



Llywodraeth Cymru
Welsh Government

Refreshed Autistic Spectrum Disorder Strategic Action Plan

Ministerial Foreword

Wales was the first country in the UK to develop a national approach and publish a strategic plan for people with autism. The Welsh Government remains fully committed to improving the lives of people with autism and to ensure their families and carers also receive the support they need.

It is important to acknowledge the progress that has been made since publishing our original action plan in 2008. One of the key achievements has been the increased profile and awareness of autism. There is a wide range of information and resources available to help people with autism and their families and carers, as well as resources for professionals. We have also established a national co-ordinator as well as ensuring there are local leads. Their focus has been on raising awareness and working to ensure there is information, advice and improved services and support available across Wales.

This new Strategic Action Plan has been developed in response to what people with autism, their families and carers have said is important to them. We have also worked with a wide range of stakeholders to identify some key priority themes and actions that will make a real difference to the lives of children and adults with autism.

The Plan sets out what we have done, what we were told and what we will do. It has three key priority areas:

- Awareness raising, information and training;
- Assessment and diagnosis; and
- Meeting support needs.

A key development is the establishment of the new National Integrated Autism Service. This service will see new specialist teams in every region, providing adult diagnosis, support in the community and advice and information for adults with autism and for their family and carers. It will support the improvements we are delivering in children's diagnosis, treatment and support services through the Together for Children and Young People programme, there will be a 26 week waiting time target from referral to first appointment and the development of a national standardised assessment pathway, to ensure consistent provision for young people with autism and attention deficit hyperactivity disorder.

We have also used our legislative powers to ensure people with autism have access to the care and support they need. The Social Services and Well-being (Wales) Act requires local authorities to establish and information, advice and assistance service and to ensure people are signposted to appropriate services and support.

Regional Partnership Boards are responsible for ensuring there are services, care and support in place to meet the needs of people in their local area. Autism has been identified as one of the key priority areas and Regional Partnership Boards will need to report on progress, including progress on delivery of the National Integrated Autism Service.

The Strategic Action Plan will be accompanied by a delivery plan, which sets out in more detail the specific actions that will be taken, including how they will be measured and monitored. An Implementation Advisory Group will be established to monitor delivery and progress. Membership will include people with autism, including children, as well as their family and carers. The group will also include representatives from statutory and third sector organisations.

An annual report will be published to provide an update on the progress being made. There will also be independent evaluation of the Strategic Action Plan and the National Integrated Autism Service.

We want to see a real difference in the services, care and support available to people with autism. We know that some of our improvements and actions will take time to deliver but we will be monitoring and reporting on progress. We are committed to delivering this programme of work and will take action to address any gaps or weaknesses in provision. This will include keeping under review the need to strengthen existing legislation or for autism specific legislation.

Rebecca Evans

Minister for Social Services and Public Health

The Refreshed Autistic Spectrum Disorder Strategic Action Plan for Wales

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Appendices

Glossary of terms

Appendix one Resources available on the ASDinfowales website.

CHAPTER ONE

Introduction

- 1.1 This new Strategic Action Plan has been developed in response to what people with autism, their families and carers have said is important to them. We have also worked with a wide range of stakeholders to identify some key priority themes and actions that will make a real difference to the lives of children and adults with autism.
- 1.2 We are committed to improving the lives of people with autism and to ensure their families and carers also receive the support they need. We intend to work closely with key stakeholders to ensure delivery of the actions set out in this Plan.
- 1.3 The aim of the refreshed Strategic Action Plan is for:

Children, young people and adults with autism and their family and carers to have their needs understood, to be supported to achieve their own wellbeing outcomes and to lead fulfilling lives.

- 1.4 In addition to the actions identified within this Strategic Action Plan, we have also used legislation to improve the services, care and support for all people, including people with autism and their families and carers. The Social Services and Well-being (Wales) Act includes a number of specific requirements, including for local authorities to establish information, advice and assistance services. Regional Partnership Boards are responsible for ensuring there are services, care and support in place to meet the needs of people in their local area. Autism has been identified as one of the key priority areas for the integration of services, care and support and Regional Partnership Boards will need to report on progress, including progress on delivery of the National Integrated Autism Service.
- 1.5 A key development is the establishment of the new National Integrated Autism Service (more information on this is included in Chapter 3). This is a service for children and adults and will complement the work for children and young people being taken forward through the Together for Children and Young People programme (more information on this programme is included in Chapter 2).
- 1.6 This Strategic Action Plan will also be accompanied by a delivery plan. This will set out in more detail the specific actions that will be taken, including how they will be measured and monitored. We want to see a real difference in the services, care and support available to people with autism and therefore close monitoring of progress and delivery will be essential (more information on this is included in Chapter 5).

1.7 Some things will take time to deliver but we will be monitoring and reviewing progress and will take action if there appear to be gaps in the services and support available. This will include keeping under review the need for autism specific legislation.

1.8 Wales was the first country in the UK to take a national approach to autism, publishing the Autistic Spectrum Disorder Strategic Action Plan in 2008. In developing the refreshed Strategic Action Plan we have worked with stakeholders, including people with autism and their family and carers. We have listened to their feedback on what has worked well and where we need to prioritise future action to improve services and support. We have refreshed the Strategic Action Plan by building on the progress achieved, as well as responding to evaluation and consultation. The three main priority areas for action are:

- Assessment and diagnosis
- Meeting support needs
- Awareness raising, information and training

Definition of Autism

1.9 We will continue to use the World Health Organisation's¹ 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."

The autism spectrum is very broad and can affect people with all levels of ability. Although there is no cure for ASD, appropriate support and intervention can help people to reach their potential. The refreshed Strategic Action Plan is for people on all parts of the spectrum and includes individuals who may also have a co-existing learning disability, as well as those diagnosed with Asperger Syndrome. It is difficult to estimate how many people are affected by ASD as studies vary. Current evidence suggests prevalence rates of around 1%² of the total population or above. Therefore based on 2011 Welsh Census data³ the number of people with autism in Wales is estimated to be approximately 31,000, although many of these may not have a diagnosis and will not necessarily be known to services.

1.10 Many people with autism will have a co-existing learning disability. Others may have mental and physical health conditions. Research indicates the most prevalent issues are sleep difficulties, gastro-intestinal problems, glue ear, epilepsy, anxiety, depression, dyspraxia, dyslexia, obsessive compulsive disorder, attention deficits and hyperactivity. The presence of autism in addition to another condition can lead to

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

² 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

³ Office for National Statistics (2012) 2011 Census, Key Statistics for Wales 2011

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 the care and support accordingly to best meet their needs.

1.11 Since publishing the Autistic Spectrum Disorder Strategic Action Plan in 2008, we have made significant progress in delivering improvements to the lives of people. The delivery of the first Strategic Action Plan has resulted in real developments in the awareness and understanding of autism and has improved access to assessment and support services. Some of our key achievements have been to support people with autism and their family and carers by:

- Developing a significant range of material available through our ASD website www.asdinfowales.co.uk, which includes information and resources for people with autism and their families or carers, as well as for professionals.
- Establishing an ASD infrastructure across local authorities which has helped to raise awareness and understanding of autism.
- Supporting awareness raising to improve the understanding of autism across groups and services through training and resources available on the ASDinfowales website.
- Improving awareness of autism which has led to a sharp rise in diagnosis of school age children.
- Improving access to diagnosis and post diagnostic support services for adults.
- Improving the support that children and young people can access in education, and increased the likelihood in the needs of young adults being recognised.

1.12 We have consulted with people with autism, their family and carers, as well as with the ASD Stakeholder Advisory Group. To understand the impact of the actions we have taken and to identify any gaps in support, we commissioned an independent evaluation which was published in early. The evaluation and stakeholder feedback has highlighted where we need to build on success to date and where we need to take further action. This includes improving the timeliness of assessment and diagnosis, consistency of services across Wales and to focus on support for individuals who may not be eligible for social care services but nonetheless have significant support needs. We also acknowledge the need to put in place mechanisms to ensure that there are strong governance and accountability structures to monitor delivery.

1.13 We have taken 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, social care and education. These include the Social Services and Well-being (Wales) Act 2014, the Well-being of Future Generations (Wales) Act 2015 and the Together for Mental Health – Delivery Plan 2016-19.

1.14 We acknowledge 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 years NICE has produced several guidelines on the diagnosis and management of autism

in children. 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 benchmark of what good services should aim to provide. More information on NICE autism guidelines can be found on the website www.asdinfowales.co.uk or directly at NICE at <http://pathways.nice.org.uk/pathways/autism>. In addition to technical advice documents NICE⁴ has also produced information for family and carers of children and young people to accompany this clinical guidance.

1.15 This Strategic Action Plan includes three key priority areas for action. These have been based on what people have told us and build on what we have achieved to date. Of particular importance is our plan to roll out an all age **National Integrated Autism Service for Wales**. This will be the first national approach to tackling unmet needs identified by people with autism and their family and carers and is backed by £6 million. More information on this service is provided in Chapter 3. We will also publish a delivery plan and put in place strong governance and monitoring arrangements, including independent evaluation (see Chapter 5).

⁴ NICE (2011) Information about NICE Clinical Guidance 128

CHAPTER TWO

ASSESSMENT AND DIAGNOSIS

2.1 Timely access to assessment services is vital for families so that each child's needs are understood and appropriate services are put in place to support them to lead fulfilling lives. An early diagnosis will also enable parents to understand their child's needs and to seek appropriate support in their caring role. Some adults with autism are not identified or diagnosed during childhood but may be helped by having access to assessment services as adults. Having an understanding of the impact of autism can help them to make sense of their lives and to seek appropriate support to manage the impact that autism can have on their daily lives.

What we have done

2.2 The first Strategic Action Plan highlighted gaps in diagnostic services and support for adults. To secure improvements we supported the Adults Diagnostic Pre/post Counselling Network, bringing together experts across health boards to develop a consistent approach to adult diagnostic services and to provide additional diagnostic training to improve professional capacity to undertake assessments.

2.3 In 2015 in response to stakeholder concerns about the provision of diagnostic services particularly for children, the Welsh Government established the ASD Diagnosis Task and Finish Group. Shortly after its formation additional funding was announced to support improvements as part of the Together for Children and Young People Programme to improve sustainability of Child and Adolescent Mental Health services. This includes £2 million annual funding to improve neurodevelopmental services. The task and finish group continued to focus on adult diagnosis only and produced a report with recommendations for action by March 2016.

2.4 To support the work of professionals involved in the diagnostic assessment of children and adults we have developed a clinicians toolkit. This is based on NICE guidelines and available on the ASDinfowales website <http://www.asdinfowales.co.uk/home/>. Also to support the identification of autism we have worked with the Wales Autism Research Centre at Cardiff University to develop an overview of the signs of autism. These overview posters have been delivered to all GP surgeries in Wales.

2.5. As part of the work we have undertaken to increase awareness of autism we have developed resources for family and carers to provide them with information once a diagnosis has been made. The Growing with Autism resources are available on the ASDinfowales website and include:

- Autism: A Guide for Parents and Carers following diagnosis
- Growing with Autism – ASD videos for parents/carers
- Child Personal Profile
- Children's Picture Cards
- Advice Sheets for parents

What we were told

2.6 The independent evaluation of the first Strategic Action Plan highlighted how the rise in awareness had contributed to a sharp increase in demand for autism assessment, which ultimately impacted on waiting times. Whilst there was an increase in the number of adults receiving assessment and diagnosis , the provision was not consistent across Wales. There was also an absence of specialist post diagnostic support.

2.7 During the consultation on the refreshed Strategic Action plan, in some areas parents expressed difficulties in achieving a referral to assessment services through schools or via primary health services. Parents were concerned they couldn't get a referral for their child for a diagnostic assessment and that without a formal diagnosis they were unable to secure additional support their child needs in school.

What we will do

2.8 We are already improving diagnosis for children and young people with autism and ADHD, through the Together for Children and Young People Programme. We have developed a nationally agreed neurodevelopmental diagnostic assessment pathway so there is a consistent approach across Wales.

2.9 The pathway will help families understand how the referral and assessment process works, what happens at each stage and what support they can expect when a decision about diagnosis is made. Once a child is accepted for assessment services they should not wait more than 26 weeks from referral to first assessment appointment. The time taken for a decision on diagnosis to be made will be dependent on the individual circumstances of the child.

2.10 It is important that families receive support throughout the process. To ensure that parents and carers have the information they need, children and young people's assessment services will work alongside the National Integrated Autism Service to ensure additional support is available and to assist children during transition and into adult services.

2.11 The National Integrated Autism Service will offer assessment and diagnostic services for adults with or without a mild learning disability. The service will build on the progress we have already made in building capacity amongst professionals to provide expert assessment services. To ensure that individuals know what support they can expect to receive we will be establishing a national neurodevelopmental diagnostic and assessment pathway for adults and establishing waiting times for assessment as the new service is rolled out across Wales. The service will operate according to agreed service standards.

2.12 We will build on our resources to support earlier identification of autism by developing a film highlighting signs and symptoms in conjunction with researchers.

2.13 The **outcomes** we want to achieve is that children, young people and adults with autism have access to timely referral, assessment and post diagnostic services which meet their needs.

We will take action to:

- Deliver improvements to children's assessment and diagnostic services. This will include the implementation of the national standardised diagnostic assessment pathway to ensure consistency.
- Improve timeliness of access, for children and young people a new 26 week waiting time target from referral to first assessment appointment.
- Ensure ongoing monitoring of progress and timeliness of assessment and diagnosis. This will be incorporated within the formal planning and performance management mechanisms of Health Boards.
- Deliver improvements to adult diagnostic services through the National Integrated Autism Service. This will include:
 - The development of a national model that will be implemented across Wales.
 - Ongoing monitoring and reporting of progress against the agreed standards for the service. Regional Partnership Boards will be required to report on progress.

CHAPTER THREE

MEETING SUPPORT NEEDS

3.1 Children, young people and adults with autism and their carers will have different support needs according to their age and abilities. For adults the NICE⁵ guidelines ‘Autism in adults: diagnosis and management (CG142)’, highlights gaps in service provision, commenting:

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. (

3.2 Feedback from stakeholders has consistently highlighted there are three main areas where there are gaps in services across the age range. We are taking action in each of these areas, which are:

- Transforming additional learning needs.
- Employment support.
- Health and social care.

Transforming Additional Learning Needs Education

What we were told

3.3 The Welsh Government has made clear its plans to transform the existing system for special educational needs (SEN) and learning difficulties and/or disabilities (LDD). This includes educational support for children with autism and autistic spectrum disorder.

3.4 Families have told us the current system is inefficient, bureaucratic and costly and is not child-centred or user-friendly. Needs are sometimes identified late and interventions are not planned or implemented in a timely or effective way.

3.5 Families say they feel they have to battle at each stage of the process to get the right support for their child and that they do not know where to turn to for advice and information.

What we will do

3.6 We will introduce a new system to support children and young people with additional learning needs (ALN) from 0 to 25 – this includes children and young people with autism and autistic spectrum disorder. The changes will be set out in legislation – in the Additional Learning Needs and Education Tribunal (Wales) Bill, which we expect to be introduced into the National Assembly in December 2016.

⁵ NICE (2013) Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. [NICE clinical guideline 142].

The Bill will introduce a new system which:

- Is for children and young people aged 0 to 25 – ensuring equity of rights and improved transition between settings.
- Has a single statutory plan – the individual development plan.
- Prioritises high aspirations and improving outcomes, focusing on the child or young person's achievement of their full potential.
- Provides a simpler and less adversarial process, ensuring learners' needs are at the centre and are continually met.
- Creates new statutory roles within health and education to ensure learners' needs are met.
- Focuses on earlier disagreement resolution, with disagreements resolved at the most local level possible.
- Introduces clear and consistent rights of appeal where disagreements can not be resolved at a local level.
- Is underpinned by a strengthened code, with mandatory requirements and statutory guidance to support the primary legislation.

3.7 The Bill is a small part of a much wider reform of the system of support for learners with ALN. This will improve the early identification of children and young people with additional learning needs and effective interventions for their needs, while ensuring their needs continue to be supported throughout their education.

3.8 We will also invest in the workforce to ensure they have the right skills to support children and young people with ALN, which includes autism and autistic spectrum disorder, and the confidence to use those skills. The work to develop this capacity and confidence is underway as part of the Welsh Government's wider programme to support professional learning.

3.9 We are focusing on skills development for education practitioners at three levels – core skills development for the general workforce; advanced skills development for the new Additional Learning Needs Co-ordinators – ALNCos who will work in schools and further education institutes – and specialist skills development.

3.10 In March 2016, we launched the Learning with Autism primary school programme, which takes a whole school approach to supporting pupils with autism providing professionals, parents, families, carers and people with autism with a wide range of resources including a website and specialised training opportunities. We will develop similar resources for early years and secondary schools.

Employment

3.11 . Rates of employment amongst young people and adults with ASD are much lower than the general population and there are many factors which can have an impact on an individual's ability to find and maintain work. The first Strategic Action Plan recognised that many able adults with autism need support to cope with anxiety and depression but they may not be eligible for social care services and many may not have received a formal ASD diagnosis.

What we have done

3.12. As part of our approach to raise awareness of autism in the workplace, between 2010 to 2015 the Welsh Government supported the role of Autism Employment Ambassador. Excellent links were developed with JobCentre Plus and Careers Wales, providing specialist advice enabling local staff to develop knowledge and skills to support people with autism into employment. The Employment Ambassador role was successful in raising awareness of autism in the workplace with employers and organisations providing employment support. Many organisations signed up to our ‘positive about working with autism charter’. Working with the National ASD Lead we will continue to develop advice to support people with autism in finding and maintaining work and to provide information and training for employers.

3.13 The Welsh Government also provides a range of employment support services in which young people and adults can participate. Young people with autism are eligible to participate in Work Based Learning (WBL) opportunities such as Traineeships and the Employability Skills programme (formerly Work Ready). Providers are 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 and other additional needs.

What we were told

3.14 The first Strategic Action Plan identified the important role that employment has in enabling people with autism to lead fulfilling lives. Through our evaluation and consultation with stakeholders we understand that the lack of employment support continues to be a very significant issue for adults with autism and there continues to be a lack of specialist support tailored to meet individual needs. The support should extend from job search to helping individuals maintain employment.

What we will do

3.15 Increasing employability has been identified as a key priority for Welsh Government. A new All Age Employability Programme is currently being developed and European funded programmes will have a key role to play, including those focussed on improving health and mental health.

3.16 We understand that young people and adults with autism will have specific support needs to help them find and maintain employment. We will work with our partners to ensure that new and existing employment support programmes are able to provide the specialist support services people with autism need.

3.17 Training packages for organisations providing mainstream employment support have been developed to raise awareness and provide advice about how professionals can adapt their practice. The ‘Working with Autism’ programme can be found on the **ASDinfowales** website 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. We will develop additional resources for this scheme which will focus on promoting the benefits of employing people with autism and training HR professionals in how to support people with autism.

3.18 We have listened to the feedback provided by stakeholders and have noted research into employment outcomes for people with autism, this has resulted in partnership working with the Big Lottery to increase employment support through targeted provision. The Welsh Government has been working with the Big Lottery on Tranche Two of the project Getting Ahead Two, which is aimed at young people, aged 16-25 with a learning disability/ difficulty or 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 young people with the intensive support required to maintain sustained and meaningful employment. A single contract of up to £10 million has been awarded for a five year project of activity which began in summer 2016.

Health and Social Care

3.19 Autism is a spectrum and individuals may also have an associated learning disability or other health conditions and for those people with complex needs, additional health and social care support should be available. However, some individuals with autism, particularly high functioning adults, may not meet eligibility thresholds for care and support services. At times these individuals will have additional support needs which if not addressed can cause problems to escalate to a crisis point, ultimately leading to the need for intensive interventions. It is well known that some adults with autism can experience anxiety and social isolation, have difficulties in education, problems in finding and sustaining employment and difficulties in establishing and maintaining social relationships and friendships.

3.20 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 placements are right for people and delivering appropriate care. Health Inspectorate Wales (HIW) register and inspect these hospitals in Wales.

3.21 Sometimes people with ASD have profound learning disabilities and behaviour that is challenging. They can also have mental ill health 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>

What we have done

3.22 There is now a specific chapter in the Mental Health Act 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 behaviour that challenges. There are also recommendations for the training for staff who work within the remit of the mental health act with people with ASD.

3.23 Some individuals with autism will be eligible for social care services and the provision of care and support in Wales has been transformed by the implementation of the Social Services and Well-being (Wales) Act. Individuals are now placed at the heart of the decisions about the care and support they receive and the well-being outcomes they want to achieve. The Act also entitles carers to an assessment of their needs so that they can receive the support they need to carry on with their caring role. It also requires local health boards and local authorities to undertake a population needs assessment and learning disability/autism are core themes in this assessment. As part of the Act we are also updating social services data, our new approach will include collecting information on the number of people with autism who have care and support plans.

3.24 Many individuals with autism will not be eligible for care and support services but will have support needs. 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 range of options for support were considered to address gaps in assessment and preventative services and from this the National Integrated Autism Service was developed.

We have developed a range of resources to support health and social care practitioners to support individuals with autism, which are available on the ASDinfowales website. <http://www.asdinfowales.co.uk/home/>

Other Interventions for Families and Carers

3.25 There is a wide range of additional support services designed to provide support for children and their families. These services are targeted at specific age groups and to cater for different needs. These include:

- 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://gov.wales/topics/people-and-communities/people/children-and-young-people/parenting-support-guidance/help/families-first/?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.childreninwales.org.uk/our-work/disability/early-support/>

- 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 <http://gov.wales/topics/health/socialcare/working/ifst/ifsspublications/briefing/?lang=en>

What we were told

3.26 Through the first Strategic Action Plan we sought to address the gaps in support for adults by establishing Community Monitoring Support projects. The continued need for targeted services was reinforced by the independent evaluation of the action plan. It highlighted gaps in services for adults and demand for additional support by individuals not eligible for health and social care services. During the consultation on the refreshed Strategic Action Plan, adults with autism and their family and carers also highlighted the absence of preventative support, problems with securing employment and the need for more services to meet these needs.

What we will do

3.27 The evidence presented by the scoping exercise undertaken in 2015 clearly demonstrated that an integrated approach works well and could meet the needs of people with autism in Wales. From 2016 the Welsh Government is rolling out a National Integrated Autism Service (NIAS) for Wales, **backed by £6 million**. The **ASDinfowales** website provides up to date information on how the NIAS is developing in each region across Wales. In summary the service will provide:

For all

- Support, advice and training for family and carers of children, young people and adults.
- Advice, support and interventions for people with autism to help them with their daily lives.
- Training and support for professionals to help them understand the needs of people with autism when they are delivering services, care and support.
- Integrated provision of services and support across health and local authorities.
- Teams of professionals providing support in the local community including psychology, occupational therapy, speech and language therapy, nursing and support workers from across health and social care.

For adults only

- diagnostic services and post diagnostic support (note diagnosis and assessment for children is provided through the Together for Children and Young People programme)

3.28 As part of the implementation of the NIAS 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.

3.29 This national approach will ensure consistency, enabling people with autism to access comparable services across Wales, whilst taking into account differing regional or local circumstances. This new service is being developed in partnership with Regional Partnership Boards, the Welsh Local Government Association and Public Health Wales, to promote joint working between health, local authorities and third sector organisations. The service will be rolled out to all regions by 2019. As we develop and roll out the service we will seek the views of people with autism, to make sure the services are meeting identified needs. This will also be included as part of our independent evaluation of the service.

3.30 The outcome we want to achieve is that children, young people and adults with autism and their family and carers can access advice and preventative services to address unmet need in education, employment and health and social care

We will take action to:

A Transforming additional learning needs

- Bring forward legislative reform for children and young people with additional learning needs in December 2016 and monitor progress.
- Continue to develop and roll out our 'Learning with Autism' programmes to improve support available to children and young people across primary, secondary and further education sectors.

B. Employment Support

- Improve employment opportunities for people with autism. This includes monitoring the delivery of the Getting Ahead Two programme to support long term youth employment for people with learning difficulties or disabilities including ASD.
- Welsh Government to take action to become an autism friendly employer.
- Work with organisations across Wales to raise awareness and for them to become autism-friendly working environments. This will include:
 - Promote the Working with Autism programme and encourage organisations to sign up to our positive about working with autism charter.
 - Developing a new HR training module

C. Health and Social Care

- Delivery of the National Integrated Autism Service. This will be implemented from April 2016 over a three year period and will include:
 - The implementation of a standard diagnostic assessment service for adults.
 - Provision of advice and support for all people with autism, including their families and carers.
 - Further development of training and support packages for professionals.

CHAPTER FOUR

Awareness Raising, Information and Training

4.1 It is vital that people with autism and families and carers have access to good quality information and expert guidance and advice. This can range from initial awareness information, to advice on referral and assessment and then post assessment support, including interventions. Feedback has highlighted the continued need to raise awareness of autism across a range of professional groups to ensure they can adapt their practice to meet the needs of people with autism.

4.2 The first Strategic Action Plan was very successful in raising awareness of autism both amongst families and across professional groups and services. This was achieved in part by establishing the autism infrastructure across local authorities, which included a local ASD Lead in each authority and local steering groups. An annual £40,000 grant was made available for each local authority to develop autism services. This grant has been transferred into the Local Authority Revenue Support Grant, and as the funding is now available every year, local authorities have greater flexibility in how they plan and provide local autism services and support.

What we have done

4.3 We have produced a wide range of autism information and resources through the work of the ASD National Lead, supported by the Welsh Local Government Association and more recently Public Health Wales. The information and resources are available on the ASDinfoWales website. The ASD National Lead and team:

- Provide expert advice and guidance, supporting the delivery of the refreshed action plan, including the national integrated autism service.
- Consult with stakeholders to co-ordinate the development of information and resources to meet identified needs.
- Provide training and information for key professional groups to identify the signs of autism. Professions supported include GPs and other health professionals, those working in education, retail and leisure and with employers HR departments.
- Host the ASD Forum which brings together local ASD leads to promote collaborative working and sharing good practice across Wales.
- Host the ASDinfoWales website to provide expert autism information and resources.



4.4 The **ASDinfowales** website provides excellent information on the resources we now have available for people with autism, their family and carers and professional groups. This was recognised at the latest Autism Europe International Congress and we have been approached by many countries for permission to use our materials. A full list of resources can be found at appendix seven, and includes.

- Guides and resources for family and carers of adults with autism.
- Training resources for professionals.
- Autism awareness training for the public.
- The Learning with Autism programme for schools and colleges.
- For ‘Autism Superhero Pledge’ for children.
- Employment resources for individuals with ASD.
- Independent living resources for individuals with autism, Adults Following Diagnosis.
- Two interactive personal profile builders.
- A diagnostic assessment toolkit for clinicians.
- Information for referrers, including detailed information on the signs of autism.
- A ‘Practitioner Toolkit’, providing information on evidence based approaches, including links and downloads.

Additional resources continue to be added to the website.

What we were told

4.5 The independent evaluation of the first Strategic Action Plan identified significant success in raising awareness of autism across professional groups and family and carers. Support for the ASD National Lead role and the development of the **ASDinfowales** website has been a positive step in providing a source of good quality expert advice, which is freely available to download for families and for professionals.

4.6 During the public consultation on the refreshed action plan earlier this year, conversations with parent groups found that many family and carers were concerned about the lack of information and guidance available, particularly post diagnosis. Many were not aware of the **ASDinfowales** website and the tailored guidance it provides. The feedback also raised the need to widen the scope of the work we are undertaking to increase awareness amongst professional groups, particularly in areas which are not devolved to the Welsh Assembly, such as considering how we work with partners in the criminal justice field. More needs to be done so that all professionals can recognise the key signs of autism and adapt services to meet individual needs.

What we will do

4.7 Through the ASD National Team and **ASDinfowales** website we are continuing to build a substantial library of information, guidance and training materials which are available for all to freely access. We 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. We are building on our Learning with Autism programme for primary schools, developing new resources for early years, secondary schools and further education. We are also focusing on training for primary care and mental health professionals, leisure service and employers. Training for Human Resources departments has also been recently developed and will be available on the website.

4.8 We recognise many useful resources have also been developed by a range of practitioners across Wales and wherever possible these will also be shared on the **ASDinfowales** website.

4.9 The outcome we want to achieve is that people with autism and their carers and professionals report that they have access to good quality information advice and training which meets their needs.

We will take action to:

- Ensure people with autism and their family and carers, as well as professionals, are made aware of the resources available on the **ASDinfowales** website. Develop a communications strategy setting out specific actions by end January 2017.
- Continue to develop information and resources to be freely available through the **ASDinfowales** website. Priority areas will be reviewed and updated on an annual basis.
- Develop and deliver training resources and material to raise awareness and provide support for professionals and others working with children or adults with autism. Priority areas will be reviewed and updated on an annual basis.
- We will work collaboratively with other organisations dealing with non devolved matters to raise awareness of autism. This will include the police, courts and the National Offender Management Service.
- Continue support for the ASD National Lead and team to provide expert advice and guidance on autism to the Welsh Government, professional groups and stakeholders.
- Continue to support the ASD Forum to enable the sharing of learning and good practice.

CHAPTER FIVE

Delivering the priorities for action and stakeholder involvement

5.1 We have achieved a great deal working with partners to deliver the first Strategic Action Plan and the ASD Interim Delivery Plan. The independent evaluation of the first Strategic Action Plan and consultation with stakeholders has enabled us to assess what has worked well and where improvements can be made. In the development of the refreshed Strategic Action Plan we have listened to stakeholders and considered all the evidence available to us. We have set out our future priorities and stated where we will take action to secure improvements to the support and services available for people with autism and for their family and carers.

5.2 People with autism and their families and carers want to see transparency in the delivery of the refreshed Strategic Action Plan. The evaluation reflected that it was hard to assess its impact because of a lack of clear outcome measures and the significant differences in how the ASD infrastructure operated across local authorities. We also know it can be difficult to find information on how many people with autism are receiving support or who are seeking access to services. For this reason we will put in place an independent evaluation for the refreshed Strategic Action Plan, focusing on the delivery of the National Integrated Autism Service. We are also updating our social services data collection to include people with autism who receive care and support services.

5.3 To ensure we can demonstrate how the refreshed strategy is making an impact, we are publishing a delivery plan with stated actions and outcomes to accompany the refreshed Strategic Action Plan. We are also establishing an ASD Implementation Advisory Group to monitor delivery and provide us with advice and guidance and we will continue to engage with our stakeholders.

Engagement with the third sector

5.4 The successful delivery of the first Strategic Action Plan relied on partnership working across the statutory and voluntary sectors. We want this collaborative approach to continue and to acknowledge the voluntary sector's vital role by ensuring they have opportunities to deliver the priorities for action in the refreshed Strategic Action Plan and have responsibility for achieving some of the outcomes. At a strategic level, voluntary sector organisations will be represented on the ASD Implementation Advisory Group. 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.

Engagement with people on the autistic spectrum and family and carers.

5.5 We value the engagement we have had with people on the autistic spectrum and their family and carers in the development of the refresh of the Strategic Action Plan and are committed to ensuring we continue this approach. The ASD Implementation Advisory Group will include people with autism and family and carer

representatives. We will engage widely with stakeholders through surveys, social media, engagements and events.

5.6 The outcomes we want to achieve is that children, young people and adults with autism and their family and carers are involved and consulted in the delivery of the Strategic Action Plan.

We will take action to:

- Establish an Implementation Advisory Group to monitor progress and delivery of the specific actions within the Strategic Action Plan and Delivery Plan. This group will be established before 1 April 2017.
- Publish an annual report setting out progress in relation to the specific actions within the Strategic Action Plan and Delivery Plan. This will include performance information and timeliness of assessment and diagnosis.
- Ensure Regional Partnership Boards report on progress in relation to meeting the care and support needs of people in their area. Autism has been identified as one of the key priority areas and the RPBs will need to report on progress, which will include progress on delivery of the National Integrated Autism Service.
- Collect information on the number of people with autism who have a care and support plan. This will be included as part of the new social services data collection from April 2017.
- Undertake independent evaluation of the refreshed Strategic Action Plan and the National Integrated Autism Service.
- Monitor the implementation of legislative requirements under the Social Services and Well-being (Wales) Act and keep the need for future autism related legislation under review.

Glossary of Terms

ALN	Additional Learning Needs
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
LD	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 Children and Young People
WLGA	Welsh Local Government Association

Appendix One



Resources available on the ASDinfowales website. www.asdinfowales.co.uk

Resources for:	Resources developed	Description
Parents / carers of children and adults	Autism: a guide for parents and carers	From explaining autism spectrum to parent stories these guides are a useful starting place for parents following diagnosis
	Autism: a guide for carers of adults with ASD	
	Parent carer films	5 films which explain how autism impacts on children and how parents can support
	Advice sheets	Advice and tips on common issues from challenging behaviours to developing sleep routines
	Personal profile builder	Create and print a personalised profile of the child/adult to help others understand how best to support them
	Service directory	Find support and services in your area
Resources to support individuals with autism	Autism: a guide for Adults	From explaining autism, to advice and tips; this guide is a useful source of information
	Planner app.	Use the app. on an android or iOS device to help plan and structure the day and set reminders for activities
	Orange wallet	Use the orange wallet to support access to public transport
Resources to support individuals with	Personal skills builder	Create and print a personalised list of

autism to apply for employment		employability skills using an autism friendly tool
	CV builder	Develop and store personal CV using an interactive autism friendly CV builder tool
	Working with autism app.	Compare personal skills and preferences with those in job advertisements and prepare for job interviews with our app.
	Searching for work tool	Uses structured online process to identify suitable employment options and apply for work
Resources for those Supporting adults With autism into Employment	Positive about working With autism	A range of resources to help employers understand the benefits of employing individuals with autism and how to meet needs
	E learning	Training film and PowerPoint outlining how to support someone with autism to apply for work
Resources for Primary schools	Certification scheme	Undertake a free 'Working with Autism' certification schemes and receive a personalised certificate for your CPD file
	Introduction and guide	A film overview of our 'Learning with Autism' scheme and a guide book for all school staff
	Learning and certification Scheme	Training films and certification schemes for teachers and learning support staff
	Self evaluation tool	Based on the Estyn inspection framework, this tool can help schools plan and gauge progress
	Autism superheroes	A digital book and charter scheme for key stage 2 pupils, leading to a personalised certificate

Resources for health and social care Professionals Supporting adults and children with Autism	Living with autism film	An overview of autism and tips on how to support adults on the spectrum
	Autism: a guide for Carers (adults and children)	From explaining autism, to advice and tips; these two guides are a useful source of information
	Practitioner toolkits	Advice and resources for those supporting adults on the spectrum, ranging from interventions to managing challenging behaviour
	Clinician's toolkit	Resources to support the diagnostic assessment process, including information for referrers
	E learning	A free online e learning module providing a personalised certificate

Issue	Developed Resources
Information on needs of individuals with ASD and families	Stakeholder consultation Summer 2015, Report and summary Report of survey of adults with ASD Autism: A Guide for Parents and Carers Autism: A Guide for Adults with ASD Autism: A Guide for Carers of Adults with ASD 6 advice films for parents and carers Living with Autism film
Diagnostic assessment – Children and adults	Online discussion and practice sharing forum Clinician toolkits Practitioner support and intervention toolkits Referrer information Evidence based signs and symptoms of ASD promotional posters Information leaflets for families Pathway flow charts Checklists and aide memoirs for clinicians Online child profile builder Online adult profile builder
Improved knowledge and understanding amongst primary school staff	Autism: A Guide for Primary Schools Training film – Head Teachers and SENCOs Training film - Teachers Training film – learning support staff Certificate scheme - teacher Certificate scheme – learning support Certificate scheme – whole school Estyn self-evaluation tool

Increased knowledge amongst peers and siblings	Autism Superheroes book Autism Superheroes digital book Autism Superheroes charter and certificated scheme
Support for professionals	Online service directory Online training directory Professional awareness raising materials
Improved practical resources	Picture card planner Child profile online builder Facebook / twitter updates Orange Wallet Scheme ASD planner phone app
Improved employment support	Working with autism training film for employment staff Working with autism certification scheme for employment staff CV Builder for individuals with ASD Employment process work book for individuals with ASD Skills builder for individuals with ASD Master skills dictionary Working with autism phone app.
Improved Knowledge amongst LD and MH professionals	Report of MH practitioner survey Mental Health Measure - Goal setting tool for individuals with ASD Coaching approach training E learning for MH and Social Care staff Training programme for CMHTs Adult interactive profile builder
Increase awareness amongst public and employers	ASD aware certification scheme Positive about working with Autism charter Advice sheets for managers and co-workers