



Research Paper 42/09

10<sup>th</sup> November 2008

# **AUTISM SPECTRUM DISORDER (ASD) SERVICES**

Research and Library Service

This research paper outlines the main aspects of the DHSSPS Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09 – 2010/11 consultation document and how they compare to the recommendations and directions for ASD service design and delivery of other relevant ASD strategies and reports, with focus on the Welsh ASD Strategic Action Plan, April 2008 (in preparation for the HSSPS Committee visit to Wales) and the NI Independent Review of Autism Services. Given the ‘person-centred’ and ‘whole-life’ focus referred to in the DHSSPS Action Plan, the provision of services outside the remit of the DHSSPS Action Plan but covered in other jurisdiction’s ASD strategies and reports, with wider remit, is also briefly discussed.

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## SUMMARY

This purpose of this research paper is to outline the main aspects of the proposed DHSSPS Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09 – 2010/11 and discuss how the Action Plan compares to the recommendations and directions for ASD service design and delivery of other relevant ASD strategies and reports. There is particular emphasis on both the Welsh ASD Strategic Action Plan (April 2008), to inform the HSSPS Committee in preparation for its visit to Wales, and on the Northern Ireland Independent Review of Autism Services (May 2008), as this Review has contributed significantly to the DHSSPS 'Action Plan'<sup>1</sup>.

The DHSSPS 'Action Plan' recognises and describes an overarching "*person-centred approach*" to ASD service provision with focus on a "*whole life*" approach. In comparison to the health and social services focus of the DHSSPS 'Action Plan' and the educational focus of the 2002 *NI Report of the task Force on Autism*, it would seem that the Welsh Strategy has a much broader remit and it has been stated that "*Wales is the first European nation to commit to a 'whole nation' model for delivering high-quality services and research into the brain disorder*"<sup>2</sup>.

The DHSSPS draft Action Plan is designed around five key themes all linked to the central tenet of the Care Pathway (attached at Appendix 1)<sup>3</sup>. The five themes are (i) Service redesign to improve care<sup>4</sup>; (ii) Performance improvement of autism services including reducing waiting times; (iii) training and raising awareness to support parents and professionals; (iv) improving communication and information provided to individuals and families; and (v) effective engagement and partnership working within Government and with voluntary/community groups and other agencies.

The Care Pathway approach appears to be widely supported and was also recommended by 'the NI Review' and by the ASD Strategic Action Plan for Wales. Such Care Pathways were developed in further detail in the Welsh Strategy with specific Care Pathways for Classic Autism with Learning Disability, Adults with Classic Autism with Learning Disability, and Asperger Syndrome Care Pathway.

The main actions proposed in the Welsh Strategy include<sup>5</sup> - mapping prevalence, needs and services; the importance of the response of Commissioners of services which it is believed "*is a crucial matter on which the success and speed of implementation of this strategic action plan will depend*"<sup>6</sup>; the importance of "*clear arrangements for transition between services for children and young people and adult services*"<sup>7</sup>; the importance of specific services for adults with ASD; and awareness raising, information and training.

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<sup>1</sup> *McGimpsey launches consultation on Autism Action Plan*, NI Executive Press Release, 17 September 2008

<sup>2</sup> News from Autism Cymru and Autism Speaks, [www.autismspeaks.org.uk](http://www.autismspeaks.org.uk), 9 November 2007

<sup>3</sup> 'The Action Plan', pages 6,7 and 9

<sup>4</sup> The proposed Regional ASD Group will be accountable to the new Regional HSC Board from April 2009 and will communicate with the DHSSPS via the Regional HSC Board

<sup>5</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, pages 2-5

<sup>6</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 4, page 21

<sup>7</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, page 4

## **SERVICE REDESIGN**

In summary, the DHSSPS propose a Regional ASD Group to co-ordinate regional planning; development of multidisciplinary ASD local specialist teams and a standardised integrated Care Pathway for children, adolescents and adults with suspected ASD. Operating at Sub-Regional level, a local ASD network is proposed for each HSC Trust area and the identification of both a lead director in each Trust and an ASD Co-ordinator in each local network. Trusts should deliver seamless care in transition stages of life with the use of a bespoke care plan and a nominated key worker is proposed.

'The NI Review' report first recommended many of the proposed DHSSPS key actions, including a Regional Network/Group, a lead director in each Trust and the establishment of local specialist multidisciplinary teams. As in the Welsh Strategy, 'the NI Review' also focused on periods of transition and how these were particularly difficult for people with ASD<sup>8</sup> and also on adults proposing the need for separate ASD teams for adults. It appears that it is in the area of *transitions* that the cross-cutting nature of services and co-operation between government departments, agencies, voluntary and community groups becomes most required.

As detailed in the main body of the paper, the development of the 'key worker' appears to be a widely supported concept with such a proposal in 'the NI Review', the DHSSPS 'Action Plan', the Welsh Strategy, the Bamford Review and the National Autism Plan for Children.

The overall direction for service redesign in the Action Plan for Wales is the model being applied to all health and social services development in Wales and is based on the concept of a four tier strategic conception of their functions. Tier 1 (first level services), Tier 2 (more specialised but essentially local services and, Tier 3 (regional specialist services for those with complicated diagnosis); and Tier 4 (specialist inpatient services). The Action Plan for Wales places emphasis on multi-disciplinary and holistic person-centred assessment, with the "*recognition that a person may have special health, education or social needs*"<sup>9</sup>. It is difficult to envisage how a DHSSPS strategy alone could achieve such holistic needs assessments for those diagnosed with ASD in Northern Ireland.

## **PERFORMANCE IMPROVEMENT**

The most immediate performance aim of the DHSSPS 'Action Plan' is a reduction in waiting times, including clearing the existing backlog, from identification of concern to assessment, from assessment to diagnosis, and from diagnosis to treatment and care. It proposes the establishment of a regional performance improvement system with specific ASD quality indicators also recommended by 'the NI Review'<sup>10</sup>.

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<sup>8</sup> The Review, Assessment and Diagnostic Services, Local and General Services, page 12

<sup>9</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 3, page 16

<sup>10</sup> The Review, Regional ASD Service Network, page 24

## **TRAINING AND RAISING AWARENESS**

The DHSSPS 'Action Plan' proposes the development and implementation of an ASD training strategy. 'The NI Review' and the Bamford Review also advocated such a training strategy for both parents and practitioners. The Action Plan for Wales highlighted,

*"raising awareness and understanding of ASD is one of the key elements in ensuring that each individual's needs are fully identified and assessed"*<sup>11</sup>.

## **COMMUNICATION AND INFORMATION**

The key action proposed by the DHSSPS is the production of a communications plan to provide information to people with ASD, their family and carers. The Action Plan for Wales also recognises the role that families and carers play in caring for, advocating for and supporting people with ASD and devotes a section of the Plan specifically to Family Carer and Support Services<sup>12</sup>. In Scotland a National Service online Network is being taken forward by the National Centre for Autism Studies, part of the University of Strathclyde<sup>13</sup>.

## **EFFECTIVE ENGAGEMENT AND PARTNERSHIP WORKING**

The key actions of the DHSSPS 'Action Plan' are to promote effective working and the sharing of information and best practice with other sectors and agencies, and to involve service users in the planning, commissioning and delivery of autism services.

'The NI Review' also recognised the important contribution made by groups from other sectors and the Bamford Review noted that a major role for the senior manager in each provider unit would be *"to involve and co-ordinate relevant statutory and voluntary agencies in provision of services for people with ASD and their families or carers"*<sup>14</sup>. The Action Plan for Wales highlights that "Partnership working will be the key to success" between agencies who commission and deliver services, partnerships with individuals with ASD, their family's carers and the professionals who support them.

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<sup>11</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 2, page 9

<sup>12</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 5, pages 41-43

<sup>13</sup> *Autistic Spectrum Disorders Needs Assessment Report*, Scottish Executive Report on Implementation and Next Steps, February 2006, page 16

<sup>14</sup> The Bamford Review of Mental Health and Learning Disability (NI), Autistic Spectrum Disorders (2006), [www.rmhdni.gov.uk/asd\\_report\\_may06.pdf](http://www.rmhdni.gov.uk/asd_report_may06.pdf), pages 34

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## 1. INTRODUCTION

### **1.1 PURPOSE AND STRUCTURE OF THIS PAPER**

This purpose of this research paper is to outline the main aspects of the proposed DHSSPS Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09 – 2010/11 and discuss how the Action Plan compares to the recommendations and directions for ASD service design and delivery of other relevant ASD strategies and reports. There is particular emphasis on both the Welsh ASD Strategic Action Plan (April 2008), to inform the HSSPS Committee in preparation for its visit to Wales, and on the Northern Ireland Independent Review of Autism Services (May 2008), as the Health Minister noted that this Review has contributed significantly to the DHSSPS 'Action Plan'<sup>15</sup>.

After providing an introduction to ASD and its prevalence in the UK, this research paper provides overviews of both the DHSSPS Action Plan consultation paper and the 2008 Welsh Assembly Government ASD Strategic Action Plan for Wales. The main body of the paper is then structured around the five key themes of the DHSSPS Action Plan – (i) Service redesign, (ii) performance improvement, (iii) training and raising awareness, (iv) improving communication and information, and (v) effective engagement and partnership working. The paper provides further details from the DHSSPS proposed Action Plan under each of these themes, with most information on service redesign, and discusses how the DHSSPS Plan compares to the recommendations and directions for ASD service design and delivery of other relevant ASD strategies and reports with, as stated above, particular emphasis on both the Welsh ASD Strategic Action Plan and on the Northern Ireland Independent Review of Autism Services. Given the 'person-centred and 'whole-life' focus referred to in the DHSSPS Action Plan, the provision of services outside the remit of the DHSSPS Action Plan but covered in other jurisdiction's ASD strategies and reports, with wider remit, is also briefly discussed.

### **1.2 AUTISM SPECTRUM DISORDER (ASD)**

The Northern Ireland Independent Review of Autism Services report ('the NI Review') describes the autistic spectrum<sup>16</sup> as generally being taken to include three diagnostic categories - autism, Asperger syndrome and atypical autism. Common features across the spectrum are difficulties in three areas of development known as the 'triad of impairments' and these are difficulties in:

- Social and emotional understanding;
- All aspects of communication; and
- Flexibility in thinking and behaviour.

Other problems, although not universally found in ASD, are common accompaniments and include sensory processing problems, specific language problems, general learning difficulties, dyslexia, dyspraxia, epilepsy and, anxiety states and depression (in adolescence and adulthood). ASD may also be present in an individual with exceptional language ability and high academic skills and/or talents. 'The NI Review' notes that professionals can "*confuse the severity of a child's needs with the severity of their*

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<sup>15</sup> *McGimpsey launches consultation on Autism Action Plan*, NI Executive Press Release, 17 September 2008

<sup>16</sup> The Independent Review of Autism Services, Chaired by Lord Maginnis of Drumglass, (May 2008) *What Are Autistic Spectrum Disorders?*, page 9

*autism*”, thus describing the child with mild autism and severe learning difficulties incorrectly as having ‘severe autism’<sup>17</sup>.

The current ASD Strategic Action Plan for Wales has adopted the World Health Organisation definition of ASD<sup>18</sup>:

*“The term autistic spectrum disorders (ASD) is used to describe the group of pervasive developmental disorders characterised by qualitative abnormalities in reciprocal social interactions and in patterns of communication and by a restricted, stereotyped, repetitive repertoire of interests and activities”.*

The behaviours that professionals look for to diagnose ASD are those described above within the triad of impairments, however there is no conclusive diagnostic test professionals can disagree over the diagnosis. This can lead to difficulties for people with ASD and their families who need assessment of their needs and services leading to appropriate interventions. Many professionals have roles to play in recognising ASD and it is thought that the education services have particular opportunities in recognising children and young people who may have ASD<sup>19</sup>.

### **1.3 PREVALENCE OF ASD IN THE UK**

The prevalence of diagnosed ASD is increasing. However it is unclear whether this is due to rising awareness and improved diagnosis or a genuine increase in prevalence. It is believed that improved diagnosis, increased awareness and more specialist provision resulting from a specific diagnosis could account for some of the increase<sup>20</sup>.

The Medical Research Council’s review of autism research suggests that “*there is fairly good agreement between epidemiological studies that ASD, if broadly defined, currently affects around 60 per 10,000 children under 8 and if narrowly defined, 10-30 per 10,000*”<sup>21</sup>.

The National Autism Plan for Children noted that in a typical local population unit of 55,000 children under 16 with 4,000 new births per year, an annual incidence of 24 new cases is implied with presentation at varying ages. This in turn suggested that there would be more than 250 children (under 16 years) with ASD at any one time in every such local health area<sup>22</sup>.

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<sup>17</sup> ‘The NI Review’, *What Are Autistic Spectrum Disorders?*, page 9

<sup>18</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, page 6

<sup>19</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 3, page 14

<sup>20</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, page 8

<sup>21</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, page 7

<sup>22</sup> National Autism Plan for Children, March 2003, National Initiative for Autism: Screening and Assessment, Executive Summary

Recently in Wales, a study of diagnostic trends in ASD in the South Wales Valleys has been undertaken over a 15 year period and it confirms the prevalence rate of 60 per 10,000 population<sup>23</sup>.

The DHSSPS Strategic Draft Action Plan ('the Action Plan') notes that autism is not easy to identify. The actual number of people with ASD in our society therefore is not easily calculated. Current estimates suggest that approximately 200 new ASD cases can be expected per year in Northern Ireland and that for every three suspected cases referred for diagnosis and assessment, one case will be confirmed. ASD "*occurs more commonly in boys than girls at a ratio of 4:1, although this varies across the ASD spectrum*"<sup>24</sup>.

In the absence of suitable 'benchmarking' information, 'the NI Review' assumed that every child with either a suspected or likely diagnosis of ASD is referred from general childcare services to the proposed ASD specific specialist Trust teams and estimated the likely number of new cases requesting ASD specialist services per year, taking into account several factors<sup>25</sup>, to be as follows<sup>26</sup>:

- Northern Trust - 50 new cases;
- Belfast Trust - 37 new cases;
- South Eastern Trust - 37 new cases;
- Southern Trust - 44 new cases; and
- Western Trust - 35 new cases.

#### **1.4 MARKERS OF GOOD PRACTICE IN SERVICES FOR CHILDREN AND YOUNG PEOPLE WHO ARE DISABLED OR HAVE COMPLEX HEALTH NEEDS**

The NHS National Service Framework (NSF) for Children, Young People and Maternity Services establishes standards for promoting the health and well-being of children and young people and for providing high quality services that meet their needs. Standard 8 focuses on *Disabled Children and Young People and those with Complex Health Needs*<sup>27</sup>, including those with ASD. Standard 8 provides a list of overview *Markers of Good Practice* as a starting point against which to measure service provision for this group of children and young people. The full list of Markers is attached at Appendix 2 (directly extracted from the NSF document)<sup>28</sup>:

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<sup>23</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, page 7

<sup>24</sup> Autistic Spectrum Disorder (ASD) Strategic Action Plan 2008/09-2010/11, Consultation Document, September 2008, DHSSPS, page 8

<sup>25</sup> Factors included numbers living in each Trust area, birth rate patterns 2004-2007 and current ASD prevalence rates

<sup>26</sup> 'The NI Review', *What Are Autistic Spectrum Disorders?*, page 45

<sup>27</sup> National Service Framework for Children, Young People and Maternity Services – Disabled Children and Young People and those with Complex Health Needs, Department for Education and Skills and Department of Health, October 2004

<sup>28</sup> National Service Framework for Children, Young People and Maternity Services – Disabled Children and Young People and those with Complex Health Needs, Department for Education and Skills and Department of Health, October 2004, page 6,

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4089112](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089112)



## **2. OVERVIEWS OF THE DHSSPS ASD STRATEGIC ACTION PLAN (CONSULTATION DOCUMENT) AND THE ASD STRATEGIC ACTION PLAN FOR WALES**

This Overview Section briefly outlines the main themes of the DHSSPS 'Action Plan' and the Strategy for Wales. Subsequent sections 3-7 of this paper describe the five key themes of the DHSSPS 'Action Plan' in more detail and discuss how they compare to the main recommendations and directions for ASD service design and delivery in other relevant ASD strategies and reports, including primarily 'the NI Review', and the current Strategic Action Plan for Wales.

### **2.1 OVERVIEW OF THE DHSSPS STRATEGIC ACTION PLAN**

The DHSSPS notes that the preparation of the Draft 'Action Plan' follows the publication of a series of documents including the *Independent Review of Autism Services*, the recommendations of the Bamford Review relating to ASD and its *Equal Lives Report*, and "*other local, national and international work*"<sup>29</sup>. The Health Minister highlighted that the *Independent Review of Autism Services* has contributed significantly to the DHSSPS 'Action Plan'<sup>30</sup>.

The overarching 'vision' of the 'Action Plan' recognises the individual nature of ASD and describes a "*person-centred approach*" to ASD service provision with focus on a "*whole life*" approach embodied in "*appropriate intervention and provision of health and social care services, education, employment, housing and social security benefits...the statutory, private, voluntary and community sectors, each of which will have a role in promoting engagement and co-ordination of services at relevant levels*"<sup>31</sup>.

It appears, therefore, that 'the Action Plan' promotes inter-departmental co-ordination in the provision of ASD services, however Lord Maginnis, as Chair of 'the NI Review', noted in his presentation to the HSSPS Committee<sup>32</sup> "*that the one constraint on our inquiry was that we did not have authority – or any great welcome in some areas – when we tried to step outside the parameters that were dictated by the Department of Health, Social Services and Public Safety...there appears to be no desire for other departments to co-operate...unless that can be overcome difficulties will emerge in the future*".

Recognition of the requirement for inter-departmental co-operation, was also evident in the Report of the Task Force<sup>33</sup> on Autism (April 2002), *The Education of Children and Young People with Autistic Spectrum Disorders* when it recommended that the "*Departments of Education, Health, Social Services and Public Safety and Employment and Learning should establish an inter-departmental working party to...develop multi-disciplinary agreement and protocols on good practice in assessment, diagnosis and*

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<sup>29</sup> 'The Action Plan', page 7

<sup>30</sup> *McGimpsey launches consultation on Autism Action Plan*, NI Executive Press Release, 17 September 2008

<sup>31</sup> 'The Action Plan', page 5-6

<sup>32</sup> Committee for HSSPS, Official Report (Hansard), *Independent Review of Autism Services*, 3 July 2008

<sup>33</sup> The NI Task Force established in November 2002 to make recommendations on educational provision for children and young people with autism.

*early/prompt intervention services for children and young people suspected of having an ASD*<sup>34</sup>.

The DHSSPS draft Action Plan is designed around five key themes as follows<sup>35</sup>:

- Service redesign to improve care, including such areas as improving co-ordination of assessment, diagnosis, care and support; and development of specialist teams at local level linked to a regional multi-disciplinary ASD group<sup>36</sup>;
- Performance improvement of autism services, including reducing waiting times for assessment, diagnosis and treatment;
- Training and raising awareness to support parents and professionals;
- Improving communication and information provided to individuals and families; and
- Effective engagement and partnership working within Government and with voluntary/community groups and other agencies as required.

The five themes are all linked to the central tenet of the Care Pathway (attached at Appendix 1) “*designed to enhance early recognition, integrated assessment, diagnosis, evidence based interventions and ongoing support*”<sup>37</sup>. It is proposed that Standards will be developed for key stages along the Care Pathway and Performance Indicators developed over the next three years<sup>38</sup>. ‘The NI Review’ also supported such a Regional ASD Care Pathway, with standards and quality service indicators, proposing that it should include child, adolescent and adult settings and services and that the pathway “*should set out the proposed journey for the child, family or individual, covering initial contact within primary/community care, formal diagnosis/assessment, and the potential support and intervention provided by more specialist ASD services including both statutory and non-statutory inputs*”<sup>39</sup>.

An extra £2.02 million is available for the three year ‘Action Plan’ and this forms part of the additional £17 million for learning disability services (including respite care). It is to be subject to ongoing monitoring by the new Regional Health and Social Care (HSC) Board and will be evaluated to “*inform the need for any future resource allocation from 2011/12 onwards*”<sup>40</sup>.

The DHSSPS plan to “*expedite change now*”<sup>41</sup> by more immediately quantifying current waiting times along the care pathway; setting clear targets for reduction of the waiting times for ASD; identifying local ASD directors and ASD co-ordinators in each Trust with the clear mandate to commence development of a local ASD network; tasking a lead HSS Board to commence the regional multi-disciplinary ASD Group; in advance of the formation of the Health and Social Care Board to move forward with a prioritised action

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<sup>34</sup> Report of the task Force on Autism, The Education of Children and Young People with Autistic Spectrum Disorders, April 2002, Executive Summary, page ix

<sup>35</sup> ‘The Action Plan’, pages 6,7 and 9

<sup>36</sup> The proposed Regional ASD Group will be accountable to the new Regional HSC Board from April 2009 and will communicate with the DHSSPS via the Regional HSC Board

<sup>37</sup> ‘The Action Plan’, page 9

<sup>38</sup> ‘The Action Plan’, page 9

<sup>39</sup> ‘The NI Review’, Regional ASD Service Network, page 23

<sup>40</sup> ‘The Action Plan’, page 15

<sup>41</sup> ‘The Action Plan’, page 17

plan, with particular reference to standardising the care pathway and commencing mapping of current service provision; and taking steps to introduce health visiting in the family home at 24 months of age.

## **2.2 OVERVIEW OF THE WELSH ASSEMBLY GOVERNMENT ASD STRATEGIC ACTION PLAN FOR WALES (APRIL 2008)**

In comparison to the health and social services focus of the DHSSPS ASD 'Action Plan' and the educational focus of the earlier *Report of the task Force on Autism, The Education of Children and Young People with Autistic Spectrum Disorders*, (April 2002) it has been stated that "*Wales is the first European nation to commit to a 'whole nation' model for delivering high-quality services and research into the brain disorder which is now thought to affect up to one in 100 people*"<sup>42</sup>.

The 'whole nation' direction commenced with the a new Chair in Autism Spectrum Disorders based in Cardiff University's School of Psychology which was described by the President of the University as "*a research and operational model for other countries to follow...[and] further emphasise the pioneering comprehensive approach to autism taken within Wales by Government*"<sup>43</sup>.

Regarding the Strategy for Wales, the National Autism Society notes<sup>44</sup> "*there is now a specific focus on autism, both on a national and a local level...Local agencies, including local authorities and local health boards, are expected to deliver the ASD strategic action plan through local health, social care and well-being strategies and local Single Children and Young People's plans*".

The Welsh Assembly Government has announced £1.8m in 2008-09 to support the first year of actions in relation to mapping of needs and services and the identification of ASD Champions, with future funding to be announced in 2009.

As appears to be the aim of the DHSSPS 'Action Plan', the Strategy for Wales also focuses on the "*provision of person-centred services and support arrangements for people who have ASD and their families*" and notes that these are to be delivered "*by effective co-operation at local, regional and in some cases national level*"<sup>45</sup>.

The actions proposed in the Strategy, to be taken by the Welsh Assembly Government, are described as those required to "*set the foundation for better services for children, young people and adults with ASD and their families*". These actions fall into the following main areas covering mainly health, social care, education and transition needs<sup>46</sup>:

- Mapping prevalence, needs and services – Commissioners and service providers should identify an ASD Champion "*with sufficient knowledge and seniority*" and

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<sup>42</sup> News from Autism Cymru and Autism Speaks, [www.autismspeaks.org.uk](http://www.autismspeaks.org.uk), 9 November 2007

<sup>43</sup> News from Autism Cymru and Autism Speaks, [www.autismspeaks.org.uk](http://www.autismspeaks.org.uk), 9 November 2007

<sup>44</sup> What is the Welsh Assembly Government ASD strategic action plan?, [www.nas.org.uk/nas/jsp/polopoly.jsp?d=1812](http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1812)

<sup>45</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, page 1

<sup>46</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, pages 2-5

carry out this mapping exercise through the Children and Young People's Partnerships and Local Health, Social Care and Well-being Strategy Groups as part of their wider mapping of needs and services, and needs assessments;

- Commissioning services – the Welsh Assembly Government believes that the response of commissioners “*is a crucial matter on which the success and speed of implementation of this strategic action plan will depend*”<sup>47</sup> and involves:
  - Pooling resources to commission services;
  - Local Health Boards having in place by end of 2008 arrangements to commission regional provision of diagnostic and treatment services to bring together appropriate specialisms and ensure equity of access across Wales to tier 3 services;
  - The Children and Young People's Partnerships and Local Health, Social Care and Well-being Strategic Partnerships supporting the establishment of an ASD co-ordinating group in each local area (multi-agency and including service users and carers); and
  - The publication of Quality Standards in Education for Pupils with ASD in 2008, by the Welsh Assembly Government;
  
- Transitional Arrangements – Commissioners and service providers are to ensure there are “*clear arrangements for transition between services for children and young people and adult services*”<sup>48</sup>. This is supported by £1.5m from the Welsh Assembly Government for a number of additional key transition workers to provide support to children and young people with SEN (including those with ASD) as they move through school to further education or the workplace;
  
- Services for adults – “*The Welsh Assembly Government will, during 2008, establish a Task and Finish Group to identify the 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*”<sup>49</sup>; and
  
- Awareness raising, information and training – Actions are directed to Commissioners and service providers in health, social care and education to support the provision of ASD awareness training for all professionals who may come into contact with people with ASD.

### **3. SERVICE REDESIGN**

#### **3.1 OVERVIEW OF SERVICE REDESIGN**

Within the DHSSPS 'Action Plan' a key aspect of the proposed service redesign is the development of local specialist ASD teams and a HSC Trust-led local integrated network in each of the five Trusts to ensure integrated working throughout the Trust. A lead

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<sup>47</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 4, page 21

<sup>48</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, page 4

<sup>49</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 1, pages 5

Director and co-ordinator is to be identified in each HSC Trust to drive the local ASD network which will then link to the Regional ASD Group who will be responsible for *“the development of the Care Pathway, regional standards and performance indicators. It will also have input into the commissioning of ASD services...[and in complex cases] explore access to other highly specialised services”*<sup>50</sup>.

‘The NI Review’ proposed a similar over-arching Regional ASD Network providing services across all the Trust areas and linked to other key agencies/sectors and to wider children’s services planning. The Regional Network was to comprise similar local specialist ASD teams working together with a regional ‘consortium’ focused on complex cases. As with the proposed Regional Group, the ASD Network was proposed to have a wider focus than the local services and *“should become the overall hub for ASD services within the region and should, for example, promote the development of a shared understanding of ASD diagnostic/treatment issues and approaches across child, adolescent and adult services...where required the Network should identify routes to more specialist services outside N. Ireland”*<sup>51</sup>.

### **3.2– SERVICE REDESIGN - DHSSPS ‘ACTION PLAN’ MAIN ACTIONS AND SERVICE NEEDS**

The full list of key actions and timetable for this theme can be found on pages 21-26 of ‘the Action Plan’. The main proposed actions and service needs are summarised below from pages 21-26 of the plan.

The current levels of autism service provision are to be established, including workforce, skill mix, tools and interventions used.

A Regional ASD Group is proposed to co-ordinate regional planning and development of ASD local specialist teams. The Group will be required to agree a standardised integrated Care Pathway (see Appendix 1) for children, adolescents and adults with suspected ASD. The Action Plan for Wales developed such Care Pathways in further detail and the more specific Care Pathways it describes for Classic Autism with Learning Disability, Adults with Classic Autism with Learning Disability, and Asperger Syndrome Care Pathway are included at Annexes 2, 3 and 4 of the Action Plan for Wales. These Pathways are described as *“fluid and fluent”* in which individuals can move between services but also receive elements of care from more than one agency at a time<sup>52</sup>. The NSF for Children, Young People and Maternity Services have published an exemplar patient journey for ASD to assist the planning of such Pathways<sup>53</sup>). The Group will also be required to promote agreed service standards and look for new innovations/developments.

Below the proposed Regional ASD Group, operating at Sub-Regional level, a local ASD network is proposed for each HSC Trust area and the proposals are to identify a lead director in each Trust, identify an ASD Co-ordinator in each local network (proposed as a

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<sup>50</sup> ‘The Action Plan’, page 12

<sup>51</sup> The Review, Regional ASD Service Network, page 23

<sup>52</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 4, page 22

<sup>53</sup> Autism Exemplar, NSF for Children, Young People and Maternity Services, [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4089206](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089206)

new function for an existing manager) and build multi-disciplinary specialist teams within each HSC Trust to provide effective and consistent ASD therapies and interventions.

It is proposed that each HSC Trust adopts standardised assessment, diagnosis, intervention and care procedures, including standardised referral processes across NI (with consideration given to UNOCINI as advocated by 'the NI Review'<sup>54</sup>). Trusts should deliver seamless care and support in transition stages of life and include the use of a bespoke care plan for smooth transition and effective linkages to other services. It is noted that of particular importance here is the proposal of a nominated key worker to co-ordinate interventions and support services at relevant life stages of the individual, recognising the need for partnership working and resource constraints in the system;

It is proposed that Trusts should implement early identification of developmental delay in all children through home-based visits by health visitors at around 24 months and consider the need for an early package of care services to cover the period from suspected ASD diagnosis to receipt of specialist services.

### **3.3 SERVICE REDESIGN – COMPARISON AND RECOMMENDATIONS FROM OTHER NI AND UK ASD STRATEGIES/ REPORTS**

'The NI Review' report covered many of the DHSSPS key actions referred to above, including a lead director in each Trust, the establishment of multidisciplinary teams and the home-based visits by health visitors at around 24 months. It also highlighted some other areas of service and need, including focus on periods of transition and how these were particularly difficult for people with ASD<sup>55</sup>

The report drew attention to the findings of the Review Team that the area of structured communication, cognitive and behavioural interventions represented the *main area of unmet need* in Northern Ireland and that intervention/treatment and support services are almost "*non existent in some areas*" especially for older adolescents and adults. With that in mind, it recommended that a separate ASD specific team should be established in each Trust area to work with older adolescents and adults and that senior/consultant level ASD posts be established in each Trust area. In addition, each team should include multidisciplinary ASD professionals to undertake therapeutic work and structured therapies.

With regard to the consideration of the need for an early package of care services, 'the NI Review' noted that the interval between referral from general Trust services to ASD specialist services should be no longer than four weeks and initial support services should be put in place during that period<sup>56</sup>, including involvement from the voluntary and community sector<sup>57</sup>;

The need for an ASD '24 hour' curriculum, was also highlighted. The Review Team noted that aspects of treatment programmes need to take place throughout the day,

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<sup>54</sup> UNOCINI was developed as a common assessment process, by the DHSSPS, to make referrals to social services and for subsequent assessments;

<sup>55</sup> The Review, Assessment and Diagnostic Services, Local and General Services, page 12

<sup>56</sup> The Review notes that this period is particularly difficult for families as they await specialist services

<sup>57</sup> The Review, Assessment and Diagnostic Services, Local and General Services, page 38

evening and weekend and that teaching and support takes place where the activity being dealt with actually takes place, for example regulation of sleep and activity levels, developing friendships and communication training.

The Bamford Review provided “*broad recommendations*” for ASD service development including the following key aspects also advocated in the DHSSPS ‘Action Plan’<sup>58</sup>:

- A “*senior manager in each Trust should be given responsibility for the development of autism specific services and the co-ordination of these across programmes of care*”;
- “*There should be a clear pathway to diagnostic and assessment service for families once ASD is suspected*”; and a “*clear referral pathway to appropriate mainstream services that may be required*”
- The development of a ‘keyworker’ model for each individual with ASD and their families/carers; and this was again highlighted in the Equal Lives Report of the Bamford Review<sup>59</sup>
- The need for forward planning and good co-operation between services at key transition stages of life.

The Equal Lives Report of the Bamford Review highlighted that a growing area of need is services for children with a learning disability who also have an ASD, “*there is increasing evidence of the real life challenges experienced by these individuals who are often caught between learning disability, mental health and child health programmes of care*”<sup>60</sup>.

With reference to standardised assessment and diagnosis, the National Autism Plan for Children published in 2003 by the National Autistic Society<sup>61</sup> recommended a three stage assessment framework as follows<sup>62</sup>:

- Stage 1 – a general multidisciplinary developmental assessment as for any child with possible developmental problem;
- Stage 2 – Multi-agency assessment (MAA) with a named key worker appointed at the start of this process. The MAA should be carried out by a multi-agency, multi-disciplinary team with the team’s core members available locally and including an educational specialist and an ASD family support worker; and
- Stage 3 – possible referral from local team to a tertiary ASD assessment with a specialist tertiary service.

The overall direction for service redesign in the Action Plan for Wales is based on the specific approach recently taken in Wales for developing all health and social services

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<sup>58</sup> The Bamford Review of Mental Health and Learning Disability (NI), Autistic Spectrum Disorders (2006), [www.rmhdni.gov.uk/asd\\_report\\_may06.pdf](http://www.rmhdni.gov.uk/asd_report_may06.pdf), pages 29, 30, 31, 32

<sup>59</sup> The Bamford Review of Mental Health and Learning Disability (NI), Equal Lives (September 2005), para. 4.13

<sup>60</sup> The Bamford Review of Mental Health and Learning Disability (NI), Equal Lives (September 2005), para. 4.10

<sup>61</sup> In collaboration with Royal College of Psychiatrists, Royal College of Paediatrics and Child Health and the All Party Parliamentary Group on Autism

<sup>62</sup> National Autism Plan for Children, March 2003, National Initiative for Autism: Screening and Assessment, Executive Summary

based on the concept of a four level/four tier strategic conception of their functions. It is proposed that *“the advantage of a tiered approach is that it matches the needs of individuals and of populations with the specialisation of service that is required. In particular it recognises that it is neither appropriate or feasible that all people with ASD should only be diagnosed, assessed and provided with interventions by the most specialised of services”*<sup>63</sup>:

- Tier 1 = direct access to first level services;
- Tier 2 = more specialised but essentially local assessments and interventions from a variety of sectors;
- Tier 3 = Access to regional specialist services for those with complicated diagnosis and assessment or challenging and variable comorbidities; and
- Tier 4 = More specialist inpatient services or access to residential schooling (e.g. those with very limited verbal communication skills).

The Action Plan for Wales places emphasis on multi-disciplinary and holistic person-centred assessment for those diagnosed or suspected of having ASD and their families, with the *“recognition that a person may have special health, education or social needs”* (a formal diagnosis is not necessarily required to begin the assessment). Social services is the lead agency for children using the existing processes of the *Framework for the Assessment of Children in Need and their Families* and for adults the Unified Assessment Process (UAP) is to be used, which means that the person’s views and wishes shape the assessment process<sup>64</sup>. It is difficult to envisage how a DHSSPS strategy alone could achieve such holistic needs assessments for those diagnosed with ASD in Northern Ireland.

The *key worker* concept is also advocated in the Action Plan for Wales as *“identified staff are empowered to work with families, carers and professionals of people with ASD to co-ordinate assessments, service provision and provide a single point of reference for the family and carers...usually a professional who already provides some service to the family or carers and takes on the co-ordination role additional to their core profession”*<sup>65</sup>.

The Action Plan for Wales focused in detail on the challenges of transitions for children and young people with ASD. It appears that it is in the area of *transitions* that the cross-cutting nature of services and co-operation between government departments, agencies, voluntary and community groups etc. becomes most required and most evident. The *“Welsh Assembly Government has recently convened a multi-disciplinary Transition External Reference Group to take forward the recommendations made by the Education, Lifelong Learning and Skills Committee in their review of SEN – part three of which focused wholly on transition and the Equal Opportunity Committee’s review of services for disabled children and young people”*<sup>66</sup>. The Action Plan outlines recommendations

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<sup>63</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 4, page 23-24

<sup>64</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 3, page 16

<sup>65</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 3, page 19

<sup>66</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 5, page 32



for the transitions from Primary to Secondary Education; School to Further and Higher Education; and School to Training and Employment at age 16 plus.

Detailed consideration of such transitions for those with ASD is outside the scope of this paper but requires the involvement of many services aside from health and social care and some of these additional services are briefly discussed in section 8.

Services for adults with ASD was also dealt with in some detail in the Action Plan for Wales, covering the areas of the Unified Assessment Process (already mentioned), Physical and Mental Health Needs, Health checks for adults with learning disability, training and employment for adults, accommodation needs and meaningful activities and social support<sup>67</sup>.

Cross-cutting service provision for adults with ASD is currently a focus of attention in England. In May 2008, the Care Services Minister announced £500,000 for Government Research into the numbers of adults with autism and their specific transition needs and this prevalence study will inform the first Government strategy on adults with autism and Asperger syndrome, due to be published in 2009. The work, including the research into transitions is being commissioned jointly between the Department of Health and the Department of Children, Schools and Families<sup>68</sup>. *Supporting People with Autism through Adulthood* is currently work in progress for the UK National Audit Office, which is studying the extent to which existing services meet the needs of adults with ASD, focusing on the transition from adolescence and the subsequent provision of health, social care, education and employment support to adults across the autistic spectrum. The study will also explore the longer-term health and economic impacts of failing to cater for adults with ASD and examine the extent to which government departments are working with Local Authorities and NHS organisations<sup>69</sup>.

In Scotland, service redesign for people with autism commenced in 2001 with the Public Health Institute of Scotland, now NHS Health Scotland, carrying out an ASD Needs Assessment. In response to its 2002 report a Reference Group was set up to take forward priorities for service improvement. Subgroups focused on diagnosis, training and information<sup>70</sup>. The Reference Group published a progress report in 2006 and with regard to service redesign it noted that “there was still a need to develop a care pathway, from childhood to adulthood”. It noted that evaluation of pilot projects would “contribute to the development of an agreed care pathway”<sup>71</sup>.

As part of service redesign in Scotland, and as recommended by the 2001 needs assessment referred to above, in July 2007, the Scottish Intercollegiate Guidelines Network (SIGN) published a national clinical guideline for the *Assessment, diagnosis and clinical interventions for children and young people with autism spectrum*

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<sup>67</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 5, pages 36-40

<sup>68</sup> Department of Health Announces Adult Autism Strategy, [www.dh.gov.uk](http://www.dh.gov.uk).

<sup>69</sup> UK National Audit Office publications, Work in Progress, [www.nao.org.uk/publications/workingprogress/adult\\_autism.htm](http://www.nao.org.uk/publications/workingprogress/adult_autism.htm)

<sup>70</sup> The Scottish Government, Autistic Spectrum Disorders, [www.scotland.gov.uk/Topics/Health/care/VAUnit/ASD](http://www.scotland.gov.uk/Topics/Health/care/VAUnit/ASD)

<sup>71</sup> *Autistic Spectrum Disorders Needs Assessment Report*, Scottish Executive Report on Implementation and Next Steps, February 2006, pages 4-5

*disorders*<sup>72</sup>. The guideline covers the areas of Recognition, Assessment and Diagnosis; Interventions, both non-pharmacological (parent-mediated, communication, behavioural/psychological, biomedical and nutritional) and pharmacological; training; and provision of information and support.

#### **4. PERFORMANCE IMPROVEMENT**

The full list of DHSSPS proposed key actions and timetable for this theme can be found on pages 27-28 of 'the Action Plan'. The main proposed actions and service needs are summarised below from pages 27-28.

The most immediate performance aim is a reduction in waiting times from identification of initial concerns of ASD to assessment, and from assessment to diagnosis, and from diagnosis to treatment and care. This includes clearing the existing backlog and all new patients then being seen within agreed waiting times.

The 'Action Plan' proposes the establishment of a regional performance improvement system with specific ASD quality indicators, taking account of standards developed; and supporting research into ASD services and outcomes.

'The NI Review' also recommended that the ASD Care Pathway should incorporate performance management standards and service quality indicators<sup>73</sup>. Indicators such as age of initial referral (from GP/community setting); age of definite diagnosis; interval between initial referral and first assessment and between first assessment and definitive diagnosis are proposed<sup>74</sup>. The Bamford Review also noted that "*Quality standards for the process of assessment and diagnosis are required to ensure consistent good practice*"<sup>75</sup>.

In Scotland, the Scottish Executive ASD Reference Group noted in its 2006 progress report that responses to a Scottish Executive consultation "*unanimously supported the adoption of the quality service standard statement [for ASD] nationally and at local level*". The ASD Reference Group is "*looking at how implementation of the standard will be measured through the work of NHS Quality Improvement Scotland*"<sup>76</sup>.

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<sup>72</sup> SIGN national clinical guideline 98, July 2007, [www.sign.ac.uk/guidelines/published/numlist.html](http://www.sign.ac.uk/guidelines/published/numlist.html)

<sup>73</sup> The Review, Regional ASD Service Network, page 24

<sup>74</sup> The Review, Case Finding Services, page 35

<sup>75</sup> The Bamford Review of Mental Health and Learning Disability (NI), Autistic Spectrum Disorders (2006), [www.rmhdni.gov.uk/asd\\_report\\_may06.pdf](http://www.rmhdni.gov.uk/asd_report_may06.pdf), page 30

<sup>76</sup> *Autistic Spectrum Disorders Needs Assessment Report*, Scottish Executive Report on Implementation and Next Steps, February 2006, page 14

## 5. TRAINING AND RAISING AWARENESS

The full list of DHSSPS proposed key actions and timetable for this theme can be found on pages 29-30 of 'the Action Plan'. The main proposed actions and service needs are summarised below from pages 29-30.

The development and implementation of an ASD training strategy is proposed to include:

- Raising awareness of ASD and sharing examples of best practice; and
- Specialist training for staff in frontline posts to promote harmonisation of assessments, diagnosis, evidence based interventions and ongoing support to individuals and families.

'The Review' also advocated such a training strategy for both parents and practitioners, ranging from general awareness to more advanced training. It proposed that such a regional training plan should be taken forward within the remit of its proposed Regional ASD Network and in potential partnership with the Education and Library Boards and Voluntary and Private Sectors and should include<sup>77</sup>:

- The establishment of a Training Co-ordinator post within each Trust area for an initial three years;
- ASD awareness training to be included as a key element of teacher training courses in N. Ireland;
- The development of autism awareness training for staff in a range of jobs and roles which bring them into contact with people affected by autism, for example staff in social security, housing services, Prison Service and PSNI; and
- A greater knowledge of referral criteria and local access points to more specialist services across Health and Social Care Trusts.

The Bamford Review also supported the need for a "*regional training strategy for parents and staff*", with two tiers of training of 'awareness' and 'specialist training'<sup>78</sup>.

The Action Plan for Wales highlighted,

*"raising awareness and understanding of ASD is one of the key elements in ensuring that each individual's needs are fully identified and assessed; that all care packages are appropriate to meeting each individual's needs; and that the core education, health and social services required to undertake assessments and interventions are effectively delivered"*<sup>79</sup>.

The key action recommended for Wales is for Commissioners and service providers in health, social care and education to support the provision of ASD awareness training for all professionals who may come into contact with people with ASD and in addition to provide awareness training for professionals the following services:

- Job centres, Careers Offices and Employment Training Agencies;

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<sup>77</sup> The Review, Case Finding Services, page 29

<sup>78</sup> The Bamford Review of Mental Health and Learning Disability (NI), Autistic Spectrum Disorders (2006), [www.rmhdni.gov.uk/asd\\_report\\_may06.pdf](http://www.rmhdni.gov.uk/asd_report_may06.pdf), page 33

<sup>79</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 2, page 9

- Further and Higher Education Institutions;
- Youth and Criminal Justice System;
- Leisure Services; and
- Commissioners of Services.

In Scotland the Scottish Executive ASD Reference Group noted, in its 2006 progress report, that local service providers still needed to support front line staff with appropriate ASD training and that “*service managers and commissioners also needed to be trained to understand the needs of people with ASD when commissioning and delivering services*”<sup>80</sup>.

## 6. COMMUNICATION AND INFORMATION

The full list of DHSSPS proposed key actions and timetable for this theme can be found on pages 31-32 of ‘the Action Plan’.

The key action proposed is the production of a communications plan to provide information to people with ASD, their family and carers. The communications plan is to include the provision of appropriate and timely information to parents in NI about developmental milestones, innovative ways of supporting individuals with ASD taking account of developments in other countries and public access to information on disability and services, including ASD Services.

The Action Plan for Wales recognises the role that families and carers play in caring for, advocating for and supporting people with ASD and devotes a section of the Plan specifically to Family Carer and Support Services which includes the provision of information; the assessment of the carers own needs; the needs of siblings and provision of age-appropriate information, the need for short break arrangements and the need for families and carers to provide therapeutic input between clinic appointments etc and therefore the training they may require to do this<sup>81</sup>.

In Scotland a National Service Network is being taken forward by the National Centre for Autism Studies, part of the University of Strathclyde. The network “*will provide an internet presence for information provision; a structure for sharing advice and receiving emotional support; an annual conference; and a hub for direction to services for people affected by ASD*”<sup>82</sup>.

## 7. EFFECTIVE ENGAGEMENT AND PARTNERSHIP WORKING

The full list of DHSSPS proposed key actions and timetable for this theme can be found on page 33 of ‘the Action Plan’. The key actions and service needs are to promote effective working and the sharing of information and best practice with other sectors and

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<sup>80</sup> *Autistic Spectrum Disorders Needs Assessment Report*, Scottish Executive Report on Implementation and Next Steps, February 2006, page 9

<sup>81</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 5, pages 41-43

<sup>82</sup> *Autistic Spectrum Disorders Needs Assessment Report*, Scottish Executive Report on Implementation and Next Steps, February 2006, page 16

agencies, and to involve service users in the planning, commissioning and delivery of autism services.

'The NI Review' also recognised the important contribution made by groups from other sectors, including Voluntary and Community sector groups with a focus on ASD, and recommended that efforts should be made to include other sectors within the Network arrangement. It proposed a range of options, including local knowledge and whether these groups could be commissioned to help statutory services with parental support and development, or employee training programmes highlighting ASD across other sectors and agencies or to provide service delivery options including therapeutic care and support<sup>83</sup>.

The Bamford Review noted that a major role for the senior manager in each provider unit would be *"to involve and co-ordinate relevant statutory and voluntary agencies in provision of services for people with ASD and their families or carers"*<sup>84</sup>.

The Action Plan for Wales highlights that *"Partnership working will be the key to success"*. This includes partnerships between agencies who commission and deliver services, partnerships with individuals with ASD, their family's carers and the professionals who support them. To develop the Plan, the Welsh Assembly Government notes it has worked in partnership with both the voluntary and the statutory sectors and with children, young people and adults with ASD who took part in the consultation exercise<sup>85</sup>.

There is a focus on effective partnership working within the current draft Autism Bill launched on 7<sup>th</sup> October, 2008 by the National Autism Society in partnership with Angela Brown MP. The Bill not only contains clauses to strengthen information about the numbers of people with autism within local authorities in England, but also clauses to strengthen inter-agency co-operation for transition planning for those with ASD from school to adulthood and also clauses to remove the barriers that prevent adults with ASD accessing the support as they currently often find themselves falling through gaps between services due to poor partnership working and *"services that refuse to take responsibility for them"*<sup>86</sup>.

With regard to partnership working in Scotland, the Scottish Executive guidance on the completion of the Partnership in Practice Agreements (PiPs) states that Pips should outline joint plans by local agencies to develop ASD services. The Pips for 2004-2007 outlined a range of such plans including converting areas of existing day services to accommodate the needs of those with ASD and involving service users in delivering training<sup>87</sup>. In addition, the Scottish Government has published, policy and practice guidance for those who commission services for people on the autistic spectrum. The guidance focuses on *"joint working with Health and the independent sector"* to ensure that service provision leaves no gaps and avoids duplication and *"joint commissioning*

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<sup>83</sup> 'The NI Review', Involvement of other sectors, page 28

<sup>84</sup> The Bamford Review of Mental Health and Learning Disability (NI), Autistic Spectrum Disorders (2006), [www.rmhdni.gov.uk/asd\\_report\\_may06.pdf](http://www.rmhdni.gov.uk/asd_report_may06.pdf), pages 34

<sup>85</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Foreword

<sup>86</sup> Autism Bill launched in Westminster, [www.nas.org.uk/nas/jsp/polopoly.jsp?d=157&a=17660](http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=157&a=17660)

<sup>87</sup> *Autistic Spectrum Disorders Needs Assessment Report*, Scottish Executive Report on Implementation and Next Steps, February 2006, pages 6-7

*and influencing across council departments” and “early intervention work, especially with NHS partners”<sup>88</sup>.*

## **8. BRIEF DISCUSSION OF ASD SERVICES OUTSIDE THE SCOPE OF THE DHSSPS ACTION PLAN**

In Northern Ireland, the Report of the Task Force on Autism, *The Education of Children and Young People with Autistic Spectrum Disorders* (April 2002), was focused on the educational provision for children and young people and provided recommendations in the areas of:

- Nursery and Pre-School Provision;
- Primary Provision;
- Post-Primary provision;
- Provision for children with ASD in combination with severe learning difficulties;
- Provision for children with ASD and challenging behaviour; and
- Further and Higher Education, Training and Employment.

As stated earlier in this paper, the recognition of the requirement for inter-departmental co-operation, was evident in the Report when it recommended that the “*Departments of Education, Health, Social Services and Public Safety and Employment and Learning should establish an inter-departmental working party to...develop multi-disciplinary agreement and protocols on good practice in assessment, diagnosis and early/prompt intervention services for children and young people suspected of having an ASD*”<sup>89</sup>.

The current Action Plan for Wales, with its cross-cutting remit and ‘*whole nation*’ model for delivering high-quality services and research into the brain disorder<sup>90</sup>, has both education services, Further and Higher Education, employment and accommodation services as a main themes in addition to health and social care aiming to support its holistic approach. The following two paragraphs indicate some of the measures covered and recommended and serve to indicate the wide remit of the Action Plan.

The Action Plan for Wales notes that development of regional education provision for children and young people with a range of needs, including ASD, is underway “*with the development of a continuum of provision in North and, currently, South Wales. To date this has included a range of provision for children and young people with the most complex needs and resourced provision for children with Asperger Syndrome*”<sup>91</sup>. It proposes that transition from school to higher learning is best managed through co-operation among schools, Career Wales, post-school education and training providers,

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<sup>88</sup> Commissioning Services for People on the Autism Spectrum, Policy and Practice Guidance, The Scottish Government, Edinburgh 2008, page 5

<sup>89</sup> Report of the task Force on Autism, *The Education of Children and Young People with Autistic Spectrum Disorders*, April 2002, Executive Summary, page ix

<sup>90</sup> News from Autism Cymru and Autism Speaks, [www.autismspeaks.org.uk](http://www.autismspeaks.org.uk), 9 November 2007

<sup>91</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 4, page 23

employers and carers. *“Plans should turn on an assessment of individual need and may involve a phased or gradual move to the new service”*<sup>92</sup>.

The Action Plan for Wales highlights that individuals with ASD need help and support to find and stay in work and estimates suggest that only 11% of adults with autism are in full-time employment. Information for employers providing work experience and employment for individuals with ASD is to be included in the Careers Wales website<sup>93</sup>. With regard to accommodation the Action Plan refers to the Welsh Government’s funding initiative ‘Supporting People’ for accommodation for vulnerable people and recommends that local authorities ensure that pre-placement assessments are undertaken for those with ASD including sensory audits<sup>94</sup>.

As part of service redesign in Scotland, and as referred to previously in this paper, in July 2007, the Scottish Intercollegiate Guidelines Network (SIGN) published a national clinical guideline for the *Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders*<sup>95</sup>. The remit of the guideline is focused on assessment, diagnosis and clinical interventions, however it does recognise that many assessments and interventions *“will be undertaken with partners in education, supported within the new framework of the Additional Support for Learning (Education) Scotland Act (2004), and with partners in social services”*. The guideline does not examine, but acknowledges, the broad range of educational and social opportunities offered to children and young people with ASD, but does consider the *“educational interventions which may influence clinical outcomes”*<sup>96</sup>.

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<sup>92</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 5, page 33

<sup>93</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 5, page 35

<sup>94</sup> The ASD Strategic Action Plan for Wales (April 2008), Welsh Assembly Government, Chapter 5, page 39

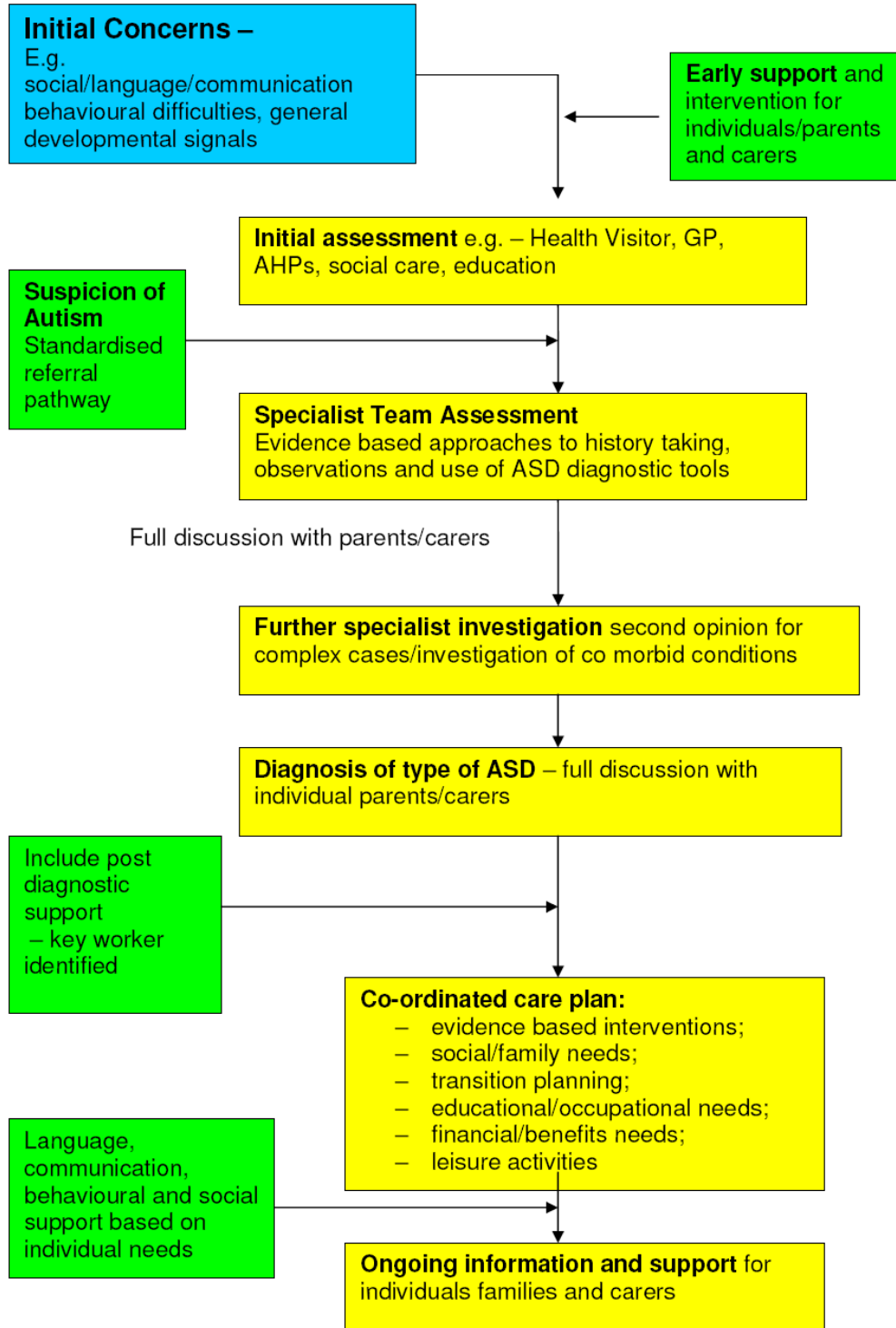
<sup>95</sup> SIGN national clinical guideline 98, July 2007, [www.sign.ac.uk/guidelines/published/numlist.html](http://www.sign.ac.uk/guidelines/published/numlist.html)

<sup>96</sup> SIGN national clinical guideline 98, July 2007, [www.sign.ac.uk/guidelines/published/numlist.html](http://www.sign.ac.uk/guidelines/published/numlist.html), pages 1-2

**9. APPENDIX 1 – CARE PATHWAY FOR ASD SERVICES<sup>97</sup>**

The diagram below is extracted from the DHSSPS Action Plan and shows the key stages along the proposed Care Pathway

**CARE PATHWAY FOR ASD SERVICES**



<sup>97</sup> 'The Action Plan', page 10



## 10. APPENDIX 2 - MARKERS OF GOOD PRACTICE IN SERVICES FOR CHILDREN AND YOUNG PEOPLE WHO ARE DISABLED OR HAVE COMPLEX HEALTH NEEDS

The NHS National Service Framework (NSF) for Children, Young People and Maternity Services establishes standards for promoting the health and well-being of children and young people and for providing high quality services that meet their needs. Standard 8 focuses on *Disabled Children and Young People and those with Complex Health Needs*<sup>99</sup>, including those with ASD. Standard 8 provides a list of overview *Markers of Good Practice* as a starting point against which to measure service provision for this group of children and young people. The full list of Markers is attached below (directly extracted from the NSF document)<sup>99</sup>:

1. Disabled children are able to access all mainstream children's services. These promote active participation and inclusion in childhood, family and community activities.
2. Disabled children and young people receive child-centered multi-agency co-ordinated services from the point of referral through identification and assessment to delivery.
3. Early identification and intervention are provided through clinical diagnosis and the *Framework for the Assessment of Children in Need and their Families*. Interventions support optimal physical, cognitive and social development, and are provided as early as possible with minimum waiting times.
4. Disabled children and young people who require ongoing health interventions have access to high quality, evidence-based care, delivered by staff who have the right skills for diagnosis, assessment, treatment and ongoing care and support.
5. Families are offered a range of appropriate family support services that are flexible and responsive to their needs and that promote their inclusion in the local community. The option of direct payments is available and promoted.
6. Disabled children and young people and their families are routinely involved and supported in making informed decisions about their treatment, care and support, and in shaping services.
7. Area Child Protection Committees (Local Safeguarding Children Boards) have strategies and protocols to ensure that disabled children and young people are safeguarded from emotional, physical, sexual abuse and neglect, in line with *Working Together to Safeguard Children*
8. Multi-agency transition planning and services focus on meeting the hopes, aspirations and potential of disabled young people, including maximizing inclusive provision, education, training and employment opportunities.
9. A range of flexible, sensitive services available to support those affected by the death of a disabled child or a child with a life-limiting illness.

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<sup>99</sup> National Service Framework for Children, Young People and Maternity Services – Disabled Children and Young People and those with Complex Health Needs, Department for Education and Skills and Department of Health, October 2004, page 6, [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4089112](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089112)



