

Government and Autism: *Opportunities and Solutions*

Autism Cymru

Wales' National Charity for Autism
Elusen Genedlaethol Cymru ar gyfer Awtistiaeth

Parents and Professionals
AUTISM &
Northern Ireland
CHALLENGING NEED





Government and Autism: *Opportunities and Solutions*

A Partnership Approach by the National Autism Charities of Northern Ireland and Wales

Launched by the Rt Hon Peter Hain MP, Secretary for State for Wales and Northern
Ireland in the House of Commons 29th March 2006

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Government and Autism: Opportunities and Solutions

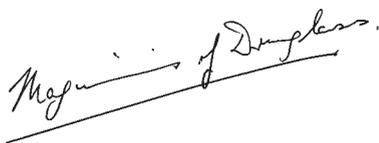
A joint initiative from Autism Northern Ireland and Autism Cymru

Foreword

Partnership work between organisations is very much part of today's modern agenda for the social care sector. This report, "*Government and Autism: Opportunities and Solutions*" is a prime example of two national autism charities working constructively together in a clearly defined and highly positive manner. The message of this Northern Ireland/Wales Partnership is clear - by thinking, sharing and working together at a national level the potential for achieving major strategic impact can be realised.

The emphasis of this report by Autism NI (PAPA) and Autism Cymru is the very real need for government to establish clear policies and specific strategies for Autistic Spectrum Disorders, which as a condition currently places huge demands upon social care budgets but is also a tremendous call upon the resilience of families and practitioners. In Wales, for example, over 2% of the total population are directly or indirectly involved in autism.

The model that this partnership creates is a significant and timely one that should serve to inspire the national charities from Scotland and England to join forces to provide a rich source of knowledge and experience upon which government can draw.



Lord Maginnis of Drumglass
Vice President
Autism Northern Ireland



Baroness Royall of Blaisdon
President
Autism Cymru

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Statement

Autism NI (PAPA) and Autism Cymru representing the nations of Northern Ireland and Wales respectively, have jointly prepared a report stating the case for Government intervention in the massively growing problem of Autistic Spectrum Disorders.

The high volume of numbers of people with autism, their families and those who support people with Autistic Spectrum Disorders is approximately around 2% of the total UK population. Economically, the call upon the public budget is significant.

The aim these two major national charities have by collaborating is very simple and two-fold : for the first time in UK, we urge you to push for Autistic Spectrum Disorders to be recognised in legislation; and for UK Government's to produce national strategies seeking to underpin and address the needs of people with Autistic Spectrum Disorders and their families.

Signed by



Arlene Cassidy
Director,
Autism NI (PAPA)



Hugh Morgan
Chief Executive
Autism Cymru

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Executive Summary

1. Autism NI (PAPA) and Autism Cymru are the national autism charities of Northern Ireland and Wales respectively. Both are governed and managed within Northern Ireland and Wales and function to serve the population within these nations. Both national charities have been the prime movers of significant political change in their respective countries.
2. The numbers of people identified with Autistic Spectrum Disorders (ASD) continues to soar within nations. In the United Kingdom, Autistic Spectrum Disorders are more common than for example, the combined total of Multiple Sclerosis, Down syndrome and Parkinson Disease.
3. Generic services are left largely un-resourced to meet this growing crisis and specialist public and especially independent sector services are growing exponentially to meet need.
4. Creative political solutions are needed to meet 'Tomorrow's Big Problem' in the disability field (Morgan, 2003).
5. The first UK example of government strategic level planning to respond to this need is emerging in Wales, through the development of the Assembly Government's All-Wales Strategy for ASD. In Northern Ireland there is evidence of the need to do so, and this is being driven by willingness of the Autism NI (PAPA) to encourage and embrace a range of lobbying, research and service partnerships.
6. As proud nations within the UK, the Northern Ireland/Wales partnership represented by Autism NI (PAPA) and Autism Cymru is the sole key example of national charities forming a partnership to work together to provide governments with the tools they need to meet this growing crises. There is a need and indeed a call to extend this pioneering and equal footing partnership to the lead national charities for both England and Scotland.
7. It is strongly recommended that UK government brings together a steering group to establish UK-wide national strategy for Autistic Spectrum Disorders.
8. In the UK generic legislative protection does not offer sufficient protection for people with autism. One example of the establishment of ASDs as clearly identified conditions within appropriate primary and secondary legislation has existed in Sweden, since 1993.
9. Strategic and legislative practice must obtain the engagement of local people within their distinct cultural frameworks in Northern Ireland, Wales, Scotland and England.

PART ONE

Profile, Successes and Opportunities

1. Introduction – The current situation

- The Profile of ASDs
- Media Portrayal
- How common are ASDs in Northern Ireland and Wales?
- What are the financial costs of ASD?
- What have been the outstanding successes of Autism NI (PAPA) so far?
- What have been the outstanding successes of Autism Cymru so far?
- What are the political opportunities and principles for strategic development?

The profile of Autistic Spectrum Disorders (ASDs) has been elevated over the past 20 years as a result of the tireless campaigning for recognition by specific groups of people: charities; parents, eminent clinicians, practitioners and academics; and last but by no means least, individuals with ASDs themselves. Historically, a significant proportion of autism-specific service provision in the UK voluntary sector has been founded by parents (Morgan, 1996) but there is recognition also more recently of the role that practitioner-led charities can play in working helping to make the case for autism, which has been described as 'Tomorrows Big Problem' in the social care field (Morgan, 2002). The role of the voluntary sector in autism has been critically important as whilst the statutory sector is responding to needs as they are identified but traditionally this means an extension of existing generic services to absorb people with newly recognised difficulties, such as ASDs.

How Autism has been portrayed by the Media

Newspapers, television, radio, and film within the past 15 years or so, have strongly influenced the concepts of autism held by the wider population. Unfortunately, the interpretation of autism projected by the media has tended to focus on emotion and ultimately is dictated by what makes a saleable story. The end result has been to give a populist view of autism, presenting individual examples of autism leading to simplistic impressions that unfortunately serve to explain all autism and all situations.

The first big global media portrayal of autism came with Dustin Hoffman's role as Raymond in the 20th Century Fox film 'Rainman'. For many in the UK the description 'autistic savant' was first heard, as was the view that all people with autism had spectacular abilities in highly unusual areas such as recall of dates, events, and mathematical calculations that could be put to good use for financial gain on the gambling tables of Las Vegas. As a piece of cinema it made for good viewing but as a piece of explaining autism, it failed to provide a satisfactory and truthful view (S4C, 2006). More recently, the winner of the 2006 Berlin Film Festival 'Snowflake' with Sigourney Weaver playing a person with an Autistic Spectrum Disorder is an attempt at trying to convey the perceptions by a person with autism of the world around her.

In 1998, the MMR debate 'kicked-off' in the UK with Andrew Wakefield's suggestion of a possible link between the triple MMR vaccine and autism, and with this another emotional story relating to autism had arrived for the media to exploit. The MMR debate brought out the very worst in people where attribution of blame and defence against these accusations became the prime public perception of

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autism. Whilst the public may have then heard of autism, their view became coloured by a perception that autism was something entirely negative and parents certainly did not want their children to have it, even to the extent of exposing them (and others) to the risk of serious childhood diseases (e.g. Dyer, 2004).

In recent years there has been a proliferation of auto-biographies of variable quality and even TV programmes and dramatisations giving more personal perspectives of living with autism. Again, these programmes tend to have strong personal and emotional hooks rather than just a focus on the quality of life for people with autism. The reality is though that, to date, the media has never used the story of autism to be of genuine service to the autism community and indeed families with autism, rather to serve their own ends (Attfield and Morgan, 2006).

How common are Autistic Spectrum Disorders in Northern Ireland and Wales?

In Northern Ireland, the most recent Department of Education (NI) publication on ASD, The Task Group Report on Autism (2002), referred to a prevalence rate of 91:10,000 (Wing and Potter, 1999) which will lead to an estimated figure of 16,000 individuals in N Ireland with ASD. In school age children this reflects a 97% increase over the three year period 1999 – 2001. Within the last 3 years 2002/05, the identified number of school age children with ASD in Northern Ireland has increased from 1,000 – 3,000.

In Wales, the Assembly Government report into the prevalence of Autistic Spectrum Disorders (Lowe 2002) delineated a 60 per 10,000 rate, but readily acknowledged that there was insufficiently robust national data to draw upon. However, this estimate has been recently reinforced by the findings of a 15 year study of diagnostic trends in ASD within the South Wales Valleys (Latif 2006, in Press). Extrapolation of this evidence would indicate that around 20,000 people with an Autistic Spectrum Disorder today live in Wales. By taking into account those families living with a person with ASD, a further 20,000 may be added to this figure. Additionally, several thousand people receive paid work either directly or indirectly to support people with ASD in Wales. Consequently, the total number of those living or working with autism in Wales today approaches 50,000; effectively well over 2% of the population of Wales (Morgan, 2005).

Action : The need for a comprehensive study of national prevalence rates in both Northern Ireland and in Wales is identified as an aid to accurate service planning for both national and local government. This may be something which can be achieved separately or by a joint initiative by the Northern Ireland and Welsh Assemblies.

What are the Financial Costs of Providing Services for People with Autistic Spectrum Disorders?

In an oft quoted study in 2001, the aggregate costs for the care provision in the UK for people with Autistic Spectrum Disorders were estimated at £1 billion per year (Knapp & Jaarbrink, 2001). These are significant figures, some of which could be reduced significantly with the introduction and implementation of appropriate support mechanisms. Researchers into autism notably Attwood (2000) refer to an “autism epidemic” which has massive implications for service planners and though the Statutory Sector is responding to needs as they are identified, this means an extension of existing generic services to absorb people with newly recognised difficulties, such as ASD.

The commissioning of services to both children and especially adults with Autistic Spectrum Disorder

remains ill-informed in many areas of the UK. In Wales, for example, there are three key aspects which must be seen to impact upon Commissioners responsible for purchasing services to people with ASD: the need to re-invest public funds currently being spent outside of county and country to develop local services; the need to refer to objective evidence to support the efficacy of the interventions/services being commissioned; and the need to look creatively at service development especially in the development of anticipatory and preventative support networks for families and those with Asperger syndrome. However, is a strategic and evidenced-based commissioning strategy being implemented in Wales and indeed Northern Ireland? The answer has to be that there is little or no evidence that it is.

What have been the outstanding successes of Autism NI (PAPA) so far?

- The variation between cultures also plays a significant role in the success or failure of services development and delivery. Where parents are the drivers of services development, it is essential that their cultural beliefs are respected and accommodated, so that imported professional support does not transgress the sensibilities of local supporters and become counter-productive. This is exemplified in Northern Ireland, Wales and many other EU countries. In this respect Autism NI (PAPA) has maintained a sensitivity to local demand and needs, and has safeguarded the Northern Ireland culture by developing local expertise where possible, emotionally engaging local parents and professionals, and by importing additional professionals who are also sensitive to the local culture.
- The Autism NI (PAPA) Mission and Ethos Statements (Appendix 3) form the backdrop to fifteen years of lobbying to secure better services for people with ASDs and their families, and to establish a more secure and appropriate placement for ASDs within public health services. In addition, the global network within which Autism NI (PAPA) operates contains the necessary expertise and experience to create appropriate services that provide the opportunity to place UK/Northern Ireland at the forefront of worldwide care - supporting those who support.
- Historically, Autism NI (PAPA) has played an instrumental role affecting change for the Department of Health and Social Services and Public Safety (DHSSPS). For instance, in 1994-96, PAPA worked with the University of Ulster evaluation of the Treatment and Education of Autistic and Communication handicapped Children (TEACCH) approach for ASDs. This evaluation, funded by DHSSPS and spearheaded by Autism NI (PAPA), ensured that TEACCH is approved as an effective approach able to be adapted to suit varied cultural climates, and paved the way for Statutory Services in NI to access training in TEACCH. This was a major step in affecting positive change for service providers as it marked the introduction of the first ASD tailored intervention to N Ireland.
- In June 1998, on behalf of the Department of Health and Social Services, Autism NI (PAPA) conducted a yearlong study into the status of provision of Diagnostic Services for people with ASD in N Ireland. The outcomes of this study highlighted the need for professional diagnostic training, the need for specific referral routes, and the need for an inter-agency approach. Consequently, there have been positive changes in diagnosis and provision in N Ireland, and, although the diagnostic service is not ideal, this study has been the framework and impetus for an ongoing improvement in services. As a result of the NI Diagnostic Scoping Study, Autism NI (PAPA) formed a Regional Diagnostic Special Interest Group that continues to meet, and to access and to initiate training.

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- In 2000, the Department of Education invited Autism NI (PAPA) to participate in a Government Review of ASD education provision in NI (The Task Group on Autism). For the following two years Autism NI (PAPA) contributed to the Task Group. The NI Minister of Education launched the findings in 2002. This Report is the most widespread investigation into ASD provision in Schools in N Ireland, and its recommendations continue to be a lobbying tool for Autism NI (PAPA). The organisation's involvement in this and in implementing its recommendations i.e. providing specialised Autism Specific Training for Education are ongoing, affecting positive change in Service Provision.
- In 2000 Autism NI (PAPA) secured funding to conduct action research into Early Intervention on behalf of the DHSSPS. This research – The Keyhole Early Intervention Research aimed to identify the needs of pre-school children and their families, to develop a home based intervention programme for pre-school children, to enhance provision for such children through a unique training for pre-school professionals and to explore the efficacy of small groups in parent support and empowerment.
- The Keyhole Early Intervention Programme recommendations, including preschool early intervention, parent training, and professional training, have been implemented in two Healthcare Boards (SH&SSB & WH&SSB) in N Ireland. The need for Professional Training is also addressed through the continuing provision of specialised training. Seven manuals, based on interventions used in the Keyhole Early Intervention Scheme, have been written for parents, the first of which is now available throughout Northern Ireland. Autism NI (PAPA) endeavours to affect positive service and policy change through action led research, and using its political lobby.
- In 2002 Autism NI (PAPA) were approached by the Department of Health to provide Specialised Autism Training. Throughout 2002 – 2005 Autism NI (PAPA) have developed a specialised training wing using a consortium of recognised local trainers, and bringing in the world's leading professionals to provide cutting edge diagnostic and intervention training to Northern Ireland.
- As a result of the Keyhole Early Intervention Programme, Autism NI (PAPA) identified the need for post early intervention services, and also the need for empowering parents to work with their children. The 'Connecting with Autism' Project is a result of this. Connecting with Autism investigates the use of educational play resources for parents to use with their own children, and is currently being evaluated by the University of Ulster to provide validation of its efficacy.
- Autism NI (PAPA) has an active Branch Network (15) throughout Northern Ireland, each of which provides proactive support in lobbying for services at a local level. Ongoing issues such as the provision of Behavioural Therapy support and Post 16 Provision are represented at Branch Level.
- In 2002, Autism NI (PAPA) invited Dr Stephen Ladyman MP (the then Chairperson of the Westminster All Party Parliamentary Group on Autism (APPGA) and champion of the Autism Manifesto) to Northern Ireland. This visit, during Autism Awareness Year, celebrated the inauguration of N Ireland's "Autism Ambassadors" (a member from each political party in Northern Ireland to be that party's voice for autism). Autism NI (PAPA) now has active relations with all local political parties who will support the case at Westminster and to the Direct Rule Ministers on behalf of Autism NI (PAPA).
- Currently Autism NI (PAPA) is collaborating with the Autism Ambassadors and the NI

Commission for Children (NICCY) to bring about change in the recommendations of the Review of Mental Health and Learning Disability to better profile Autism.

- Autism NI (PAPA)'s current multi-party Autism Ambassadors are extremely proactive, and provide their support in a variety of ways on issues related to ASDs. The recent pledges of support given by the party representatives (SDLP, DUP, Alliance, UUP and Sinn Fein), have provided an opportunity to raise the profile of ASDs nationally, and to take positive steps to support Westminster to create appropriate services for ASDs and thereby, to become a world leader in Care.
- In 2005 Autism NI (PAPA) was invited to become a partner in the development of a European Autism Information System funded by the European Commission.
- With a view to providing both the evidence to support the case presented by Autism NI (PAPA), and giving the Ministers the information that they need to take this forward and inform the Government. Autism NI (PAPA) felt that an investigative study, that addressed all the relevant issues, should be carried out. The relevant issues for the study were identified as including: the level of understanding and recognition of ASDs "What makes Autism unique"; current services and models of care; legislation in relation to ASDs and the impact on communities; cultural evolution of services and EU parallels.

What have been the outstanding successes of Autism Cymru so far?

Autism Cymru is a strategic-level national charity actively working in partnership with both national and local government and other agencies in Wales. It provides a service to all those connected with the autism community in Wales such as people with ASD, families, practitioners, clinicians, managers, funders, politicians.

- During 2001/2 Autism Cymru worked in partnership with the Welsh Assembly Government to prepare the case for a government-led national strategy for ASD in Wales. On 4th December 2002, The Minister for Health and Social Services announced the development by the WAG of an All-Wales Strategy for Autistic Spectrum Disorders. Autism Cymru has played a full and active partnership with the Welsh Assembly Government, and provided the Chair of the Expert Working Group (2002-04) in the development of this pioneering strategy which is due for launch during 2006.
- Also on 4th December 2002, the Minister for Health and Social Services launched the All-Wales Autism Resource, the bi-lingual information source for people with ASD, parents, funders, practitioners etc. Established and run by Autism Cymru during 2005 alone this pioneering resource attracted 16,000 genuine visitors per week.
- Since 2002 Autism Cymru has been delivering an All-Wales Autism Education and Training Programme. Endorsed by the Minister for Education and Life-Long Learning, this programme has now provided training opportunities attended by over 3,500 practitioner and parents. Autism Cymru also organises the bi-annual Wales Autism International Conference at Cardiff City Hall, averaging 500 participants each day, placing Wales as a major player on the international stage.
- Since 2003 Autism Cymru has co-ordinated three very successful mainstream Primary,

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Secondary, and Severe Learning Disability/Moderate Learning Disability fora in Wales. These fora attract contributions from each of the 22 LEAs in Wales. Members of the fora have an intrasite developed specifically for their use.

- Autism Cymru has been working in partnership with no less than 9 of Wales LEAs and also with the Times Educational Supplement to deliver the 'Inclusive Schools and ASD Training Project'. This Project recognises that majority of children with ASD are educated in mainstream schools. The aim is to create mainstream schools that are autism aware and indeed 'friendly and supportive' to all their children with ASD. The first certificates to schools will be presented by the Minister for Education and Life-Long Learning on 5th May 2006 in Rhondda Cynon-Taff. This objective for this innovative scheme will see it rolled out across all of Wales' LEA's over the next few years.
- The National Assembly for Wales have invited Autism Cymru to deliver training to key advisors and to develop a self-audit tool for schools in each of Wales' regions during 2006.
- In October 2005, Autism Cymru ran the world's largest on-line international conference for ASD attracting almost 10,000 delegates resulting in a resolution to the United Nations signed by participants urging all governments to create a national strategy for Autistic Spectrum Disorders.
- In 2005, North Wales Police and Autism Cymru formed a partnership to establish an Emergency Services Awareness of ASD (including Fire and Ambulance Services). Financial support was received by the Welsh Assembly Government in the form of a grant to evaluate the scheme (in conjunction with the University of Bangor). In March 2006, at the request of the Police, this will be rolled out across North Wales and, in due course, throughout the whole of the nation.
- During 2004 Autism Cymru drew together academic researchers and clinicians from Welsh universities and Health Trusts to prepare the case for the development of a Welsh Autism Research Centre and Network. Chaired by Professor Bill Fraser, this work will lead in 2006 to the launch of a multi-site Welsh Autism Research Centre, starting at the University of Swansea during 2006.
- Channel S4C (the Welsh Channel 4) made Autism Cymru its 'Charity fo the Year 2006' following its S4C's previous holder, 'Make Poverty History'. Launched with a programme broadcast on 13th February this Year will see several television programmes made on autism in Wales, together with a host of major fundraising events including rock concerts, pro-celebrity snooker tournament, and a week long series of sponsored walks, sailing, horse-riding and biking across Wales by celebrities. The profile of autism in Wales will be higher and more positive than ever.
- In 2005 Autism Cymru was the first national charity to be invited to become a collaborating partner in the development of an European Autism Information System funded by the European Commission. This project started in January 2006 and is due to last 30 months. The project is being viewed as the first attempt by the European Parliament to identify the characteristics of autism across the member states, to gain some consistency in the identification and diagnosis of autism and also to establish an European Autism Alliance.
- Autism Cymru was the first autism charity in Wales to embrace the Welsh Language and to ensure that all its publications either in hard copy, or on the internet are produced bi-lingually. A Welsh language version of this report is available in Wales.

What are the Political Opportunities and Principles for Strategic Development?

The Autism NI (PAPA)/Autism Cymru Partnership calls for:

- UK governments to give a lead by exercising their responsibility and authority to bringing about a change of culture in relation to ways in which individuals with ASD and their families are supported. There are two key ways of achieving this, the development of a national strategy for ASD; and by including reference to ASDs in primary and secondary legislation (considered in Part 3)
- The simple and most cost-effective way of achieving significant change is for central governments to establish a UK-wide strategy for Autistic Spectrum Disorders, which can then be adapted for use in individual countries. The expertise held by the four national societies for Northern Ireland, Wales, Scotland, and England (i.e. Autism NI (PAPA); Autism Cymru, Scottish Society for Autism, and the National Autistic Society) respectively could be usefully employed to advise and inform government. Strategy established within the UK would inevitably become highly influential throughout the world.

Strategy Principles

- Provide a service that is as close as possible to the person's home
- Ensure that a person centred approach is taken to the assessment of need
- Ensure that every individual with ASD is recognised and acknowledged
- Encourage consistently applied policies for multi disciplinary agency working for practitioners and involving service users, parents and carers
- Ensure that all those working within the field (at all levels) are provided with appropriate training
- Establish a collaborative; multi-disciplinary approach to the planning and delivery of service provision following diagnosis
- Encourage formal mechanisms for the dissemination of good practice
- Ensure that easily accessible and objective information is available to children with ASD and their families to promote a close partnership within the voluntary sector to help facilitate the effective provision of family support and, where appropriate other services

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PART TWO

What Makes Autism So Unique?

- The Reality
- Historical Glance
- The Dilemma
- The Distress
- The Confusion
- The Solution

What makes Autism unique?

The Reality

Autistic Spectrum Disorder is a relatively new term used to describe children and adults who have the following features in common and are affected in their ability to :

- Understand and use non-verbal and verbal communication
- Interpret social behavior which in turn affects their ability to interact with children and adults
- Think and behave flexibly (i.e. to know how to adapt their behaviour to suit specific situations)

They may also be quite different from each other, in their abilities and areas of strengths and weaknesses. Different sub-groups within the spectrum have been described. These include: Asperger syndrome; High-functioning autism and Kanner syndrome

Today in the United Kingdom, Autistic Spectrum Disorders are more common than for example, the combined total of Multiple Sclerosis, Downs syndrome and Parkinson Disease.

Historical Glance

ASD has a short and embattled history and the trend for this does not seem to be abating; a brief history of the key battles in ASD serves to emphasise how misunderstood ASD is and continues to be.

- 1944-mid-1960's- parents and concerned professionals campaign, and succeed in proving that ASD is not a form of Schizophrenia and to cease the prescription of damaging drugs and Electroconvulsive Therapy for ASD.
- Mid-1960's-late 1980's parents and concerned professionals campaign, and succeed in demonstrating that ASD is not caused by faulty parenting or "refrigerator mothers".

- 1980 - 1994 parents and concerned professionals campaign, and succeed in ensuring that “Autism” is recognised as a broad spectrum of disorders including individuals with average and above average IQ.
- 2000 onward – increasing recognition that ASD has become such a big issue that government leadership is essential in order to protect, support and enable individuals to have a quality of life which would be expected by the wider population.

The Dilemma

Debates continue relating to proper intervention, relating to chronological versus mental age, relating to adequate day services, respite, education the list is depressingly long; these battles sap up public monies in endless rounds of legal wrangling. Such problems would be resolved if ASD is afforded its own programme of care.

Individuals with ASD are placed in services according to their symptoms. This is comparable with an alcoholic being placed in an elderly service because of forgetfulness!

ASD does not fit easily into either programme of care, and current and previous attempts to squeeze it in to save funds have resulted in damaging Court Cases, and much worse tragic consequences. Autobiographical accounts tell of individuals attempting suicide before they receive suitable support. Anecdotal evidence from the experiences of the voluntary bodies in Northern Ireland and Wales over recent years are chillingly similar. Nationally, examples of the suicides of parents and their children with ASD are appearing with increasing frequency in the media.

The current generation of adults with ASD reflects the legacy of poor and inadequate service provision. A quick review of recent research in the UK makes disturbing reading:

- 80-90% of individuals diagnosed with ASD will develop a mental health problem.
- 5% of individuals with ASD are in employment or higher education, a remarkably low and damning figure considering a succession of Government initiatives to encourage people into the workplace and into education.
- 74% of frontline workers in health and education feel they are poorly trained and don't fully understand ASD.
- There is some evidence that carers of an individual with ASD are coping with higher stress levels than those within any other disability group. (Wolf, 1989) (Dunmet al, 2001), and are more likely to suffer from depression than carers of any other non-physical condition. In addition, families living with ASD can also be faced with massive personal and financial burdens, especially when they seek ASD-specific rather than generic intervention methodologies for their children.
- The average waiting time for a diagnosis in N Ireland is between 24 – 36 months. In Wales the figure can be as high as 10 months and with a crumbling tertiary service for Wales (i.e. for difficult to diagnose cases); many families are being forced to seek diagnosis over the border in England.

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The Distress

It has been said that ASD is one of the cruellest developmental disorders as the child appears to have all the potential to be “normal” and generally looks like any of his/her normally developing peers. The sheer “normalness” of appearance in some children with ASD can raise society’s expectation of him/her to an unrealistic level, this can result in crushing humiliation and alienation for parents when their “normal” child has an outburst of challenging behaviour and they have to endure society’s disdainful misunderstanding of their child. Evidence of this sad trend is the growing need for Autism NI (PAPA)’s “my child is not spoiled; my child has autism” cards which are frequently distributed in supermarkets, hairdressers and other similar public places. In Wales, the Emergency Services Attention Card, developed jointly by North Wales Police and Autism Cymru is a recognition that individuals with ASD can easily find themselves in contact with the Criminal Justice System who fail to recognise the reasons for the strange displays of behaviour.

The personal strains of waiting for diagnosis, waiting for intervention, struggles with schools, and the education system take their toll on the mental health of carers. Depression is the most frequently diagnosed mental health condition in the UK – there is little doubt that parents of children with ASD are particularly vulnerable in this statistic. Adequate services support and understanding in ASD would surely be a significant step forward.

The Confusion

The NI Review of Mental Health and Learning Disability recommendation that Autism should become the responsibility of Mental Health Services exemplifies the confusion of where Autism should reside. This recommendation conflicts with the latest DHSSPS policy and funding of ASD diagnosis and early intervention through Child Health. In addition, vital and extensive expertise in Autism resides in Learning Disability Services.

The Solution

The opportunity must not be missed to seize the initiative and carve out a new groundbreaking service within each of the four nations of the UK.

PART THREE

Snapshot of National Policy Contributions To Autism

- Northern Ireland
- Wales
- Scotland
- England
- Related UK Wide Developments:
- The Swedish Snapshot

Introduction

A brief “nation by nation” status check across the UK provides evidence of a lack of Government prioritisation of Autism. Note that this is not an exhaustive list and may well wish to be completed more fully by the national societies of England and Scotland in particular. However, these snapshots do service to demonstrate the high levels of activities undertaken in the name of the autism communities. There is a growing body of evidence calling for ownership of the Autism issue by government. In Wales, the eagerly awaited Welsh Assembly Government’s All-Wales Strategy for ASD, should, it is anticipated, provide a Government framework for the delivery of services to people with autism throughout the country. The section continues with a review of the range of strategic policy documents commissioned by the Government. Findings concur regarding the need for resourced strategic and legislative change for Autism. The section concludes with an example of what can be achieved through an effective parental and practitioner lobby and an informed and motivated political process.

N Ireland

- Statutory Provision in N Ireland falls within the remit of Child Health, Mental Health and Learning Disability.
- In 2005, Quality Standards for ASD provision in schools was issued by the Department of Education.
- In 2006, the SH&SSB Strategy for Children with Autism will be formally launched. The WH&SSB Autism Strategy Working Group convened in 2006.
- Autism NI (PAPA) is the main Voluntary Body for ASD in N Ireland and provides:
 - information and advice on ASD
 - research
 - specialist training
 - parent support service
- Statutory Strategic Planning for Autism is embryonic with only 2 of the 4 Health and Social Services Boards developing protocols.
- The Department of Education (NI) have driven strategic development within ASD service provision.
- Early Day Motion (EDM) in June 2005 in recognition of Autism NI (PAPA)’s role in the N Ireland Autism Community.
- Autism NI (PAPA) is leading the accreditation of ASD training in NI.
- Autism NI (PAPA) are Collaborating Partners in the EC funded development of a European Autism Information System

Government and Autism: *Opportunities and Solutions*

Wales

- The Welsh Assembly Government's (WAG) pioneering 10 year All-Wales Strategy for ASD is due for consultation during 2006 and reflects Wales' highly progressive political motivation to address the needs of the autism community in the nation. It should be remembered that Wales is a country with an influential history in the learning disabilities field as back in 1981 the former Wales Office produced the groundbreaking All-Wales Strategy for Mental Handicap, a strategy which had significant impact not just in Wales but also outside and especially in Scandinavia.
- In 2002 the WAG put £4m into the development of a regional school for ASD, Ysgol Plas Brondyffryn in Denbigh, North Wales
- Autism Cymru is Wales' national charity for ASD and made the case to the WAG which led to the All-Wales ASD Strategy. Since 2001, Autism Cymru has delivered :
 - Bi-lingual information on ASD to the Wales autism community
 - Partnerships in research
 - Comprehensive range of training opportunities
 - Whole nation approach with Police for Emergency services throughout Wales
 - Inclusive Schools and ASD Training Project now with 9 LEAs in Wales
 - Partnerships with the media, particularly TES Cymru and with Channel S4C
- Autism Cymru work has been recognised in House of Commons Early Day Motions in 2003 and 2005.
- The WAG National Framework for Children in Wales has sections referring specifically to ASDs
- Autism Cymru represent Wales as Collaborating Partners in the EC funded development of a European Autism Information System
- In 2003, the National Autistic Society set-up a Cross Party Working Group on Autism

Scotland

Interviews with key personnel in Scotland highlight the following issues points:

- Over the past 3-5 years lobbying has increased in Scotland which has raised awareness.
- Diagnostic procedures and methods of assessment have improved. There is a need for training and awareness raising for professionals.
- In 2001, the Public Health Institute of Scotland ASD Needs Assessment Report recommended that guidelines should be developed to improve the assessment and management of ASD in Scotland. In 2005, the Scottish Intercollegiate Guidelines Network published draft clinical guidelines.
- In 2002 "The Same as You" Report references Autism and Asperger Syndrome. However it calls on authorities to assess needs rather than to meet them. In 2005, National Clinical Guidelines are drafted by NHS/Scottish Intercollegiate Guidelines Network.
- The Scottish Society for Autism is a registered Charity and is the nationally recognised organisation for ASD. SSA is also the main provider of ASD specific support for Scotland.
- The Scottish Executive recognises and refers to the SSA.
- The SSA have has developed a comprehensive Strategic Plan for 2004-2009.
- In Education a new code of practice is to be introduced in Autumn 2005 as a direct result of the new Education Act 2004.
- In 2001, the National Autistic Society set-up a cross Party Working Group in ASD in the Scottish Parliament

England

- ASD falls under the remit of Mental Health and Learning Disability.
- Social Services are enabled to purchase Services off the independent sector when no other services are available.
- The National Autism Plan for Children (NAPC) 2003 refers to 60 in 10,000 children under the age of 8 years requiring specialist provision. A crisis is building with no strategy approved to address it.
- Autism Spectrum Disorders Good Practice Guidance (2002) from DH/DFES similarly is lacking strategic implementation “teeth”.
- The National Autistic Society (NAS) is viewed as the lead voice of the ASD community in England and in 2000 set-up the Cross Party Working Group for Autism in Westminster.

Related UK Wide Developments:

1. British – Irish Inter-Parliamentary Body Report (Feb 2005: Special Education)

This report found that children (with ASD) and their parents are not receiving help due to failure by Statutory Bodies to specify the needs of the child and failure to meet their statutory requirements.

2. Disability Discrimination

The Disabilities Discrimination Act (DDA) has no ASD specific legislation. There is no statutory requirement for practitioners who work with people with ASD to have minimum training – unlike the statutory protection afforded to individuals with hearing or visual impairment.

3. Anti Social Behaviour Order (ASBO)

This does not have a policy or any recommendations for individuals with ASD despite the social and behavioural difficulties of individuals with ASD being common knowledge.

The Swedish Snapshot

- **Sweden Code of Statutes**

The Act (1993: 387 in the Code of Statutes) was passed in May 1993 and was developed from the previous Act of 1985: 568. The 1985 Act already included people with Autism. The Act of 1993 however considerably strengthened the rights of people with certain disorders (including Autism) and changes the responsibility from county council to municipal authorities.

- **Rationale behind the Act**

- There was a need to change the concept from the 1985 Act of Childhood Psychosis to use the term of Autism and ASD.
- There was a need to update and further empower rights under the legislation.
- The considerable work done by the Swedish Autistic Society and other disability organisations had a significant impact on shaping decisions.

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- **The Impact**

- The change in the legislation (from 1983 to 1993 Act) played a big part in recognising ASD and acted as a catalyst for new centres of Autism in Sweden.
- It was a revolution for people with ASD.
- People following within the definition of the Act were legally entitled to a certain measure of support to obtain “good life conditions” from the municipal authority.
- Lack of funding/resources was no longer an obstacle to access to services.
- Due to the legal rights of individuals with ASD’s in Sweden, greater emphasis is placed upon training and education.

EUROPEAN COMMISSION PARLIAMENT INITIATIVES

In 1992, the European Commission published a European Charter for Autism (Appendix 4). In recent years the EC has funded research into the genetics of Autistic Spectrum Disorders and, in 2006, is funding an initial 30 month project to create a European Autism Information System which will include the development of a European Autism Alliance.

Conclusion

It is apparent that, despite the many initiatives and high profile awareness raising activities, the desperate plight of the person with ASD remains unresolved. There is a huge demand for consolidated efforts to provide appropriate services for this large population of individuals. The impact on the economy and on health in the interim is inestimable but of sufficient magnitude to warrant government direction and leadership. The bottom up strategy has influenced practice but not policy.

The policy shift must come from the top down. Ownership by Government of the ASD 'issue' is the unavoidable way forward. The United Kingdom has the capacity to easily create an authoritative strategy for autism and there is considerable expertise and knowledge contained within the four key national charities in Northern Ireland, Wales, Scotland and England which can be effectively utilised by government to achieve this.

The identity of Autistic Spectrum Disorders (including Asperger Syndrome) as separate from other disorders and or disabilities in legislation will be a major step forward. There is also an opportunity to follow the example set by Sweden, where significant impact on services, health and the economy has been made by including ASDs in their 1993 Code of Statutes, resulting in the practical initiation and implementation of appropriate support.

8. Steps Forward

- The recognition of Autism Cymru and Autism NI (PAPA) at Government level. This was achieved in May 2003 by Autism Cymru and in June 2005 by Autism NI (PAPA).
- Agreement on an Alliance Launch at Welsh and NI Assemblies and at Westminster with the Swedish Autism Society as guests.
- Expansion of Alliance to Scotland and England based upon an agreed political action agenda.
- Development of links with APPGA, PACE, NAS and significant other ASD lobbying groups in England.
- Establish the existence of ASD in UK legislation as has been achieved in Sweden.
- To impact upon European recognition of Autism in the development of the EAIS and the development of an European Autism Alliance.

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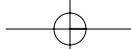
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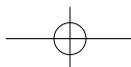
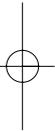
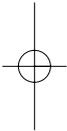
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Appendix One

THE NORTHERN IRELAND/WALES PARTNERSHIP: WHAT DOES IT MEAN IN PRACTICE?

- Sharing of training, information, and skills from one country to another
- Joint campaigning on relevant National, United Kingdom, European and World-Wide issues
- Joint Research Opportunities
- Sharing of Issues and mutual support

Appendix Two

Autism Cymru and Autism NI (PAPA) Early Day Motions (Most recent first)



The United Kingdom Parliament
The HOUSE OF COMMONS

1217 Autism Cymru

07/12/05

That this house commends Autism Cymru as Wales' national autism organisation and applauds its pioneering work at strategic level in inspiring the development by the Welsh Assembly Government of a national strategy for Autistic Spectrum Disorders (ASD); congratulates Autism Cymru's creation of the world's largest on-line conference in October 2005 with 10,000 interactions from every corner of the globe; welcomes its current partnership with North East Wales Police and emergency services and the intention to bring about an all-Wales appreciation of the needs of people with Autistic Spectrum Disorders during 2006; notes Autism Cymru's partnership with Local Authorities in Wales through the co-ordination of three national ASD Forums for primary, secondary and severe and moderate learning disabilities schools and also the delivery of an Inclusive Schools and ASD project in partnership with several local education authorities; and congratulates Autism Cymru for being selected by S4C as its Charity of the Year 2006.

467 Northern Ireland's Autism Organisation

29/06/05

That this House commends Parents and Professionals and Autism (PAPA) as Northern Ireland's autism organisation since 1990; further commends PAPA's pioneering innovative work responding to a demonstrable constituency of families with Autistic Spectrum Disorders; further commends PAPA's capacity and practice for discerning needs from families, both informing policy makers, and shaping services; further commends the PAPA NI evaluation and establishment of appropriate TEACCH

training in statutory services; further commends the 1997 PAPA NI study on behalf of the Department of Health and Social Services into Diagnostic Services, highlighting the need for (a) professional diagnostic training, (b) specific referral routes and (c) an interagency approach; further commends the PAPA NI led Diagnostic Scoping Study resulting in a diagnostic special interest group; further commends the 2002 Education Task Group investigation into ASD provision in schools in Northern Ireland, initiating specialised autism specific training with PAPA NI; further commends the PAPA NI keyhole research, identifying the needs of pre-school children and families, to develop home based intervention programmes for pre-school children, enhancing provision for them, and exploring the efficacy of small groups in parent support; further commends the PAPA NI Connecting with Autism Project currently being evaluated by Ulster University, empowering parents to work with their children; and further commends the 2005 PAPA NI specialised training wing, officially commended by the Department of Health and Social Services.

1215 Autism Cymru

12/05/03

That this House notes the pioneering work being undertaken throughout Wales by Autism Cymru; commends their strategic endeavours over the past two years in acting as a catalyst for the planning work being conducted by the Welsh Assembly Government to develop the world's first national strategy for autism; recognises Autism Cymru's All-Wales Education and Training Programme has provided autism training for over 1,000 practitioners and carers; congratulates Autism Cymru on its partnership with local authorities, especially in West Wales, in leading the development of local strategies and co-ordinated service delivery; celebrates the launch last December of AWARES.org, the All-Wales Autism Resource website which is the world's first national web-based resource which receives over 4,500 visitors per week; welcomes the ground-breaking work being developed by Autism Cymru and its partners in the voluntary sector, most notably Ysgol Plas Brondyffryn, Denbigh and the Welsh Assembly Government, which serves as a model to other countries; and looks forward to Autism Cymru hosting a major international conference on autism at Cardiff City Hall in May 2004.

Appendix Three

AUTISM NI (PAPA) MISSION STATEMENT

PAPA seeks to ensure that people within the autistic spectrum and their carers have access to appropriate services, enabling people with Autism to be valued members of their community.

THE AUTISM NI (PAPA) ETHOS

“PAPA is a parent led partnership organisation having been formed to promote positive collaboration between parents, professionals and individuals with Autism to address the need for appropriate services.

This partnership ethos extends to the charities promotion of a multi disciplinary, cross agency response to issues such as assessment, diagnosis and early intervention.

The charity's mission to support parents and individuals with an Autistic Spectrum Disorder is core to its work and is based on individualised assessed need.

The charity is committed to promoting best practice, accessible to all irrespective of family circumstances.”

Appendix Four

EUROPEAN CHARTER FOR AUTISM

CHARTER OF RIGHTS

People with autism should share the same rights and privileges enjoyed by all of the European population where such are appropriate and in the best interests of the person with autism.

These rights should be enhanced, protected, and enforced by appropriate legislation in each state.

The United Nations declaration on the Rights of Mentally Retarded Persons (1971) and the Rights of Handicapped Persons (1975) and other relevant declarations on Human rights should be considered and in particular, for people with autism the following should be included:

⇒ INTRODUCTION

- ⇒ THE RIGHT of people with autism to live independent and full lives to the limit of their potential;
- ⇒ THE RIGHT of people with autism to an accesible, unbiased and accurate clinical diagnosis and assessment.
- ⇒ THE RIGHT of people with autism to accessible and appropriate education.
- ⇒ THE RIGHT of people with autism (and their representatives) to be involved in all decisions affecting their future; the wishes of the individual must be, as far as possible, ascertained and respected.
- ⇒ THE RIGHT of people with autism to accessible and suitable housing
- ⇒ THE RIGHT of people with autism to the equipment, assistance and support services necessary to live a fully productive life with dignity and independence
- ⇒ THE RIGHT of people with autism to an income or wage sufficient to provide adequate food, clothing, accommodation and the other necessities of life.
- ⇒ THE RIGHT of people with autism to participate, as far as possible, in the development and management of services provided for their wellbeing.
- ⇒ THE RIGHT of people with autism to appropriate counselling and care for their physical, mental and spiritual health; this includes the provision of appropriate treatment and medication administered in the best interests of the patient with all protective measures taken.
- ⇒ THE RIGHT of people with autism to meaningful employment and vocational training without discrimination or stereotype; training and employment should have regard to the ability and choice of the individual.
- ⇒ THE RIGHT of people with autism to accessible transport and freedom of movement.
- ⇒ THE RIGHT of people with autism to participate in and benefit from culture, recreation and sport.
- ⇒ THE RIGHT of people with autism of equal access to and use of all facilities, services and activities in the community.
- ⇒ THE RIGHT of people with autism to sexual and other relationships, including marriage, without exploitation or coercion.

- ⇒ THE RIGHT of people with autism (and their representatives) to legal representation and assistance and to the full protection of all legal rights.
- ⇒ THE RIGHT of people with autism to freedom from fear or threat of unwarranted incarceration in psychiatric hospitals or any other restrictive institution.
- ⇒ THE RIGHT of people with autism to freedom from abusive physical treatment or neglect.
- ⇒ THE RIGHT of people with autism to freedom from pharmaceutical abuse or misuse.
- ⇒ THE RIGHT of access of people with autism (and their representatives) to all information contained in their personal, medical, psychological, psychiatric and educational records.
- ⇒ List of Members who signed
Presented at the 4th Autism-Europe Congress, Den Haag, May 10th, 1992.

Adopted as a Written Declaration by the European Parliament on May 9th, 1996.

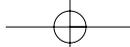
Declaration on the rights of people with autism.

The European Parliament,

- A. noting that at least 1,000,000 citizens within the EU are affected by autism, which is a mental disability, and that people with autism can have impairments in communication, social contact and emotions, which can affect all senses including touch, smell and sight,
- B. bearing in mind its resolutions on the human rights of disabled people, the rights of people with mental handicap, and the Disabled People's Parliament ; bearing in mind also the UN Declaration on the Rights of People with Mental Handicap 1971 and 1975, the European Union's third action programme on disability and the Charter for Persons with Autism,
 1. Calls on the Institutions of the Union and the Member States to recognize and implement the rights of people with autism ;
 2. Points out that people with autism should have the same rights enjoyed by all EU citizens (where such are appropriate and in the best interest of the person with autism) ; these should be enhanced and enforced by appropriate legislation in each Member State and include :
 - (a) the right to live independently ;
 - (b) the right to representation and involvement as far as possible in decisions affecting their future ;
 - (c) the right to accessible and appropriate education, housing, assistance and support services ;
 - (d) the right to freedom from fear, threat and from abusive treatment ;
 3. Instructs its President to forward this declaration to the Institutions of the Union and the governments and parliaments of the Member States.

Schedules

Schedules to the basic Charter which was presented by the International Association Autism Europe at its Congress at The Hague, Holland, May 10th 1992.



Wales' National Charity for Autism
Elusen Genedlaethol Cymru ar gyfer Awtistiaeth

Autism Cymru
6 Great Darkgate Street
Aberystwyth
Ceredigion
SY23 1DE

T: 01970 625256
F: 01970 639454
E: sue@autismcymru.org
W: www.autismcymru.org



CHALLENGING NEED

Autism NI (PAPA)
Donard
Knockbracken Healthcare Park
Saintfield Road
Belfast
BT8 8BH

T: 028 9040 1729
F: 028 9040 3467
E: info@autismni.org
W: www.autismni.org

