism NI has created the largest portfolio of NI research on ASD across the Voluntary and Statutory sectors on issues ranging from specific interventions (such as TEACCH and social skills models) to cross agency early intervention models and programmes (Keyhole® Programme) as well as Training (DHSSPS ASD Training

Strategy for ASD 2006), Diagnosis of ASD and Family Support (“Hidden Community” and “Is anyone Listening”). The Research partnership with UU has involved Education.

Advocacy and Awareness of ASD

Building upon the above Research portfolio, Autism NI has combined its training and family support functions to create awareness of ASD.

April has been established as Autism Awareness Month and further strengthened by the UN designation of April 2nd as World Autism Awareness Day.

Media/press contacts and relationships have been established and this was extended to our regional groups from 2005 with specialised media and lobby training. From this exercise in participative parent empowerment a Policy Committee emerged which evolved into the Parent Autism Lobby (PAL).

Training.

Autism NI has brought world experts to NI and been responsible for many “firsts”, e.g. first PECS training in Ireland, first Diagnostic (ASD) training.

2004 – Autism NI Regional ASD Training Department (established and funded by DHSSPS).

2006 – NI ASD Training Cross Departmental Strategy (UUJ) (funded by DHSSPS).

N.B. Achievements:-

Autism NI is an Accredited Examination Centre (AQA)

Autism NI provides the only accredited ASD courses outside NI Universities.

Autism NI co-founded the UU web based ASD module.

Autism NI has trained 4,000 – 6,000 delegates annually.

Autism NI has had its training function independently evaluated and audited.

Innovative packages for all sectors, e.g. Justice System.

Family Support.

Developed from membership and Branch mandate.

Specialised Family Support training (for siblings, grandparents and fathers).

Family Support service model – commissioned across three HSCTs.

Helpline.

Strategic Development Role.

The only ASD Charity in NI to be regularly evaluated over 20 years.

Partnership across sectors (15 Voluntary partners and Statutory Sector).

The ASD Diagnosticians Forum (Founder Member).

ASD strategies within HSCTs (Autism NI initiation, lobby role and involvement).

DENI Task Group report (Autism NI was Steering Group member).

Bamford Review (Autism NI exposed flawed recommendations re ASD).

DHSSPS Action Plan

The Autism Bill (NI)

Celtic Nations Autism Partnership (and Atlantic Autism Alliance).

All Party Group on Autism.

Challenges for the future.

ASD Budget

ASD Policy

RPA

Role of the Voluntary Sector.

The Autism Bill (NI).....expanded below.

NEED?

HUMAN AND FINANCIAL COST.

EQUALITY?

IMPACT FOR FAMILIES FROM THIS BILL.

DHSSPS ACTION PLAN & DENI FRAMEWORK.

IMPLEMENTATION OF THE AUTISM ACT (HOW?).

AMENDMENTS? E.G. ADVOCATE ROLE, "PUBLIC SERVANTS".

THE PARENT AUTISM LOBBY (DAVID HEATLEY, CHAIRPERSON).

A PRINCIPLED STAND BY AUTISM NI – THE COST.

NEED?

I can quote you figures from recent research carried out by the Voluntary Sector

80% of mothers experiencing high levels of anxiety through to 50% who are on long term anti depressant medication.

64% of adults with ASD live at home, 13% live on their own, and 25% are financially independent.

57% of adults with ASD have suffered depression, 65% anxiety and 34% mental health problems as a result of lack of support.

I can quote you prevalence figures from DENI....

5000 school age children with ASD (900 in 2002)

suspected prevalence rise of 1:100 to 1:60 within the past 3 yrs.

I can quote you targets set by DHSSPS regarding waiting lists for diagnosis.

I can remind you of the recent Judicial Decision regarding ASD services failures.

I can reference to the Committee the AutismNI Report cataloguing the hours spent on ASD statutory service reviews and strategies even prior to the current DHSSPS and DENI work.

I can reference to the Committee the DHSSPS funded University of Ulster report "An ASD Training Strategy for NI" written prior to the yearlong deliberations of the DHSSPS Action Plan on the self same topic.

I can encourage the Committee to consider the NI Assembly Research and Library Service reports on the pros and cons of strategies versus legislation in the NI context.

BUT....the conclusion remains the same! There has been more talk than effective action.

Prevalence rates increase by 500% and funding increases by 100%

HUMAN AND FINANCIAL COST.

I can quote you the work carried out in Australia, Canada and UK regarding the costs to the State of mishandling the issue of ASD set against the backdrop of the cost effectiveness of intensive early intervention and family support.

I can reference to the Committee the analysis completed by AutismNI - “Autism: The Costs”

But the reality remains - The cost of ineffective leadership and engagement on the issue of ASD in Northern Ireland is incalculable and shameful.

Wales, by comparison, has been ‘ASD informed’ and systematic and professional.....building upon existing expertise and not throwing the baby out with the bathwater and reinventing the wheel as we are in Northern Ireland under the cloak of service redesign.

All this means is pushing clinicians to rush through increasing numbers of diagnoses to meet targets adopted from Hospital environments (trolley waits etc)...and the result for ASD is incomplete or recycled or delayed assessments as quality of contact and diagnosis suffers.

We will address the human cost through the presentation of one single case story and if the Committee wishes we can elaborate on the detail in members questions afterwards.....this is one of many that lie behind the statistics referenced earlier.....Finn case study!!! (submitted to Alex Easton MLA, Acting Chairperson)

EQUALITY?

In addition to the APGA consultation and contact with the ECNI and Disability Action, I met this week with Brice Dixon and representatives from the NIHRC to progress mutual understanding on the purpose and need for the Bill to address the issue of equality for ASD within disability law. [The NIHRC questioned the selection of DHSSPS as the lead department in view of the need for all such legislation to be synchronised with the UN Convention on Disability under OFMDFM].

The UK/ROI –

DDA repealed and Equality Act introduced, definition of disability in ROI includes “sensory”.

N. Ireland debating still –

The Bill of Rights (NI)

Northern Ireland compliance with the UN Convention on the Rights of Persons with Disabilities.

The above developments will impact on ASD if ASD is “at the table”

The Autism Act (NI) will guarantee that ASD has a seat at the table.

Meanwhile, the DDA is the only show in town and it doesn't include ASD per se. It needs to be updated to take account of the changing world of disability as a greater proportion of our population are being diagnosed with ASD. Remember please, that in 1995 when the DDA was introduced, we had a couple of dozen children formally diagnosed with ASD, no training in diagnostic techniques and tools and only one or two professionals committed to the need for diagnosis.

So let's make a difference now. Why wait when we can make practical changes now to make services and benefits more accessible and less of a fight for families.

IMPACT FOR FAMILIES FROM THIS BILL.

DLA guidance use DDA definition of disability.

DSD regulations regarding housing adaptations (physical markers dominate).

DE discipline codes need to recognise “ASD behaviours”.

ASD Awareness for public and ASD training for public servants....e.g.Finn case study!! (submitted to Alex Easton MLA, Acting Chairperson)

ASD Service planning across departments and transitions.

Emotion impact of recognition.

DHSSPS ACTION PLAN & DENI FRAMEWORK.

Limited by lack of “buy in” from other departments.

DHSSPS ASD Strategy relies on medical not social model so balance of resources have gone to diagnosis not early intervention or family support.

DENI ASD Framework does not include an operational partnership role for the voluntary sector.

DHSSPS engagement model with non mandated carers and individuals with ASD is reckless....unsupported and unresourced.

IMPLEMENTATION OF THE AUTISM ACT (HOW?).

Leadership is crucial.

Respect is essential.

Secondment from Wales (MOU).

THE PARENT AUTISM LOBBY (DAVID HEATLEY, CHAIRPERSON).

I will shortly hand over briefly to David Heatley who will present his own perspective on the Autism Bill with evidence from the PAL parent mandate from across Northern Ireland.

A PRINCIPLED STAND BY AUTISM NI – THE COST?

AutismNI has remained constant to its political lobby dating back to 2001 and to its pledge in 2006 to campaign for ring fenced funding, a cross department strategy and legislative recognition for ASD.

Since 2008, AutismNI has been subject to threatened investigations and withdrawal of DHSSPS, Regional Board and HSCT funding as well as expulsion from the RASDN Reference Group – unless it “parked legislation”.

In 2010, those threats were directed personally towards the CEO and Director of Development.

In 2010, AutismNI won recognition of its principled, dignified and professional stand for social change from the Voluntary Sector when presented with the CO₃ Voyager Leadership award in Political Impact.

AutismNI may pay the ultimate price for this principled stand unless this position is reversed and relationships are actively reconstructed.

Submission by AutismNI (16.12.10).

Parents Autism Lobby

The Parents Autism Lobby is the parents voice from within the charity. We represent 30 groups across Northern Ireland, the list is on the sheet provided.

These Branches vary from perhaps ten members to much larger groups of over fifty members, a few have over one hundred members affiliated to them.

AutismNI has approx. 800 registered families(+agencies)who are members of the charity, but all branches also have families that have not formally “joined” the charity, but who would count themselves as members of the local group.

Therefore I can quite confidently say that PAL represents over 1000 families across Northern Ireland.

This mandate gives me confidence in backing every statement that Autism NI has made at this presentation.

I have been in very regular contact with the Branch/Support Group Network by phone and by letter.

I have personally visited almost half of the groups in person over the past nine months and have meetings set up for another five by the first week in February. In all my contacts I have had no parent, not one who thinks we would be better off without legislation.

So what do I hear:

Why has it taken so long?

Is it not just common sense?

We need joined up government

Services are terrible!

After diagnosis no one was there to help or explain!

Everyone is too busy to help me, I'm on my own!

Unless you live with Autism you can't possibly understand!

The branches I have mentioned before vary from some that are totally new and still being set up, to some branches that have been established for many years. The expertise within these branches is only surpassed by the expertise and professionalism of the AutismNI Staff Team, many of whom are also parents of individuals with ASD.

The very first Diagnostic Training in Northern Ireland took place in 1997. That training was set in place by AutismNI and was funded by the East Antrim Branch. Since then there has been training every year, thanks to AutismNI. In recognition of this, AutismNI was made an honorary member of the independent NI Autism Diagnosticians Forum, a grouping of ASD experts unique within the UK and Ireland. Most Diagnosticians and other experts in Autism within Northern Ireland have received much of their training through the charity.

Parents are very angry that the twenty years of work, expertise and partnerships that is AutismNI has been to a large extent overlooked in the past year and a half.

The AutismNI Lobby started in 2001.

AutismNI is a founder member of the Celtic Nations Autism Partnership and the Atlantic Autism Alliance.

In 2006 Northern Ireland was ahead of Wales in its aim for a National Autism Strategy...but politics got in the way.

Our parents, sadly, are used to being let down. So much has been promised in the past, seeds were sown, but the fruit never ripened, it withered on the vine.

Please make sure that this is not another blind alley.

The Autism Community desperately need this bill.

They are disadvantaged by a disability that is not recognised in law

Parents are already under unbelievable stress because of the very nature of the condition, and not only the parents but the siblings, the grandparents, the wider family circle, the carers and the schools.

This Bill needs to “Do What it says on the Tin” it needs to be strong and watertight. It needs to go through...

...If however it fails

...we will be back,

...we will not let it rest,

...we will lobby, lobby, lobby because we are so sure that it is the only way forward that can ensure equality for ASD.

Ballycastle Support Group: Ballycastle

Ballymena Support Group: Ballymena

Ballynahinch & Dromara Support Group: Ballynahinch

Brookfield Support Group: Moira

Castledearg Branch: Castledearg

Clifden Support Group: Bangor

Craigavon & Banbridge Support Group: Lurgan

Crumlin & Glenavy Branch: Crumlin

Down Branch: Dundrum

Dungannon & Armagh: Dungannon

East Antrim Branch: Ballyclare

Fermanagh Branch: Enniskillen

Helping Hands Affiliated Group: East Belfast

Hollywood Support Group: Hollywood

Lisburn Branch: Lisburn

Mid-Ulster Branch: Maghera

Newry & Mourne Branch: Warrenpoint

North Coast Branch: Coleraine

North Down & Ards Support Group : Newtownards

North West Branch: Londonderry/Derry

Omagh Support Group: Omagh

Peninsula Support Group: Kircubbin

Strabane Support Group: Strabane

South Belfast Branch: Knockbracken

South Down Branch: Newry

Tor Bank Partnership Group: Dundonald

West Belfast Support Groups (4):

Ballyowen Health Centre, Anderstown

Holy Child School, Anderstown

Good Shepherd Nursery, Poleglass

St Paul's School, West Belfast

Autism NI position on the Autism Bill (NI) 2011.

- **Clause 1.** - Autism NI supports the changes to the DDA. The inclusion of social and communication impairments in the definition of disability is a long overdue update to existing legislation and it will secure recognition of ASD and implement measures to achieve improved access to services, statutory benefits and public facilities.

AutismNI views the current “mental and physical” definition of disability to be discriminatory against ASD.
- **Clause 2.** – Autism NI supports the critical need for a cross department ASD strategy to establish lifelong service plans that ameliorate the particular challenges experienced by individuals with ASD across life transitions.

Autism NI is also mindful of the need to consult with, integrate and recognise the contribution of the Voluntary Sector and families they represent and assumes that as this is accepted best practice, this principal will be automatically integrated within any strategy in an efficient and time effective model.
- **Clause 2(2) and 2(7) and (8)** – Autism NI views this legal requirement on all departments to plan and implement the ASD strategy as an injection of much needed accountability and transparency into ASD planning and provision by government. Failure to comply becomes a matter for the Northern Ireland Executive to address.
- **Clause 2(3) and (4)** – Autism NI supports this measure and is mindful that DENI has been the lead agency in ASD data collection with more recent steps being planned by DHSSPS and therefore applauds the provision within the Bill for cross departmental data synchronisation as the basis for future planning across life transitions.
- **Clause 2(5) and (6) and (9) and (10)** – Autism NI supports the monitoring network outlined within these clauses that will provide the NI Assembly with the necessary information, access and mechanism to analyse and assess the need to introduce the currently deferred role of the Autism Advocate to arbitrate, investigate and advocate for individuals with ASD and their families. Autism NI regrets the omission of the role of an Autism Advocate to secure progress, consistency, effective structure and much needed respected leadership but respects the need to limit additionality in the current economic climate if possible.

- **Clause 3(1)** – Autism NI commends the recognition of the lifelong nature of ASD and interprets this clause as the commitment to the critical cross departmental planning process across life transitions.
- **Clause 3 (2)** – Autism NI is appreciative of the Bill’s prioritisation of the areas detailed to further clarify the more general clause above and to remind us of the need for placement of support services in the home, school and community. Furthermore Autism NI would be concerned about the critical gap regarding recognition of the overwhelming evidence that supports the effectiveness of early years intervention. Autism NI therefore puts on record, for the Bill implementation stage, the critical relevance of international and local research on the pivotal importance of quality accredited intensive early intervention practice models such as those profiled by Autism NI (Keyhole®), PEAT, SPEAC and CEAT.
- **Clause 3(3)** – Autism NI, founded upon the principals of community development, family support and empowerment, commends the Bill in drawing out legislative recognition of the support needs of families living with ASD.
- **Clause 3(4)** - Autism NI welcomes this legislative support for a government ASD awareness campaign across the community. Autism NI has over the past 20yrs led this critical work within existing resources, having established campaigns to build upon Autism Awareness Month (April) embracing the Cuppa-Aid events and the UN designated World Autism Awareness Day (April 2nd). Autism NI would welcome the opportunity to provide continuity and reduced duplication through the lead role in the continued evolution of this work.
- **Clause 3(5)** – Autism NI supports the need for a cross departmental training strategy as part of the strategy required under this legislation and therefore supports this clause. It is to be hoped however that this clause, requiring ASD training for civil servants, would fall within that remit. Autism NI would welcome consideration over the change from ‘civil servants’ to ‘public servants’ under the rationale that there are various levels of awareness and targeted training needed across all sectors likely to be in contact (to varying degrees) with people with ASD
- **Clause 3 (6)** –Autism NI recognises the lead role of the DHSSPS within the planned legislation and reinforced within this clause.

Summary comments:

Autism NI's relationship with the DHSSPS has suffered over the last two years as a direct result of a divergence of opinion regarding the role of legislation for ASD. Autism NI would welcome proactive intervention from the Minister of Health, Social Care and Public Safety in June 2011 to restore a positive working relationship and a recognised role for Autism NI in view of previous threats to funding and participation.

Autism NI would also welcome consideration by the Minister of Health, Social Care and Public Safety, of a Memorandum of Understanding with the Welsh Assembly Government in view of the Welsh experience in implementing a cross departmental mechanism for ASD. This would secure the required partnership assistance towards establishing effective implementation structures especially in the oversight of joined up and planned services across the transitions. Within this, a secondment of the current Wales ASD implementation officer would be an advantage.

NB. Autism NI is proud to be associated with the Autism Bill (NI) and is hugely grateful to Dominic Bradley, the APGA members and all the MLAs who have listened studied and acted.