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# The ASD Strategic Action Plan for Wales (2008)

## Evaluating the Foundation Phase

February 2011



# **The ASD Strategic Action Plan for Wales (2008): Evaluating the Foundation Phase**

**February 2011**

Hugh Morgan OBE  
ASD Implementation Manager  
Welsh Assembly Government

## Foreword

### April 2008.....

*“The ASD Strategic Action Plan is the start of a process.....Some of this work will never have been done before. Some will require longer term planning but until we make the first step we will never make progress” April 2008*

Edwina Hart AM MBE  
Minister for Health and Social Services

Jane Hutt AM  
Minister for Children, Education, Lifelong Learning and Skills

### March 2011.....

*“We have indeed made the first important steps. This evaluation of the impact of the ASD Strategic Action Plan in Wales to date, conclusively demonstrates rapid and substantial progress made over and above the actions contained within the original ASD Strategic Action Plan. A tremendous amount of work has been undertaken by a great many people within autism communities and across the statutory and independent sectors in Wales. To all, the Welsh Assembly Government is extremely grateful.*

*We are though very aware that there is so much more to do and whilst many of the successes are documented here, so also are the areas that we need to develop further and to act upon.*

*Within Wales we must to continue to act with “one voice” to ensure the next phase of the ASD Strategic Action Plan builds constructively and positively upon the firm foundations that have been laid. This will be essential in order to progressively develop and improve the services and support that individuals with autism in Wales so richly deserve”*

Gwenda Thomas AM  
Deputy Minister for Social Services

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## Executive Summary

1. **Funding:** the Welsh Assembly Government Autistic Spectrum Disorder (ASD) Strategic Action Plan was launched on 22nd April, 2008. Between November 2008 and 31st March 2011, a total of £5.4m ring-fenced funding for ASD has been issued to support its implementation, plus a further £5.1m Revenue Support Grant issued over the same period to Local Authorities to support delivery of services to children with ASD. Further funding was allocated to take forward specific actions to support adults with ASD and this is summarised in Chapter 2. A further £2.076m of ring-fenced funding has been committed by the Welsh Assembly Government to deliver the ASD Strategic Action Plan during 2011/12.
2. **Delivery Strengths:** significant and demonstrable progress has been made against the actions originally identified in the ASD Strategic Action Plan. Particularly strong delivery has been seen in the areas of infrastructure and planning developments, collaborative service commissioning and ASD project establishment, awareness-raising and training, and also service planning for adults with ASD.
  - **Infrastructure:** Wales is unique within UK nations in establishing an identified staffing infrastructure for ASD within its statutory services. Since the introduction of the ASD Strategic Action Plan in 2008 each of the twenty-two Local Authorities within Wales has a nominated lead officer for ASD. Some Local Authority areas also have an ASD lead for children and another for adults. In all twenty-two cases the identified ASD lead officer coordinated the construction of the local ASD Action Plan. Between May 2009 and March 2011 there has been an ASD Regional Support Team located in the Social Services Improvement Agency (part of the Welsh Local Government Association). Since June 2008 there has also been a National ASD Implementation Manager based in the Welsh Assembly Government to drive forward the foundation stages in the delivery of the ASD Strategic Action Plan, this role ceases in March 2011 and will be replaced by a new post of 'expert advisor on ASD'. From April 2011, the SSIA will operate a web-based ASD e-resource (which will include the provision of e-learning), coordinate an ASD Learning and Improvement Network and appoint a national co-ordinator to deliver these initiatives.
  - **Local ASD Planning:** prior to the introduction of the ASD Strategic Action Plan no Local Authority in Wales had a local ASD Action Plan. All twenty two Local Authority areas now have a local ASD Action Plan which is reviewed and updated on a regular basis.
  - **Collaborative commissioning and project establishment:** twenty two new ASD projects in Wales were established during 2010/11 as a direct result of collaborative commissioning with funding provided within the ASD Strategic Action Plan. A larger number of other projects within individual Local Authority areas have arisen as a direct result of the development of Local ASD Action Plans.

- *Awareness-raising and training:* in the 18 month period leading to 30<sup>th</sup> September 2010, over 5,000 people in Wales attended training courses on ASD delivered across the twenty two Local Authority areas. Over 250 ASD training/awareness-raising courses were delivered across the same period in Wales. Seventeen Local Authorities also reported that they had delivered wider awareness-raising activities to raise the public profile of autism. Nineteen Local Authorities reported that the awareness of the needs of adults with ASD had improved over the same period. Eleven web-based awareness-raising booklets for a range of practitioners groups and families were published by the Welsh Assembly Government in February 2011 and a further four are under development for launch during the Spring and Summer of 2011.
  - *Adults with ASD:* very significant efforts have been made in Wales since 2008 to collaboratively plan and commence delivery of a range of service developments to adults with ASD. In 2011 the introduction of pioneering and inter-linked national projects such as the creation of an All-Wales diagnostic and pre/post diagnostic network; regionally delivered community and monitoring support schemes for adults with Asperger syndrome; and the earlier introduction of the Wales ASD Employment Ambassador, who was officially launched in December 2010, will firmly place Wales at the cutting-edge of international thinking and practice in the field. Many Local Authority areas are already reporting an increase in awareness of the needs of adults with ASD. Research will be needed to evaluate these schemes since they are so new in conceptual and practice terms.
3. ***Stakeholder engagement:*** the development of local ASD Action Planning has moved from zero in 2008 to over 400 stakeholders within an eighteen month period. Again this feature is unique within the UK. The largest representation on local ASD stakeholder groups is that of parents, individuals with ASD and voluntary organisations. Almost all Local Authority areas hold ASD stakeholder meetings, on a monthly to three monthly frequencies, but there may be a benefit from greater consistency between Local Authority areas. A national ASD stakeholder group has also met on five occasions since January 2009 of which the Autism Cymru and the National Autistic Society Cymru are full members.
  4. ***ASD Research in Wales:*** has moved on exponentially since 2008 and Wales has emerged a key player on the international autism research stage. The Welsh Assembly Government supported Autism Cymru's successful efforts to create the UK's first named Professorial Chair in Autism in Wales and the establishment of the Wales Autism Research Centre, both in Cardiff University. The Learning and Disability and Autism Research Network (Clinical Research Collaboration Cymru) is playing a significant role in inspiring and supporting autism research in Wales. The objective of research into older persons with ASD, which was a key action in the ASD Strategic Action Plan, was completed by Bangor and Glamorgan Universities and proposals for further development from the Chair in Autism, Cardiff University, have been submitted to the Welsh Assembly Government for consideration.



5. **Partnerships with the Voluntary Sector:** the many parts of the voluntary sector in Wales have made a significant contribution to the planning and delivery of the ASD Strategic Action plan for Wales both at local and national level. Autism Cymru's efforts into raising the profile of the Welsh autism research agenda has attracted considerable investment into, and acclaim for, Wales. Charities such as Cartrefi Cymru, National Autistic Society Cymru, Touch Trust, Autism Initiatives and C-SAW are delivering a wide range of services to people with autism in Wales. Both the National Autistic Society Cymru and Autism Cymru have been fully consulted and involved in decision-making over developments and direction of the ASD Strategic Action Plan. A response to the National Autistic Society Cymru's campaign report 'The Life We Choose' (2011) is given in Chapter Five.
6. **Recommendations:** despite the strong progress that has been made during the early implementation of the ASD Strategic Action Plan a number of areas have been identified for attention which require strengthening during the next phase of delivery. Key areas are identified within each chapter but the headlines can summarised as follows:

<b>Data Collection</b>	There is a need for greater consistency in the methodology of data collection within and between Local Authorities and LHBs. This will require guidance and support facilitated by the Welsh Assembly Government. The outcome will provide more accurate evidence of numbers, needs and services which can be used to tailor on-going implementation of the ASD Strategic Action Plan. The gathering of such information on ASD from local to national level will be unique within the United Kingdom.
<b>Mentoring support and guidance</b>	This is needed for the very small number of local authorities who are not holding regular stakeholder group meetings or not engaging as fully as they should with all stakeholders.
<b>Regional collaborations and value for money evaluation of project developments</b>	Further consideration should be given to address the need for continued coordination of regional planning and collaborations; and also for the assessment, monitoring and evaluation of the many ASD projects being initiated with funding from the Welsh Assembly Government.

<p><b><i>Welsh Assembly Government awareness-raising materials:</i></b></p>	<p>To add to the fifteen Welsh Assembly Government ASD awareness-raising 'booklets' already published or in preparation, by developing a booklet for Leisure providers in Wales. Further, BME adaptations of all existing materials need to be available, if requested, and promoted appropriately.</p>
<p><b><i>Research with deliverable outcomes:</i></b></p>	<p>It is imperative to retain a balance between research and deliverable actions. It is therefore recommended that the immediate priority during 2011-12 will be to considerably strengthen the robustness of data collection in terms of numbers, need and services within local areas (as identified above); to be followed during 2012-13 with the commissioning of research to explore the impact of the ASD Strategic Action Plan upon individuals with ASD, their families and practitioners. The culmination of both processes will lead to the identification of key deliverable actions which can inform years five to ten of the implementation of the ASD Strategic Action Plan for Wales.</p>
<p><b><i>Evaluation of Children's ASD Assessment and Diagnostic provision in Wales</i></b></p>	<p>In 2010 the Assembly Government commissioned the Wales Autism Research Centre to undertake an evaluation of Children's ASD Assessment and Diagnostic provision in Wales. Funding has been allocated to take forward this work from 2011-12 (see Chapter Three). It is recommended that this important evaluation (the first national evaluation on this subject in the UK) is published by the authors.</p>
<p><b><i>Adults with ASD</i></b></p>	<p>The implementation during 2011 of the range of services to adults with ASD: diagnostic network; community support; employment and other developments is tremendously exciting but as these initiatives are so new on the UK scene, delivery will require careful on-going monitoring and evaluation particularly during the first 12-18 months.</p>

## **Introduction**

The Welsh Assembly Government's Autistic Spectrum Disorder (ASD) Strategic Action Plan was launched on 28<sup>th</sup> April 2008. It contained a 'state of play' analysis of autism within Wales and its aim was to *"set a clear direction of travel for the development of services in Wales by ensuring that specific and measurable actions are undertaken and, on the basis of evidence of prevalence and need, commissioning inter agency services at local, regional or national levels as appropriate"*. It sought to broaden our understanding of Autistic Spectrum Disorder (ASD), its prevalence in Wales and it was implicit it could only be achieved through collaborative working between all parts of the statutory and voluntary sector and by developing a mutually supportive 'can do' approach.

The publication of the Assembly Government's ASD Strategic Action Plan was also particularly noteworthy as it was believed to be the first national ASD strategy to be published and subsequently implemented by any government anywhere in the world. Equally, as there was no similar initiative elsewhere upon which to benchmark the Welsh ASD Strategic Action Plan, it was clear that the Assembly Government was treading upon new ground.

It was intended that ASD Strategic Action Plan should run in three-year cycles alongside the planning cycles for Children and Young People's Plans and Local Health, Social Care and Well-being Strategies.

In November 2008 the first funding was issued to local areas as part of ASD Strategic Action Plan. In just over two years the many developments which have emerged as the result of the Welsh Assembly Government's ASD Strategic Action Plan have moved well beyond those stated originally and has drawn many people and agencies together for the cause of autism in Wales. In comparison with other countries in the UK it is now crystal clear that Wales has developed unique structures and processes in response to autism (see bottom of this report for key features) and the financial investment in the ASD Strategy made by the Welsh Assembly Government has proportionately exceeded that made by Governments in England and Northern Ireland who have since published their own ASD Strategies (Scotland's ASD Strategy is under development).

The value of the ASD Strategic Plan for Wales is therefore that it has been an effective springboard for the many new developments within the autism field in Wales; that it will grow in response to lessons learned and evaluation; and that it can continue to be the impetus which enables Wales to effectively respond to ASD over the remaining life of the strategy.

## **Methodology employed in this evaluation**

Several sources of evidence have been considered in the preparation of this national review and in so doing provide the most objective, if early, analysis of progress made by the ASD Strategic Plan. This review marks out the actions identified in the original action plan, identifies progress against these initial areas but also highlights where there has not been progression or where attention is needed to strengthen a specific area. It takes into account progress over and above those actions determined in the original action plan which has been made during

the intervening period. It also draws upon the findings of an interim survey which was distributed to all twenty two Welsh Local Authority areas in autumn 2010 to which all responded. This survey focused on seven key areas, which were designed to give empirical evidence rather than opinion:

- data collection of need and services at local level
- stakeholder engagement
- local ASD Action Planning
- transition planning
- awareness-raising and training of practitioners and the public
- projects developed since the introduction of the ASD Strategic Action Plan
- assessment and diagnosis for children and adults with ASD

A further short survey was undertaken of several voluntary agencies in Wales and a separate survey undertaken by the National Autistic Society Cymru (2011) has also been considered. Other documentary evidence was sourced and drawn upon, such as, the written response by the Welsh Assembly Government to the Enterprise and Learning Committee's report of their inquiry into "Specialist Provision For Young People With Autism In Further Education" (2010) and the "Compendium of ASD Good Practice in Wales" developed by the Welsh Local Government Association; which is due for publication in March 2011.

## Chapter One:

### Has the ASD Strategic Action Plan delivered its original objectives?

This chapter identifies the original actions contained within the ASD Strategic Action Plan (named "Task"), and identifies progress made against these. It highlights examples of good practice but also areas which require attention.

**Summary:** Significant progress has been made against the actions originally identified in the ASD Strategic Action Plan. Particularly strong delivery has been seen in the areas of infrastructure development, collaborative service commissioning, awareness-raising and training and also service planning for adults with ASD. Stakeholder engagement in local ASD Action planning moved from zero in 2008 to over 400 stakeholders within an eighteen month period but can benefit from greater consistency between Local Authority areas. The key task requiring further strengthening is that of data collection within Local Authority areas and recommendations are made to address this and other areas including transition planning and the coordination of trans-authority or regional opportunities and collaborations.

### Section A: Mapping prevalence, needs and services

Commissioners and Service Providers were identified as the key drivers for the development of local actions identified in the Strategic Action Plan. They were asked to:

**Task:** *set up systems to identify and record the number of people within their existing client populations who are known to have ASD and map services for children, young people and adults as well as family and carer support services, across all statutory, voluntary and independent provision (including self-help support groups).*

#### **Progress:**

- In November 2008, the Welsh Assembly Government asked all Local Authorities in Wales to liaise with Local Health Boards to map out local need and services provided. An early assessment was made via a Welsh Assembly Government baseline survey issued to Local Authorities in the Spring of 2009. A subsequent interim survey issued later in the autumn of 2010 sought to see if progress had been made. Eleven of Local Authorities reported the collection of data for adults and children with autism have improved compared to eighteen months previously. The other half of Local Authorities reported there was change.
- Eleven Local Authority areas have developed a database for children with autism whereas a similar database for adults was held by just seven. In ten cases there was a flow of data concerning individuals and needs between Local Authorities and Local Health Boards; whereas in twelve cases this was not so.

- The Welsh Assembly Government and Betsi Cadwaladr University Local Health Board (BCULHB) have jointly funded a feasibility project to develop a North Wales database for 0-28yrs olds with ASD. This project commenced in the autumn of 2010 and findings are due in 2012. This project is being viewed as a pilot by the Welsh Assembly Government.

**Example: Bridgend 'Mapping':** *Within Bridgend, part of the Assembly Government's ASD Strategic Action Plan funding was used to appoint a person to work on updating the disability register to include all those with a diagnosis of ASD. Data for children up to the age nineteen is now robust and the post-holder is working proactively with other teams and organizations to map adults with ASD and the services they use. One of the results of this is a "visual map". The post-holder has worked with IT to develop this and they can now extract various data from their records. For example, they now know the geographical spread of ASD across the area – there are no unexpected clusters – and they can quickly map the number of miles people have to travel to their support services (see Appendix 1)*

- Whilst improving within a significant numbers of authorities, there is still much work to be undertaken to reach a confident level of data collection and therefore to create the capacity to accurately predict and plan service need. In the autumn of 2010, Local Authorities were asked what would help them in developing systems to collect data. There were three key issues reported:
  - i. Lack of mechanisms for sharing of information between LAs and the NHS
  - ii. Concerns over the confidentiality of sharing information
  - iii. The resources (time and knowledge) to focus upon data collection

**Recommendation:** It is clear that significant local progress has been made in this complex and previously unexplored area (indeed within the UK) and the innovative WAG/BCUHB jointly funded database feasibility project underway across North Wales may provide some further answers in due course. However, it is important that during the next phase of the ASD Strategic Action Plan a big effort is made to guide and support local areas to establish consistency in the accurate collection of data especially around numbers, individual need, but also the services provided and needed.

Welsh Assembly Government guidance for data collection is therefore required, (in consultation with areas and regions already doing good work such as Bridgend and North Wales), as is support and training for those involved in data collection. The objective will be also to ensure an informed and consistent approach so that national as well as local and regional data can inform policy and practice initiatives.

**Task:** identify an ASD champion with sufficient knowledge and seniority, who will work with key stakeholders to promote this work, subsequent planning, service delivery and monitoring

**Progress:**

- Following representations from the Welsh Local Government Association in the summer of 2008, it was agreed to change the title to 'ASD lead'.
- By the summer of 2009 every Local Authority area in Wales had identified a local ASD 'lead'. There was no consistency of professional background and hosting department for the ASD lead between Local Authority areas, and 'appointees' have hailed from Education, Social Services and Health. In one case the nominated lead was a very senior officer within a Local Authority but the day to day work was devolved to an ASD 'coordinator'.
- Some areas have since developed a lead for adults with ASD as well as a lead for children.

**Example:** Vale of Glamorgan: An ASD project manager was appointed by the Vale to further develop the local ASD action plan and to implement the plan locally. A significant part of the project manager's role has been to increase awareness of ASD across teams and services in the area and in this aspect has gone into some unusual but important areas. The project manager has successfully raised the profile of ASD within the following services / areas:

*Learning Disability Team; LD Transition Team; Mental Health Team; Health team (as part of LD); Children and Young Peoples Partnership; Disability Equality; Corporate Training team; Family Support Team; Vale School Governors management board; Local Assembly member and MP; Local Councillors; Youth group coordinators; Community Focused Schools Manager; Outdoor Education Adviser and Duke of Edinburgh Award Officer; Older People Strategy Coordinator; Vale Centre of Voluntary Services; Barry Further Education College; Crossroads; Children with Disability Steering Group; Face2Face; Cardiff Interagency Transition Group; Student Volunteering Cardiff University; Mobility and Inclusion Manager First Great Western and the Vale Older Persons Transport Group.*

- Funded through the ASD Strategic Action Plan, a regional ASD Support Team consisting of four people commenced operation in May 2009 and were located in the Social Services Improvement Agency (SSIA) which is part of the Welsh Local Government Association. The primary purpose of the team was to provide mentoring support and guidance to local ASD leads and to identify opportunities for regional collaborations especially where low incidence, high cost services were needed (this team ceases to operate at the end of March 2011 and will be replaced by a web-based ASD e-resource and an ASD Learning Improvement Network (LIN), coordinated by a national coordinator based within the SSIA).

**Recommendation:** The ASD Regional Support Team has been valued by many local ASD leads and the Regional Support Teams have also played a key role in assessing and monitoring local and regional projects funded through the Assembly Government's ASD grant. The ASD LIN being developed by the Social Services Improvement Agency will provide networking and practice-sharing, although further consideration will need to be given to how mentoring support, cross-border or regional opportunities and collaborations can be coordinated and delivered in view of the cessation of the posts of ASD Regional Support Officers.

**Task:** estimate current and future demand for services on the basis of the best evidence (see Chapter 2).

**Progress:**

- In order to determine the current and future demand for services Local Authorities were asked by the Welsh Assembly Government to establish Local ASD Action Plans. Prior to the introduction of the ASD Strategic Action Plan no Local Authority in Wales had a formal Local ASD Action Plan.
- By 30<sup>th</sup> September 2010 all twenty-two Local Authorities had produced a local ASD Action Plan. In all cases the person who played the key role in the coordination of the ASD Action Plan was the identified lead ASD officer.
- All Local Authority Action Plans refer to and reinforce the objectives laid out in the Welsh Assembly Government ASD Strategic Action Plan.
- All Local Authorities reported that the production of the Local ASD Action had resulted in new or helped to support existing specific ASD related projects (**Appendix 2**).
- Nineteen of Local Authority areas actively engage their local ASD stakeholder group in the preparation and review of their local ASD Action Plan.
- Fourteen Local Authorities “publish” their Local ASD Action Plan whereas eight do not.

**Recommendation:** The value of having a Local ASD Action Plan is being demonstrated at a range of levels (see also in sections below). It is however, strongly recommended that all Action Plans are published and that all stakeholders have the opportunity to contribute and comment on the plans and are engaged in the regular review process. Support and guidance will be needed to achieve this.



**Task:** *The Welsh Assembly Government will commission research into the prevalence of ASD in older people in Wales and their needs.*

**Progress:**

- The University of Glamorgan (Professor Ian Stuart Hamilton) and University of Bangor (Professor Richard Hastings) were commissioned to undertake an initial pilot study into this previously under-researched area. The findings of their report 'The Circumstances and Support Needs of Older People with Autism were accepted by the Welsh Assembly Government in January 2010. A paper by Professor Stuart-Hamilton related to this research is due for publication during 2011 in the academic journal "Advances in Mental Health and Intellectual Disabilities".
- The needs of adults with ASD became the subject of a Welsh Assembly Government conference held in Aberystwyth Arts Centre in June 2010, the second day of this conference focused on older people with ASD and speakers included Michael Baron MBE a leading protagonist in Europe on the need for services to be planned and developed for older adults with ASD.
- Professor Sue Leekam, Chair in Autism, Wales Autism Research Centre, Cardiff University, was subsequently asked by the Welsh Assembly Government to work with others to consider and provide advice to the Assembly Government on how best to address the research actions in the WAG commissioned report. Professor Leekam's report was submitted to the Welsh Assembly Government in February 2011.

## Section B: Commission Services

**Task:** Commissioners should ensure that Children and Young People's Plans and Local Health, Social Care and Well-Being Strategies, completed in 2008, include an overview of the arrangements for commissioning of services for children, young people and adults with ASD over the lifetime of the plans, including those to be commissioned locally or otherwise.

**Progress:** By end September 2010, all but one local ASD Action Plan had been seen and recognised within the local Children's and Young People's Plans. Fourteen had received recognition within Local Health, Social Care and Well-Being Strategies.

**Task:** Commissioners should identify where they will make use of their powers to pool resources (including accommodation, staff and financial resources) to commission services.

**Progress:** The regional support provision created in 2009 when the Welsh Assembly Government commissioned the Welsh Local Government Association to establish a team of three regional support officers supported by a coordinator, sought to facilitate the development of partnerships between LAs in order that resources, planning and practice and could be shared (these positions cease on 31<sup>st</sup> March 2011 and will be replaced by the development of a web-based ASD e-resource and Learning Improvement Network (LIN) that will be managed by a national coordinator based within the SSIA).

- In each of the three regions (Mid & West; North; and SE Wales) network meetings of local ASD lead officers coordinated by the ASD Regional Support officers were established.
- The Welsh Assembly Government hosted two national annual ASD leads meetings in collaboration with the Welsh Local Government Association during 2009 and 2010.
- In 2010, twenty-two new ASD projects were commissioned by the Welsh Assembly Government resulting from regional and local collaborations. These projects received total funding of £282,094 and are listed in Chapter Three.

**Example:** Carmarthenshire ASD stakeholder group used some of their ASD Strategic Action Plan funding to initiate actions to increase the range of short break provision. The short breaks pilot focuses on young people aged 16-25 years and consists of two different types of short breaks. One project has a fixed base which combines a programme of activities for the young people with activities in the community. This is being used by young people with autism whose needs and difficulties are quite complex. The other part of the short breaks project is series of small groups of young people undertaking a range of activities such as fishing, and forest craft. Outcomes for both types of short breaks are: improvement in self confidence/esteem; experiences of being part of a group; extending a young person's range of experiences; independence; developing a pathway into other services and activities in the community.

**Task:** *The Welsh Assembly Government will publish the final version of Quality Standards in Education for Pupils with ASD in 2008. The quality standards will provide schools and LEAs with guidance on minimum service requirements for pupils with ASD and ensure a consistent approach to meeting needs across Wales.*

**Progress:**

- Since the publication of the ASD Strategic Action Plan the successful delivery of the Autism Cymru bi-lingual Inclusive Schools and ASD Training and Research programme to over 500 schools in Wales, in partnership with Local Education Authorities, has redefined the need for Quality standards in ASD to be produced. Delivery of training to all schools in Wales has been seen to be a more effective use of resources than an 'off-the shelf booklet'. (Ref: Written Report by the Welsh Assembly Government to the Enterprise and Learning Committee Report of their Inquiry into Specialist Provision of Young People with Autism in Further Education, July 2010). Since July 2010 and based on feedback from schools, the quality standards developed for ASD are to be included in an Inclusion Toolkit which is being developed as part of the school self evaluation process of the School Effectiveness Framework (SEF). This complements Estyn's inspection framework. The SEF aims to ensure improved learning outcomes for all and will be the overarching vehicle for all initiatives aimed at improving the quality of education in Wales.
- Awareness-raising materials for those working in early years, primary, secondary schools and Colleges of Further and Higher Education with children and young people were published on the web by the Welsh Assembly Government in February 2011.

**Task:** *The Welsh Assembly Government will issue guidance to Local Education Authorities (LEAs) on the development of the regional provision of goods and services for children and young people with Special Educational Needs (SEN) across Wales.*

**Progress:** Draft guidance regarding development of regional provision for young people with SEN is being updated in order to take account of developments emerging from the statutory reform pilots and from recommendations made by the Post-16 SEN/Learning Difficulties or Disabilities (LDD) Funding Task and Finish Group.

**Task:** *LHBs should have in place by the end of 2008 arrangements to commission, within the lifetime of the Children and Young People's Plan and Local Health, Social Care and Well-being Strategy, regional provision of diagnostic and treatment services to bring together the appropriate specialisms (including paediatric and adult psychiatry and learning disability) and ensure equity of access across Wales to 'tier 3' services for those individuals who need them.*

**Progress:** Although this action is far wider than ASD, significant progress and investment has been made in the evaluation, planning and preparatory stages of delivery against this action within the ASD Strategic Action Plan.

- **Adults: a)** the Adults with ASD Task & Finish Group which met during 2008/9 investigated and drew together evidence to underpin recommendations made to the

Welsh Assembly Government for the development of an All-Wales Diagnostic and pre/post Diagnostic Counselling Network for Adults with ASD. In 2010 the Welsh Assembly Government announced funding of £752k over three years to implement this action, the first such approach taken to the diagnosis of Adults with ASD in any of the UK nations. The preparatory stages of the Network commenced in February 2011, led by Dr Roger Banks of Betsi Cadwaladr University Health Board.

- **b)** The reconvened Adults Task & Finish Group has, during 2010/11, investigated the interface of mental health in relation to ASD and will be reporting back to the Welsh Assembly Government in the late Spring of 2011.
- **Children: a)** In 2010 the Welsh Assembly Government commissioned Professor Sue Leekam, Director of the Wales Autism Research Centre, to identify and evaluate the 'state of play' in relation to the assessment and diagnosis of children with ASD in Wales (see Chapter 3). Professor Leekam's recommendations are due to be implemented by the Welsh Assembly Government and £200k has been allocated to this effect during 2011/12.
- **b)** In 2010 The Welsh Assembly Government entered into an agreement with the Betsi Cadwaladr University Health Board, to commission a feasibility project into the development of a North Wales database for children and young people with ASD. This is an eighteen month pilot project.

**Task:** *Children's & Young People's Partnerships and Local Health, Social Care and Well-being Strategic Partnerships should support the establishment of an ASD co-ordinating group in each local area. This group should be multi-agency, include service users and carers, and inform and support agreed cross-agency approaches to strategic planning for and commissioning of services for people with ASD. Provision for supporting the attendance of users and carers must be considered. Trying is not enough; practical help should be available. Links should also be made to voluntary sector organisations with interests in the area.*

**Progress:**

- Stakeholder engagement has been a cornerstone in the planning and the delivery of the Welsh Assembly Government's ASD Strategic Plan. This has impacted at national, regional and local level.

**History of ASD stakeholder engagement in Wales**

*On 4<sup>th</sup> December, 2002, the Welsh Assembly Government announced that it would develop a national strategy for autism. Stakeholders (i.e. families, individuals with ASD, practitioners from a range of statutory and independent sectors organisations) were included as contributors in the planning process for the ASD strategic action plan between 2003 and 2007. When the draft ASD Strategic Action Plan went out to consultation in May 2007, three major consultation events were commissioned by the Welsh Assembly Government and jointly organised by Autism Cymru and the National Autistic Society and were held throughout Wales attracting over three hundred participants. Over 500 stakeholders made submissions to the Welsh Assembly Government in response to the consultation report reflecting individual and group views on what was needed to be contained in the ASD Strategic Action Plan for Wales.*

- By 2009 all Local Authority areas in Wales had formed a local ASD stakeholder group and had produced a local ASD action Plan.
- By September 2010, no less than 400 stakeholders were participating in the Local ASD Action Planning Groups hosted by the 22 Local Authorities in Wales.
- Family members, individuals with autism and voluntary sector organisations represented the largest membership on local ASD stakeholder Groups across the country, taking 127 places between them. Local Health Boards had 87, Local Authority Social Services were the next largest contributors with 85 representatives from Social Services and there were 57 from Local Education Authorities. The remaining 53 being made up of smaller representation from a range of agencies including Further Education Colleges, Careers Wales, Job CentrePlus, private sector companies and others.
- Almost all local stakeholder groups met on a monthly to quarterly basis. One though had held just two meetings over an eighteen month period by the autumn of 2010.

**Example: Stakeholder Engagement in Monmouthshire :**

*Early on in the Local ASD Action Planning process three local parent and carers support groups were identified who might be able to help inform development of the Local Autism Action Plan. After hearing people's concerns and expectations, and gathering examples of what was also working well in the area, the first draft of the Local ASD Action Plan was drafted and circulated to those individuals who had participated.*

*Alongside this engagement with local parent and carers groups, a planning day was arranged to further gauge people's opinions. This also allowed people affected by autism who had been unable to access support groups to input into the consultation.*

*An Autism Information Day was also held and heard from key note speakers such as the local ASD lead, leisure representatives, and the staff from the local autism 'Virtual team' - a group of professionals from different Social Services departments who work with people with autism in the County. This event also promoted transparency, giving people an opportunity to better understand the authority's aims, and to meet many of the key staff.*

*People affected by autism have played a central role in making key decisions, including procurement and appointments. For example, a parent of someone with autism was a member of a panel which selected a company from a group of tenders to deliver autism training to professionals including individuals, their parents and carers in the area.*

- Fifteen Local Authorities also have a further ASD Planning mechanism referred to as a 'steering or strategic' ASD group. Again, the largest single representation was from parents, individuals with autism and voluntary sector orgs, followed by LHBs and Social Services Departments and then LEAs.
- Public newsletters prepared by the Welsh Local Government Association in association with the Welsh Assembly Government have been provide those with an interested in autism in Wales with regular updates on progress of the ASD strategic Action Plan.

**Recommendation:** stakeholder engagement has evolved well since the introduction of the ASD Strategic Action Plan and there are currently twenty two stakeholder groups operating which feed into the development of the local ASD Actions. It is clear however, that whilst many areas have established effective mechanisms, a small number of areas need guidance and help to improve engagement.

## Section C: Transitional arrangements

- a. **Task:** *There were a number of tasks within this section in the ASD Strategic Action Plan. All these actions though referred to the wider SEN group, largely focussed on children and did not focus specifically upon autism. (For example, “Commissioners and service providers should ensure there are clear arrangements for transition between services for children and young people and adult services, in line with the actions set out in the National Service Framework for Children, Young People and Maternity Services”). Therefore for the purpose of this report the progress detailed below removes the wider SEN aspect and refers to progress being made specifically in relation to ASD.*
- b. **Progress:**
- All Local ASD Action Plans in Wales refer to transitions for children and young people with ASD.
  - Twenty-one Local Authorities also detail transition from School to FE/HE/Employment in their local ASD action plans.
  - Fourteen Local Authorities detail ‘situational’ transition from one setting to another which is not age dependent.
  - Seventeen Local authorities link their local ASD Action Plan into wider local transition projects.

### **Quotations from five local areas adapting transition to the needs of individuals with ASD**

1. *“Our LEA has modified their transition planning from primary school to secondary to include issues regarding the environment, sensory processing, and knowledge of how the child best learns. Support staff spend time with the child in their primary school prior to transfer. ‘Supporting People’ provides ASD specific support in the move-on accommodation for people with Asperger syndrome. The ASD project workers in Community Support Services work with people with ASD during the transition from school to FE/HE/Employment or adults services. The Social Worker for adults with Asperger syndrome works with people during transition from school to FE/HE/employment or adults services to ensure appropriate ASD specific assessment and care planning”.*
2. *“We have an ASD transition key worker – but all key workers offer a transition service to students with ASD; support young people with a Learning Disability who have complex needs and / or challenging behaviour (some of whom have an ASD) between secondary school and FE / HE into adult services”.*

3. *“We have put in bid for a transition worker. We aim to develop and establish a key worker service to support disabled young people between the ages of 14 and 18 years, who have a diagnosis of Autistic Spectrum Disorder and who live within the local authority boundaries”.*
4. *“It is important to note that the majority of the children and young people currently identified as having Autism also have very significant learning disabilities. So the ASD specific issues for these children and young people are included in our broader transitions arrangements. There have been particular challenges in meeting the needs of those young people with Asperger syndrome and significant mental health difficulties and we are currently working through these. We have linked our ASD Action plan to the Transition Strategy and Action plan for the authority”.*
5. *“We have the published a transition booklet developed by our ASD Support Officer with direct involvement and support with pupils, family and school”.*

#### **Recommendations for next phase of ASD Strategic Action Plan**

**Whilst some substantial progress has been made and there are increasingly good examples of ASD transition planning and support in many individual local authorities, there is a need for consistency and sharing of good practice. The new ASD Learning Improvement Network (LIN) for ASD will be a useful resource for sharing practice but will benefit from being informed by, link to and draw upon, wider transition projects within Wales.**

**It is recommended also that ASD transition plans within each local authority in Wales take into account the whole age range, includes older persons with autism who may be approaching retirement or perhaps entering older persons care services, but also those of any age who are likely to be in full-time care provision whose transitions and whose loss of attachments from one service to another can be enormously traumatic.**

## **Section D: Services for Adults**

- c. **Task:** *The Welsh Assembly Government will, during 2008 establish a Task and Finish Group who will identify specific issues that adults face and take forward work to tackle them, and investigate, evaluate and report on the evidence for effective interventions and models of services for adults.*

**Progress:** A Task & Finish Group was formed and reported to Welsh Assembly Government in 2009 making recommendations in five key areas. The Task & Finish

Group reconvened in May 2010, to investigate a further five areas. Full details of the developments in services to Adults with Autism are contained in Chapter Two.

## **Section E: Awareness raising and training materials.**

**Task:** *Consideration to be given the development of a web-based, bilingual, self-instructional awareness-training package for families and practitioners in Wales (possibly using existing bilingual web-based routes that are demonstrated by, for example Awares.org). The needs of black and ethnic minority communities will also be included in considering the range of awareness raising and training materials.*

*Commissioners and service providers in health, social care and education sectors should support the provision of ASD awareness training for all professionals who may come into contact with people with ASD. In addition, professionals in the following services should receive awareness raising information: Job Centres, Careers Offices and Employment Training Agencies (particularly on the needs of adults with ASD entering the job market); FE/HE Institutions - a good starting point would be the training of College Disability Officers and their teams; the Youth and Criminal Justice system, in particular Youth Offending Teams; Leisure services. Commissioners of Services. As part of the ongoing development plan for the Careers Wales online site, a section will be developed to provide information to employers that provide work experience and jobs to people with Autism.*

### **Progress:**

- Eleven ASD bi-lingual awareness web-based materials were launched by the Deputy Minister for Social Services on 3rd February 2011. A twelfth, being developed for multi-faiths in Wales, is due to be launched in July at an interfaith and autism conference being held in Cardiff University. The current materials produced are for families, family practitioners; early years and primary school practitioners; secondary schools and further and higher education; primary healthcare practitioners; opticians and dentists, employers and related agencies; housing and day care providers; older persons services; and criminal justice system practitioners. All are being delivered as a web resource and ten also as hard copy booklets. The two Education booklets were published and circulated as electronic copies only. Other nations are now requesting copies of these materials **(Appendix Three)**.
- Further materials for those involved in housing services such as for those working in homelessness services, housing management services, and buildings design are being developed as a collaborative project between the Deputy Minister for Housing and the Deputy Minister for Social Services. These web-based materials are due to be launched in March 2011 **(Appendix Three)**.



**Example: Rhondda Cynon Taff : Directory of Autism Services**

*People with autism and their families are not always aware of all of the services and support available for them locally or nationally. In response to this need, which was identified by the Rhondda Cynon Taff local autism plan, a Directory of Services has been published. The Directory of Services recognises that good quality, comprehensive post-diagnostic information and support is essential for people with autism and their families.*

*The Directory includes contact details and information about local, Wales and UK autism-specific support, as well as information on support and services which is applicable to people with disabilities more generally.*

*There are also signposting to sources of information and support available in early years, social care, education, the Local Health Board, employment support and benefits, leisure services, and holidays and family days out.*

*A copy of the Directory is also provided to people with autism and their families at the point of diagnosis, when they are most in need of reliable information and support.*

- Careers Wales have been commissioned by the Welsh Assembly Government to establish a training programme for Careers Wales staff in relation to autism and this will be delivered in 2011/12, with awareness-raising also being provided by Autism Cymru under the European Deis Cyfle programme.
- Job CentrePlus and the Welsh Assembly Government are preparing approaches to the autism awareness-raising and training of staff for delivery during 2011/12.
- As a key part of awareness-raising the development of an ASD specific assessment tool in order to trigger and inform the Unified Assessment Process (UAP) is currently under preparation in collaboration with one local authority in Wales and will be due for launch during 2011/12.
- Raising the Public awareness of Autism: seventeen LAs reported that they had also delivered public awareness-raising activities on autism and these included Autism “Fayres”; Information Days, leaflets, DVD’s and local newspaper articles.
- Twenty-one Local Authorities reported that the provision of awareness-raising and training events had improved over the past 18 months, one said that it remained unchanged.
- Local Authorities were asked to provide details of ASD training courses provided in the 18month period leading to 30<sup>th</sup> September 2010. Twenty of the 22 local Authorities were able to give specific information on numbers, whereas two gave less certain figures. There were over 5,000 participants attending training courses on ASD across all LA

areas in Wales. Over 250 seminars/workshops/conferences on ASD were delivered. The highest attendance figures were produced for Flintshire and Carmarthenshire who had 656 and 541 participants attending 17 and 14 courses respectively.

- Nineteen Local Authorities reported an improvement over the past 18 months in terms of awareness of the needs of Adults with ASD, whereas three reported unchanged awareness. Raising awareness around the needs of adults featured as an action in all Local ASD Action Plans.
- Twelve Local Authorities included a separate ASD awareness/training plan within their local ASD action plan, whereas ten did not.

**Recommendations :**

1. **Awareness-raising materials for Leisure providers have yet to be developed. Monmouthshire were commissioned by the Welsh Assembly Government to pilot an awareness-raising scheme for leisure providers in SE Wales during 2010/11. Monmouthshire County Council should be asked to lead the development of Welsh Assembly Government awareness-materials for leisure providers which can add to the list above.**
2. **BME adaptations need to be available and promoted appropriately.**
3. **All Local ASD Action Plans must include an ASD Training programme and there needs to be recording of content and participation.**

## **Section F Resources**

13. **Task:** The Welsh Assembly Government has announced £1.8m in 2008-09 to support the first year's actions in relation to mapping of needs and services and the identification of ASD Champions. .

**Progress:**

**Ring-Fenced funding for children with ASD**

Funding did not begin until 2008-09

2008-09 £1.8m

2009-10 £1.8m

2010-11 £1.8m

**Revenue Support Grant (RSG) non- ring-fenced funding for Children with ASD**

Recurrent annual funding of £1.7m since 2008/09.

**Ring-Fenced funding for children and adults - 2011/12**

£2.076m has been agreed to take forward the ASD Strategic Action Plan in 2011/12.

## Chapter Two: Adults with Autistic Spectrum Disorders

**Summary:** Very significant efforts have been made in Wales since 2008 to seek to collaboratively plan and commence delivery of a range of service developments to adults with ASD. Many Local Authority areas are reporting an increase in awareness of the needs of adults with ASD. In 2011 the introduction of pioneering and inter-linked national projects, such as: the creation of an All-Wales diagnostic and pre/post diagnostic counselling network; regionally delivered community and monitoring support schemes for adults with Asperger syndrome; and the introduction of the Wales ASD Employment Ambassador in 2010, will help place Wales at the cutting-edge of international thinking and practice in the field. On-going monitoring and evaluation will be needed to measure the impact of these schemes since they are so new in both conceptual and practice terms.

**Task:** “The Welsh Assembly Government will, during 2008, establish a Task and Finish Group who will identify specific issues that adults face and take forward work to tackle them, and investigate, evaluate and report on the evidence for effective interventions and models of services for adults” April 2008.

Through this action the Welsh Assembly Government set in train a focus on the needs of adults with ASD in Wales, which has evolved over the first three years of the ASD Strategic Action Plan. Up to that point it was clear that adults with ASD had not been prioritised in any strategic way and the requirement for a concentrated exploration of the key areas of support needed to be driven by a newly formed Adults with ASD Task & Finish Group.

The Task & Finish Group contained eleven members, with representation derived from key agencies within the statutory and voluntary sectors across Wales. Several sub-groups were also convened (membership shown in Appendix 3). Seven meetings of the main Task & Finish Group were held between October 2008 and May 2009. A report with first stage recommendations was made by the Task and Finish Group to the Welsh Assembly Government in September 2009. The Deputy Minister for Social Services issued a statement on 22<sup>nd</sup> January 2010 accepting the report and recommendations of the group and agreeing funding of £1.7m to support the implementation of the recommendations over a three year period. The recommendations were grouped into five key subject areas

- Diagnosis
- Access to Services
- Community and monitoring support
- Employment and related issues
- Housing

Due to the Comprehensive Spending Review and consequential delays to the Welsh Assembly Government's Budget announcements confirmation of the funding to start several of these actions could not be given until February 2011. A summary of progress on actions being taken to support adults with ASD are detailed in the Table below.

**Table**

<b>Action</b>	<b>Funds Allocated</b>	<b>Timescale</b>
All-Wales ASD Diagnostic and pre/post counselling network	£752k over three years from point of Implementation (2011/12 – 2013/14).	BCUHB lead partner supported by Abertawe Bro Morgannwg University Health Board The network commenced operation in February 2011, some preliminary work has been done and the network has representation from across all of the Local Health Boards.
Regional Community & Support Monitoring Projects for Adults with Asperger syndrome	£720k over three years from point of implementation (2011/12 – 2013/14)	Funding was approved in February 2011 to allow these projects to be implemented from April 2011.
Employment & Related Issues	£130k over two years (2010/11 – 2011/12)	The Wales Autism Employment Ambassador was appointed in August 2010; training and awareness raising for Careers Wales and Job CentrePlus is to be delivered in 2011-12.
Housing	£10k over one year (2010/11)	This has developed into a joint project between the Assembly Government's Health and Social Services and Housing Departments. In March 2011 web-based materials for housing providers, including homelessness services; housing managers and building designers will be launched. Survey of available LA housing properties to be matched with autism housing providers due by May 2011.

Advocacy training	£10,000 over one year (2011/12)	Following the publication in February 2011 of awareness-raising materials for those working in Advocacy Services; planning and delivery of this action is underway
Access to Services	£20k over one year (2011/12 – 2012/13)	Information for Commissioners around service models commenced with the Assembly Government's two day Adults with ASD (including a focus on older persons with ASD) conference in June 2010. Development of training materials around UAP commence April 2011 in collaboration with Ceredigion Social Services Department.
Conference upon the needs of Adults with ASD	£10k over one year (2010/11)	This successful two day conference was led by the Welsh Assembly Government, coordinated by Autism Cymru and held in Aberystwyth University during June 2010. Day One focussed upon the needs of Adults whereas Day Two concentrated upon Older Adults with ASD. In addition to a range of speakers, workshops were led by Autism Initiatives, Opportunities Housing Trust; Cartrefi Cymru, and the National Autistic Society

### Reconvened Adults Task & Finish Group

In January 2010, the Deputy Minister for Social Services asked the Adults with ASD Task and Finish Group to reconvene in 2010/11 to consider a further five areas relevant to Adults with ASD:

- Criminal Justice System
- Further & Higher Education
- Impact of the Dept of Work and Pensions Welfare Reforms
- Older Persons
- Mental Health

A similar consultative process has been followed with this new group, which seeks the views of individuals with autism, carers and practitioners and again engages with a considerable number of people. The report and recommendations from the reconvened Adults with ASD Task & Finish group will be prepared and submitted to the Welsh Assembly Government during the late spring 2011.

**Example:** *The Welsh Assembly Government funded ASD Employment Ambassador is the first such position in the UK. Formally launched in December 2010 Robert Lloyd Griffiths, Director of the Institute of Directors (Wales), was appointed to this key role and is already conducting meetings at the very highest levels of business in Wales. The first employer to sign up to Wales' Autism Employment Charter has been Admiral Insurance. Mr Lloyd Griffiths reports 'I detect that there is a genuine willingness among business to embrace the fundamental message of my role, that of recognising that those with ASD can add value to an organisation and should be given every opportunity to maximise their potential'. A project group has been established to monitor and support the work of the Employment Ambassador.*

## **Local developments for adults with ASD**

Whilst the Welsh Assembly Government's direction in this previously under-developed area has been the catalyst, there are a number of developments being established at local and at regional level which move the agenda on significantly. There has been an increase in awareness of the needs of adults with autism in Wales since the development of local ASD Action Plans as evidenced by the references and actions to adults contained within these action plans.

### **Example: Betsi Cadwaladr University Health Board (BCUHB) – North Wales Adults with ASD Project Group**

*The purpose of the Adult ASD Project Group is to clarify and agree the particular issues relating to Health Services in the context of ASD, oversee the development of responses to those issues and by engaging directly with regional and national colleagues, facilitate delivery of the Welsh Assembly Government's ASD Strategic Action plan. The group has four work streams:*

*Work stream 1: Adult ASD Assessment/Diagnosis Service, with reference to the multi-faceted nature of presentations.*

*Work stream 2: An ASD Training and Awareness Strategy ensuring that Health practitioners have a level of awareness of ASD or competence to deliver assessment/diagnosis or support as required by their work.*

*Work stream 3: Development of a database of people with a diagnosis of ASD, which will build on the information held in the developing child database.*

*Work stream 4: Service/interventions for adults. The aim of the work stream is to develop a model for the delivery of health interventions for adults with a diagnosis of ASD offering effective access in a timely manner to appropriate treatment and support services.*

**Recommendation:** *The implementation during 2011 of the range of services to Adults with ASD: diagnostic network; community support; employment and other initiatives is tremendously exciting but as these initiatives are so new on the UK scene, delivery will require careful on-going monitoring and evaluation particularly during the first 12-18months.*

## Chapter Three: Key developments which have emerged over and above the original ASD Action Plan

**Summary: Twenty two new ASD partnership projects between agencies (mostly operating cross local authority boundaries) were established in 2010, including: the Wales Autism Research Centre's 2010 evaluation of children's ASD diagnostic service throughout Wales which sets the basis for significant developments to be implemented from 2011 onwards; a joint project initiated by the Deputy Minister for Housing and the Deputy Minister for Social Services will lead to awareness materials for housing management providers (including those in homelessness services) being launched in March 2011, with further developments due by May 2011 and three editions of newsletters providing updates on the ASD Strategic Action Plan have been distributed by the SSIA.**

### **Collaborative Projects between Local Authorities and Funded by the Welsh Assembly Government**

Local and regional ASD action planning, resulting from the ASD Strategic Action Plan, led to the development in 2010 of collaborative schemes between areas and agencies which would be of benefit to individuals with ASD, their carers and those who work with them.

The Welsh Assembly Government asked the Implementation Manager, together with the ASD Regional Support officers (SSIA), to evaluate collaborative proposals from each of the three regions in Wales. 22 projects received approval during 2010 attracting funding totalling £282,094. The Regional Support Team was asked to monitor the delivery of these projects with each being viewed as a pilot project to inform future development of the ASD strategy in Wales. This successful process will be repeated in the 2011/12 financial year and the Welsh Assembly Government have allocated almost £300k for future collaborative projects.

#### **Mid & West Wales**

##### **Development of a Social Networking Site for Young People with ASD:**

Following a successful pilot in Bridgend, a safe area for young people with ASD to develop social networks online has been provided. The scheme will be expanded so that young people from across the Mid and West Wales region can benefit also.

##### **Creating a Social Networking Site for Parents / Carers:**

Similarly this service means that parents / carers will be able to easily access support, from other parents / carers, information and advice from their own homes or local libraries.

##### **Developing Access to Sport, Recreation and Leisure Provision:**

This project works on developing the ASD knowledge and skills of staff in activity centres in West Wales. This will help children with ASD and their families to access this activity.

### **Development of ASD Shared Care Provision:**

An existing building is to be refurbished to create an environment that is suitable for individuals with ASD. This will then form a shared care provision that will provide respite care for children with ASD in Pembrokeshire, with potential access in the future from Ceredigion and Carmarthenshire families.

### **Social Use of Language Programme:**

Social use of Language Programme (SULP) is a programme that helps with personal, emotional and social development. This project has involved staff from Mid and West Wales working with Wendy Rinaldi, the programme's creator, to translate the programme into Welsh. The bilingual programme will help children with ASD to develop their social use of language.

### **Tier 3 Education Project:**

The Mid and West Wales Education Consortium embarked on a scoping exercise to evaluate the standards of tier 3 education provision for children with ASD across the region.

### **ADOS and 3Di Training:**

These projects enable clinicians to develop skills and use evidence based tools in the assessment and diagnosis of ASD across the Mid and West Wales Regions. Thirty Five clinicians undertook the course.

## **South East Wales**

### **ASD Outcome Focussed Workshops:**

Parents / carers said that they needed more advice in relation to behavioural difficulties. These workshops help parents/carers to look at techniques that may help them to cope with behavioural problems. The workshops are run in each local authority area across South East Wales region.

### **Awareness Raising Targeted at Leisure Providers:**

This project aims to raise awareness of the needs of individuals with ASD when accessing leisure activities and included a conference for leisure providers. The objective being that this will make it easier for people with ASD to use leisure centres in the region.

### **Post Diagnostic Support Package:**

This package provides written information, advice and contact information for parents and carers of children and young people with ASD. It will be provided to all carers in South East Wales at the point of diagnosis.



### **Parent / Carer Programme Training:**

Identified health staff receive training so that they will be able to run training programmes for parents / carers. In some areas this will mean that this programme is available for the first time.

### **ASD Emergency Services Card Scheme:**

The current scheme operating by Autism Cymru with the four Police Forces throughout Wales will be expanded to involve autism awareness raising and training for fire and ambulance staff across the South East Wales Region.

## **North Wales**

### **Socialeyes' Facilitator Training:**

Developed by the National Autistic Society 'Socialeyes' is a programme that can help people with ASD to develop social skills and social understanding. Training has taken place for facilitators which will mean the programme will be available to individuals in North Wales.

### **Developing Autism Friendly Schools:**

This project developed by Autism Cymru, in partnership with LEA's across Wales, extends the Autism Friendly nature of secondary schools in NW Wales.

### **Smiles Project:**

Smiles is an activity based group for children with ASD and their families currently based within one of Conwy's Leisure Centres. It provides physical activities as well as art and craft. It helps to improve social communication skills and relationships as well as create a social network for children with autism and their families.

### **Prevalence of Adults with ASD Development Project:**

This a six month clinical research project which is looking at how many adults with ASD live in North Wales. It will also try to find out what the key issues are for these adults are. This information will help to ensure services for adults with ASD are developed in the way that is needed and will tie in with other initiatives on data collection currently underway in North Wales.

### **Follow Up Study of a Cohort With ASD:**

This project follows up individuals who have been diagnosed with ASD in North Wales since 1988. The project will look at the level of language and autism in order to see how they impact on long-term quality of life.

### **TEACCH Training:**

This project involves training for professionals. The main aim is to help to prepare people with Autism to live and work more effectively at home, school and in the community.

### **ADOS/ADI-R Training for Clinicians:**

This project enables clinicians to undertake training in the assessment and diagnosis of ASD across North Wales.

### **ELKAN ASD Training:**

This training enables teaching assistants to support children with ASD's speech and language development in the classroom across North Wales.

**Recommendation: 1. Co-ordination, monitoring and evaluation (including the value for money) of each of these projects will need to take place and consideration will also need to be given to those projects which demonstrate the potential for being developed in other parts of Wales. 2. In view of the Welsh Assembly Government's commitment to provide funding for a similar process during 2011, detailed assessment of project proposals including follow up questions and visits, where appropriate, will need to be undertaken.**

### **Welsh Assembly Government Commissioned Evaluation of ASD Children's Assessment and Diagnostic Provision in Wales**

Prior to the introduction of the ASD Strategic Action Plan, assessment and diagnostic services to children, young people and adults with ASD in Wales had never been quantified or nor indeed evaluated. In terms of adults, the Adults with Task & Finish Group undertook this work during 2009, which has subsequently led to the development of the All-Wales diagnostic and pre/post counselling network for adults with ASD, which commenced implementation in February 2011. In reality, the circumstances within adults were far clearer to explore and to make recommendations on, simply because of the paucity of clinicians who were experienced in this specialist field. On the other hand, children's diagnostic services are a far more complex area to investigate and from which to determine a way forward.

Therefore in 2009-10 the Welsh Assembly Government commissioned the Wales Autism Research Centre in Cardiff University to:

- Obtain information on (a) how and by whom diagnostic services are delivered (b) the methods used in the diagnosis process and (c) how specialist services are delivered and funded.
- Obtain clinicians' views about the effectiveness of current diagnostic services, including their evaluation of strengths, weaknesses and potential for improvements.

## Project Team

The project team was led by Professor Sue Leekam, Chair in Autism, Cardiff University (Principal Investigator). The key questions explored were how referrals came to be made; and the external factors influencing the diagnostic process such as the child's need for services, the views of parents, and resources (time and funding). The experience of making the decision was explored from both the families and practitioners perspective and how this experience could be made better for both.

**Families:** For many families the diagnostic disclosure is “something that they will remember for the rest of their lives” and often is “a huge blow.” Several participants had experienced families in tears at the time of diagnosis. In other cases diagnostic disclosures are met with happiness and relief from parents, if they feel that, upon receiving the diagnosis, “someone has finally acknowledged what they already knew for years.” Even when parents are expecting it, however, sometimes “the rubber stamp is different” and there is a lot of sadness. No matter what the parents’ reaction though, “it’s not just a yes or no – it’s about coming up with an understanding of the child that helps something move on” and therefore “a huge responsibility.”

**Practitioners:** Because the experience of giving the diagnosis can be anxiety provoking and emotional for health professionals, many stated the benefits of being supported by colleagues, both in reaching the diagnostic decision, and during the diagnostic disclosure interview. Participants commented that the most important thing is that “it’s never done on your own,” in order that these issues do not affect the diagnostic decision. For one service, one of the professionals present would already be known to the parents—having attended school or home visits, thereby forming a relationship with the families, but this was not always possible given limited resources.

The project demonstrates that over 250 practitioners in Wales in 2010 were engaged in children's ASD diagnostic process.

**Table 1:**  
**Number of professionals identified as being involved in children's ASD diagnosis**

Professional group	Number
Clinical psychologists	37
Educational psychologists	64
Paediatricians	51
Psychiatrists	28
Speech and language therapists	15
Other*	30
Total	253

\*e.g. Occupational therapists, specialist nurses.

The diagnostic process for many practitioners is necessarily a lengthy process, often taking from several months up to one year and there was a general agreement of the need to have need to have greater dialogue with parents about the nature of the diagnostic process and why

such time is taken and the time to do it in a certain way. The training provided in the use of diagnostic instruments such as ADOS; ADI, DISCO was until recently time-consuming and expensive with participants having to travel to the south of England to undertake courses.

**Training:** *In 2010 the first ADOS and ADI courses in Wales were funded through the ASD Strategic Action Plan with over 50 attendees. Interestingly this new training provision in Wales appears to be playing its part in achieving an early impact with one lead clinician reporting that in her area in the last six month period they had received 70 referrals and closed 60 cases; with an average waiting time of 1.61 months and an ability to be much more responsive to urgent referrals.*

The capacity to deliver the assessment process in the first language of the child was a key question. After averaging responses, the results indicate that within Wales in 12% of cases the family's first language is Welsh. In 5% of cases the child is assessed in Welsh (indicating a shortfall of 7%), and in 6% of cases the history is taken in Welsh (a shortfall of 6%). In an average of 4% of cases the family's first language is neither Welsh nor English (e.g., Punjabi). In 2% of cases an interpreter is used (shortfall of 2%). The availability of post-diagnostic support for families and services following was also explored

This research project, commissioned by the Welsh Assembly Government, therefore has investigated some very key issues in relation to the assessment and diagnosis of children with ASD and made recommendations to improve provision. Two key areas have been recommended: Changes to organisational systems and the development of an all-wales network of expertise and mentoring. The Welsh Assembly Government has allocated funding during 2011/12 to take this work forward.

**Recommendation: The Wales Autism Research Centre Report 'Children's ASD Diagnostic Services in Wales' to be published by its authors.**

## **The Housing Needs of Adults with Autism living in Wales**

This is an innovative joint project established by the Deputy Minister for Housing, the Minister for Health and Social Services and Deputy Minister for Social Services in October 2010. The immediate priorities identified the need for the development of easily accessible information for a wide range of Housing practitioners; and also improved identification of available Local Authority housing stock provision suitable for providers of housing services to people with autism living in Wales. This project is a helpful addition to the existing Welsh Assembly Government awareness-raising materials launched in February 2011 entitled "Information for Practitioners who have an Interest in Developing Property or Services for Housing/Day Opportunities" (Haake/Albert et al).

The web-based materials aimed at those involved in housing management services; homelessness services and will be of relevance to individuals with ASD will be jointly launched by Ministers at the end of March 2011. The specific work to identify available and suitable Local Authority housing stock which may be appropriate for people with ASD in Wales will be completed by May 2011 (**Appendix 2**).

### **Example: Ceredigion and Hafal**

*Local mapping carried out prior to and during the first year of the Assembly Government's ASD grant funding has shown that people with ASD access most of the existing Supporting People teams and services in Ceredigion. Consultation with parents, carers and people with Asperger Syndrome showed a need for increased support to move out of the family home toward greater independence.*

*As a result a project providing ASD specific temporary/move-on accommodation, including ASD specific support has been set up by Supporting People with Hafal. This new service will provide three self contained units of temporary accommodation for people who have ASD, with assistance from Supporting People floating support and Social Services. It is intended to provide an alternative to generic temporary homeless accommodation and is an interim measure for people whose accommodation is unstable and where a planned move may prevent homelessness or crisis.*

## **The ASD Strategic Action Plan: Communication**

There are currently three key areas involved in the process of communicating progress made by the ASD Strategic Action Plan. Firstly, this can and should be achieved at local level, particularly by Local Authorities who hold regular meetings with their ASD stakeholder groups and in the review of the progress being made within their local ASD Action Plans. Secondly, the voluntary sector in Wales has a key role to play in accurately identifying progress to their 'readership' as well as raising issues and campaigning. Thirdly, the Welsh Assembly Government, in partnership with the Welsh Local Government Association, have since 2010 produced three editions of an ASD Strategic Action Plan newsletter issued to local ASD Leads; the autism community; and an e-bulletin to local and national politicians. These newsletters are available through the SSIA ([Johanna.manikiza@wlga.gov.uk](mailto:Johanna.manikiza@wlga.gov.uk)).

## **Chapter Four: Establishing a Research Agenda for Autism in Wales**

**Summary: Autism research capability in Wales has grown exponentially in the last few years and significant investment is now being attracted into Wales for research into autism. There is increasing potential in Wales to underpin government policy with evidenced-based research and for Welsh researchers to engage in investigative science which helps increase our understanding of autism and its impact upon individuals and families.**

Research into autism in Wales can play an important role in both underpinning Welsh Assembly Government policy development and expanding our knowledge on the causes and approaches to autism. Since the development of the Wales ASD Strategic Action Plan for Wales, four very significant autism research initiatives have commenced and as result Wales now has a strong and cutting edge presence on the UK and international autism research stage; which is already drawing investment into the country from outside Wales. The four initiatives are:

1. The appointment of the Professorial Chair in Autism, in the School of Psychology, Cardiff University (April 2009)
2. The launch of the Wales Autism Research Centre, Cardiff University (September 2010)

3. The establishment of the NISCHR Clinical Research Centre LDAN (Learning Disability and Autism Research Network 2007)
4. The research into Older Persons with ASD in Wales commissioned from Bangor and Glamorgan Universities by the Welsh Assembly Government.

### **The appointment of the Professorial Chair in Autism and the Wales Autism Research Centre, Cardiff University**

Initiated by Autism Cymru, the appointment of the UK's first named Professorial Chair in Autism, Professor Sue Leekam, and the development of the Wales Autism Research Centre (WARC) was established through an unique collaboration between Autism Cymru and Autistica, the School of Psychology, Cardiff University and the Welsh Assembly Government.

These developments were supported by generous donations from the organisations above and from Autism Initiatives, Baily Thomas Charitable Fund, Waterloo Foundation, Jane Hodge Foundation, Research Autism and Freemasons Grand Charity.

The mission for WARC is to create positive change for individuals and families affected with autism by advancing scientific research in areas of risk factors, early identification, diagnosis, cognitive development and intervention; working in partnership with practitioners, charities and the Welsh Assembly Government to integrate scientific evidence with policy and practice.

The objectives for WARC are to conduct internationally competitive scientific research projects; to facilitate Inter-disciplinary research and research networks; to develop research and training that supports and influences practice and policy; to improve public and professional awareness of research. The Director of the Wales Autism Research Centre is Professor Sue Leekam whose contact details are in the Appendix Four at the end of this report.

Two examples of current research into ASD in Wales by WARC:

- **Interventions in ASD**

Clinical and educational interventions form an essential part of the designated social care pathway of every individual with an autism spectrum disorder, but there is a need for more effective evidence-based therapeutic interventions. The Centre is working on a project to evaluate how effective individual interventions can be, so that this information is available for practitioners. In particular, the project will focus on the symptom domain that creates severe difficulties for families; the domain of restricted, repetitive behaviours.

Connected to this project is study that will investigate triggers and functions of repetitive behaviour and how these behaviours change over time. This research will form part of a wider research programme of national and international research collaboration on repetitive behaviours and anxiety including researchers at Cardiff University, Newcastle University and Durham University in the UK, and Melbourne University in Australia.

## **Neuroimaging Studies in ASD**

- Neuroimaging studies in ASD: Members of the WARC are using different brain imaging techniques to explore differences in brain activity and structure in people who have an ASD. One project uses magnetoencephalography (MEG), spectroscopy (MRS) and diffusion (D-MRI) data to investigate differences in the processing of brain activity during sensory stimulation (Anastasia Kourkoulou and Dave McGonigle). Furthermore, a project is currently being developed to use D-MRI to investigate structural connectivity in the brain (Sarah Carrington). All imaging is carried out at the CUBRIC centre.

## **The establishment of the NISCHR Clinical Research Centre LDAN (Learning Disability and Autism Research Network)**

The Learning Disabilities and Autism Network aims to provide the infrastructure to support large scale, high quality research into the health and social care of people with learning disabilities or autistic spectrum disorders. Such research will impact on treatment and service design and delivery in Wales and beyond. Priority areas are addressing disparities in health and development and evaluating evolving service models and resource use. To date, there have been six research activity groups (RAGs) concentrating on mental capacity, autism, challenging behaviour, health and healthy living, palliative care and service evaluation. The primary universities involved in LDAN are Bangor, Cardiff, Glamorgan and Swansea. The LDAN Co-ordinator is Dr Susie Nash, who is based in the School of Psychology, Bangor University (full contact details are contained in **Appendix 3**).

Two examples of current research into ASD in Wales undertaken within the Network are:

- Understanding anxiety in children with Autism Spectrum Disorders (ASD): An awareness-raising module designed to integrate new research evidence into practice in schools
- Population-based investigation of behaviour problems and parental well-being in children with autistic spectrum disorders

## **Research into Older Persons in Wales commissioned from Bangor and Glamorgan Universities through the ASD Strategic Action Plan**

Research into the prevalence and needs of older people with ASD had not previously been undertaken in the United Kingdom prior to the introduction of the ASD Strategic Action Plan in Wales. It was determined by the Welsh Assembly Government that this was an important gap and it was essential to find out more as relatively little is known about Autism Spectrum Disorder (ASD) in later life, though the available evidence indicates that it is as prevalent as in childhood and youth.

The Universities of Bangor and Glamorgan (led by Professor's Richard Hastings and Ian Stuart Hamilton respectively) were commissioned in October 2008 to undertake a one-year collaborative pilot research study, which could help provide evidence to the Welsh Assembly

Government. A random selection of GPs were sampled to find out if they had older adults with ASD on their caseloads; and an on-line questionnaire (of basic biographical information, general health, quality of life and score on the Autism Quotient [AQ] measure) was undertaken of adults in their forties who had been diagnosed with ASD or suspected they had ASD. The findings indicated health and quality of life problems are very significantly greater than in the population norms, with strong indications that the difficulties often found with younger people with ASD (such as social isolation and anxiety) persist throughout adult life, even in individuals in high-income professions. Their Research Report 'The Circumstances and Support Needs of Older People with Autism' was accepted by the Welsh Assrmbly Government in January 2010. in Professor Stuart-Hamilton's journal paper drawing upon this research is due for publication during 2011 in "Advances in Mental Health and Intellectual Disabilities".

Whilst this was a very small scale study of ASD in the older population, it gave sufficient insight to warrant further examination by the Welsh Assembly Government into this area of vulnerability within the autism community. As a result the Welsh Assembly Government asked Professor Sue Leekam, Chair in Autism in the Wales Autism Research Centre in Cardiff University, to take account of the research findings from the Bangor and Glamorgan study, and to provide advice on how best to address the research actions in the report. This advice has now been received and is under consideration.

## **Chapter Five: Partnerships with the Voluntary Sector**

**Summary: the Voluntary Sector in Wales continues to play an important role in the planning and delivery of the ASD Strategic Action Plan in the areas of research, campaigning, self-help groups, parent support, training, public awareness-raising; and as partners with Local Authorities and LHBs, as well as partnerships between charities themselves.**

### **Voluntary Sector in Wales:**

The long-standing culture of partnership between national and local government with the Voluntary Sector in Wales in relation to ASD has been expanded by the introduction of the ASD Action Plan and can now be quantified at both local and national levels. A claim can be justifiably made that there has been a stronger and more productive partnership in relation to autism between government and the voluntary sector in Wales than has existed in other nations within the United Kingdom. At least part of this success is down to having had a strategic vision for autism in Wales for almost ten years, significantly longer than any other nation. This partnership between government and the voluntary sector was strikingly illustrated through the joint development by Autism Cymru and the Welsh Assembly Government of the initial concept of an ASD Strategy for Wales in 2001/2. This partnership was then expanded during 2003-6 to include many other voluntary and statutory sector agencies leading to the creation of the ASD Strategic Action Plan for Wales; An extensive consultation process jointly coordinated by Autism Cymru and the National Autistic Society took place in 2007, and was then followed by delivery by the Welsh Assembly Government, through its partners across the voluntary and statutory sectors, from 2008.



Local Authority responses to the 2010 survey demonstrate that all Local Authorities in Wales view the ASD voluntary sector as significant and important partners in the planning and delivery of services to people with autism, their families and those who work with them at a local level. All twenty two Local Authorities in Wales commission services from charities and from not-for-profit groups concerned with autism. Some authorities also commission services from the private sector. Voluntary sector groups also have good representation on Local Stakeholder groups, with fifty-one personnel from various charities participating across Wales in these groups. At a national level, voluntary sector representation on the National ASD Stakeholder Group is made by the National Autistic Society Cymru and Autism Cymru.

In addition to this engagement, the voluntary sector is playing a distinct and cogent role in campaigning and also in research and service developments which can underpin on-going implementation of the ASD Strategic Action Plan; but can also have the effect of attracting new investment from outside of the country into Wales (as illustrated with the development of the Wales Autism Research Centre in Cardiff University).

### **Partnerships developed by Charities in Wales**

#### Example 1

##### ***Charity-led Research Partnerships : The Wales Autism Research Centre & Chair in Autism : Cardiff University***

*These major research initiatives were initiated by Autism Cymru in 2005/6 who then pulled together a partnership with Autistica and Cardiff University to raise the £750k funding necessary and in so doing received support from the Welsh Assembly Government. Professor Sue Leekam was appointed as Chair in Autism in April 2009 and the Wales Autism Research Centre was opened by the Minister for Health and Social Services in September 2010. <http://www.cardiff.ac.uk/psych/home2/warc/>*

#### Example 2

##### ***Charity-led Campaigning : The Cross Party Autism Group:***

*This well-attended group was initiated by the National Autistic Society Cymru in May 2003 and is generally viewed as one of the most vibrant of all Cross Party Groups in the National Assembly for Wales and is notable also for being the only cross party group to hold meetings in North Wales. The NAS Cymru continue to provide the secretariat for this informal group which meets on a quarterly basis providing those with an interest in autism the opportunity to raise and discuss issues.*

#### Example 3

##### ***Between Charity Partnerships: 1) Adults with ASD. 2) Welsh Language Early Years Playgroups***

*1. With a shared core philosophy and similar beginnings, Autism Initiatives and C.S.A.W have developed a partnership in North Wales which has turned into a merger to better utilise shared practices, resources and training, and to further develop quality services to people with autism. A new office has opened in Denbigh and the organisation is beginning to receive referrals from social services*

*to develop supported living services for adults with autism. They are currently in very supportive discussions regarding the Lodge building on the Gwynfryn site and both look forward to beginning the development of the building to enable them to meet their vision of the delivery of a range of flexible services to meet the unique individual needs of people with autism.*

*2. For several years Mudiad Ysgolion Meithrin (the Welsh Language Playgroups Association) and Autism Cymru have been working in partnership to provide ASD training throughout Wales for all Welsh language Playgroups.*

#### Example 4

##### **Collaboration between Local Authorities and Charities**

*Partnerships between Local Authorities and Charities have become particularly apparent with the implementation of the ASD Strategic Action Plan. For example, Conwy commissioned the Touch Trust to provide creative, touch-based art of movement for young people and adults with autism; Neath Port Talbot and several other LAs have commissioned the Earlybird (NAS) programme; Gwynedd & Anglesey and fourteen other LEAs The Inclusive Schools & ASD Research and Training Programme (Autism Cymru).*

#### Example 5

##### **Support for Parents provided by charities and self-help groups**

*Many of the charities and not-for-profit groups working in Wales regularly provide support and information to parents. Formed in 2002, the Gwynedd & Anglesey "Gwynedd and Anglesey Autism/Asperger syndrome Support Group" has been one of the longest established parent support groups; this is similarly true of the GAS (Gwent Autistic Society), NAS Cymru, SNAP Cymru have all played a key role with families as have organisations such as Mencap Cymru and C-Saw.*

#### Example 6

##### **Charities play a key role in providing ASD Training events in Wales : delivering seminars and workshops through to International Conferences**

*The Wales International Autism Conference which first started in 2006 runs over two days and attracts some of the biggest names in the world of autism to Wales. In June 2011 it is again being held in Cardiff City Hall and coordinated by Autism Cymru. With speakers including international contributors, such as Temple Grandin, Judith Gould and it is hoped Lorna Wing.*

*Seminars, day events, workshops have been regularly organised by charities in Wales over the past ten years and in recent years there has been an increase in bespoke training delivered by 'autism' charities such as NAS Cymru and Autism Cymru at the request of local authorities in Wales.*

## Example 7

### **Charities led service–provision for Children and Adults with ASD**

*There are several examples across Wales. The National Autistic Society Cymru have range of services to adults in SE Wales; Cartrefi Cymru provide housing and other services to people with ASD as well as those with Learning Disabilities; Autism Initiatives are developing services to adults in North Wales. There are further examples within the not-for-profit and private sectors from Opportunities Housing Trust through to the Ludlow Street Healthcare Group, Priory Group, Orbis Education, and The Options Group.*

## Example 8

### **Voluntary Sector contributions to Public Awareness-Raising**

Over many years, charities in Wales have contributed very significantly to raising the wider public's awareness of autism. Examples include autism charity 'tents' in the annual National Eisteddfod; public campaigns run by NAS Cymru ; S4C's charity of the year award to Autism Cymru and the consequential range of television programmes on autism; and "Holly's Ball" being held in the Millennium Stadium on 2 April, 2011 organised by Jo Salmon, a parent from Caerphilly.

### **Voluntary Sector engagement in the Welsh Assembly Government's Interim Evaluation**

The National Welsh Assembly Government Stakeholder group includes representation from the National Autistic Society and Autism Cymru, currently represented by Rebecca Evans and Professor Bill Fraser CBE respectively (other representation on the group includes representation from the Association of Directors of Social Services [ADSS]; Association of Directors of Education in Wales [ADEW]; Local Health Boards; a person with autism, and the Wales Autism Research Centre, WLGA, and Welsh Assembly Government).

Both voluntary organisations, NAS Cymru and Autism Cymru, have been fully involved with all developments planned through the ASD Strategic Plan since 2008 and also in the planning and methodological design of the 2010 Local Authority interim survey. The intention to prepare and issue the survey to authorities during the autumn of 2010 was discussed in the National Stakeholder Group meeting in January 2010. It was however, felt by the Stakeholder Group that a full empirical study of the impact of the ASD Strategic Plan focussing on the quality of life for individuals with autism was a highly skilled task which would need to be undertaken around year four (2012-13) but that this would need to attract full academic research rigour and therefore be funded and directed appropriately.

## 'The Life We Choose'

The National Autistic Society Cymru undertook a survey and launched their report, 'The Life We Choose' (Evans et al), in January 2011. This report formed the basis of the Conservative Party debate on the Assembly Government's ASD Strategic Action Plan in the National Assembly for Wales on the 9<sup>th</sup> February 2011. The NAS Cymru Report highlighted a number of areas "to shape the work the Welsh Assembly Government is taking forward on autism". The table below responds to each area raised.

Issue Highlighted by NAS Cymru	WAG/LHB/LA/Vol Sector development
<p><b>Diagnosis and Post-Diagnosis Support</b></p> <ol style="list-style-type: none"> <li>1. To push forward with the development of Adults Diagnostic Network.</li>   <li>2. Take a strategic approach to training of diagnosticians for children &amp; for GPs.</li>   <li>3. Promote the NICE ASD Guideline.</li> </ol>	<ol style="list-style-type: none"> <li>1. This innovation resulted from the work of Adults ASD Task &amp; Finish Group 2009/10 and commenced delivery in February 2011. BCUHB have led the creation of an all-Wales ASD Adult Diagnostic Network. This has been supported by £752k from the Assembly Government and is unique in UK.</li>   <li>2.               <ol style="list-style-type: none"> <li>a) Professor Sue Leekam's evaluation of ASD children's diagnostic services in Wales (2009-10) was commissioned by the Assembly Government. Funding has been allocated take forward the findings from this report from April 2011.</li> <li>b) Training, mentoring and support for diagnosticians throughout Wales is a key element in above.</li> <li>c) Over 50 diagnosticians were trained in ADOS in North and Mid &amp; West Wales in 2010/11. This was achieved through Assembly Government funding.</li> <li>c) ASD Awareness-raising materials for Primary Healthcare Practitioners were launched in February 2011 and were endorsed by British Medical Association (BMA).</li> </ol> </li>   <li>3. The Welsh Assembly Government and also agencies in Wales from LHBs to Autism Cymru, have contributed feedback to development of the NICE ASD Guidelines. Wales has also had a representative on the NICE workgroup (Dr Anne-Marie McKigney of ABMUHB). Initial observations are that Welsh clinical practice is in-line with the NICE Guidelines.</li> </ol>

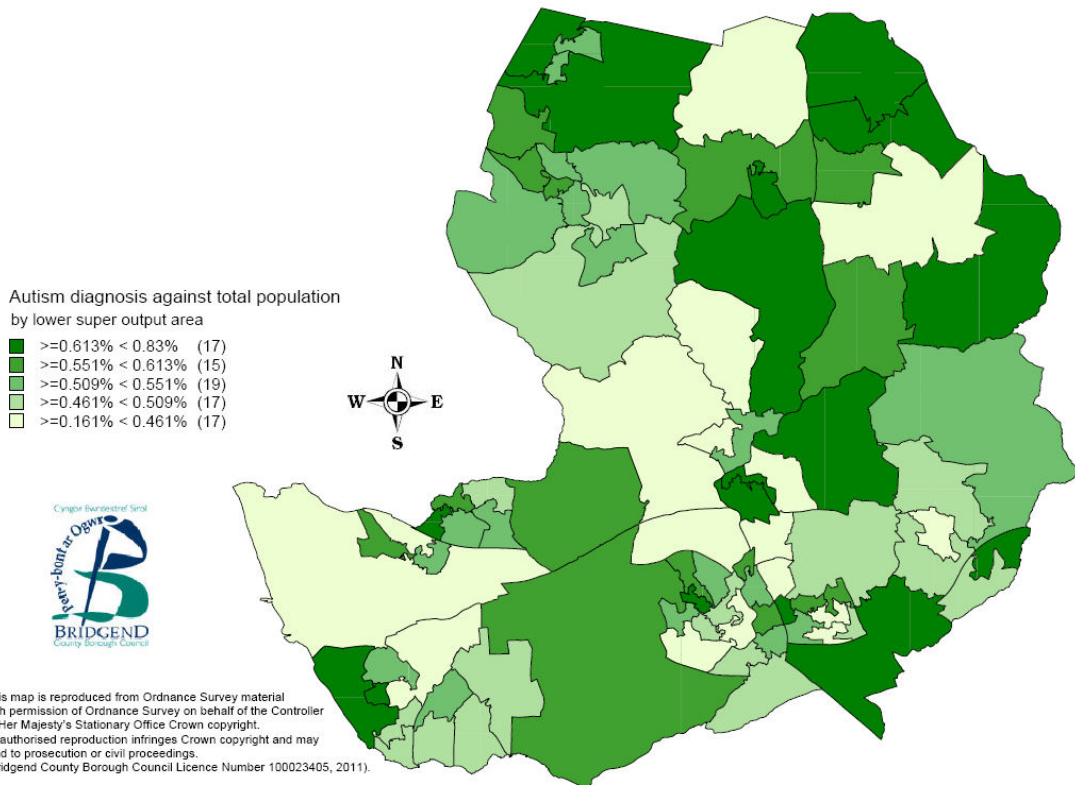
<p>4. Pathways for children and adults with ASD are put in place.</p> <p>5. Undertake analysis of Local ASD Action Plans for post-diagnostic support for families.</p>	<p>4. There are already a number of pathways published for ASD, not least within the existing 2008 published ASD Strategic Action Plan. This is however, not a static position as Wales has adopted the social model of disability and applies this approach to ASD. Clinical pathways must therefore increasingly evolve to include the social context of autism.</p> <p>5. a) All twenty-two Local ASD Action Plans already give attention to post-diagnostic support.  b) In 2010, the Assembly Government commissioned LAs in SE Wales to produce a post-diagnostic support pack for families which could be used as a pilot for the rest of Wales.  c) Several examples of post-diagnostic support will be illustrated in the Compendium of ASD Practice Development Wales produced by the SSIA.  d) it will always be important to review regularly</p>
<p><b>Education</b></p> <p>1. Local Action Plans address the need for a range of educational provision locally and that parents are given the best information and support to make the right choice for their child.</p> <p>2. Ensure autism training for trainee and fully qualified teachers.</p>	<p>1. All Local ASD Action Plans include a focus on education and a number of ASD leads have come from the education sector in Wales. The SEN Code of Practice for Wales sets out a transition process for pupils with SEN prior to leaving school. This process begins at age 14 and involves all relevant professionals, including Careers Wales which provides parents and learners with independent careers advice and guidance. The need for improved local planning was recognised by the Post-16 SEN/LDD Funding Task Group, which made recommendations aimed at greater consistency of approach across Wales; regional collaboration and more attention to value for money in the commissioning process.</p> <p>2. Initial Teacher Training (ITT) is designed to equip students with the necessary essential requirements to enable newly qualified teachers to teach across the key stages and subjects for which they have been trained. It covers special educational needs but the time available for more specialist areas of study is limited. The Welsh Assembly Government is of the view that more detailed specialist training in SEN is best undertaken once a teacher has completed their ITT and induction year.</p> <p>In October 2007 the Welsh Assembly launched a bi-lingual e-learning module for teachers of SEN as part</p>

<p>3. Ensure that the review of statements fully acknowledges the complex nature of autism and gives legal backing to the provisions that are deemed necessary to support children with autism in education.</p>	<p>of an innovative new training course for teachers and support staff. This course aims to improve the understanding and knowledge of teachers working with pupils who have SEN and also raise awareness of the factors involved in developing an inclusive school. The course includes a section on ASD which provides an overview of the spectrum, the challenges facing children with ASD, identification, assessment and diagnosis and aspects related particularly to curricular areas in education including references to developing social and communication skills. ASD is further explained through case study material. This development is overseen by a sub group of representatives from every HEI in Wales.</p> <p>The Welsh Assembly Government have also produced training materials for meeting the needs of children and young people with Additional Learning Needs for newly qualified teachers and teachers during their Early Professional Development period. These materials contain information on Autism.</p> <p>3. The Welsh Assembly Government, via DCELLS, has provided funding of £2m over 2009-2012 to establish pilot projects to further develop a system for ensuring all pupils with ALN have their needs met appropriately and in a timely manner. One of these four pilot projects is aimed at developing and trialling an alternative to the current statutory assessment system for children and young people with severe and complex needs. Following a review of the pilot schemes next steps will include rolling out what is deemed as good practice in relation to multi-agency working and, if required, consultations on draft proposals for new legislation.</p>
<p><b>Services to Adults with Autism</b></p> <p>1. Prioritise the development of guidance for LAs in the use an application of the Unified Assessment Process (UAP).</p> <p>2. Work with the UK Government to ensure that Courts treat disability hate crimes as seriously as other hate crimes.</p>	<p>1. This action is already contained within the Adults Task &amp; Finish Group Report of which NAS are members. Planning in 2010/11 with Ceredigion Social Services Dept and implementation in 2011/2012.</p> <p>2. In accordance with the Government of Wales Act 2006, Welsh Ministers have a statutory duty to "...make appropriate arrangements with a view to securing that their functions are exercised with due regard to the principle that there should be equality of opportunity for all people". Where issues are non-devolved the Welsh Assembly Government will,</p>

<ol style="list-style-type: none"> <li>3. LAs should review their LA action plans with regard to the provision of counselling, social skills training and employment support</li> <li>4. Revisit how individuals with autism and their families are consulted with and involved in local stakeholder groups.</li> <li>5. The appropriate committee in NAW should undertake a short enquiry into homelessness and autism in Wales.</li> <li>6. The newly appointed Wales Autism Employment Ambassador should make it a priority to raise awareness amongst employers of the positive aspects of employing people with autism and recognise good practice in the development of autism-friendly environments and practices.</li> </ol>	<p>where appropriate, make representation to the UK Government.</p> <ol style="list-style-type: none"> <li>3. SSIA to be asked to do review this with each LA.</li> <li>4. See chapter 1 'stakeholder engagement' and recommendation.</li> <li>5. The Assembly Government are launching web-based ASD housing materials for those involved in homelessness services and for social landlords in the Spring 2011.</li> <li>6. This is the role of the newly recruited Wales Autism Employment Ambassador, launched at the CPAG on 1<sup>st</sup> December 2010.</li> </ol>
<p><b>Support for parents and carers of people with autism</b></p> <ol style="list-style-type: none"> <li>1. There should be a focus on meeting the support and information needs of parents, carers, and siblings in the second implementation phase of the ASD Strategic Action Plan.</li> <li>2. Local ASD Action Plans should be reviewed to examine how they are meeting the training and support needs of parents, carers and siblings.</li> <li>3. The appropriate Welsh Assembly Government Committee should make a short inquiry into short breaks for children, young people and adults with autism.</li> </ol>	<ol style="list-style-type: none"> <li>1. Recommendations contained in this report are consistent with this suggestion it but it should however, be acknowledged that considerable strides have been made in this area with many examples of practice arising from local ASD Action Plans.</li> <li>2. SSIA and Local ASD Leads will be asked to work with LAs to review local action plans in this respect.</li> <li>3. There is already some developing practice in this area within local areas as detailed in Chapter Three.</li> </ol>

## APPENDIX ONE

### Confirmed diagnosis of Autism (adults and children) shown as a percentage of the total population of Bridgend County Borough





## APPENDIX TWO

### Projects arising from local ASD Action Plans

	Project 1	Project 2	Project 3	Project 4	Project 5
Isle of Anglesey	music interaction therapy (MIT)	Respite care unit for children	Care-pathway development	Keyworker transition	NWC
Conwy	Asperger syndrome Social Group	Audit of Children's Assessment & Diagnosis service	SMILES Play activities programme	Socialeyes' facilitator training	
Gwynedd	Training: to multiagency staff	Ditto	music interaction therapy	Care-pathway development	Asperger syndrome Social Group
Denbighshire	Keyworker transition	Outreach service: Plas Brondyfryn	SMILES: Play activities programme	Activities and play: C-SAW Play Scheme	Integrated Services: health and social work staff in one unit
Flintshire	Training: delivered to practitioners working with people with ASD	Assessment team: of specialists*	CIDS (Children's Integrated Disability Service): provide services	Earlybird pProgramme	TEACCH: training to two new special schools
Wrexham	Parent satisfaction survey	Gaps analysis: awareness and support social skills training	Training: to multiagency staff - Training Strategy developed.	18-25 Asperger syndrome Social Group	
Powys	Training: to professionals (to SCATs; MWW)	Care-pathway development	Proposal to host ASD Outreach service	Autism Cymru Police Emergency Card Scheme:	Activities and play: play opportunities
Ceredigion	Asperger syndrome Social Group	New post: created: ASD development officer	Accommodation: and support to individuals move out of family home	Activities and play: School awareness training	Earlybird: Programme
Cardiff	Residential provision: proposal to build and provide accommodation	Activities and play: Increase the range of short break provision	Parents and carers Group	Training: to multiagency staff	Packs / handbooks: diagnosis packs for parents
Pembrokeshire	Referral system: proposal to implement a new early years referral system	New post: Educational Psychologist	Conference: for parents, teachers and governors	Assessment team: of specialists*	Consultation: examine services for adults with ASD
Swansea	Activities and play: Holiday play scheme	Packs / handbooks: Development	Developed guidelines for identification and assessment with ASD	Earlybird Programme	Training: in Education, child & family services and adult services
Neath Port Talbot	Earlybird Programme	Training: to parents including TEACCH	New post (s): Multi disciplinary transition planning panel		
Bridgend	Siblings day	New post: monitor progress	DVD	Training: ASD School Council - giving those who attend mainstream schools 'a voice'	Research: assess the current level of service provision and identify gaps
Vale of Glamorgan	Training: to professionals working with people with ASD	Post: training provided by Occupational Therapists	Policy: Change Disability Equality Policy to include Autism as a specific disability	Packs / handbooks: E-Learning to teach basic awareness of autism	Activities and play: Modify the childcare registration. Create and deliver a play based ASD
Cardiff	Outreach service: provide ongoing support and advice to nurseries and early years settings	Training: provide training, support and advice to mainstream schools with children with ASD.	Activities and play: bespoke day opportunity		
RCT	Conference: for people with autism, their families and carers and professionals	Packs / handbooks: directory of services circulated to practitioners, people with autism and their families	Packs / handbooks: developing a post-diagnostic information	Asperger syndrome Social Group	Training: provided for families and professionals
Merthyr Tydfil	Earlybird Programme	Activities and play: School programme:	Parents and carers group	ASD Commissioning strategy	Service: development of respite care services
Caerphilly	Caerphilly Autistic Spectrum Service				
Blaenau Gwent	Parents and families Group	Service: specialist day service	Training: to professionals (i.e. foster carers)	Workshop: delivered by professionals for parents and carers of children with ASD	Conference: to raise awareness of the needs of individuals with ASD
Torfaen	ASD family support workers	Outreach service: trouble shooting workshops to secondary schools	Public awareness - Autism Fayre		
Monmouthshire	Conference: ASD Information Day	Two workers to provide support to Families	Training: to professionals and parent/carers	Accommodation: housing support services	Conference: professionals and individuals, parents and carers
Newport	Workshop: for parents	Activities and play: Leisure Day	Employment programme: Bid	Conference: 19th January 2011	ASD independent living and transitional accommodation

Please note green shaded area of wider significance

## APPENDIX THREE

### Welsh Assembly Government ASD Awareness-Raising Materials Published Spring/Summer 2011

TITLE	AUTHORS
<b>A Resource for Families in Wales</b>	Shirley Parsley, Rebecca Evans, Helen Davies (all National Autistic Society), Teresa James (Monmouthshire County Council & Parent), Professor Kathy Lowe (ABMU Local Health Board), Denise Inger (SNAP Cymru), Sue Glen (Parent)
<b>A Guide for Practitioners Providing Family Support in Wales</b>	Shirley Parsley, Rebecca Evans, Helen Davies (all National Autistic Society), Teresa James (Monmouthshire County Council & Parent), Professor Kathy Lowe (ABMU Local Health Board), Denise Inger (SNAP Cymru), Sally Rees (Care Co-ordination Network UK)
<b>A Guide for Practitioners Working in Pre-School/Primary/Special Schools Settings in Wales Early Years Primary Education</b>	Lynn Plimley (Autism Cymru), Sue Benbow and Christine Cole (both Pembrokeshire LEA), Sylvia Fowler (Heronbridge School, Bridgend), Enid Moore (Darland School, Bridgend), Gill Fairclough (Glyndwr University), James Vilares (Cardiff University)
<b>A Guide for Practitioners working in Secondary Schools and Further &amp; Higher Education Colleges in Wales</b>	Lynn Plimley (Autism Cymru), Sue Benbow and Christine Cole (both Pembrokeshire LEA), Sylvia Fowler (Heronbridge School, Bridgend), Enid Moore (Darland School, Bridgend), Gill Fairclough (Glyndwr University), James Vilares (Cardiff University)
<b>Primary Healthcare Settings</b>	Johanna Manikiza (ASD Regional Support Officer), Cath Jones (Child and Adolescent Mental Health Service), Teresa James (Monmouthshire County Council & Parent), Sarah Robinson (Hope GB & Parent); and reviewed by Andrew Dearden (British Medical Association) and Professor Sue Leekam (Wales Autism Research Centre)
<b>Information for Opticians and Dentists</b>	Sharon Walters (ASD Regional Support Officer), Pauline Roberts (National Autistic Society), Gill Fairclough (Glyndwr University), John Fozzard (Conwy Social Services Dept)
<b>Criminal Justice System</b>	Maggie Bowen (Autism Cymru), Owen

	Davies, Dean Piper, Anthony Matthias (all Welsh Assembly Government), Geraint Spacey (Monmouthshire Youth Offending Team), Phillipa Thody (HM Prison Service), Rowena Williams (ABMU Local Health Board), Rob Heaton-Jones (NOMS Cymru), Suzanne Sweeney (South Wales Police), Simon Humphries (North Wales Police & Parent), Gareth Crowe (North Wales Police), Brigit Villeneuve and Gareth Morgan (both Autism Cymru)
<b>Information for Practitioners who have an Interest in Developing Property or Services for Housing/Day Opportunities</b>	Louise Albert, Nick Haake, Helen Leigh (all National Autistic Society), Andrew Hole (Pentan Partnership Architects), Professor Kathy Lowe (ABMU Local Health Board),
<b>Employment and Work Related Issues in Wales</b>	Mary Rendell (ASD Regional Support Officer) with help and guidance from people with ASD, their families, The Shaw Trust, Careers Wales, and Job CentrePlus
<b>A Guide for Practitioners Working in Advocacy Services in Wales</b>	Mary Rendell (ASD Regional Support Officer), Gabrielle Eisele (The Windfall Centre), and young people and adults with ASD who shared their experiences with the authors)
<b>A Guide for People Working with Older Adults</b>	Professor Ian Stuart Hamilton (University of Glamorgan), Dr Gareth Morgan (Welsh Assembly Government), Yvonne Apsitis (United Kingdom Home Care Association)
<b>An Inter-Faith Self-Audit Tool for Ministers of Religion (Publication July 2011)</b>	Inter-Faith Workgroup led by The Rev, Dr John Gillibrand
<b>A Guide to Housing Management for housing practitioners and people in rented housing (Publication March 2011)</b>	Jane Pagler (Supported Housing Adviser, Community Housing Cymru), Mary Rendell (ASD Regional Support Officer), Chris Price (Coordinator of the National Homeless and Supporting People Networks); Welsh Assembly Government Officials

<p><b>A Guide for Homelessness Practitioners (Publication March 2011)</b></p>	<p>Jane Pagler (Supported Housing Adviser, Community Housing Cymru), Mary Rendell (ASD Regional Support Officer), Chris Price (Coordinator of the National Homeless and Supporting People Networks); Matthew Richards, Supporting People Team (Ceredigion County Council), Welsh Assembly Government Officials</p>
<p><b>Living in the Community – Building Design for people with autism (Revision into Welsh context of recent Brand et al 2010 doc)</b></p>	<p>Jane Pagler (Supported Housing Adviser, Community Housing Cymru)</p>

## APPENDIX FOUR

**ASD Adults Task & Finish Group Contributors 2008-10. (It will not be possible to give details of contributors to the Reconvened Adults Task & Finish Group until after the Group's report to the Welsh Assembly Government has been submitted in the late Spring 2011).**

<b>Adults Task &amp; Finish Group</b>	<p><b>Chair :</b> Hugh Morgan : ASD Strategic Action Plan Implementation Manager, Welsh Assembly Government'</p> <p><b>Members :</b>John Carter, Welsh Assembly Government (Older People and Long Term Care) Jeni Clarke-Moore, Welsh Assembly Government (Nursing Group); Chris Griffiths, Consultant Nurse, ABM Trust; Nick Haake, National Autistic Society Cymru; Chris Maggs, The Association of the Directors of Social Services Cymru ; Helen Matthews, Royal College of Psychiatrists (Learning Disability Division) Simon Prothero Welsh Assembly Government (Housing Directorate); Carol Rea :The Association of the Directors of Social Services Cymru; Sarah Watkins, Welsh Assembly Government (Medical Division) Liz Withers, National Autistic Society Cymru; <b>Secretariat :</b>Alyson Collins, Welsh Assembly Government (Older People and Long Term care)</p> <p>The Welsh Assembly Government also agreed Observer status for a representative of the Northern Ireland Assembly (DHSS) to attend meetings of the Group</p>
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<p><b>Diagnosis and Access to Services Sub-Group Membership</b></p>	<p>John Carter, Welsh Assembly Government (WAG); Jeni Clarke-Moore, WAG; Bridget Craddock, ABMU Trust; Phil Davies, City and County of Swansea; Christopher Griffiths, ABMU Trust; Nick Haake, National Autistic Society (NAS) Cymru; Tony Harris, Torfaen County Borough Council; Glyn Jones, ABMU NHS Trust; <b>Chris Maggs, City and County of Swansea – Sub-group leader (Access)</b>; Martine Marshallsay, ABMU MHS Trust; <b>Helen Matthews, Hywel Dda - Sub-group leader (Diagnosis)</b> Hugh Morgan, ASD Strategic Action Plan Implementation Manager, WAG; Carol Rea, City and County of Swansea; Keith Self, Monmouthshire County Council; Dr. Sundari, Gwent NHS Trust; Judith Tomlinson, National Public Health Service; Peter Watkin, ABMU Trust; Sarah Watkins, WAG; Liz Withers, NAS Cymru</p>
<p><b>Community &amp; Monitoring Support Group Membership</b></p>	<p>Julie Boothroyd, Monmouthshire County Council; Peter Chamberlain, Newport City Council; Christopher Geake, Cartrefi Cymru; <b>Nick Haake, National Autistic Society (NAS) Cymru Sub-group leader</b> Mary Harris, Vision 21 Claire Lister, Conwy County Borough Council Mary Rendell, Ceredigion County Council; Judith North, REACH; Rita Steffenson, Advocacy Matters Wales Dr Sundari Gwent NHS Healthcare Trust; Liz Withers, NAS Cymru</p>
<p><b>Employment and related issues</b></p>	<p>Michael Barry, WAG; Barrie Lewis, Jobcentre Plus; Hugh Morgan, WAG; Mike Moss, WAG; Bob Waller, WAG; Bon Westcot, Job Centre Plus; Liz Withers, NAS Cymru</p>

**Service-user group membership**

**Cardiff** : Mark Annis; Anon; Carl Joseph; Anon; Collette Morgan; Karen Thompson; **Bangor**: David Abbot; Rowan Crawshaw; John Green; Robert Mann; Robert Murphy; **Caerleon** :Gavin Cashman; Matthew Howard; Aled Lewis; Andrea Sutton; Karen Thompson; Styn Vanerlinden

## **APPENDIX FIVE RESEARCH CONTACTS**

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## **Examples of Key features of the Welsh approach to Autism (relative to other UK Nations at February 2011)**

- Wales is the sole nation with an all-age ASD strategy covering Health, Social Services and Education
- Scale of ring-fenced funding to support implementation (£5.4m -2008-11) exceeds that of England (£500k [2010 only]) (£2.2m Northern Ireland 2008-11); Scotland is currently developing a strategy
- Unique Local ASD infrastructure within Welsh statutory sector: local ASD lead ; local ASD Stakeholder Groups; local ASD Action Plans produced
- The UK's first named Chair in Autism research (Cardiff University)
- The Wales Autism Research Centre (the first national autism research centre in the UK)
- The UK's first national Autism Employment Ambassador
- The UK's first national approach to diagnosis for Adults with the creation in 2011 of the All-Wales Assessment/Diagnosis and Pre/Post Diagnostic Network for Adults with ASD
- The UK's first national evaluation of children's assessment and diagnosis in ASD which is leading to the development from 2011/12 of an All-Wales diagnostic Network for children with ASD
- Welsh Assembly Government ASD awareness-raising materials launched during 2011 the first by any government in UK