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Welsh Government  
Consultation Document

# Refreshed Autistic Spectrum Disorder Strategic Action Plan Wales

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Action required: Responses by 27 May 2016

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.  
This document is also available in Welsh.

## Overview

This consultation seeks views on the draft refreshed Autistic Spectrum Disorder Strategic Action Plan Wales (ASD SAP). The action plan has been developed in consultation with people with ASD, their families and carers, and the ASD Stakeholder Advisory Group. The overall outcome for the action plan is that:

**Children, young people and adults with autistic spectrum disorder and their parents and carers have their needs understood, and are supported throughout their lives to achieve their well-being outcomes.**

The draft refreshed ASD SAP is based on the priorities for action identified by stakeholders and the advisory group has provided expert advice on what actions should be taken to deliver improvements to services and support. We are now consulting on our proposals for action. The consultation period is twelve weeks and comments received will be considered and where necessary this draft document will be amended to reflect the views expressed and will be published as the refreshed ASD Strategic Action Plan.

## How to respond

You can respond to the consultation by completing the consultation response form at appendix nine at the back of this document, returning it by post to the following address:

Developing Policy for Children and Adults Division  
Social Services and Integration Directorate  
Welsh Government  
Cathays Park,  
Cardiff.  
CF10 3NQ

Alternatively the consultation form is available on our web site at:

<http://wales.gov.uk/consultations/?eng>

returned to us by email to:

[childrenanddisabilities@wales.gsi.gov.uk](mailto:childrenanddisabilities@wales.gsi.gov.uk)

**Further information and related documents** **Large print, Braille and alternative language versions of this document are available on request.**

**Contact details** Developing Policy for Children and Adults Division  
Social Services and Integration Directorate,  
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**email:** [childrenanddisabilities@wales.gsi.gov.uk](mailto:childrenanddisabilities@wales.gsi.gov.uk)

**telephone:** 029 2080 1439

**Data protection** How the views and information you give us will be used:

Any response you send us will be seen in full by Welsh Government staff dealing with the issues which this consultation is about. It may also be seen by other Welsh Government staff to help them plan future consultations.

The Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. This helps to show that the consultation was carried out properly. If you do not want your name or address published, please tell us this in writing when you send your response. We will then blank them out.

Names or addresses we blank out might still get published later, though we do not think this would happen very often. The Freedom of Information Act 2000 and the Environmental Information Regulations 2004 allow the public to ask to see information held by many public bodies, including the Welsh Government. This includes information which has not been published. However, the law also allows us to withhold information in some circumstances. If anyone asks to see information we have withheld, we will have to decide whether to release it or not. If someone has asked for their name and address not to be published, that is an important fact we would take into account. However, there might sometimes be important

reasons why we would have to reveal someone's name and address, even though they have asked for them not to be published. We would get in touch with the person and ask their views before we finally decided to reveal the information.

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# CHAPTER ONE

## Introduction

### Background

1.1 The Welsh Government published the Autistic Spectrum Disorder Strategic Action Plan (ASD SAP) in 2008, the first strategic approach to autism in the UK. Since then we have made significant progress in raising awareness of autism, providing training and establishing and ASD infrastructure in local authorities. We have addressed the needs of adults with autism improving diagnostic services, providing community support and raising awareness of autism with employers. We have published an independent evaluation of the outcomes of the first ASD SAP, a summary of the key findings is at appendix three. The evaluation identified the key improvements achieved and where more action should be taken.

1.2 A Ministerial commitment was given to refresh the ASD SAP, and this was commenced by consulting with our stakeholders to establish priorities for action and then establishing an ASD Stakeholder Advisory Group to provide expert advice. In May 2015 an Interim Delivery Plan was published setting out where immediate action was required, the outcomes of which then informed the development of the refreshed action plan. A summary of the achievements is at appendix five. Over the last year we have worked with our stakeholders again hosting stakeholder workshops and on-line surveys to provide us with more information on where we needed to focus resources in the future.

1.3 The refreshed Autistic Spectrum Disorder Strategic Action Plan (ASD SAP) sets out the Welsh Government's commitment to support children, young people and adults with autism throughout their lives. This plan will be based on a significant programme of activity over the next three years to deliver a national integrated autism service. This is backed by a **£6 million investment**. More information on this new service can be found in chapter four on addressing unmet needs.

1.4 We want to ensure needs are understood and there is information and support available to enable people to lead fulfilling lives. The over arching aim of this action plan is that:

**Children, young people and adults with autistic spectrum disorder and their parents and carers have their needs understood, and are supported throughout their lives to achieve their well-being outcomes.**

The action plan was developed with expert advice and guidance from a wide range of stakeholders and sources. These are listed below with information on how to find out more about each one:

- The advice of the expert ASD Stakeholder Advisory Group (membership at appendix 1)
- The advice of the ASD Diagnosis Task and Finish Group (membership at appendix 2)

- Feedback gathered from stakeholder consultation events and surveys ( a summary of key findings at appendix 4)
- The evaluation of the first ASD SAP, a summary of findings is at appendix 3. The document can be found at <http://gov.wales/statistics-and-research/outcome-evaluation-autism-spectrum-disorder-strategic-action-plan/?lang=en>.
- The outcomes of the ASD Interim Delivery Plan published in May 2015 appendix 5.
- Information gathered from trusted academic and service delivery sources. (appendices 6, 7 and 8).

1.5 The action plan does not provide detailed information on autism, such as appropriate diagnosis pathways or interventions available. All of this information can be found on the website which supports the action plan [www.asdinfo.wales.co.uk](http://www.asdinfo.wales.co.uk). A list of all the resources available on this website and from other authoritative sources is provided at **appendix 8** and a list of other trusted sources of information is provided at **appendix 7**.

1.6 The action plan does take into account new legislative and policy developments across the Welsh Government which will have an impact on the way in which services are planned and delivered, particularly across health and social care and education. These include:

### **The Well-being of Future Generations (Wales) Act 2015**

1.7 The Well-being of Future Generations (Wales) Act is about improving the social, economic, environmental and cultural well-being of Wales, it will have a key impact on the Welsh Government's future priorities. It will require the public bodies listed in the Act, which includes health boards and local authorities to think more about the long-term, work better with people and communities and each other, look to prevent problems and take a more joined-up approach. This will help us to create a Wales that we all want to live in, now and in the future. To make sure we are all working towards the same goals.

1.8 The Act establishes Public Services Boards (PSBs) for each local authority area in Wales. Each PSB must improve the economic, social, environmental and cultural well-being of its area by working to achieve the well-being goals. The delivery plan for the refreshed ASD Strategic Action Plan will be mapped against the priorities in the Act.

- A healthier Wales
- A more equal Wales
- A prosperous Wales
- A Wales of Vibrant Culture and thriving Welsh language
- A Wales of Cohesive communities

More information on the Well-being of Future Generations (Wales) Act can be found here <http://gov.wales/topics/people-and-communities/people/future-generations-bill/?lang=en>

## The Social Services and Well-being (Wales) Act 2014

1.9 The Social Services and Well-being (Wales) Act 2014 reflects our commitment to sustainable social services and will be implemented from April 2016. The Act seeks to fundamentally change the way in which social care is planned and delivered, placing a new focus on preventative services, improving individual well-being and encouraging co-production between those who need support services and service providers. Key new duties include a requirement placed on local authorities with health boards to undertake a population needs assessment to identify local service needs and to plan to meet future support needs. This will include identifying people with autism and their carers who may need social care support. Local authorities are also required to provide an Information, Advice and Assistance service for local citizens. More information about the Act can be found here: <http://gov.wales/topics/health/socialcare/act/?lang=en>

1.10 The design and delivery of health care services is also being placed on a new footing to ensure we focus the resources available on those who are in the greatest need. A new emphasis on Prudent Healthcare sets out the changes we must put in place in the way we all think about health care to make sure the resources are targeted on those that need them the most. Access to care and treatment must be based on clinical need not on time spent on waiting lists, which should mean those in the greatest need being prioritised for support. More information on Prudent Healthcare can be found at <http://gov.wales/topics/health/nhswales/prudent-healthcare/>).

## Together for Mental Health – Delivery Plan 2016-19

1.11 Together for Mental Health, <http://gov.wales/topics/health/nhswales/healthservice/mental-health-services/strategy/?lang=en> is the Welsh Government's 10 year strategy to improve mental health and well-being. Published in October 2012, it is a cross-Government strategy and covers all ages. It encompasses a range of actions, from those designed to improve the mental well-being of all residents in Wales, to those required to support people with a severe and enduring mental illness. The strategy is implemented through three-year delivery plans which set out the key actions for the Welsh Government and stakeholder agencies in the statutory and third sectors. The second delivery plan covers the period 2016-19 and contains actions in relation to Together for Children and Young People Programme (T4CYP) neurodevelopmental work stream which includes support for children and young people with autism. This is discussed in more detail in chapter three.

1.12 Other key policy areas include the on-going reform of the special educational needs system of support, which is discussed in chapter five. Up to date information can be found here <http://gov.wales/topics/educationandskills/schoolshome/pupilsupport/additoinal-learning-needs-reform/?lang=en>

1.13 There are links to be made with the Welsh Government's tackling poverty agenda seeking to improve outcomes for the most disadvantaged communities. This includes the work we are undertaking to promote skills, employment and economic development through our skills strategy and the Youth Progression and Engagement



Framework, more information can be found here:  
<http://gov.wales/topics/educationandskills/skillsandtraining/youthengagement/?lang=>  
and is discussed in Chapter 5.

1.14 The Welsh Government's revised equality objectives for 2016-20 aim to ensure that public services are fair and accessible to disabled people and to people with the other protected characteristics under the Equality Act 2010. There are still inequalities which need to be addressed and a new Strategic Equality Plan, to be published later in 2016, will set out what the Welsh Government will focus on to help meet the equality objectives. More information can be found at <http://gov.wales/topics/people-and-communities/equality-diversity/?lang=en>

### Definition of Autism

1.15 It is important to re-state our accepted definition of autism, to ensure consistency with the first Autistic Spectrum Disorder Strategic Action Plan. The refreshed ASD SAP will continue to use the World Health Organisation's<sup>1</sup> definition of autism:

***“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 restricted, stereotyped, repetitive repertoire of interests and activities.”***

1.16 The autism spectrum is very broad and can affect people with all levels of intellectual ability. Although there is no cure for ASD appropriate support and intervention can help individuals to reach their potential.

1.17 This action plan is concerned with people on all parts of the spectrum and includes individuals who may also have a co-existing learning disability and those who are more able including those diagnosed with Asperger Syndrome. It is very difficult to estimate how many people are affected by ASD as studies vary. Current evidence suggests prevalence rates of around 1%<sup>2</sup> of the total population or above. In considering the wealth of evidence available, the Welsh Government supports the figure of 1% as the best estimate of prevalence. Therefore based on 2011 Welsh Census data<sup>3</sup> the number of people with autism in Wales should be approximately 31,000, although many of these may not have a diagnosis and will not be known to services.

### NICE Guidance on autism diagnosis and service provision

1.18 This action plan recognises the importance of National Institute of Health and Clinical Excellence (NICE) guidance on autism. NICE is a widely recognised body providing authoritative advice and information on a range of health issues. In recent

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<sup>1</sup> World Health Organisation (1993) The ICD -10 Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research

<sup>2</sup> Baird, G., Simonoff, E., Pickles, A. et al. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet* 2006; 368:(9531)210-5

<sup>3</sup> Office for National Statistics (2012) 2011 Census, Key Statistics for Wales 2011

years NICE has produced several guidelines on the diagnosis and management of autism in children and adults. The purpose of the NICE guidance is to drive and measure quality improvements and describe what a good service should look like. Health boards should take the guidance into account when planning autism services as they are the accepted bench mark of what good services should aim to provide. More information on NICE autism guidelines can be found on the [www.asdinfo.wales.co.uk](http://www.asdinfo.wales.co.uk) website or directly at NICE at <http://pathways.nice.org.uk/pathways/autism>. In addition to technical advice documents NICE<sup>4</sup> has also produced information for parents and carers of children and young people to accompany this clinical guidance

## Autism and Co-existing conditions

1.19 Many people with autism have a co-existing learning disability. Others may have mental and physical health conditions. Research indicates the most prevalent are sleep difficulties, gastro-intestinal problems, glue ear, epilepsy, anxiety, depression, dyspraxia, dyslexia, obsessive compulsive disorder, attention deficits, hyperactivity. The presence of autism in addition to another condition can lead to complex difficulties which may not respond to traditional approaches. It is therefore important that practitioners identify both autism and the co existing condition and plan care accordingly.

## Equality Impact Assessment

1.20 We have carried out an equality impact assessment, considering the available evidence to examine whether the refreshed ASD SAP will have a positive or negative impact on people with protected characteristics as set out in the Equality Act 2010<sup>5</sup>. We have considered the evidence about prevalence rates for autism being far higher in males than females and we have considered the different needs of older people with autism. In 2009 we commissioned research into the circumstances of older people with ASD<sup>6</sup>, which contributed to the decision to increase the support made available for adults. There is also an established relationship between autism and learning disabilities. The Statement of Policy and Practice for Adults with a Learning Disability, 2007 sets out Welsh Government policy on learning disabilities. Welsh Ministers also receive advice on learning disability issues from the Learning Disability Advisory Group. Information on this group and its work can be found here: <http://www.ldag.info/>:

1.21 To demonstrate our commitment to support disabled people to live independent and inclusive lives, in 2013 the Welsh Government published the 'Framework for Action on Independent Living'<sup>7</sup>, which sets out how we will be working to tackle the barriers to independent living experienced by disabled people. The framework can be found here <http://gov.wales/topics/people-and-communities/equality-diversity/rightsequality/disability/framework-for-action/?lang=en>

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<sup>4</sup> NICE (2011) Information about NICE Clinical Guidance 128

<sup>5</sup> National Assembly for Wales (2010) Equality Act 2010 (Statutory Duties) (Wales) Regulations 2011

<sup>6</sup>Stuart-Hamilton et al. (2009) The Circumstances and Support Needs of Older People with Autism. Welsh Government

<sup>7</sup> Welsh Government (2013) A Framework for Action on Independent Living

1.22 Our assessment found there was little evidence relating to autism in minority ethnic groups and we recognise that more work could be done in this area. We will ensure the ASD SAP considers the impact of autism on people with protected characteristics and wherever possible will act to improve equality and inclusion.

### **Welsh Language Impact Assessment**

1.23 We have undertaken a Welsh Language Impact Assessment, which has identified the need for the provision of support services in Welsh where required. We recognise that some individuals may require diagnosis and support services in Welsh and we are monitoring the impact of this through our consultation with stakeholders. We will continue to ensure that all autism resources are produced bilingually and the ASDinfo web site [www.asdinfo.wales.co.uk](http://www.asdinfo.wales.co.uk) is available in both languages. In addition the Social Services and Well-being (Wales) Act 2014 also requires local authorities to carry out a population assessment of the needs for care and support, this assessment will include the requirement to assess the need to provide services in the Welsh Language.

### **Children's Rights Impact Assessment**

1.24 From May 2014 Welsh Ministers have a duty to show due regard and consideration of children's rights when exercising all of their functions. A children's rights impact assessment has been carried out which enabled us to consider how the plan can support children's rights and improve the services and support they receive. This is an all age action plan and we have sought to identify children's needs, this will include how we ensure children pass through transition phase to adult support seamlessly.

## CHAPTER TWO

### Awareness raising, Information and Training

2.1 The first ASD SAP established an autism infrastructure across local authorities, which included a local ASD Lead in each authority and created local steering groups, providing £40,000 each year for every local authority to develop autism support. The infrastructure grant funding has now been transferred into local authorities Revenue Support Grant, which means the funding is available each year and local authorities have flexibility in how they use the funding to provide local autism services and support. Local authorities will continue to have a duty to identify needs and provide information and support for people with autism under the Social Services and Well-being (Wales) Act being implemented from April 2016. These include a duty to undertake a population needs assessment and a duty to provide an Information, Advice and Assistance Service. More information on the Act is at chapter one.

2.2 The Welsh Government will continue to support the local ASD infrastructure by funding the National ASD Leads Forum hosted by the ASD National Development Lead. This will bring together local ASD leads to develop and share good practice.

### Role of the ASD National Development Lead

2.3 To provide expert advice and co-ordination of autism support we will continue to support the role of the ASD National Development Lead and a development team. This role is jointly hosted by the Welsh Local Government Association and Public Health Wales creating a bridge between two key areas of service provision for people with autism – local authorities, including social care and education and health services. The key responsibilities of the role include supporting the Welsh Government and working with key experts to provide:

- Advice and support on ASD assessment and diagnosis for children and adults.
- Advice, and develop information for people with autism and their parents and carers.
- Awareness raising, training and information for professional staff, including schools and GPs.
- Advice on interventions and support including transitions.
- Support to the local authority ASD infrastructure, including the ASD Learning and Information Network.

### ASDinfoWales website

2.4 An essential part of the ASD National Development Team, managed by the ASD National Development Lead is to host and develop the [www.ASDinfoWales.co.uk](http://www.ASDinfoWales.co.uk) website. The further development and promotion of this website will be key to the delivery of the refreshed ASD SAP.

## Awareness raising and Training

2.5 Parents, carers and professional staff have repeatedly told us they need a reliable and up to date source of information on autism, which meets their needs . The first ASD SAP was very successful in supporting the development of a range of resources which are available on the ASDinfoales website, this includes guidance for parents and adults with autism. Through the ASD Interim Delivery plan we are continuing to develop resources to meet identified needs. There is an extensive range of resources and information currently available on the website. These include:

- An ASD Service Directory and Training Directory.
- Advice and information for parents and carers of children including a reference guide, information films and advice sheets.
- A guide for parents and carers of adults with autism.
- Training resources for professionals, including those working in employment support ('Working with Autism'), schools ('Learning with Autism') and health and social care ('Living with Autism').
- Autism awareness training for the public, which includes a e learning resource and a certification scheme.
- 'Autism Superhero Pledge' which includes an informative comic book and certification scheme for key stage 2 children.
- Employment resources for individuals with ASD, including an ASD friendly CV builder, job seeking tool and phone app.
- Resources for parents and carers, including advice sheets and downloadable picture planner cards.
- Independent living resources for individuals with autism, including the 'Orange Wallet Scheme', ASD Planner and Autism: A Guide for Adults Following Diagnosis.
- Two interactive personal profile builders (one for adults and one for children) which can be used by professionals, parents, carers and individuals with ASD.
- A diagnostic assessment toolkit for clinicians, which includes bespoke resources, links and downloads.
- Information for referrers, including detailed information on the signs of autism.
- A 'Practitioner Toolkit', providing information on evidence based approaches, including links and downloads.

2.6 We are building a substantial library of information, guidance and training materials which are available for all to access and are without charge. We know that more needs to be done and through the delivery of this action plan we will continue to work with our stakeholders to identify gaps in information and advice and to invest in further resource materials to raise awareness of autism across professional groups. In particular we will focus on training for primary care and mental health professionals, leisure service and employers, including planned training for HR departments. A full list of the resources available on the website is at appendix 8.

2.7 We recognise there are many useful resources that have been developed by practitioners across Wales and we encourage individuals to share these with the

ASD National Development Lead so they can co-ordinated and made available to all where possible.

**We will take action to:**

- Continue to support the role of the ASD National Development Lead to provide expert advice and guidance on autism to the Welsh Government, professional groups and stakeholders.
- Continue to support and develop the ASDinfoales website to provide an authoritative source of information and advice on autism in Wales.
- Focus on and deliver awareness raising and training in the priority areas identified by stakeholders. To include schools, nurses, leisure services and employers.
- Continue to support the ASD Forum to enable local authorities to share good practice.

## CHAPTER THREE

### Assessment, Diagnosis and Support

3.1 Access to timely diagnostic services for both children and is a continuing priority for the ASD SAP and is an action in the ASD Interim Delivery Plan. We know that more needs to be done and in response to stakeholder's concerns, in March 2015 we brought together a diagnostic task and finish group to focus on improving diagnostic services for both children and adults which reflects best practice contained in NICE guidelines which were highlighted in chapter one.

#### **The Together for Children and Young People (T4CYP) programme – neurodevelopmental work stream.**

3.2 The Together for Children and Young People programme was launched in February 2015, to ensure the sustainability of Child and Adolescent Mental Health Services (CAMHS) in Wales. The NHS is leading service change and reconfiguration, supported by the Welsh Government, which has commissioned the Chair of the Academy of Medical Royal Colleges Professor, Dame Sue Bailey to provide the external advice and scrutiny to the NHS as it seeks to embed a cultural and organisational change within CAMHS and its partners that contribute to the development of a healthy resilient child.

3.3 In addition to a remodelling of specialist NHS CAMHS it is also reviewing services that promote well being and resilience, services that provide early supportive interventions to vulnerable groups and a particular focus on children and young people with neurodevelopmental disorders such as ASD and ADHD, which includes £2 million of funding support.

3.4 A national working group has been established to provide strategic leadership and support for the delivery of high quality services and agree its priorities for a three year WLGA/Public Health Wales 1000 lives improvement programme. The remit of the group is to:

- Achieve a better understanding of Attention Deficit Disorder (ADHD)/ Autistic Spectrum Disorder (ASD) across all agencies.
- Agree bespoke care pathways for individuals with ADHD/ASD.
- Give timely access to those needing specialist assessment and treatment services.
- Draw together the skills of mental health, paediatrics, therapists and learning disability services to develop high quality assessment of needs, diagnosis and provision of evidence based intervention as needs emerge rather than dependent solely on attainment of a diagnosis.

3.5 The first meeting was held in November 2015 and the group will align with the Welsh Government's ASD Diagnosis Task and Finish Group which will now focus on adult diagnostic assessment.



3.6 The new funding available is making a difference to waiting times and diagnostic practices for children and young people. We will monitor the implementation of the T4CYP programme and the actions agreed to improve adult diagnostic services.

### **ASD Diagnosis Task and Finish Group.**

3.7 The ASD Diagnosis task and finish group met five times. Although initially established to consider both children's and adult's diagnosis, following the launch of T4CYP and the establishment of a neurodevelopmental implementation group, to avoid duplication members of the task and finish group representing children's services joined the T4CYP implementation group. The ASD Diagnosis task and finish group then considered adults diagnostic services and has provided advice to ministers on the options for achieving improvements to ensure there is support for diagnosis across the lifespan and which takes into account NICE guidelines for diagnosis and support for adults with autism.

3.8 We want to build on the successes of the ASD Adults pre/post counselling network and will seek to improve the diagnostic pathway for adults through putting in place additional support across health and local authorities as part of our plans for an integrated autism service for Wales. This will include support for professionals who provide diagnostic services, and to raise awareness of autism amongst commissioners and other professional groups.

#### **We will take action to:**

- Deliver improvements to children's ASD diagnostic services through the T4CYP programme and monitor its success.
- Deliver improvements to adults diagnostic services and post diagnostic support through our plans for an integrated service and monitor success.



## CHAPTER FOUR

### Addressing support needs

#### Meeting Needs

4.1 Many people with autism, particularly adults who are high functioning may not be able to access formal care and support services, other than those generally available to all citizens. However it is well recognised that many will still have support needs which if not addressed can cause difficulties to escalate to a crisis point, ultimately leading to the need for intensive health and social care interventions. Adults with autism frequently experience anxiety and social isolation; many have difficulties in relation to education and have problems in finding and sustaining employment. Adults with autism can also have difficulties in establishing and maintaining social relationships and friendships and often find it difficult to access community provision without support.

4.2 NICE<sup>8</sup> guidelines Autism in adults: diagnosis and management (CG142) , highlight current gaps in service provision, describing:

*A significant proportion of adults with autism across the whole autistic spectrum experience social and economic exclusion. The condition is often overlooked by healthcare, education and social care professionals, which creates barriers to accessing the support and services they need to live independently. (page 4).*

4.3 The first ASD Strategic Action Plan recognised that providing low level support services can help to prevent an escalation of needs. Between 2010-2015 Welsh Government funded regional Community Monitoring Support Projects which provided informal advice and signposting for adults in relation to a variety of needs including social skills and employment support. Data from these projects has been used to inform us about the needs of adults with ASD. The Outcome Evaluation of the ASD SAP also identified gaps in services and a demand for additional support for those not eligible for formal health and social care services, recommending that more could be done to address these gaps.

4.4 During 2015, a scoping exercise was undertaken to examine a range of autism services in different parts of the UK which aimed to meet gaps in support. Existing models were examined for their strengths and weaknesses and the different models were reviewed to determine whether they would meet the diverse range of support needs which have been highlighted by stakeholders.

#### A National Integrated Autism Service for Wales

4.5 The evidence presented by the scoping exercise clearly demonstrated that an integrated approach to supporting people with autism works well in many areas outside Wales. It is clear that an integrated autism service could also be an effective vehicle to improve services for children, young people and adults across Wales.

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<sup>8</sup> NICE (2013) Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. [NICE clinical guideline 142].

From 2016 the Welsh Government will be launching a National ASD Integrated Autism Service for Wales, **backed by £6 million of development funding.**

4.6 This new service will bring together existing children's ASD neurodevelopmental teams within health boards to provide diagnostic assessment and specialist interventions (therapies) for children with ASD. New diagnostic provision will also be made available for adults through the development of specialist adult teams. New community support teams will be developed in health board areas, these teams will offer an enabling approach, using a co-production model, providing behavioural advice, low level support, access to community services, support programmes and sign posting. This service will also provide training for parents and carers across the age range. Close links will be made to the T4CYP programme to make sure that assessment pathways are consistent for children, young people and adults.

4.7 As part of the implementation of the National Integrated Autism Service we will build on existing services by developing professional capacity and enhancing skills, to improve diagnostic assessment and post diagnostic support, . The new services will be based on the good practice contained in NICE guidelines and will include a focus on multi-agency and multi-disciplinary working, ensuring that people with autism received joined up services and support.

4.8 This will be a national approach, ensuring there is consistency across areas, ensuring that people with autism are able to access comparable services across Wales, whilst taking into account regional differences. The Welsh Government will ensure that this new service is development in partnership with Regional Partnership Boards, and with the Welsh Local Government Association and Public Health Wales, which will promote joint working between health, local authorities and third sector organisations. The service will be rolled out to all health board areas by 2019. As we develop and roll out the service we will include people with autism, to make sure the services are meeting identified needs.

### **Specialist Health Care and Support Needs**

4.9 Some people with autism and/ or learning disabilities with complex needs can access care through specialist health care services. These can be in the NHS, in hospitals and other services provided by the independent healthcare sector. Sometimes due to the specialist nature of the care, placements may not be local. The health boards and the National Commissioning Team are responsible for making sure the placements are right for people and they are delivering appropriate care, Health Inspectorate Wales (HIW) register and inspect these hospitals. There is a policy recommendation that commissioning of these services is reviewed and that the provision of appropriate more locally based services be developed. Reporting on the progress of this policy will form part of the delivery plan.

4.10 Also sometimes people with ASD have very profound learning disabilities and have problems with challenging behaviour. They can also become ill with mental health problems that mean they may be at risk of causing serious harm to themselves or others. If this happens it may be necessary for a doctor or approved mental health act practitioner to recommend they have treatment under the Mental Health Act (1983). The Mental Health Act has a code of practice that has just been

amended and can be accessed at

<http://www.wales.nhs.uk/sites3/documents/816/mental%20health%20act%201983%20code%20of%20practice%20for%20wales.pdf>

4.11 There is now a specific chapter in this code of practice about people with learning disabilities and/or autism. The chapter is based on the principles of the least restrictive options for the least period of time and expects that positive approaches will be used to help people to manage their challenging behaviour and to help them get better. There are also recommendations for the training for staff who work within the remit of the mental health act with people with ASD. The use of the Act for people with learning disabilities and/or autism in health services is overseen by Health Inspectorate Wales.

### **Interventions for Families and Carers**

4.12 There are numerous interventions which may be available to support people with autism. It is important that these are evidence based and where relevant relate to NICE guidelines and information. The Research Autism website provides evidence based information on the effectiveness of interventions, treatment and therapies, contact details can be found in appendix 6.

4.13 Autism does not just affect the individual with autism. It has an impact on their family and carers. The Social Services and Well-being (Wales) Act 2014 gives carers a right to an assessment of their needs to enable them to continue in their caring role.

4.14 There are also a wide range of additional support services designed to support children and their families. These services are targeted at specific age groups and needs and include the:

- Families First Programme – this is designed to improve the outcomes for children and young people and their families. More information on Families First can be accessed by visiting <http://www.wales.gov.uk/topics/childrenyoungpeople/parenting-support-guidance/help/familiesfirst/?lang=en>
- Early Support Programme – aims to ensure that support services for young disabled children are better co-ordinated. More information can be found on the Children in Wales website <http://www.earlysupportwales.org.uk/>
- Flying Start – targeting children under 4 years old in the most disadvantaged communities. More information is available from the Flying Start Co-ordinator in your area <http://gov.wales/topics/people-and-communities/people/children-and-young-people/parenting-support-guidance/help/flyingstart/?lang=en>
- Integrated Family Support Service (IFSS) designed to promote collaborative working to meet the needs of some children and families with complex problems. More information can be found at: <http://gov.wales/topics/health/socialcare/working/ifst/ifsspublications/briefing/?lang=en>

4.15 We know there is more we can do to raise awareness of autism amongst professionals supporting families and carers and this will be addressed as part of our approach to provide resources and training for professional groups.

**We will take action to:**

- Plan and deliver an integrated autism service in Wales to address unmet needs.
- Monitor the use of the Mental Health Act in people with ASD, including those who also have learning disabilities and ensure the implementation of latest best practice guidelines when working with people with ASD and/or those subject to the Mental Health Act.

## CHAPTER FIVE

### Education and Employment

5.1 Access to a good education and career advice and support can have a lasting positive impact on the lives of children, young people and adults with autism. Education and employment were identified as priorities for action by stakeholders, and reflected in actions in the ASD Interim Delivery Plan. The Welsh Government is making significant changes to the way in which people with additional learning needs are supported during their education, through introducing new additional learning needs legislation and by improving on-going support once they become adults. We have supported the role of the ASD Employment Ambassador and are working in partnership with Jobcentre Plus, Careers Wales and with work based learning providers to raise awareness of autism in the work place. We are also collaborating with the Big Lottery to focus Dormant Account money on supporting people with learning disabilities and autism into employment.

#### Children and Young People

5.2 All children and young people with autism are entitled to the same rights to education and employment as their peers. The needs of children and young people with autism will vary but we are aware that many of them will have difficulty accessing the curriculum and reaching their potential.

5.3 For children and young people with autism to have a successful and happy educational experience, schools and other educational settings should provide a learning environment where children and young people with autism have an appropriately differentiated curriculum, feel safe and are understood by their peers and teaching and non-teaching staff.

5.4 At our consultation events parents expressed concerns about the support available for school age children, both in mainstream and specialist schools. There were important improvements which could be made particularly around raising awareness of autism within the school and the wider community. We have addressed this in part by developing training resources for professionals as set out in the ASD Interim Delivery Plan, to increase awareness and provide training packages for the school community. More information on these resources can be found on the ASDinfo.wales website

#### Special Educational Needs Reform

5.5 The Welsh Government has previously signalled an intention to replace the existing legislative systems for Special Educational Needs and Learning Difficulties and/or Disabilities (SEN and LDD) and introduce a unified legislative framework to support learners with additional learning needs to age 25. A draft Bill to that effect was consulted upon during 2015. The legislative change is a small part of a much wider reform of the system of support for learners with SEN and LDD. This wider approach is aimed at improving early identification and effective interventions, whilst

ensuring a learner's needs continue to be supported throughout their education journey.

5.6 In 2015, the Welsh Government concluded two critical studies into the skills and knowledge of the education workforce; and assessment of the capacity of the specialist services to support learners and education settings. Welsh Government is now working with delivery partners to address workforce development needs identified through these studies. Ensuring our workforce has the necessary tools and confidence to use those tools, will reduce the need to refer to specialist support services. This in turn, will also improve the capacity of specialist services to focus on those learners with more complex needs.

5.7 We have recently commenced rolling out person-centred practice across all education settings. Financial support has been provided to all local authorities and Further Education Institutions to assist this roll out, along with the publication of a range of resources now available on the Learning Wales website. The roll out of this approach to planning will benefit learners in the immediate term and will provide an essential building block upon which our legislative reforms will be set.

## Transition

5.8 From the feedback we received from parents it is clear that post 16 transition arrangements for children with ASD can be stressful. To identify current arrangements we commissioned a piece of work aimed at the *Identification of Transitions Arrangements from School to Post 16 Further Education and Training for Young People with Learning Difficulties and/or Disabilities*. Once published this report will provide local authorities and key stakeholders with information on what works and where improvements can be made in respect to post 16 transition.

5.9 In respect to transition out of college we have asked Estyn (the education inspectorate in Wales) to examine arrangements in mainstream and specialist colleges for measuring learner progress and the extent to which these colleges prepare learners for transition out of college. Estyn will be reporting on their findings in respect of independent specialist colleges in Wales in Spring 2016; and their findings in respect of further education colleges will be reported on in Spring 2017.

## Further Education

5.10 The Welsh Government provides additional funding to further education colleges in Wales to help them secure the additional support necessary to make their provision accessible to young people with learning difficulties and/or disabilities.

5.11 Learners with statements of SEN in their final year at schools who want to access further education or training are entitled to a Learning and Skills Plan. This Plan is drawn up by Careers Wales on behalf of Welsh Ministers. It sets out the young person's individual education and training needs and identifies suitable provision to meet those needs. The Plan is intended to ease transition by helping to ensure that the right kind of learning support is put in place for individual learners with more complex difficulties when they attend college.

## Specialist Further Education

5.12 Sometimes a young person needs support that can only be delivered by an independent specialist college. If the Learning and Skills Plan and the evidence gathered as part of the SEN transition process shows that specialist provision is essential to meet a young person's education and training needs, then Careers Wales, with the young person and their family, will collate that evidence and prepare and submit a funding application to the Welsh Government to secure that provision. Funding applications for September are made by 31 January each year. The Welsh Government considers each application according to whether it falls within the duties placed on Welsh Ministers under the Learning and Skills Act 2000.

5.13 An information document has been published setting out the process by which the Welsh Ministers determine the funding of placements for learners at specialist colleges. This can be accessed at <http://gov.wales/topics/educationandskills/publications/guidance/p-16-funding-for-learners-with-learning-difficulties/?lang=en>

## Raising Awareness and Developing Skill amongst those who provide employment support

5.14 A training package for those providing mainstream employment support has been developed to raise awareness and provide advice about how professionals can adapt their practice. The 'Working with Autism' programme can be found at [www.ASDinfoWales.co.uk](http://www.ASDinfoWales.co.uk), and includes a training film, training presentation and certification scheme. The programme is also supported by a range of resources to assist professionals in day to day work with individuals with autism. We will encourage staff working in employment support services to undertake this short training programme.

## Young People – work based learning support

5.15 Young people with autism will be eligible to participate in Work Based Learning (WBL) opportunities such as Traineeships and Skills for Employment Wales (formerly Work Ready). Providers may be able to access Additional Learning Support funding to meet any additional costs necessary to make the learning provision accessible to learners with learning difficulties and disabilities.

Traineeships – This programme supports young people aged 16-18 to gain sustained employment by helping increase their skills and motivation. The programme is designed to offer bespoke and tailored provision, which enabled any barriers or issues to be addressed, which may be preventing the young person moving into further education, employment or training.

Apprenticeships – This programme offers a unique package of support, qualifications and life time skills to all who take part.

Jobs Growth Wales - The Jobs Growth Wales (JGW) programme provides employment support for young people.



Skills for Employment Wales – information can be found in the support for adults section below.

### **Youth Engagement and Progression Framework (YEPF)**

5.16 Youth Engagement and Progression Framework (YEPF) published in 2013, seeks to streamline the education and employment pathway following compulsory education and includes young people with additional needs. It builds on the work already undertaken to improve literacy and numeracy breaking the link between poverty and attainment.

5.17 As part of the YEPF we developed a Youth Guarantee which is the offer, acceptance and commencement of a suitable place in education or training for a young person making the first time transition from compulsory education at age 16.

5.18 The Common Area Prospectus (CAP) tool, developed by Careers Wales has now been rolled out across Wales and allows young people to see the range of options available to them when making their choices for post-16 learning.

### **The Getting Ahead/Moving Forward Project**

5.19 The Getting Ahead Programme, operated by the Big Lottery is funded by money that has been dormant in bank and building society accounts for the last 15 years or more.

5.20 The first tranche of “Getting Ahead” aimed to engage, prepare and motivate young people aged 16–18 years into undertaking a six month paid supported work placement for 25 hours per week in order to enhance their chances of progressing into sustainable employment, further learning or training by increasing their employability skills. This tranche has focussed on young people who have been offenders or who are care leavers and are not in education, training or employment.

5.21 The Welsh Government has been working with the Big Lottery on Tranche Two of the project Getting Ahead Two, which will be aimed at young people, aged 16-25 with a learning disability/ difficulty, and includes ASD. The aim of the programme is to create and support long term youth employment opportunities by engaging young people and employers. It will provide these young people with the intensive support required to maintain sustained and meaningful employment. We anticipate this project will be launched by August 2016. A single contract of up to £10 million has been awarded for a five year project of activity to commence by August 2016.

### **Employment support for adults with ASD**

5.22 Rates of employment amongst adults with ASD are much lower than the general population and there are many reasons to explain this. The first ASD SAP recognised that many more able adults with autism have support needs, such as requiring support to cope with anxiety and depression but they are not eligible for social care services and many may not have received a formal ASD diagnosis. Chapter 4 sets out how we are seeking to address unmet needs, and this will include supporting adults to find employment and to maintain work or volunteering.



5.23 As part of our approach to raise awareness of autism in the workplace, since 2010 the Welsh Government has supported the role of ASD Employment Ambassador (EA). The role was extended in February 2015 and the EA has developed excellent links with JobCentre Plus and Careers Wales, providing specialist advice enabling local staff to develop knowledge and skills to support people with autism into employment. Links have also been made with employers groups such as the Confederation of Small Businesses. As part of the implementation of this action plan we will assess what more needs to be done to engage with employers to raise awareness of autism in the workplace and to assess whether increased knowledge is leading to improved employment outcomes.

### Future Skills and Employment Support

5.24 The Welsh Government is prioritising the need to improve post 19 skills to ensure Wales develops into a highly skilled nation. Our **Policy Statement on Skills**, published in 2013 sets out the future skills and employment policy for the decade ahead. The key policy actions include:

- Assisting individuals who are looking for work to have access to appropriate support programmes within Wales.
- Providing individuals with access to the information they need to improve their skills as well as preventing vulnerable individuals dropping out of the workforce.
- Supporting individuals to improve their Essential Skills so they are best placed to access work opportunities or progress while in employment.

5.25 The Welsh Government is seeking to simplify access to employment and skills support. The **Skills Gateway** provides learning and skills information via a single point of access, working with the voluntary sector and other specialist organisations to ensure that disabled individuals and people with additional learning needs are supported in accessing development opportunities.

### We will take action to:

- Monitor legislation and seek to influence policy developments in post 16 transitions in health, social care, employment and education working across Welsh Government departments particularly where reform and re-alignment is being taken forward.
- To monitor the implementation of the Big Lottery Dormant Account Money project for people with learning difficulties/disabilities including ASD.

## CHAPTER SIX

### Delivering the priorities for action

6.1 We have already achieved a great deal in taking action to address the most pressing areas of concern through the delivery of the first ASD SAP and the ASD Interim Delivery Plan. The evaluation of the ASD SAP enabled us to assess what had worked well and where improvements could be made to services. In the refreshed ASD SAP we have considered all the evidence available and the views of expert stakeholders. We have set out our future priorities and stated where we will take action to secure further improvements to the support and services for people with autism and their parents and carers.

6.2 We need to be transparent in the delivery of the refreshed ASD SAP. The independent evaluation of the first ASD SAP reported it was hard to assess its impact because of a lack of clear outcome measures and significant differences in how the ASD infrastructure operated across local authorities. There was also a lack of formal governance arrangements in place so it was difficult for stakeholders to assess the progress being made. We also know that it can be difficult to find out information on how many people with autism are receiving support or are seeking access to services. We will put in place independent evaluation for the refreshed action plan which will establish measurable outcomes at the beginning of implementation. This will enable us to develop a picture of how improvements are being made to the lives of people with autism and to identify gaps in service through seeking stakeholder feedback.

6.3 To ensure we can demonstrate how the refreshed strategy is making an impact, we will deliver the refreshed ASD SAP through publishing a new delivery plan which builds on the success of the ASD Interim Delivery Plan. The plan will have stated actions and outcomes. We will also appoint an ASD Implementation Advisory Group to monitor delivery and provide us with advice and guidance. We will ensure that we continue to engage with our stakeholders, making sure they are represented on the advisory group and through regular consultation.

The actions we will be delivering through the delivery plan will be:

- Continue to support the role of the ASD National Development Lead to provide expert advice and guidance on autism to the Welsh Government, professional groups and stakeholders.
- Continue to support and develop the ASDinfoales website to provide an authoritative source of information and advice on autism in Wales.
- Focus on and deliver awareness raising and training in the priority areas identified by stakeholders. To include schools, nurses, leisure services and employers.
- Continue to support the ASD Forum to enable local authorities and partners to share good practice.

- Deliver improvements to children’s ASD diagnostic services through the T4CYP programme and monitor its success.
- Deliver improvements to adult diagnostic services and post diagnostic support through our plans for an integrated service and monitor success.
- Continue to implement awareness training on autism to all health care professionals to ensure the impact of “diagnostic overshadowing” is reduced and people with autism have equal access to quality health care.
- Plan and deliver an integrated autism service in Wales to address unmet needs.
- Put in place an independent evaluation of the refreshed ASD SAP which will establish outcome measures prior to implementation.
- Monitor the use of the Mental Health Act with people with ASD, including those who also have learning disabilities and ensure the implementation of latest best practice guidelines when working with people with ASD and/or those subject to the Mental Health Act.
- Monitor legislation and seek to influence policy developments in post 16 transitions in health, social care, employment and education working across Welsh Government departments particularly where reform and re-alignment is being taken forward.
- Monitor the implementation of the Big Lottery Dormant Account Money project for people with learning difficulties/disabilities including ASD.
- Develop a Delivery Plan to accompany the refreshed ASD SAP with measurable outcomes.
- Establish an ASD Implementation Advisory Group to monitor progress in delivering the priorities for action.

## Engagement with Stakeholders

6.4 The successful delivery of the first ASD SAP relied on partnership working across the statutory and voluntary sectors. We want this collaborative approach to continue and there is a need to acknowledge the voluntary sector’s role by ensuring they have opportunities to deliver the priorities for action in the refreshed ASD SAP and take responsibility for achieving some of the outcomes. At a strategic level voluntary sector organisations will be represented on the ASD Implementation Advisory Group.

6.5 In practical terms we will ensure third sector organisations have opportunities to demonstrate they are best placed to deliver the agreed outcomes in the Delivery Plan. We will ensure any future project funding available to deliver the priorities for

action will include an expectation that there will be collaborative delivery; that available funding will be accessible to voluntary organisations; and that there is an open and transparent application system.

## Stakeholder Involvement

6.6 To want people with autism and their parent and carers to have an active role in the delivery of the ASD SAP, we will ensure they have a role in monitoring delivery and have a voice in providing feedback on where we can make improvements. We will:

- Publish the refreshed ASD SAP and the National Delivery Plan on our website [www.wales.gov.uk](http://www.wales.gov.uk) and on the ASDinfo Wales website [www.asdinfo.wales.co.uk](http://www.asdinfo.wales.co.uk)
- Ensure the ASD Implementation Advisory Group includes members with autism and their parents and carers and voluntary organisations representing people with autism to provide their views on its impact.
- Produce an annual report on progress in implementing the National Delivery Plan. This report will be published on the [www.wales.gov.uk](http://www.wales.gov.uk) website and on the ASDinfo Wales website. [www.asdinfo.wales.co.uk](http://www.asdinfo.wales.co.uk) and will seek feedback on the progress made.
- We will continue to engage widely with all stakeholders, through surveys, social media, engagements and events tailored to meet the needs of people with autism and their parents and carers, seeking their views on the implementation of the refreshed ASD SAP and future priorities.

## Next steps

6.7 The consultation on the refreshed ASD Strategic Action Plan will last for 12 weeks, during this period we will analyse the feedback we receive. We will seek advice from the ASD Stakeholder Advisory Group on where improvements can be made, which will be included in the final version of the refreshed ASD SAP, which we will publish during 2016. This document will be accompanied by a delivery plan which will contain measurable outcomes.

## APPENDIX ONE

### ASD Stakeholder Advisory Group Members

<b>Name</b>	<b>Organisation represented</b>	
Jim Crowe	Learning Disability Wales	2013 – current
Nadine Honeybone	Parent/ Founder of Autism Directory	2013 – current
Professor Sue Leekam	Wales Autism Research Centre Cardiff University	2013 – current
Johanna Manikiza	ASD National Development Lead, 2013 - current Welsh Local Government Association	
Naomi Alleyne	Welsh Local Government Association	2013 – 2014
Hugh Morgan OBE	Autism Cymru	2013- 2014
Joe Powell	All Wales People First	2013 – current
Meleri Thomas	National Autistic Society Cymru	2013 – current
Kevin Tribble	Hywel Dda Health Board	2013 – 2014
Sundari Umapathy	Aneurin Bevan Health Board	2013 – current
Simon Burch	Association of Directors of Social Services	2013 – 2014
Bernard Boniface	Association of Directors of Social Services	2014 – 2015
Christine Griffiths	Welsh Therapies Advisory Committee	2013 – current
Robert Lloyd Griffiths	Autism Employment Ambassador	2013 – 2014
Keith Ingram	Autism Employment Ambassador	2015 – current
Jacquelyn Elias	Association of Directors of Education	2014 - current

## Welsh Government officials advising on government policy

Penny Hall – Chair	2013- current
Julie Annetts	2013 – current
Ruth Conway and Bethan Cowan	2013 – current
Jacky Davies	2013 - current
Jeni French	2013 – 2014
Helen Chapman and Vicky Best	2013 - current
Nick Lee and Tracy Samuel	2014 – current
Sue Beacock	2015 – current

Secretariat: Alyson Collins and Susan Ellis, Welsh Government

## APPENDIX TWO

### ASD Diagnosis Task and Finish Group members

<b>Name</b>	<b>Organisation</b>	
Chris O'Connor – Chair	Aneurin Bevan Health Board	2014 – 2016
Carolyn Samuel	Abertawe Bro Morgannwg Health Board	2014 – 2015
Alka Ahuja	Aneurin Bevan Health Board	2014 – 2015
Anne Marie McKigney	Aneurin Bevan Health Board	2014 – 2015
Julie Mullis	Cardiff and Vale Health Board	2014 – 2015
Jenny Hunt	Cardiff and Vale Health Board	2014 – 2015
Tansy Mayfield	Cardiff and Vale Health Board	2014 – 2016
Darrell Clarke	Cwm Taf Health Board	2014 – 2015
Zed Sibanda	Cwm Taf Health Board	2014 – 2015
Juan Delport	Cwm Taf Health Board	2014 – 2016
Catrin Simpson	Cwm Taf Health Board	2014 – 2015
Rebecca James	Powys Teaching Health Board	2014 – 2016
Johanna Manikiza	Welsh Local Government Association	2014 – 2016
Louise Albert	National Autistic Society Cymru	2014 – 2016
Catherine Jones	Wales Autism Research Centre	2014 – 2016
Sue Leekam	Wales Autism Research Centre	2014 – 2016
Tracy Jelfs	Association of Directors of Social Services	2014 – 2016
Christine Griffiths	Welsh Therapies Advisory Committee	2014 – 2016
Heather Payne	Health, Welsh Government	2014 – 2015
David Williams	Health, Welsh Government	2014 – 2016
Penny Hall	Social Care, Welsh Government	2014 – 2016
Julie Annetts	Social Care, Welsh Government	2014 – 2016
Wendy Thomas	Carmarthenshire County Council	2014 – 2016
Jacquelyn Elias	Association of Directors of Education	2014 – 2016

Sarah Dudley	Hywel Dda Health Board	2015 – 2016
Alan Downey	Betsi Cadwaladr Health Board	2015 – 2016
Christine Fretwell	Aneurin Bevan Health Board	2015 – 2016
Phil Dore	Welsh Local Government Association	2015 – 2016
Helen Matthews	Hywel Dda Health Board	2015 – 2016

Secretariat: Alyson Collins and Sue Ellis, Welsh Government



## APPENDIX THREE

### Summary of the findings of the Outcome evaluation of the Autistic Spectrum Disorder (ASD) Strategic Action Plan 2008 for Wales

At the end of 2012 the Welsh Government commissioned the People and Work Unit to undertake an external independent evaluation of the ASD SAP. The evaluation had two main objectives.

- To undertake a comprehensive assessment of data availability and gaps to inform the development of indicators to measure progress; and
- To undertake an assessment of how the ASD SAP is meeting its original aims.

The researchers undertook a theory based evaluation and gathered data from a range of sources including:

- A desk based review of literature and data.
- Interviews and discussions with people with ASD, their parents and carers and a range of key stakeholders from public, academic and voluntary sectors including ASD leads/co-ordinators.

#### Key Findings

- Since the ASD SAP's launch in 2008 a national and local ASD infrastructure has been developed which has helped raise the profile of ASD.
- Training and awareness was a focus of the infrastructure and a wide range and large number of services have been reached. The improved training and awareness is reported to have had positive outcomes but coverage has been uneven across service and groups so more work is needed.
- There is an increased awareness of ASD, which has contributed to a sharp rise in diagnosis amongst school age pupils. There has been an increased pressure on diagnostic services contributing to lengthening waiting times.
- It has improved the support that children and young people can access in education, and increased the likelihood in the needs of young adults being recognised and is valued by parents and carers.
- Improvements in diagnosis for adults is a key outcome, there have been new services in some areas, however the numbers of adults receiving a diagnosis is small and there are gaps and weaknesses in diagnostic services and pre/post counselling services in some areas.
- The impact of increased rates of diagnosis is limited by high thresholds for eligibility for social care and a lack of specialist services for adults who do not have a co-existing learning disability.
- There have been improvements in transition since 2008, but the lack of services for adults with ASD can limit the impact of transition planning, and

many adults struggle to make the transition into employment and independent living.

- Improved diagnostic rates in childhood had led to increased number of young adults with ASD, which means they are much more likely to have their needs understood and supported in further and higher education.
- ASD awareness raising and training has improved capacity in some employment services but despite this adults struggle to access effective support to find jobs and employment rates remain low.
- The Community Monitoring and Support project posts were intended to provide sign posting for adults with ASD with low level support needs. The lack of statutory support services has blunted the impact of this work.
- The establishment of the ASD infrastructure and website has meant that parents and carers access to information has improved.
- Parents and carers consistently report that it remains difficult to identify support and services and that they experience high levels of stress and anxiety as a consequence.

## Conclusions

Stakeholders welcomed the ASD SAP its was widely felt to have contributed to raising the profile and awareness of ASD, enabled the development of a local infrastructure and is perceived to have had a positive impact on people with ASD, on their families and on professionals.

The ASD SAP did have a number of weaknesses, including a lack of explicit priorities; a lack of detail of what was required and weak governance and accountability structures making it difficult to direct developments across Wales. This has contributed to an uneven impact across Wales, so that the strategy has helped to create islands of good practice but struggled to create systemic change. The logic model used highlighted some of the key strengths and weaknesses, in particular:

- Local and regional projects played a key role in creating change and improving outcomes, but contributed to uneven impact across Wales.
- The impact of the infrastructure on commissioning was limited, because it focussed on services it commissioned rather than those commissioned by local authorities or health boards.
- New national standards for education and transition were not developed which limited the SAPS impact.
- In many areas the SAP defined the standard to be reached but did not articulate an effective means for reaching it, so much depended on local initiatives and priorities. Overall progress has been made in all the key areas that the SAP focussed upon and the strategy has contributed to improving the experiences of both individuals with ASD and their families. Nevertheless it did not fully achieve its aims in relation to services for adults and there is a need to continue and refresh the SAP

## APPENDIX FOUR

### Summary of Stakeholder Consultation responses 2015

In March 2015 the ASD Diagnosis Task and Finish Group was established to review ASD diagnosis and support services. To support this work the ASD National Development Lead and development team engaged in a range of consultation activities, reaching over a 1000 parents, carers and individuals with an ASD who shared their views with us via surveys and workshops.

The consultation activity explored individual's experiences of the diagnostic assessment process and ongoing support needs and provision. A great deal of valuable and insightful information was received and it is important to thank all those who were kind enough to share their experiences. The full consultation report can be accessed here or can be viewed at:

<http://gov.wales/docs/dhss/publications/160119asdsummary15en.pdf> and on the ASDinfo Wales website.

In summary the main feedback received confirmed existing knowledge of gaps in services and where improvements should be sought. This information is already being used in the development of support and resources and will inform the development of the refreshed ASD Strategic Action Plan. In relation to diagnostic assessment, the most common improvements parents and carers told us they need were:

- **a reduction in waiting times for a diagnosis**
- **more information about the process, what to expect and the time it will take**
- **more information, advice and support at the point of receiving a diagnosis**

For ongoing support, the most common support needs parents, carers and individuals with an ASD identified were:

- **support for emotional and behavioural issues**
- **support with ASD specific issues, social skills and life skills**
- **better access to social and leisure opportunities in their local area**
- **improved knowledge and skill within schools**
- **improved understanding of ASD amongst employers and those who support into employment**

In relation to support needs of parents and carers, the most frequently reported needs were:

- **access to advice in a timely manner**
- **more social leisure activities to reduce isolation**
- **more information and training opportunities**

## APPENDIX FIVE

### Outcomes of the ASD Interim Delivery Plan

The ASD Interim Delivery Plan published in May 2015 set out our immediate priorities for action and we are making good progress.

- We have established an ASD Diagnostic Task and Finish Group, it has met five times and will provide advice to Ministers by March 2016.
- £2 million of funding has been announced to support neurodevelopmental services for children and young people, including ASD and ADHD. This funding has been provided to health boards
- A scoping exercise for a service to address unmet needs has been completed. We are developing options to plan and deliver an integrated ASD service to address unmet needs.
- We continue to develop our website [www.ASDinfo.wales](http://www.ASDinfo.wales) offering information and resources for people with autism, their families and professionals. The website attracted **18,000** page views in 2015, trebling the previous year's traffic.
- The ASD National Lead has represented Wales at the Autism Europe conference held in the European Parliament, highlighting how Wales continues to lead the field in many areas of autism support.
- We have developed ASD awareness materials and training for teachers and GPs across Wales. The resources are available on the ASDinfo.wales website and the training will be rolled out from March 2016 accompanied by a media campaign.

## APPENDIX SIX

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## APPENDIX SEVEN

### Sources of Independent Advice

There are many sources of information about autism. In developing this action plan we have used information from the following sources:

#### National Autistic Society

A UK charity for people with autism (including Aspergers syndrome) and their families. Providing information, support and pioneering services and campaigning for a better world for people with autism. [www.autism.org.uk](http://www.autism.org.uk)

#### The National Institute for Health and Clinical Excellence (NICE) provides national guidance and advice to improve health and social care

NICE's role is to improve outcomes for people using the NHS and other public health and social care services. By **producing** evidence based guidance and advice for health, public health and social care practitioners. **Developing** quality standards and performance metrics for those providing and commissioning health, public health and social care services and **providing** a range of information services for commissioners, practitioners and managers across the spectrum of health and social care [www.nice.org.uk](http://www.nice.org.uk)

#### Research Autism

This website is aimed at anyone with an interest in autism, including people with autism spectrum disorders, parents and carers, service providers and policy makers. It is one of the largest, most up-to-date, and most scientifically reliable websites in the world for information about autism; the issues facing individuals with autism; and the interventions used to help them [www.researchautism.net](http://www.researchautism.net)

#### Wales Autism Research Centre, Cardiff University

WARC was established in 2010 as the first national autism research centre in the UK. In addition to internationally recognised research in areas of behaviour and diagnosis, biological and cognitive processes and families and relationships, the centre plays a key role in the autism community with a strong reputation for translation of research into policy and practice. <http://sites.cardiff.ac.uk/warc/>

## APPENDIX EIGHT

### Resources available on the ASDinfo Wales website

[www.asdinfo Wales.co.uk](http://www.asdinfo Wales.co.uk)

#### Local Support

The website hosts a service and training directory along with contact information for local ASD leads to help users locate local support options.

#### Are you ASD Aware?

Visit our online ASD awareness scheme to develop a basic understanding of ASD and receive a certificate to acknowledge that you are ASD aware. Businesses and organisations can also join the scheme, and be part of the directory of ASD aware organisations in Wales.

#### Living with Autism

Access our range of useful resources for adults with ASD and those who support them, including:

- Autism: a guide for adults following diagnosis
- Autism: a guide for those who support adults following diagnosis
- ASD planner app., an app to support planning and structure around daily activities
- Orange wallet scheme, a resource to help individuals with ASD to use public transport
- Goal setting tool, an interactive tool to help individuals with ASD to identify need and set goals across a range of areas
- Adult personal profile builder – an interactive tool to develop a profile of needs, likes and dislikes
- Living with Autism – a short film to highlight the difficulties many adults with autism face, and how to support them

#### Working with Autism

Many individuals with autism find the process of searching and applying for jobs difficult. 'Working with Autism' provides a range of tools to support individuals with their job search, and also to increase knowledge and understanding amongst professionals working in employment support. The tools include:

- An ASD friendly CV builder
- A skills dictionary and personal skills list builder
- An employment workbook, to help individuals with ASD understand and engage in the work application process
- An information film and certification scheme, for professionals supporting people into employment
- A phone app. to assist individuals with ASD to match their skills to potential employment opportunities



## Positive about working with Autism

This scheme is aimed at employers and includes a charter for ASD friendly employers and employment support resources.

## Growing with Autism

Supporting a child with ASD can be difficult at times. This section aims to provide parents and carers with advice about how to adapt their approaches to take into account the needs of children with ASD, and to provide them with useful resources to support them to do this. The section includes:

- Autism: A Guide for Parents and Carers following diagnosis
- A series of short films providing advice for parents and carers
- Interactive child profile builder
- Parent and carer advice sheets
- Picture card planner tool
- 'Autism Superhero' charter for siblings

## ASD Practitioner Support

A series of 'toolkits' to support professionals in their specialist diagnostic and post diagnostic interventions. The toolkits include:

- Information for referrers, including 'Autism: do you know the signs?' posters
- Information and resources to support diagnostic assessment
- Information leaflets for individuals with ASD and parents / carers
- Assessment planning tools
- Behaviour charts
- Advice sheets
- Information and resources for interventions

## Health and Social Care Practitioners

Children and adults with ASD will have contact with health and social care practitioners for a range of reasons. These resources encourage practitioners to adapt their practice to accommodate the needs of individuals with ASD, and include:

- E-learning and certification scheme for practitioners working with adults with ASD
- A short awareness film for Primary Health Care Practitioners
- Diagnostic assessment referral advice and signs of autism posters
- Child and adult profile builders
- Awareness raising materials

## Learning with Autism

This whole school awareness raising programme for mainstream primary schools will ensure a supportive, inclusive approach for children with ASD attending mainstream primary schools. Schools can achieve 'ASD Aware School' status by completing the programme. This innovative programme includes:

- Autism: A Guide for Mainstream Primary Schools
- An introductory short film, explaining how school impacts on a child with ASD
- Training films for Teachers and learning support staff
- Certification schemes for teaching, learning support and non-learning support staff
- 'Autism Superheroes' comic strip and pledge certification scheme for pupils
- Resources and advice sheets to support implementation in schools

## APPENDIX NINE

### Refreshed Autistic Spectrum Disorder Strategic Action Plan Wales

#### Consultation questions response form

Your name:

Organisation (if applicable):

E-mail:

Telephone number:

Your address:

Postcode:

Do you agree to be identified in the list of responses? Yes/No – please cross out which doesn't apply.

<b>Consultation questions</b>	<b>Response</b>
<p><b>Chapter Two</b> <b>Awareness raising, Information and Training</b></p> <p>Do you agree with our proposals to improve awareness of ASD:</p> <ul style="list-style-type: none"><li>• To develop and promote the ASDinfoales website.</li><li>• To provide information and training to professional groups.</li><li>• To continue to develop resources for people with autism, their parents and carers.</li></ul> <p>Are there specific areas where we need to do more to raise awareness and provide information, training and development?</p>	

<p><b>Chapter Three</b> <b>Assessment, Diagnosis and Support</b></p> <p>Do you agree with our plans to improve diagnostic services for children and young people through the T4CYP programme?</p> <p>Do you agree with our plans to deliver an integrated autism service for Wales which will seek to improve diagnostic services for adults.</p> <p>What more could we do to improve diagnostic services and support for children and their families?</p> <p>What more could we do to improve diagnostic services and support for adults?</p>	
<p><b>Chapter Four</b> <b>Addressing support needs</b></p> <p>Do you agree with our proposals to deliver an integrated autism service in Wales to prioritise the unmet needs of adults with autism and develop support services?</p> <p>What other areas of support for people with autism need to be addressed as a priority?</p>	
<p><b>Chapter Five</b> <b>Education and Employment</b></p> <p>Do you agree with our plans to ensure the needs of children, young people and adults with ASD are supported in our education and employment policies?</p> <p>What else can we do to improve education support for children, young people</p>	

<p>and adults?</p> <p>What else can we do to improve employment support for young people and adults?</p>	
<p><b>Chapter Six</b> <b>Delivering the priorities for action</b></p> <p>What are your views on our plans to publish a delivery plan to help us deliver and monitor the implementation of the refreshed Action Plan?</p> <p>What are your views on our plans to establish an ASD Implementation Advisory Group, to include a range of stakeholders including people with autism?</p> <p>What else do you think should be done to ensure we deliver the priorities for action and monitor progress?</p>	
<p>Do you have any other comments about the priorities for action identified in the refreshed ASD SAP and our plans for delivery and monitoring implementation?</p> <p>Are there any further priorities for support which should be addressed in this action plan?</p>	

## GLOSSARY OF TERMS

ASD	Autistic Spectrum Disorder
ASD SAP	Autistic Spectrum Disorder Strategic Action Plan
CAMHS	Child and Adolescent Mental Health Service
HIW	Healthcare Inspectorate Wales
LA	Local Authority
LHB	Local Health Board
LDD	Learning difficulties/disabilities
NAS	National Autistic Society
NICE	National Institute of Health and Clinical Excellence
PHW	Public Health Wales
SEN	Special Educational Needs
T4CYP	Together for Young People Programme
WLGA	Welsh Local Government Association