



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

**Working Together for ASD :
Models and Exciting Developments from the Celtic Nations
Hugh Morgan – CEO of Autism Cymru**

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Introduction

I am grateful to the Scottish Autism Network for the opportunity to speak to you today, and it is a privilege for me to do so here in Strathclyde University. Just so that you know a little bit about me - I have worked in the autism and related learning disability fields since 1975 initially in the public sector and then, for the past 20years within the Voluntary Sector and I guess that I come very much from a 'hands-on background' in terms of working in and setting-up and managing services to people with autism and especially those adults with ASD and their families.

But over the past 5 or 6 years especially, my own thinking and practice has been influenced and indeed shaped by the opportunities presented by the political devolution which has taken place from the Westminster-based UK government to the development our own government's in Wales and Northern Ireland. Of course, if almost goes without saying that you in Scotland are one step ahead of us in having a full Scottish Parliament, but certainly we are getting there in Wales, where we already have devolved responsibility for Education, Health and

Social Services. I have to say also that the influence of highly successful philanthropists within the field and most definitely Dame Shirley, whom you have heard this morning, has created a reference point for me in terms of the potential of what can be achieved by taking highly strategic, creative, confident and ultimately ambitious 'solutions-based' approaches to government. The fresh and inspirational impact that the Dame Shirley's of this world have made has made to the autism movement and to individuals with autism, from the ground upwards, must not be underestimated. The political cause of autism has therefore been helped considerably by political devolution and by genuinely strategic 'thinking', and it is both 'all of yours and my' role, as supporters, advocates and protagonists of autism to make sure that we campaign and lobby together in effective, informed and above all a highly consistent manner. The opportunities to make major shifts to government policy are there – and the responsibility lies with us to make sure we make the best use of these opportunities.

Now, a little later in my talk I would like to expand upon this theme and explore practice and developments within the Celtic Nations. The common theme running throughout my talk will, I hope, leave you with the impression that the models that we have developed and will develop in the future within the Celtic Nations not just give us opportunities to export, share and influence our own models practice within our 3 nations - but equally gives us a great opportunity to influence and develop government policy. So at this stage, it may therefore be helpful to you if I map out what I plan to cover during the next 40 minutes or so :

Slide 1 : Format

- *Context : International perspectives; size of the issue*
- *Partnerships : family-practitioner; examples from the Celtic Nations*
- *Way Forward : Celtic Nations Autism Partnership*

What themes can be found in relation to the experience of autism in the many countries of the world?

Slide 2 International Snapshots :

In many countries the following factors seem to apply :

- *The experience of person with autism and of his/her family tends to be much the same*
- *Where service developments have taken place, these have largely resulted from the efforts of parents with interested practitioners. International recognition derived primarily from these two groups*
- *Progress in any country has been slow, with services for adults coming well behind those for children*
- *No country provides a full range of services to meet the individual needs of all people with asd and their families living in that country*
Taken from H. Morgan 1996 'Adults with Autism' Cambridge University Press

Are Prevalence Rates the best guide we have to size of the ‘issue’?

In terms of the size of the ‘issue’ and by moving from international perspectives and narrowing to the UK I would suggest that prevalence rates are just one indicator of the size of the autism issue. For me, prevalence rates are not the complete picture and in itself does not help us to fully understand nor to make the case to government. So, in order to make the case for shifts in policy-determination at government level one must look beyond ‘simple’ prevalence rates of say 60 per 10,000 of the population.

Take Wales for example – a population half the size of Scotland – but over twice as large as Northern Ireland. Wales has around 20,000 children and adults with ASDs living in the nation – based of course upon 60 per 10,000. However, this number is not the correct gauge for determining how many people are affected by autism in Wales. For, if we double the 20,000 to include families, and then add the 10-15,000 of us who are working directly or indirectly with people with autism – perhaps as teachers or classroom assistants in mainstream schools, or as careers officers; as residential workers, as field-work social workers; then suddenly we start to talk about 50-60,000 people being involved in autism some way or another in Wales. Or, to put it another way this equates to 1 in 50 of the population in Wales! The implications of reaching this level of analysis are truly vast : What a tremendous draw upon the public purse such a demand must represent; but what a potential force for lobbying and change if we can pull and harness the various aspects of the autism movement together. I will come back to the last point towards the end of my talk and the role that you can all play in making this happen.

The Formative Level of Partnership Working in ASD

Lets take a salutary step back by reminding ourselves of the first level of partnership - and if you like formative level - of partnership working – for it all starts with the effectiveness of the relationship between individual families and individual practitioners. Whatever role we have – as researchers, policy-makers, clinicians, educators, teachers, and so on, we must never forget that this is where the development of informed knowledge and responses to autism begins.

Understanding parental expectations is part of this relationship building process and I will give you one example with regard to the parents of adults with ASD.

Back in 2002, I and others initiated with the Local Authority in Ceredigion, a county in West Wales, the development of a county planning group for adults with autism which aimed to inform and indeed influence the future direction of autism services and resource allocation by the county. Ceredigion itself has a population of just over 70,000 – so there were more people in the Millennium Stadium last weekend to see Wales get a true pasting by the All-Blacks than live in the county of Ceredigion. The planning group was small in number – we had representation from Health, Social Services, Autism Cymru, Parent but in order to achieve the substantial work necessary this planning group needed to draw upon other individuals and groups to create the body of evidence about current practice, gaps in provision, and the services needed. One of these groups consisted of the local parent support group and also, recognising that many parents (particularly in such a rural area) rarely attended parents groups meetings (if ever in some cases), efforts were made to elicit their views by interview or questionnaire.

One key area for us in the evidence collection related to parental expectations : what did parents really want for their adolescent and adult autistic son or daughter? The conclusions reached from the responses to this question were illuminating and indeed humbling : The answer was simple – **NOT MUCH!** Parent's expectations were reasonable, balanced, and often very insightful if occasionally they gave a somewhat 'tired' impression from the life-long struggle to get services in place. Ref : Mary Salter's paper in the GAP Journal May 2004 issue which spelt out this in a lot more depth and detail

The experiences and expectations of parents of adults with asd expressed in Ceredigion are to my mind a good litmus test for what we can expect elsewhere in many other areas of the UK. In working in the ASD field – which has been traditionally a very parent-driven field; the key issue for those of us as practitioners in the first instance is to begin to understand the roller coaster of parental emotions and to have a grasp on what it is that they are looking for from practitioners. (Incidentally, I do not like using the word 'professional' as in my experience some parents are more professional than some 'professionals').

So lets just very quickly remind ourselves of what Parents/Families are looking for from Practitioners – taken from Attfield & Morgan 2007 'Living with ASD' Sage Publications

SLIDE 4 WHAT PARENTS WANT FROM PRACTITIONERS

- *Information : Parents want to know who and what they are dealing with – to feel empowered. Early diagnosis critical in this process*
- *To be listened to : time to tell their stories - acknowledgement that they know their son/daughter best. Tolerance and respect.*
- *Recognition of the journey they are on : the battles that may have fought – why some have needed to become 'warrior parents'*
- *Equal Partners with practitioners : for the benefit of the person with asd*

- *Keyworker : to ensure consistency over period of time and to avoid the 'falling off the cliff' scenario*

SLIDE 5 What practitioners expect from parents

- *Civility*
- *Respect*
- *Acknowledgement of their commitment to the person with ASD and the family*
- *Appreciation of their knowledge*
- *Attempts by parents to understanding the constraints they are working under*

SLIDE 6 Reflective Practice : Practitioners

- *Think about what you really can offer families you work with*
- *Are you ready to listen to their problems?*
- *Do you make time to explain things?*
- *How do you indicate that you value their experience and knowledge?*
- *How do you give them a feeling of participation in their child's life?*

SLIDE 7 Reflections for Parents

- *Examine your attitude to the practitioners you have worked with – are these positive or negative?*
- *What do you know of their knowledge and experience?*
- *How aware are you of the difficulties practitioners may have in meeting the needs of your family?*

So, we can see that process for both practitioners and parents in working together needs some careful thought and constant reflection to ensure that the partnership is worthwhile and that barriers do not creep in.

Models of Partnership WITHIN the Celtic Nations

So, having taken a somewhat cursory glance at ‘working together’ at an individual level, now lets look at some of the models of partnerships within the three Celtic Nations of Scotland, Northern Ireland and Wales.

SLIDE 8 Examples of Partnership Models within the Celtic Nations (not a definitive list!)

- *Scotland : Scottish Autism Network (workshops, exhibitions at today’s conference) eg ARC in Maryhill; Education Advisory Service in West Lothian; Fife Council Social Work Service; Highland Council Children’s Service; Autism Training in Argyll*
- *Northern Ireland : ‘Autism Ambassadors’ within NI ‘Assembly’; Dept Health, Social Services & Public Safety funded ASD training project; Police Service of Northern Ireland ASD programe; The Jigsaw (Keyhole) Early Intervention Project.*
- *Wales : Welsh Assembly Government’s –All Wales Strategy for ASD; All-Wales LEA Inclusive schools Training & Research Project; All-Wales Autism Information Resource (www.awares.org); S4C Television’s adoption of Autism Cymru as ‘Charity of the Year 2006*

There are clear strategic and political advantages in identifying significant models of practice. The use of locally-based success stories can be a very effective way of creating the key and objective messages that need to be given to policy-makers. Indeed the projection of models of practice which are seen to be working well can serve as the basis for replication in other parts of the nation. My experience in Wales is that Policy-makers actually want to know that there are success stories and not just to be pilloried from not delivering policies and resources, and that there is the potential for these to be used as the basis for further and

similar developments elsewhere. The key is now to be thinking 'political ownership' and 'nation-wide' delivery.

To repeat : Scotland as you are well aware has a population of about 6m; compared to Wales which is 3m and Northern Ireland 1.25m. Each of us has our own governments at various stages of development in terms of policy-making powers. Obviously my first hand knowledge is gained from what is happening in Wales, and I will also refer to NI, but I start here a very brief summary of developments in Scotland, not least by mentioning the excellent partnership example set-up by the Scottish Autism Service Network here today.

In the preparation for this talk I was given several very good examples of collaborative practice in Scotland. Because I am speaking to an esteemed Scottish audience today, I will not repeat these examples verbatim and trust that it will suffice if I say that these examples encompassed a range of services developed and delivered collaboratively covering screening, assessment and diagnosis, information and training, intervention support methodologies; residential, day and outreach services to adults, and support for families. These collaborative services, take place in urban Glasgow through to the Scottish Highlands, involving local parent-led groups such as the Autism Argyll, several local authorities and Health Trusts and national charities, such as the lead Scottish charity the Scottish Society for Autism, and the National Autistic Society. Several of these models of good practice are being demonstrated here in this conference as workshops or as exhibitions. Of course also in Scotland, the Scottish Executive has published various reports on autism and you have had the excellent Public Health Institute of Scotland's Report on autism published a few years ago with its clear recommendations for change and the recent subsequent work underway on this. The main issue though with such reports be they from Wales, Scotland, Northern Ireland or England, is that whilst the quality may be good, consistently

they lack ‘teeth’ and we need now to be more strategic in our thinking, and should have come by now to expect far more in terms of tangible outcomes – and yes this means resources!

NORTHERN IRELAND

Let’s move to Northern Ireland where quite recently the focus appears to have been changing from locally-based action to over-arching nation-wide approaches. In this way Autism NI is starting to mirror developments in Wales over the past 5 or 6 years.

For example Arlene Cassidy the CEO of Autism NI (PAPA) has reached out to the members of the Northern Ireland Legislative Assembly and now has cross-party Autism Ambassadors from the Assembly working with Autism NI to promote the recent ‘Government and Autism Report, which was jointly prepared with Autism Cymru. Their lobbying of Peter Hain (Secretary of State for Northern Ireland and Wales) has led to subsequent significant progress regarding their political campaign for:

- NI ASD Programme of Care
- NI Autism Strategy
- NI Autism Act/UK Legislation

The Department of Health, Social Services and Public Safety in NI has recently agreed to fund the Autism NI training project for the next 3 years and by so doing actively endorses and promotes the Autism NI training strategy across the range of Statutory and voluntary agencies throughout NI.

There is a new also Partnership with the Police Service of Northern Ireland (PSNI) to develop ASD awareness, throughout the province – drawing heavily upon the model pioneered by Autism Cymru across much of Wales. You can begin to pick up that there

are very practical benefits to come out of closer relationships between our national charities.

There are plenty of other examples from NI of collaborative work - not the least the Jigsaw and Keyhole early intervention and family support projects now operating through to adolescence.

Wales

Turning to Wales which I do feel better qualified to talk about; as in Scotland and Northern Ireland there are several examples of good autism practice at local level, be it by local parent-groups; by the public or private sector and indeed by larger charities. If you recall I highlighted one example of public/voluntary sector partnership a little earlier in the county of Ceredigion which subsequently led to the appointment by the LA/Health Authority of a Development Officer for Adults with ASD (a post for which I am part of the mentoring team) and which is now expanding towards the creation of a LA autism team for adults. Also, in some areas, there is no doubt to me that we in Wales can learn from Scotland and Northern Ireland in effective locally co-ordinated approaches.

However, as I am stressing to you in my talk today, we need to move from thinking about local initiatives to *nation-wide approaches* – it is a critical way of making major impact. Over the past 5 years the approach of Autism Cymru has been to inspire “Whole-nation” approaches to autism. Back in 2001 I took the view that if we cannot do this in a country with just 3m population, with our own government, and own national charity governed and staffed within the country of Wales, then we do not deserve to be doing the job. I have selected examples for you today which represent some key overarching areas impacting upon autism

throughout Wales : namely in the areas of Government Policy; Education; Bi-lingual Information and the Media.

The first significant government approach to autism in Wales is about to be published by the Welsh Assembly Government and this started off life as the All-Wales Strategy for ASDs in December 2002 when it was announced by the then Wales Health & Social Services Minister. This cradle-to-grave government strategy for autism was the direct result of the lobbying made by Autism Cymru. The process of the production of the strategy has been tortuous, but at least for the first two years involved over 100 people from across Wales who actively participated in task and finish groups representing all key areas of the autism community. There are undoubtedly lessons to be learned about the process of government strategy development for autism – particularly the way that the case was made and the positive but also not so positive part played by officials and also the helpful and occasionally not so helpful role played by the voluntary sector. You will understand if I cannot comment any further on this 10yr government strategy for autism, until after it has been published by the Government in Wales, apparently according to the Minister within the next few weeks. We, in Autism Cymru, are proud of having inspired a government to do this – but equally are preparing ourselves for the long fight once the strategy is implemented to push for greater and greater resources going into autism in Wales.

So that was an example of significant political and policy progress. The second key example from Wales represents a nation-wide approach to the educational system in Wales in relation to autism and specifically to mainstream primary and secondary schools throughout in Wales. Within this there are 2 key whole-nation approaches which have made significant difference to the awareness of ASDs within mainstream schools in Wales over the

past few years : namely the Inclusive Schools and ASD Training and Research Project and the 3 Wales Schools ASD Forums

SLIDE 9 All-Wales Inclusive Schools & ASD Training and Research Programme

- *Aims to enable every mainstream and secondary school in Wales to become 'autism-friendly'*
- *Represents a partnership between LEAs, Autism Cymru and the Times Educational Supplement*
- *Delivered by Maggie Bowen & Lynn Plimley currently to 13 of Wales' 22 LEAs (several hundred schools)*
- *Certificates presented by Minister for Education & Life-Long Learning to the first 22 schools in Rhondda Cynon Taf, in March 2005.*

SLIDE 10 What does the project entail?

- *2 days training*
- *At least a term of whole school activity relating to ASDs e.g. training, using a self evaluation tool to address short, medium and long term plans*
- *½ day for feedback and to discuss the way forward*
- *Supported by the Welsh Minister for Education & Life-Long Learning*

SLIDE 11 What does the project do?

- *Has a long-term impact on schools and the way they cater for pupils with ASDs*
- *Makes sure that the impact on schools is measurable*
- *Make ASDs a whole-school responsibility- involving not only teaching staff and LSAs but lunch time staff, caretaker, governors etc*
- *It creates ASD Resource areas*

SLIDE 12 Schools Self-Evaluation Tool

- *Ensures that schools can assess where they are in relation to ASDs*

- *They can use it to plan, monitor and review their approach to pupils with ASDs*
- *Encourages them to think creatively e.g. the provision of a 'safe haven', arrangements at lunch and break times, using strategies to remove barriers to communication etc*

Other Advantages

The project has helped other pupils with additional learning needs: eg

- *Structure and visual cues can be useful to a number of pupils*
- *Looking for triggers for inappropriate behaviour*
- *Relaxation exercises and sensory gardens*

SLIDE 13 The Future?

- *Lot of interest in Project throughout Wales – aim to get all 22 LEAs signed-up and every mainstream schools in Wales to become 'autism-friendly'*
- *Over half Welsh LEAs now have a rolling programme in place*
- *All-Wales Steering Group has been established to continually revise and up date the content of the project in the light of Welsh legislation*
- *To avoid the Post Code Lottery!*

SLIDE 14 The 3 All-Wales Schools ASD Fora (2002-present)

Funded by The Three Guineas Trust and co-ordinated by Autism Cymru the 3 Schools Fora meet twice yearly to bringing together Welsh practitioners from All 22 LEAs in Wales from the following

LEA settings :-

Primary schools

Secondary schools

Special schools

SLIDE 15 BI-LINGUAL INFORMATION : THE ALL-WALES AUTISM INFORMATION RESOURCE

- *On-line bilingual information resource for Wales (www.awares.org). Developed and managed by Autism Cymru. Links into autism connect (world-wide portal for autism)*
- *Launched by Minister for Health & Social Services in Dec 2002 who described it as 'key building block in the development of the WAG's 'All-Wales Strategy for Autism'*
- *Includes daily news, extensive library of papers, comprehensive list of services throughout Wales; discussion boards;*
- *Receives 16,000 genuine visitors per week*
- *Has hosted the world's largest online conferences last year and this year ie autism2005 and autism2006 with 10k delegates*

SLIDE 16/17/18/19 Relationships with the Media : AUTISM CYMRU THE S4C WELSH CHARITY OF THE YEAR 2006 S4C year

This annual award by S4C (the Welsh Ch4) was a major step forward for ASDs in Wales. Autism Cymru beat over 100 charities to receive this award which, throughout the year, has ensured that the profile of ASD on television has been higher and more positive than ever before. Many programmes on ASD been shown; frequent news features on autism; a Rock Concert, Pro-Celebrity Snooker event and during one week in June a televised Costal Challenge walk for ASD involving several thousand people and raising funds for autism in Wales.

So, moving from models from Practice to joint working between nations where do we go from here?

The first is that we have to stop simply highlighting the need – and have to quickly get to the point of expecting delivery by governments. Political devolution has given us control of our own

destiny. There needs to be a big co-ordinated push forward for autism and especially policy-making within our own countries. These days our expectations need to be far higher. Uniting the autism lobby, and sharing our experiences and knowledge from Scotland, NI and Wales will give genuine force to this process and the Celtic Nations Autism Partnership will help us to achieve this. The Key messages to take away from this conference about the Celtic Nations Autism Partnership are :

SLIDE 20 Ways Forward : The Celtic Nations Autism Partnership

- *Will be a true and equal partnership started by Scottish Society for Autism, Autism Northern Ireland, and Autism Cymru.*
- *Launches in Cardiff, Edinburgh and Belfast over next year.*
- *Follows on from the successful Autism Cymru – Autism NI Partnership launch by Peter Hain in Westminster, March 2006.*

SLIDE 21 Aims of the Celtic Nations Autism Partnership

- *Giving real political and practical clout to partnership working*
- *Sharing of approaches to practice, training, information, and skills from one country to another*
- *Joint campaigning on relevant national, UK, European and World-Wide issues*
- *Joint Research Opportunities*
- *Sharing of problems and mutual support*

SLIDE 22 : Examples of national partnership in practice : What has been achieved over past 9 months by the Autism NI and Autism Cymru partnership?

- *Wales Police forces ASD programme developed jointly with Autism Cymru (with funding from WAG) now being used as the model by the Police Service Northern Ireland in partnership with Autism NI*

- *Joint campaigning report 'Government & Autism : Opportunities and Solutions' launched by Peter Hain in Whitehall, March 2006*
- *Autism NI's CD-Rom for teachers drawn upon by Autism Cymru in delivery of the LEA mainstream schools training programme throughout Wales*

Cont'd

- *Presentations/exhibitions by Autism NI at conferences in Wales, and vice-versa*
- *Joint applications for research and project bids both Wales and Northern Ireland*
- *'Snow Cake'*
- *Desire by NI Politicians to draw upon work in Wales to help inform strategic policy development in NI*
- *etc*

SLIDE 23 Concluding Points

- *Lets start thinking big! We must stop simply identifying need.*
- *We need to take strategic-level 'whole-nation' approaches – within our nations*
- *We have to quickly harness the individual strengths, culture and identities of each the Celtic Nations so that we create an enormously powerful political lobby*
- *We must now start to share and export good practice between our three nations*
- *The forthcoming Celtic Nations Autism Partnership will provide a vehicle for doing so easily and effectively – So get 'on-board' with it!*

SLIDE 24 : For Further Information

Contact :

John Macdonald, Scottish Society for Autism

Arlene Cassidy, Autism Northern Ireland

Hugh Morgan, Autism Cymru