



# A Review of ASD Strategies and Practice

ASD in Northern Ireland:  
Past and Future Directions:

November 2006





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## Introduction: Measuring the Challenge

Since 2002, the identified number of school age children in Northern Ireland with an Autistic Spectrum Disorder (ASD) has more than trebled from 1,000 (Task Group on Autism figures) to almost 4,000 (Dept of Education figures). This matches a worldwide trend of diagnosis of ASD and is vindicated by new research indicating an increase in the prevalence of ASD.

The latest prevalence rates for ASD in the USA and UK concur at 1 per 100-150 of the population. Research by Baird et al (2006) indicates a prevalence rate of 1 in 86. It is worth noting that only 4 years ago the statistic of 1 in 1000 was widely quoted; thus there has been a significant increase in prevalence rates in Northern Ireland and worldwide.

The alarming rise in numbers of individuals with ASD has been referred to as an “Autism wave” moving through our schools (DENI Task Group on Autism, 2001 p. 88) and as “Tomorrows Big Problem” in the social care field. (Morgan, 2002).

Parliamentary questions tabled throughout 2006 by Lord Maginnis of Drumglass illustrate the nature of this “Autism Wave”.

The number of children in each of the former Northern Ireland Health Board areas suspected of having ASD and awaiting initial assessment are detailed below:

Health Board Area	Number of children on waiting list
Eastern	253
Northern	117
Southern	128
Western	188
Total	686
<b>Maximum wait for diagnosis</b>	<b>35 months</b>

(Ref Hansard Vol 680) This bleak statistic of a 35 month waiting time for children with suspected ASD is made all the more intolerable with the indisputable fact that early intervention is the key to improving life for children with ASD.

Notwithstanding this, there have been strategic developments, research and policy review affecting the status of ASD in Northern Ireland throughout the years. The purpose of this report is to briefly review these developments and research to provide a context for decision makers, and service planners in Northern Ireland.

The following chapters will be organised chronologically reflecting the rootless nature of policy development without the compass of a strategy and a vision for ASD legislation.

This document will set out the research conducted in Northern Ireland that has guided some of the strategic development; and also the strategic developments, and policy documents and service developments pertaining to ASD in Northern Ireland.

## Chapter One: The Backdrop to Change

### The Voluntary Sector

Throughout the world, the emergence of voluntary action and the formalising of this into the creation of National Autism Societies has always acted as a catalyst of social change – the enhancement of specialist expertise and the development of a range of services. The Voluntary Sector has always been in the vanguard of ASD provision and the lobby for a co-ordinated strategy and a legislative foundation.

It has been noted that Autism services in Northern Ireland have also been a victim of the “Troubles” in Northern Ireland. When other national ASD charities were formed in the 1960s the voluntary response to ASD in Northern Ireland got off to a sporadic start. The first voluntary organisation for Autism in Northern Ireland was founded in 1977; however it did not flourish in the civil and political turmoil of that time; it was only in 1989 when a group of concerned parents and professionals began to gather in a parent’s front room in Lisburn that the national charity for Northern Ireland began to gather momentum; this was the seed planted by local people in Northern Ireland which grew into Parents And Professionals and Autism (PAPA), which later evolved into Autism NI.

Today there is a growing variety of Autism organisations operational in Northern Ireland; some general Learning Disability and/or children’s organisations that have developed a speciality in ASD service provision for example Barnardos and other organisations dealing with specific issues, diagnosis, interventions, and geographic area. Autism Initiatives, anxious not to duplicate the work and role of Autism NI (PAPA) have played a major role in developing adult support services in Northern Ireland. There is no doubt many of these groups exist in an atmosphere of tension, competition and replication; which is a regrettable distraction from the work that needs to be done, and a reflection of the historically directionless nature of service planning, and lack of accountability for ASD. Chapter Two will profile the range of organisations that have, by focusing on the provision of ABA (Applied Behaviour Intervention), influenced ASD practice and increased the profile of ASD in Northern Ireland.

### Research Response (Pre 2002)

Research conducted by Howlin and Moore in 1997 recorded parental views of ASD service provision throughout the UK. The study reports high levels of dissatisfaction amongst parents in Northern Ireland. This dissatisfaction was primarily with diagnosis and access to diagnosis. The study reports that children in Northern Ireland received a later diagnosis than their peers throughout the UK. The study notes that parents in Northern Ireland experience long delays in receiving diagnosis, and a tendency to receive a diagnosis of “Autistic Traits”. Numbers of families seeking a diagnosis in Northern Ireland were so small in the research that the numbers were combined with the Isle of Man and Cumbria and still this made up a tiny percentage of the overall number. Families living in Northern Ireland are referred to as “isolated”.

In the 1990s in Northern Ireland, services had much to do, not just in terms of diagnosis but in raising awareness of ASD amongst the general public so that parents could be aware of potential “bell ringers” in their child.

During this time ASD was part of children's disability and there was little or no specialism in ASD in Northern Ireland. However the recently formed PAPA was beginning to lobby the DHSSPS to commission some research into ASD. The following research pieces were commissioned by the DHSSPS and conducted by PAPA and the University of Ulster. They represent the very first research into ASD in Northern Ireland, and also signify the time when statutory services in Northern Ireland began to acknowledge the unique and complex nature of ASD.

### **Northern Ireland Evaluation of TEACCH (1994/6)**

This was the first piece of research commissioned by the DHSSPS for ASD in Northern Ireland. This came about directly as a result of the PAPA lobby to provide specialised training for professionals working with individuals with ASD in Northern Ireland. This recognised ASD specialist educational intervention as vital and opening the door to the integration of such approaches into special and mainstream education and adult day care provision.

The research makes 15 key recommendations which can be condensed into three broad points:

1. Further investment in TEACCH for individuals and families with ASD in Northern Ireland.
2. Address gaps in service provision for home based programmes, education, training and more effective dissemination of knowledge throughout Northern Ireland.
3. Organise local TEACCH teams with local TEACCH co-ordinators.

### **Northern Ireland Diagnostic Scoping Study (1997/8)**

This research was commissioned because parents were experiencing acute problems accessing diagnosis for their children in Northern Ireland. The report identified the deficit in diagnostic expertise and quantified the increasing demand with the following recommendations:

- Parental access to information on diagnostic services, professional support and a comprehensive range of training opportunities
- The development of explicit referral routes between families, primary care teams, education, child development services and specialist diagnostic services for people with ASD
- Introduction of an inter agency co-ordinated approach to care assessments / action plans and service responses for persons with ASD
- Provision of a multi-disciplinary awareness programme supported by access to professional development programmes designed to promote competence in ASD
- Improve the co-ordination and efficiency of local diagnostic services for people with ASD
- Enhance and improve the range of services provided by local child development centres and the establishment of a centralised Northern Ireland diagnostic service
- Close working relationships between local and centralised diagnostic services

### **Keyhole® Early Intervention (ASD) Research (1999/02)**

The Keyhole® project aimed to design, develop and implement an holistic approach to interventions with families who had pre-school children aged between two and four years. This included a home based teaching service; training courses for staff and support

groups for parents. The project was externally evaluated by the University of Ulster and key recommendations for future action are identified:

- Early referral to specialist teams
- Home based intervention
- Pre-school provision
- Training of community personnel
- Training and support for parents

### **The Task Group on Autism Report (2001/02)**

Commissioned by the Department of Education Northern Ireland this was a review a review of ASD prevalence rates, existing provision, best practice models and making recommendations for future service development within a strategic context.

- Access to multi-agency, multi-disciplinary diagnostic and assessment services
- Training for parents, or and people who work with children and young people with ASD
- School based and home based educational and therapeutic provision

### ***Impact of Research (Pre 2002)***

*The impact of these fledgling research pieces has been far reaching. TEACCH training is now widely available throughout Northern Ireland and is now considered a fundamental element of training for any professional working in ASD in Northern Ireland. In 2004 Autism NI (PAPA) delivered the first TEACCH training designed specifically for parents.*

*The Keyhole® project gave birth to Northern Ireland's own unique model of Early Intervention and later to the development of a pre-diagnosis resource kit, and models of parental support. Keyhole® is now available in 3 Health and Social Care Trusts and currently being integrated in the remaining 2 Trust areas of Northern Ireland.*

## **Research Response (Post 2002)**

### **Keyhole® Connecting with Autism Research (2003/06)**

An extension of the previous Keyhole® project and the first example of Action Research making a difference in Northern Ireland – designing, piloting and developing the Rainbow Resource Kit (a backpack of booklets/tasks/toys for home intervention). The kits are now being distributed world wide.

### **Keyhole® Western Autism Programme Research (2004/06)**

In 2004 Autism NI (PAPA) and the WHSSB developed a partnership to deliver the Keyhole® Early Intervention Service in the WHSSB area. This was funded by the Northern Ireland Children's Fund. The project was so successful it has been extended into 2008 and an evaluation by the University of Ulster on the project 2004/07 has been completed.

## **Evaluation of the Need and Early Intervention Support for Children (aged 2-4) with an Autistic Spectrum Disorder in Northern Ireland (2006)**

Commissioned by DENI and conducted by Autism NI and the University of Ulster the research was involved with reviewing existing provision, identifying best practice models and analysing the status of Strategic Planning in Northern Ireland for ASD. The report produced some interesting statistics and recommendations, which are far reaching. A summary of these recommendations:

Education, Health and the Voluntary sector must make an integrated response to the needs of children and their families. Particular members of staff should receive particular specialised training in certain areas and act as a source of good practice and consultancy for other staff members. Children should be able to access help without a diagnosis. A service spokesperson from either Health or Education should be appointed in each area.

- Multi-disciplinary assessment should be available to all within 4 months of referral; a dataset of children diagnosed should be developed and an individualised plan should be available for all parents.
- Children with suspected ASD and developmental delay should be seen as early as possible, where possible before their 3rd birthday.
- Personnel should be able to implement practical strategies to help the child and parents. Regular service audits should be implemented with input from parents.
- Home based support should be available as should training on communication strategies i.e. PECS. Parent's needs should be a primary focus at times.

Primary healthcare workers and front line early years staff should all have a greater awareness of ASD. Parents and families should be provided with helpful, accessible material about ASD and how to help with behaviours. Three levels of training from specialist to fundamental should be available.

The report concludes that a "strategic push" (p.52) is required to fully implement these changes.

## **Evaluation of the Need for a Northern Ireland Training Strategy for ASD (completion 2007)**

This research is involved with reviewing existing provision and projected need in training in Northern Ireland and was commissioned by the DHSSPS and is being conducted by Autism NI (PAPA) and the University of Ulster. The findings, anticipated in December 2007, will make a powerful contribution to ASD strategy in Northern Ireland.

### ***Impact of Research (Post 2002)***

*The trend is apparent. Successful research partnerships between Autism NI and the Statutory sector in Northern Ireland have resulted in action research followed by real and tangible change.*



*Throughout the developments listed above Autism NI the national charity was growing and support groups and branches were being formed at the rate of one or two per year. This resulted in:*

- Increasing awareness, access to information and peer support which led to parent empowerment resulting in the accelerated development of the Autism NI (PAPA) regional Branch Network and the establishment of the first of a number of parent led organisations dedicated to specialist service provision.*
- Models of best practice, linked to the Research referred to above, being developed during this period – driven by the dedication of individual professionals and funded out of “existing resources”. There was an inevitable and critical impact upon staff workload and existing budgets for Learning Disability Services which carried most of the burden for the accelerating need for Autism provision.*

*It was recognised that “Tomorrow’s Big Problem” had arrived early!*

***It is worth noting that the support and vital expertise of a range of statutory and voluntary agencies was key to the development of the work and the integration of the findings of the above research into mainstream services e.g. Down and Lisburn Trust/ SEELB/ Barnardos/ Homefirst HSS Trust/ WHSSB / SHSSB.***

## Chapter Two: Developments in ABA Provision

Voluntary organisations working specifically with Applied Behaviour Analysis (ABA) have also had a major impact on service provision in Northern Ireland. The main ABA groups have all had their individual milestones which have significantly changed the complexion of service provision in Northern Ireland.

### Parents' Education as Autism Therapists (PEAT) NI

Was formed in 1997 and initially was based in the University of Ulster in Coleraine; however it has stretched out from an academic base to provide specialist ABA intervention, support and advice to parents in Northern Ireland. PEAT has hosted some of the major names in ABA in the world in Northern Ireland. In 2005 PEAT produced a handbook of ABA (JKP Publishing) and delivers a variety of home based and educational courses on ABA. PEAT pioneered and now deliver an MSC course in ABA at the University of Ulster and has developed an educational CD-ROM for parents and professionals interested in ABA. PEAT also organises recreational and social activities for children and their families.

### Centre for Early Autism Treatment (CEAT)

CEAT was formed by professionals qualified in education and ABA in 2004; it develops and delivers a range of specialised individualised and systematic ABA interventions for families in Northern Ireland. CEAT operates out of their centre in Belfast and employs a range of ABA and education specialists to work with children and deliver ABA intervention.

### Special Provision for the Education of Autistic Children (SPEAC)

SPEAC provides the first ABA specific unit in a school in Northern Ireland. This centre is based in Tor Bank School and is a pioneering partnership between the SEELB and SPEAC in Northern Ireland. The service delivery is based upon the successful TreeHouse School in London. The Centre is staffed by individuals trained in the delivery and science of ABA and children are selected by an agreed criteria; SPEAC also delivers an outreach programme to promote and disseminate the programme and deliver training in communities throughout Northern Ireland. It is the ambition of SPEAC to have an ABA school in Northern Ireland.

### The Impact Trust

The Impact Trust and the Impact Centre for Learning and Development is committed to changing the lives of children with ASD using ABA in the Impact Centre. Impact was pioneered by parent Kate McVeigh in Ballygawley Northern Ireland. Kate's dedication in setting up the Trust was acknowledged by the Beacon Trust who recognise individuals chosen for their exceptional philanthropic contribution through the giving of their time, money and skills in order to benefit specific charitable causes and who join the ranks of previous winners such as Sir Bob Geldof, Jamie Oliver and environmentalist, Zac Goldsmith, all of whom have all been recognised for their charitable work through what has become known as the 'Nobel Prize of the charity world', first coined by Chancellor Gordon Brown.

Chair of the Beacon Fellowship Charitable Trust, Martyn Lewis notes: “Kate is an example of how just one person, touched by tragedy can grow through determination and experience, to become a source of support and advice to hundreds and possibly thousands of people who share a similar life changing experience. The reassurance and knowledge Kate has passed on to so many families through the Impact Trust has enabled countless children with Autism to develop and grow in a way most parents would never have dreamed. Kate has vastly raised awareness in Northern Ireland where there is now a far wider understanding of the challenges of Autism”.

Kate was instrumental in bringing over experts in ABA to Northern Ireland who then set up the Centre for Early Autism Treatment (CEAT) profiled above.

## Chapter Three: The Political and Strategic Context

In response to the identified building tension between families and services over the deficit between supply and accelerating need, Autism NI (PAPA) developed a specific strategy which it launched in 2002 building on the evidence of need extracted from The Task Group on Autism Report:-

- The building evidence of need had to be communicated directly to Government – proving the need for ASD specific service structure.
- The need to lobby Government for a regional, cross Departmental ASD Strategy to avoid the waste of duplication, make best use of existing resources and identify new funding sources.
- The campaign to secure future provision within a policy and legislative context – The Northern Ireland Autism Act.

### Political Action, Strategy and Funding for ASD

The following tables illustrate the correlation between political activity, strategic planning and access to new funding sources:

**Table 1 (2002 – 2004)**

Political Action	Strategic Developments
2002 Autism NI lobbies the NI Assembly	Task Group on Autism launched ASD (2001 – 2002) – funding secured. Minister of Education announces the establishment of the Centre of Excellence for Autism at Middletown, Co Armagh (referenced below)
*NI Assembly hold 2 debates on ASD (see below)	DHSSPS support and fund Autism NI's Training Agency development. WHSSB/ Autism NI set up "Autism West"
NI Assembly Autism Ambassadors appointed	DHSSPS Priorities for Action (2003/04) – ASD funding secured
NI Assembly Committees/Ministers briefed on ASD	4 Board paper on ASD provision (early years only)
	SHSSB Strategy for Children with ASD – funding secured
	DHSSPS Priorities for Action (2004/05 ASD funding continued)

## \* NI Assembly: Autism Debates

### 1. 23rd April 2002 Motion proposed by Joe Byrne SDLP – passed unanimously

*That this Assembly calls on the Minister of Health, Social Services and Public Safety to introduce a training programme for Health Visitors, School Nurses, Keystage 1 and Nursery School Teachers to facilitate the early detection of autism and to make adequate provision in collaboration with the Department of Education to meet the needs of autistic children.*

### 2. 10 September 2002 Motion proposed by John Fee SDLP – passed unanimously

*That this Assembly calls on the Ministers of Education and Health, Social Services and Public Safety to instigate a comprehensive review of the services provided for people, adults and children, with Asperger's syndrome and the training of professionals specialising in the treatment of such individuals.*

## Centre of Excellence for Autism in Middletown Co Armagh

In April 2002 the then Minister for Education Martin McGuinness announced that a cross Border “Centre of Excellence” for ASD was to be established in Middletown Co Armagh.

“The work of the Centre will focus in particular on research, training of teachers and other professionals, and the development of guidance and advice on good practice in diagnosis, assessment and approaches to working with children with Autistic Spectrum Disorders”.

(DENI Press Release: 11 April 2002 [www.archive.nics.gov.uk](http://www.archive.nics.gov.uk))

The centre was planned to be opened in October 2003, however there have been prolonged complications attached the site. A Board of directors and key staff were appointed in early 2007; it is anticipated that the centre will now open in 2008. The centre will have a residential facility, gym and pool, and will provide expertise on all aspects of ASD for families and professionals throughout the Island of Ireland.

There have been detractors from this proposed facility. Many within the ABA lobby express their desire for an ABA school; or for the centre of excellence to have some presence of ABA within the remit.

Others question the logistics of the location and the ambitious remit of the centre; some public representatives have called for a series of centres of excellence throughout Northern Ireland.

**Table 2: (2004 – 2007)**

<b>Political Action</b>	<b>Strategic Developments</b>
NI Assembly in suspension	DHSSPS Priorities for Action (2005 – 2006) – funding suspended
	Bamford Review struggles with understanding/addressing ASD
	DENI publish “Evaluating Provision for ASD in Schools”
	DENI continue to implement ASD Action Plan from Task Group
2006 NI Transitional Assembly set up	
Autism NI lobby the Transitional Assembly	
NI Assembly Pledge for Autism (Jan 2006)	
Westminster: Early Day Motion for Autism NI (Jan 2006)	Autism NI secure Speaking Rights at WHSSB Executive Board meeting
Whitehall: Launch by Sec of State of Autism Cymru and Autism NI partnership (Mar 2006)	WHSSB agree ASD as a key funding priority and ASD Strategy
NI Assembly “Sign up for Legislation” campaign	Autism NI secure Speaking Rights at NHSSB Executive Board meeting
Autism NI Programme of ASD briefings	NHSSB begin ASD Service Framework
	DENI/UU/Autism NI Review of Early Years and Strategic Planning
	NICCY Review services for young people with AS
2007 NI Assembly Debate in support of NI Autism Act	Autism NI lobby EHSSB regarding Strategic Plan for ASD

## The Celtic Nations Autism Partnership

In March 2006, Autism NI and Autism Cymru formed a strategic partnership to exert pressure on their respective devolved Governments to establish clear policies and specific strategies for ASD. Northern Ireland has already benefited from this partnership and it has secured the support of leading political figures in Northern Ireland and throughout the UK to strengthen its existing political lobby. In June 2006 the Scottish Society for Autism joined the partnership and the Celtic Nations Autism Partnership was established – to promote exchange of best practice across the nations and mutual support for the campaign for legislation for ASD. In 2007, The Irish Society for Autism will be invited to become part of the partnership. The partnership continues to grow, hosting regional launches through the member nations and engaging government departments in the Autism debate. A delegation from the partnership as well as political and public representatives will soon begin a series of fact-finding missions, linking with colleagues in other jurisdictions who have already secured legislation for ASD.

## Analysis of ASD Strategies in Northern Ireland

This review will not analyse UK wide Strategy documents as this would repeat the process and practice of the Northern Ireland Strategies referred to below. A list of key UK strategies can be found in the literature reviews of the specified Strategies:

### The NI Task Group on Autism Report

The NI Task Group on Autism Report of 2002 was the catalyst for operational development within Education and was the base-line which informed successive strategy documents from the Health and Social Care sector.

- The Task Group's prevalence study remains the most comprehensive government data collection exercise carried out in Northern Ireland and it identified the critical rise in the numbers of children with ASD in Northern Ireland.
- The Task Group Report recommendations regarding early diagnosis and intervention, social skills training, sensory issues, multi agency and multi disciplinary assessments, parental involvement and training etc are standards that are reflected in subsequent strategy papers.
- Resources were secured to implement key recommendations and the ongoing postcode lottery of provision has been addressed somewhat by the appointment of a special ASD educational psychology service linked to the expansion of ASD advisory teams, the development of an early year's curriculum and an acceleration of ASD training provision.
- Less successful has been the efforts to implement cross departmental liaison and progress within DEL to push forward post 16 provision.

Models of best practice highlighted by the report were Autism NI's work on training provision and the partnership with Down Lisburn Trust, SEELB and Barnardo's on early year's provision.

The consultation process was extensive across all sectors and Autism NI was a member of the Task Group.

## **The NI Review of Mental Health and Learning Disability (The Bamford Review)**

The Bamford Review set out to do the following in the context of Learning Disability and Mental Health Services in Northern Ireland:

*“To work towards a set of recommendations which contain the best practice, policy and legislative perspectives.*

*To anchor our recommendations in a broad financial and economic context.*

*To make recommendations on workforce implications.*

*To make recommendations on the effective management of services.*

*To keep all stakeholders fully informed of the progress and directions of the Review.*

*To ensure that user and carer partnership is intrinsic to the Review at all stages.”*

Despite the high emphasis placed on consultation and user involvement within the Bamford Review – the extensive remit of the Bamford Review and the selective nomination of Committee members resulted in an enduring lack of understanding about Autism and little appreciation of the policy or strategic issues needing to be resolved.

Representations by Autism NI, scores of letters from parents, intervention from local politicians and individuals with ASD elicited a consultation workshop. The workshop report was not an accurate record of the conclusions reached as the Review Steering Group had, at a later date, introduced the controversial recommendation to place “the organisational responsibility for autism” within the Mental Health programme of care.

The final months of the Bamford Review witnessed an unprecedented protest from parent groups and statutory agencies. The Autism workshop report was amended twice and the Secretary of State, Peter Hain, was moved to intervene to restore ASD to the temporary caretaking of the Learning Disability Programme of Care.

The Bamford Review’s most meaningful recommendation for Autism refers to the identification of an ASD coordinator in each provider unit. However, many questions remain unresolved and an opportunity has been wasted.

## **The SHSSB Children’s Autism Strategy (2005)**

The Strategy was deliberately child focused in order to target scarce resources as efficiently and as effectively as possible building upon expertise that SHSSB had already pioneered and developed within “existing resources” and through the personal commitment of key professionals and parents.

The Strategy was specifically informed by an earlier service evaluation conducted by Prof Roy McConkey and was based upon the mainstreaming of the Keyhole® early years methodology.



The document reflects provision across the statutory and voluntary sectors at the time and identified the pressure upon waiting lists for diagnosis and difficulties in recruitment of specialist staff.

Specifically, the SHSSB Strategy outlines a commitment to the development of diagnostic and early intervention provision and subsequent investment in these areas is evident from the expansion of the relevant teams as well as the appointment of ASD Family Support Workers and a partnership with Autism NI in the provision of models of family support and training.

The Strategy references the development of the Child and Adolescent Mental Health Service and the appointment of an Intervention Therapist for children receiving a diagnosis of ASD when they are older. This need for “rapid” rather than “early” intervention was a recommendation of the Task Group Report.

The SHSSB Strategy was written within the context of the DHSSPS income stream from Priorities for Action targeted to early years diagnosis and assessment. In addition, SHSSB’s commitment to the Strategy ensured that provision for ASD was also written into their successful funding proposal for DHSSPS Wraparound Funding and ongoing monitoring of the Strategy recommendations is facilitated.

### **The Four Board Paper**

This document was compiled without external consultation in response to an action detailed in DHSSPS Priorities for Action.

The focus was limited to the provision of assessment and diagnostic services in early years.

Each Board detailed current unequal provision and proposed an agreed model of delivery within a specified budget set by DHSSPS.

The challenge that emerged for all Boards was that only a half of the originally proposed budget became available for year one and the additionality for year two was not provided. (Priorities for Action funding)

Lack of consistent development funding added to the unequal provision across Boards and held back strategy-led service development at a critical time

### **WHSSB ASD Strategy “Spectrum for Change” (2006)**

WHSSB agreed to initiate a Strategic Review and to prioritise ASD for funding following a lengthy 3 year lobby culminating in a presentation to WHSSB Executive Board by Autism NI professional and parent representatives.

This Strategy was an ambitious undertaking in terms of remit and the allocation of a 6 – 9 month completion period.

Extensive consultation across all sectors was implemented at key intervals.

This is the first whole-life Strategy for ASD in Northern Ireland.

The Strategy reviewed current provision, models of best practice (Keyhole early years intervention/Autism Initiatives adult support service) and the contribution of the voluntary sector in the provision of models of family support and training.

Standards and Principles were drawn from user consultation as well as Northern Ireland and UK wide strategy documents e.g. National Autism Plan for Children (NIASA).

In common with the SHSSB Strategy, the WHSSB document recommends ongoing monitoring and connects its key service recommendations to a phased service development model linked to a specified budget.

As with the SHSSB Strategy, the process has secured a higher priority in securing funding for ASD services. In this case the funding streams are Health and Well-being and the Children and Young People's Package.

The WHSSB document is distinctive in its dedication to detailed, longer term planning in the form of aspirational goals within 10 Key Themes identified through user consultation. This will enable WHSSB/WHSC to update the Strategy without having to re-create detailed foundation principles.

### **NHSSB Framework for Autism Services (pending)**

It is too early to comment on this project which was initiated, following an Autism NI (PAPA) presentation to the Executive Board of NHSSB.

## **Comparative Analysis: A Summary**

The need for a policy led, cross- Departmental, regionally co-ordinated Strategy for Autism services is evident from a critical analysis of existing Northern Ireland Strategic documents:

- Existing strategies are weighted towards operational issues without the detail required by operational workplans.
- Most of the strategies struggled to engage the commitment of the Education sector to the process. This could be attributed to lack of pre planning time caused by the urgency to use the strategic planning process to access funding to meet an already identified need. This reflects the operational bias referred to above.
- The emergence of a number of the strategies as a direct consequence of lobbying activity by individual parents and by Autism NI is evident. In SHSSB a parent presented the case for Autism directly to the SHSSB Executive Board and achieved agreement for a co-ordinated review of services within a strategic context. This initiative was picked up by Autism NI and achieved the same success with Western and Northern Boards.

- The correlation between Strategy development and an increase in the prioritisation of Autism for funding perpetuates the need for lobby activity.
- The reluctance by DHSSPS to view the emergence of these strategies as evidence of need, perpetuates a culture of duplication and inefficient and uneven allocation of resources across Northern Ireland.
- The identification of best practice models of service across the strategies is a useful basis for future service development. However the absence of an EHSSB Strategy prevents the accurate profiling of locality based models of best practice such as Barnardo's Forward Steps and Positive Futures' Supported Living Service as well as services such as the social skills groups facilitated by Autism Initiatives and Autism NI.
- A regional ASD Strategy would, by implication, have to be framed within the context of the ever evolving Review of Public Administration (RPA). This would facilitate the long overdue debate regarding the placement of ASD and the service structures required to address a disability which does not fit within any of the pre-existing programmes of care. In view of the indecision illustrated by the Bamford Review in producing three different versions of the ASD report and in light of the previously identified service challenges, this seems to be the most rational way forward.
- Above all it is imperative that service provision and entitlements are protected by legislation.

*In 1978, The Warnock Report provided the rationale behind the closure of ASD schools in England in order to promote social inclusion within mainstream schools. In 2005, Baroness Warnock publicly admitted that "there is clear evidence that it does not suit every autistic child". Between 1978 and 2005 how many children with ASD suffered?*

*The Bamford Review could have consigned ASD provision to the programme of care (Adult Mental Health) which has yet to secure funding and service structures to develop its expertise and treatment plans for ASD.*

This is clear evidence that Autism is vulnerable to periodic policy and strategic reviews and that legislation must be the gatekeeper for the Autism provision.

## Chapter Four: Recommendations and Conclusions

- The findings of this Review support the correlation between political activity and strategic development for Autism. This highlights the vulnerability of the strategic planning process and supports the need for legislation as a driver for policy change and regional strategy as in Sweden and the USA.
- This Review also identifies the critical impact when DHSSPS Priorities for Action funding and policy for ASD faltered. The need for action on a regional scale was subsequently vindicated with the emergence of ASD strategies at Board level. However, it begs the question as to whether this level of uncoordinated effort and duplication can be reconciled to the aspirations of consistency across structures – promoted by the Reform of Public Administration (RPA).
- Evaluation of the Need and Early Intervention Support for Children aged 2-4 yrs with an ASD in Northern Ireland” (DENI 2006).

This significant Department of Education review specifically commented on:

- The gaps in provision and it highlighted the need for a co-ordinated regional strategy
  - The absence of ASD policy documents across ELB's, in preference for generic Special Educational Needs policies.
  - The fact that only 3 of the 11 Health and Social Services Trusts had evidence of an ASD policy document and that all were linked to a specific service. None had developed a strategic approach. The activity at Health and Social Services Board level had not filtered through.
  - Models of best practice were detailed as well as the firm and active research base in Northern Ireland.
  - The role of Autism NI was noted as an established strategic facilitator for change.
- In addition, DHSSPS have commissioned Autism NI to conduct a strategic review of ASD Training provision across Northern Ireland. Prof Roy McConkey (UU) is carrying out the independent evaluation on behalf of Autism NI. It is evident therefore that government departments are already in possession of sufficient pieces of the NI ASD Strategy. Coordination of data is the final activity required on their part. It is critical that priority must be given to overarching legislation (The NI Autism Act).
  - The co-ordination of existing strategy and practice models is crucial to ASD strategy and legislation development in Northern Ireland.

Current UK policy and strategy documents and worldwide research have been analysed and have influenced the Northern Ireland strategies and research referenced in this document. WHSSB in particular commissioned a comprehensive literature review and identification of “Gold Standards” which is available from Autism NI.

**The map is available and laid out before us. This document aims to put the compass in the hands of Government.**

The following table outlines one option for government level co-ordination of a regional strategy for ASD which will inform and be informed by the NI Autism Act.

## The Northern Ireland Autism Act



\*One for each District Council area

**Publications in this series (downloadable from the Autism NI website)**

Government and Autism: Opportunities and Solutions

Blueprint for Change

Making History: Westminster 2006







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