



US Congressional Hearing:
31st May 2011

Sub Committee on Africa, Global Health and Human Rights.

Subject:

Global Perspectives on Autism – A Growing Public Health Crisis

Submission witness:

Arlene Cassidy (CEO, AutismNI)

Evidence on the status of ASD in Northern Ireland.

Introduction:

The autism movement in Northern Ireland began in 1990 with the establishment of AutismNI, in the midst of a prolonged period of civil conflict known as 'The Troubles' which left a well documented legacy of under investment in social and economic infrastructure.

The global autism awareness movement and the establishment of the autism societies in mainland UK and the Republic of Ireland in the 1960's and 1970's had had no impact. Northern Ireland remained isolated. This reality combined with the general social impact of the Troubles resulted in a deficit in strategic service development and expertise in ASD that is still being addressed today.

AutismNI therefore became a magnet for concerned parents and committed professionals from across all sectors as a source of support, information and as a catalyst for change. Many of AutismNI's achievements since have therefore been the result of innovative partnerships, across health, social care and education which have been driven by committed pioneers.

AutismNI reached out to autism experts in North Carolina, New York and the UK and as a consequence significant progress was made in the specific areas of assessment, diagnosis and early intervention underpinned by an active research partnership with the University of Ulster. AutismNI assumed a training accreditation and family support function, developing a family support network of 30 branches (or chapters) across the region as well as international links across the globe.

There has been an absence of government ownership and leadership regarding autism until quite recently. The result has been a real lack of strategic planning and resourcing of autism services across Northern Ireland.

The opportunity to address this deficit came with the end of Direct Rule from London and the introduction of devolved government to Northern Ireland with the setting up of the Northern Ireland Assembly.

The Current Need:

In 2010, AutismNI produced two research reports ("The Hidden Community" and "Is Anyone Listening") into the pressures experienced by families 'living with autism'. The following statistics are taken from those reports:-

- 80% of mothers contacted were 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 had suffered depression, 65% anxiety and 34% mental health problems as a result of lack of support.

In 2010, in evidence submitted to the NI Assembly Health Committee, AutismNI noted that despite a 500% increase in the numbers of school age children between 2001 and 2009, financial investment within health and social care had increased by only 100%:-

- Department of Education figures estimate 5000 school age children with ASD in 2009. The figure was 900 in 2002.
- In addition, Department of Health figures indicate a prevalence rise from 1:100 to 1:60 within the past 3 yrs.

The Current Provision:

In 2002, as a result of recommendations made within the Task Group on Autism Report, the Department of Education established a regional team of advisors and educational psychologists as well as the Middletown Centre for autism to support pupils with ASD.

This report was designed to trigger comparable investment from and joint planning with the Department of Health but failed to do so. One impact has been the under utilisation of the Middletown Centre resulting in an extremely negative report from the NI Audit Office regarding value for money measures.

In 2008, the Department of Health and Social Care, began the implementation of an ASD Strategy that includes engagement across all sectors. At the same time, the Department of Education announced a separate ASD strategy would be undertaken within their department.

Other government sectors have engaged with 'the autism issue' on a project by project basis which is frequently initiated by the voluntary sector. Examples include partnerships with the Department of Employment and Lifelong Education regarding EU or Lottery funded social enterprise and supported employment schemes.

There are a growing number of supported living/residential services for adults with ASD but these are largely crisis rather than strategic developments. Yet again the voluntary (non profit) sector is the key initiator.

The private sector has failed to establish itself in the provision of ASD services in Northern Ireland. This is largely the result of the under investment in terms of recognition of ASD as well as lack of funding and strategic planning by the statutory (public) sector.

New Innovative Developments in Northern Ireland:

It can be argued that the above catalogue of activity fits neatly under this title. However there is a huge opportunity opening up before us that has the potential, if carefully managed, of putting the last 9 years of government interest in ASD in the shade.

The Autism Act (NI) 2011 now commits the Northern Ireland government to the establishment of a cross department strategy for ASD and with this, the legislation also, registers autism under disability legislation protection for the first time. The equality and human rights issue addressed at last to ensure ASD is recognised and on the government agenda for change alongside other conditions. "Autism has come in from the cold"(Dominic Bradley MLA during the final Assembly debate on the then Autism Bill)

The Autism Act is truly significant for Northern Ireland in addressing the historic lack of strategic cohesion but is also a beacon for the wider global ASD community because it.....

- is the result of a 5 year lobby partnership led by Autism NI working with the All Party Group on Autism (APGA) at the NI Assembly and supported by the wider Autism community across NI.
- supersedes the English Autism Act (2010) as the most comprehensive and progressive legislation for Autism across the UK and Ireland.
- is equality and rights based, bringing entitlements for people with Autism into line with the rest of the disability sector.
- is the first legislation binding all government departments to plan, cooperate and implement an agreed strategy and services for individuals with a disability.
- sets in place a system of scrutiny and accountability that is overseen by the NI Assembly.

The impact for families can be significant because the Act will.....

- by implementing changes to DDA, impact with the removal of the IQ score of 70+ as a barrier to accessing services.
- by implementing changes to DDA, clarify the legal basis for discrimination cases regarding Autism in the areas of, for example, employment and benefit entitlement.
- by implementing changes to DDA and creating an Autism awareness campaign, improve public knowledge and understanding of the condition, potentially reducing isolation felt by families living with Autism in their local communities.
- bring a legal basis for the recognition of Autism and an end to the denial of the condition by certain professions.
- require all government departments to plan together for Autism for the first time ever. The government strategy will mean that some government departments will be contributing to Autism services for the first time.

Key Influencers:

In the introduction to this evidence there was an acknowledgment of the establishment of devolved government to Northern Ireland and across the United Kingdom.

Within the ASD voluntary (non profit) sector this has seen the emergence of a greater sense of national identity, common purpose and cooperation as is witnessed by the work of the Celtic Nations Autism Partnership (CNAP) www.celticnationsautism.eu.

In 2006, the achievement of Autism Cymru and the Welsh Assembly Government in working together to implement a national ASD strategy inspired AutismNI to campaign for similar cohesive cross sector planning for Northern Ireland.

In 2007, assisted by the NI Bureau and the Autism Society of America (ASA), a cross community delegation of NI Assembly political representatives (led by CNAP) met with Congressman Smith and Congressman Doyle (as Co-Chairs of the US Congressional Autism Caucus) and the final piece of the jigsaw fell into place as the role of legislation to effect social change for ASD impacted upon the Northern Ireland delegation.

With the signing of the ASD Memorandum of Understanding (MOU) between Congressional and NI Assembly Representatives, began an affinity which was made tangible by the immediate establishment of the All Party Group on Autism (APGA) at the NI Assembly and the ongoing desire to bring the full aspiration of the MOU to fruition.

AutismNI has maintained its liaison role between the ASD community, the APGA and CNAP to inform and empower the campaign for the recognition and establishment of equality and human rights for individuals with ASD in our community. This is now embodied in the aspirations attached to our fledgling legislation.....the Autism Act (NI) 2011.

It therefore is a great source of pride to us that the example of this achievement (set within the unique context of Northern Ireland's history) is beginning to influence discussion in Wales, Scotland and the Republic of Ireland over the precedent set by the NI Assembly to address inequalities within UK disability legislation.

Arlene Cassidy
CEO – AutismNI

www.autismni.org
27th May 2011

The Political Viewpoint re ASD:

Extracts from Party Manifestos - NI Assembly Election 2011

DUP:

- “Conduct a value for money review of the Autism Centre at Middletown.
- Overhaul the Regional Autistic Spectrum Disorders Network and speedup diagnosis and intervention for autism.
- Further improve the processing system to take greater account of, and show more sensitivity to, the difficulties experienced by people with conditions such as autism”.

SDLP:

- “SDLP MLA Dominic Bradley brought an Autism Bill through the Assembly. This legislation will ensure government plans holistically and realistically for the future needs of people with autism, their families and carers. We made sure that all parties signed up to the SDLP’s Autism Act. This groundbreaking piece of legislation will ensure that people with autism, their families and carers now have access to the full range of services they require throughout the course of their lives. We will support the new developments in safeguarding children and encourage Trusts to continue developing family support services for children in need. In particular, we will emphasise the continuing necessity for respite care for children with learning needs and children with autism”.

Alliance:

- “The Alliance Party supports the Autism Act. The views of people with autism and their carers should influence policy across all departments. The full range of appropriate services and easy access to mainstream services should be available in a timely on-going manner. Awareness training for staff and the public in all settings and earlier detection, intervention and support would enhance the experience of people with autism and their carers. Agreed referral and care pathways are required including seamless transition between child and adolescent mental health and adult mental health services. Support systems for parents, families and other carers are crucial including resourcing for parent groups”.

Historic Commitment:

Final Assembly Debate on the Autism Bill (March 2011)

DUP:

- “We are proud that the DUP have supported the Autism Bill (NI) from the outset and are delighted that all major parties saw how morally right this was.” Jonathan Craig MLA, Ian McCrea MLA and Alex Easton MLA

Sinn Fein:

- “Sinn Fein welcomes this Bill reaching the final stage of the process. It will create a legislative framework to develop a strategy for those on the Autism spectrum who have previously fallen between two stools.” Michelle O’Neill MLA

SDLP:

- “The Autism Act (NI) 2011 now supersedes the ‘adult services only’ focus of the Autism Act (England) 2010 and becomes the most comprehensive and equality based law for Autism across the UK and Ireland. The NI Assembly has truly come of age in having the vision to identify and address a longstanding gap in our disability sector.” Dominic Bradley MLA

Alliance:

- “This is a vital first step but families need to know their new rights under the law and the real impact this will have. This battle was not won overnight and it was waged against massive ignorance and reluctance to recognise Autism. The work to activate the potential of this new law will be just as vital and I have no doubt that Autism NI, once more, will be at the forefront in ensuring that people with Autism in Northern Ireland and their families no longer get second rate consideration. They are to be congratulated for their selfless work on this new law.” Kieran McCarthy MLA