This subject profile provides an overview of policies, strategies and legislation guiding care and support for people with Autism Spectrum Disorder.

The 2nd April is World Autism Awareness day.

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EXECUTIVE SUMMARY

- Autism Spectrum Disorder (ASD) is a lifelong developmental condition which affects social communication, social interaction and behaviour. Symptoms may include a range of difficulties with verbal and non-verbal communication and repetitive or very specific behaviour or interests. The term ‘spectrum disorder’ is used because the degree of impairment people with ASD experience varies greatly and affects people in different ways.

- It is estimated that there are over 50,000 people in Scotland with ASD.

- In June 2016, the Scottish Intercollegiate Guidelines Network (SIGN) published new clinical guidelines on assessment, diagnosis and interventions for ASD (SIGN 145). They reflect recent evidence on assessing, diagnosing and providing clinical interventions for people with ASD across all stages of life. The guidelines follow the most recently published diagnostic criteria (the Diagnostic Statistic Manual of Mental Disorders, DSM-5 2013) replacing a group of distinct disorders including ‘Asperger syndrome’ and ‘Atypical Autism’ with the collective term ‘Autism Spectrum Disorder’. The new guidelines reflect a range of difficulties which people may experience to different degrees.

- The key strategy shaping national and local initiatives to support people with ASD is the Scottish Strategy for Autism, a 10-year strategy published in November 2011. It is intended to support improved diagnosis and access to services for people with ASD, and their carers and families. It aims towards increasingly individualised support and services, which see different local and national agencies working together to develop best practice and support people with ASD in a way which involves them as fully as possible. In December 2015, the Scottish Government published Strategic Priorities for 2015 - 2017.

- As many people with ASD may have additional learning disabilities or health needs, a wide range of other policies can affect their care and support. The most recent overarching strategy shaping support for all people with disabilities is A Fairer Scotland for Disabled People: Scottish Government Delivery Plan for The United Nations Convention on the Rights of Persons with Disabilities (2016a).

- There is no single piece of legislation in Scotland which focuses exclusively on the rights and needs of people with ASD, their families and carers. In May 2010 the Autism (Scotland) Bill was introduced to Parliament. The Bill aimed to place a statutory duty on the Scottish Government to produce an autism strategy and provide guidance for local authorities and NHS bodies. The Scottish Government subsequently consulted on a draft autism strategy and took the view that new legislation was not required to underpin an autism strategy. The Bill fell during the Stage 1 debate in January 2011.

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1 The Scottish Intercollegiate Guidelines Network (SIGN) produces evidence-based clinical practice guidelines for the NHS in Scotland.

• Legislation safeguarding the rights of people with ASD and supporting relevant services may include mental health legislation and incapacity legislation, as well as legislation relating to wider public services. However as the symptoms, experiences and needs of people with ASD vary, such legislation does not pertain to all people with ASD in the same ways.

• In recent years, the place of ASD in Scotland’s mental health legislation has been questioned. The Mental Health (Care and Treatment) (Scotland) Act 2003 (the 2003 Act) and the Mental Health (Scotland) Act 2015 applies to all those with a ‘mental disorder”: a broad term defined in the 2003 Act as including any mental illness, personality disorder, or learning disability “however caused or manifested” (asp 13 s 328.1). Although ASD is a developmental condition rather than a mental illness or learning disability the term ‘mental disorder’ has in practice included people with ASD. In May 2016, the Mental Welfare Commission and the Scottish Council for Learning Disability opened a scoping consultation on the format of a forthcoming review of learning disability and autism in Scottish mental health legislation. Findings were published in January 2017 (Scottish Government, 2017). It is expected that the review will begin in April 2017.

• Some people with ASD may be subject to the Adults with Incapacity (Scotland) Act 2000 which relates to people aged 16 or over who lack the capacity to act or to make some (or all) of their own decisions due to a mental disorder or inability to communicate. It is expected that the Scottish Government will lead a review of the Act and develop changes by 2018 (Scottish Government, 2016a).

AUTISM SPECTRUM DISORDER

Autism, or Autism Spectrum Disorder (ASD), is a lifelong developmental condition which affects social communication, social interaction and behaviour. The term ‘spectrum disorder’ is used because the degree of impairment of people with ASD experience varies. Some people with ASD may be significantly disabled by the condition. Others may be less severely affected but may find many everyday tasks and situations challenging, and require a high level of support. Some people with ASD may not find that the condition particularly restricts them, and are able to live independently and participate in all pursuits they wish, perhaps benefitting from some support and adjustments.

Symptoms of ASD may include a range of difficulties with verbal and non-verbal communication, and interacting with others. Some people with ASD may have very limited verbal ability, while others may have difficulty interpreting tone, gesture or figurative language. People with ASD may demonstrate repetitive behaviour, ranging from repetitive movements and gestures to highly specific interests and strong preferences for routine. Some people with ASD may have sensory processing difficulties, for example they may be very over-sensitive or under-sensitive to noise, light or texture.

Many people with ASD have an “uneven profile of abilities”, with strengths in certain areas and difficulties in others. Autism Network Scotland (ANS) advise that the term ‘autism spectrum’ (also often called the ‘autistic spectrum’) does not only indicate a condition with “high functioning” and “low functioning” ends but the individual range of skills and difficulties a person with ASD may have. It can also reflect the impact of different environments and social situations, for example, some people with ASD may find noisy environments particularly difficult (Autism Network Scotland online).³

³ Autism Network Scotland is a hub of information about ASD services in Scotland, promoting awareness of ASD and developing networks among professionals.
NEW GUIDELINES FOR ASSESSING AND DIAGNOSING ASD

The Scottish Intercollegiate Guidelines Network (SIGN) published new clinical guidelines on assessment, diagnosis and interventions for ASD in June 2016 (SIGN 145). These updated previous SIGN guidelines (SIGN 98) published in 2007, which related to children and young people with ASD. The new SIGN guidelines reflect recent evidence on assessment, diagnosis and clinical interventions for children and young people with ASD, adults and older people. This follows “increasing understanding that autism spectrum disorder (ASD) is a lifelong condition in which the core features of ASD persist while manifesting differently according to different age stages” (SIGN 145, p.1). This briefing bases descriptions and definitions of ASD on the new SIGN guidelines, and aspects of the description and definition of ASD in this briefing may therefore differ from some descriptions in previous literature.

A key difference between SIGN 145 and earlier guidelines is that it follows the diagnostic criteria and terminology in the most recently published diagnostic classification system: the Diagnostic Statistic Manual of Mental Disorders (DSM-5) (2013). Previous classification systems presented a number of different disorders including ‘Asperger Syndrome’, ‘Childhood Autism’ and ‘Atypical Autism’. These are described as “pervasive developmental disorders” which indicates that they affect all aspects of people’s lives. DSM-5 replaces this group of distinct disorders with the collective term ‘Autism Spectrum Disorder’, and streamlines diagnostic criteria, reflecting a range of difficulties which people may experience to different degrees.

As a result of the new classification system, it is expected that ASD will become the most commonly given diagnostic term and people will no longer tend to be diagnosed with ‘Atypical Autism’ or ‘Asperger syndrome’. However, the National Autistic Society note that clinicians “may often use additional terms to help describe the particular autism profile presented by an individual”. The National Autistic Society also note that “for many people, the term Asperger syndrome is part of their day-to-day vocabulary and identity, so it is understandable that there are concerns about the removal from DSM-5 of Asperger syndrome as a distinct category. Everyone who currently has a diagnosis on the autism spectrum, including those with Asperger syndrome, will retain their diagnosis. No one will ‘lose’ their diagnosis because of the changes in DSM-5” (National Autistic Society online).

For more information about the new SIGN guidelines and diagnostic classification systems see Annex A: Assessing and Diagnosing ASD.

CHARACTERISTICS OF AUTISM SPECTRUM DISORDER

People with ASD have some degree of difficulty in two areas:

Social communication and social interaction

This includes difficulties with both verbal and non-verbal communication. These may range from having very limited verbal ability to subtler difficulties interpreting meaning, including, for example, a tendency to interpret statements literally, difficulty understanding more complex sentences, difficulty interpreting humour or ambiguity. People with ASD may also be less able to interpret tone, gesture and facial expressions.

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4 ICD-10, the other diagnostic classification system in general use, describes pervasive developmental disorders as “A group of disorders characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual’s functioning in all situations” (ICD-10 F84).

5 Much of the literature on ASD refers to a “trio of impairments” indicating difficulties in three main areas, however the most recent SIGN guidelines follow DSM-5 in streamlining these difficulties to a “dyad of impairments” because it is difficult to distinguish “social interaction” from “social communication”.

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People with ASD may find it difficult to follow the unwritten ‘rules’ of different social situations, or to interact with others in a conventional way. Some people with ASD may behave socially ‘inappropriately’, showing less awareness of other people’s needs or preferences. People with ASD may be less able to understand other peoples’ needs, wishes or emotional responses, and less able to anticipate what others might think or feel.

**Restricted, repetitive patterns of behaviour, interests or activities**

Restricted, repetitive behaviour could range from “stereotyped” behaviour: repetitive actions such as rocking, pacing, flapping one’s hands, to specialised personal interests. The degree to which repetitive behaviour affects people with ASD varies. People may find repetitive actions calming or enjoyable. People with ASD may have very strong preferences for routine, and small changes to routines can be distressing. Some people with ASD may develop very specific interests.

Other difficulties that people with ASD may experience include sensory processing difficulties: they may be very over-sensitive, or under-sensitive to aspects of the environment such as texture, smell or noise. People with ASD may have intense reactions to particular sensations or objects, and find them distressing or fascinating.

More information about the kinds of difficulty people with ASD may experience in these areas is available at from the [National Autistic Society](#).
TERMS USED

Autism Spectrum Condition

In line with most medical literature this briefing uses the term Autism Spectrum Disorder, however some people prefer the term Autism Spectrum Condition (ASC) and feel this term avoids the stigma associated the word disorder. It also reflects the view that people on the Autism Spectrum may interpret and interact the world around them in a different but equally valuable way. The University of Cambridge Autism Research Centre suggests the term ‘condition’ recognises “both the disabling aspects of autism” as well as “aspects of autism that are simply different” (defined by the term ‘neurodiversity’). Some of these differences involve areas of strength” such as “attention to detail, memory for detail, and pattern recognition or systematizing” (Autism Research Centre online).

Asperger syndrome

Asperger syndrome is now thought of as a particular “profile” of ASD rather than a distinct condition. People with Asperger syndrome typically have some degree of difficulty with social communication and interaction and restricted or repetitive behaviour but do not experience the same delays developing language skills or cognitive skills as other people with ASD and do not usually have learning disabilities.

Pathological Demand Avoidance (PDA)

PDA is a recently recognised autism profile. People with PDA feel a high level of anxiety when expected to meet social demands, and may display highly avoidant or disruptive behaviour when required to do so. People with PDA typically have better social understanding and communication skills than other people on the Autism Spectrum, though they may experience difficulty regulating their emotions and managing their behaviour. More information on PDA is available from the National Autistic Society.

Social Pragmatic Communication Disorder (SCD)

SCD is a newly recognised condition, included in DSM-5 (2013). People diagnosed with SCD may experience a range of difficulties with verbal and non-verbal communication which are similar to those experienced by people with ASD. However, people with SCD do not have symptoms of restricted or repetitive behaviours. More information on the diagnostic criteria is available at Autism Speaks.

AUTISM SPECTRUM DISORDER, OTHER DISABILITIES AND HEALTH CONDITIONS

Many people with ASD also have other disabilities and/or health conditions which require care and support. NICE estimate that 50% of people with ASD have a learning disability and 70% exhibit symptoms of one or more physical or mental health problem (NICE 2014). It is thought that around 40% of people with ASD exhibit symptoms of an anxiety disorder (National Autistic Society online).

Many people with ASD also have neurological disorders, such as epilepsy. It is generally thought that up to a third of people with ASD also have epilepsy, compared to around 1% of the general population (Autism Speaks online). More recently, studies have indicated that ASD is also more prevalent among people with epilepsy (Scott and Tuchman 2016).

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6 The National Institute for Health and Care Excellence (NICE) is the national body which publishes clinical guidelines for NHS healthcare practitioners in England and Wales.
In 2015, a study in Sweden found that there was a 16 year gap in life expectancy between people with ASD and the general Swedish population. Leading causes of death included epilepsy and suicide. Adults who had ASD and no additional learning disability were found to be over 9 times more likely than the general population to die as a result of suicide (Hirvikoski et al 2015). The UK Charity Autistica aims to invest £10 million in funding over the next five years towards research on mortality risks for people with autism (Autistica online).

**PREVALENCE AND DIAGNOSIS**

The prevalence of ASD in the UK has been estimated at 1 in 100, based on a 2006 study of childhood autism in South Thames (Knapp et al 2007; Baird et al, 2006). In 2012, an NHS survey concluded that prevalence was slightly higher than this at 1.1% (Brugha et al 2012).

Estimating prevalence from rates in published research cannot offer accurate estimates of the number of people actually affected by a given condition, and there is no authoritative national data on the total number of people with ASD in Scotland. As a guide, an estimated prevalence of 1.1% represents around 58,000 people in Scotland.

**DIAGNOSIS**

Diagnosis of ASD is based on the clinical assessment of a person’s behaviour and their developmental history. Various diagnostic criteria and screening instruments may be used in the course of a clinical assessment. In Scotland, SIGN 145 outlines best practice in the assessment and diagnosis of ASD. Diagnostic assessment conducted by a specialist multidisciplinary team is regarded as optimal. For further information, see SIGN 145 4: Recognition, Assessment, Diagnosis.

It is thought that autism has historically been underdiagnosed and/or misdiagnosed. Over the past 30 years diagnosis of autism has increased by around 25%. However, the number of people diagnosed with autism is still lower than estimates of prevalence would suggest (Parkin 2016).

In 2004, the then Scottish Executive undertook an audit of services for people with ASD. It found that 35 children per 10,000 population were diagnosed with ASD, with wide variation in the rate of diagnosis across different age groups and different health boards. It found only 2.2 adults per 10,000 population were diagnosed with ASD (2004a). The Scottish Commission for Learning Difficulties publishes information on adults with learning difficulties known to local authorities. In 2015, it reported that 4,617 adults were identified as being on the autism spectrum.
It is generally thought that better knowledge and awareness of ASD, and better diagnostic processes are the principle factors behind higher rates of diagnosis among younger people and younger children. The Scottish Government’s 2004 audit also found wide variation between the rate of adults diagnosed with ASD in different health boards (p.10).

**Additional Support Needs**

One measure of increased levels of diagnosis of ASD is the growing number of school pupils in Scotland considered to have additional support needs related to ASD.

The **Education (Additional Support for Learning) (Scotland) Act 2004** established the duties of local authorities to make suitable provisions for children with additional support needs (ASN): a broad category defined as circumstances “where, for whatever reason, the child or young person is, or is likely to be, unable without the provision of additional support to benefit from school education” (asp 4 s1).

Since 2012, the number of pupils with ASN related to ASD has increased by almost a third: from 8,650 to 11,722. The rate per 1,000 pupils has increased from 12.9 to 17.2. However, this should be seen in the context of an overall increase in the total number and the rate of pupils with ASN. The overall rate of pupils with ASN has increased by around 28% within the same period. The following figure illustrates the increase in the total number of pupils with ASN related to ASD between 2012 and 2015 by gender.

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7 The number of diagnoses may have increased since 2004.
Figure 2: The number of pupils with Additional Support Needs related to ASD.

Source: Scottish Government, Pupil Census Supplementary Data Tables 2012–2015. Table 1.8

**Gender**

More males are diagnosed with ASD than females. The proportion of men and women diagnosed with ASD varies between studies, but is generally between 4 to 1 and 5 to 1 (Fombonne *et al* 2011). While it has generally been thought that ASD is more common among men and boys due to genetics, recent research proposes that other factors may also influence different rates of diagnosis and that ASD has been underdiagnosed in women and girls to some degree.

Research by Gould and Smith (2011) argues that women on the autism spectrum display different characteristic behaviours to men. They suggest that girls with ASD may imitate the behaviour of peers closely, which makes diagnosis less likely because people tend to associate ASD with specific interests in “technical hobbies and facts” which fit a “narrow male stereotype” (p. 37). They suggest girls with ASD may develop specific interests which are similar to those of other girls at the same developmental stage, but are distinguished by the “quality and intensity of these interests and the length of time spent on these” (p.36). They argue that changing diagnostic procedures could help identify women and girls with ASD.

Research into the relationship between ASD, gender, genetics and environmental factors is ongoing. Current, evidence suggests that differences in rates of diagnosis between men and women are principally due to genetic factors, but that many women who have ASD are not correctly diagnosed. The most recent SIGN Guidelines (SIGN 145) provide more information about gender differences and misdiagnosis (4.1.8).

**CAUSES OF AUTISM**

Research indicates that the causes of ASD are principally genetic, but the interaction between our genes and environment is complex and the likelihood of developing ASD may be influenced by a range of environmental factors.
Some research suggests that environmental factors could include, for example, being born prematurely, prenatal exposure to alcohol or to some medications (NHS online). Many other risk factors have been explored and evidence on most is inconclusive.

SCOTTISH GOVERNMENT POLICIES

The key policy steering national and local initiatives to support people with ASD is the Scottish Strategy for Autism, published in November 2011. The following section provides brief background to the strategy, outlines its key aims and priorities, and discusses its implementation to date. Further details can be found on the Scottish Strategy for Autism website. Annex 1 of the full strategy provides a detailed overview of the policy landscape.

BACKGROUND

- In 2000, the then Scottish Executive published a review of services for people with learning disabilities, *The Same as You?* It took a person-centred approach to care and support, stressing the need to ensure people with learning disabilities are involved in decisions about their care, services and day-to-day life. It included improving the diagnosis of ASD and establishing national networks to support people with ASD as priorities (p.28).

- In 2001, the Public Health Institute of Scotland published a needs assessment report which surveyed services for people with ASD and recommended improvements. It recommended there should be a national audit of services for people with ASD.

- Following from this report, in 2002 an ASD Reference Group was established. It was tasked with identifying priorities for action and monitoring progress in service provision.

- In 2004, the then Scottish Executive led an Audit of Services for people with ASD in Scotland.

- From 2005, the Scottish Government funded a range of pilot projects, including “One Stop Shops”. One stop shops provide people with ASD, their carers and families, and others involved in supporting people with ASD, with advice and training before and after diagnosis.

- In 2009, the Scottish Government launched the Autism Toolbox, a resource for schools which provides guidance on supporting pupils with ASD and working effectively with other agencies.

- In 2010, the Scottish Government led a consultation on a draft Autism Strategy, and the Scottish Strategy was published in November 2011.

THE SCOTTISH STRATEGY FOR AUTISM

The Scottish Strategy for Autism (2011) is a 10 year strategy which seeks to improve care and support for people with ASD. It outlines seven “underpinning values”; a series of time-defined goals; 10 indicators for current best practice in providing ASD services; and 26 specific recommendations. Annex B details these goals, indicators and recommendations in full.

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8 The Public Health Institute of Scotland (PHIS) was the national body responsible for promoting and improving public health. It was succeeded by NHS Health Scotland in 2003.
Values

The seven values underpinning the strategy are:

- **Dignity**: people should be given the care and support they need in a way which promotes their independence and emotional well-being and respects their dignity;
- **Privacy**: people should be supported to have choice and control over their lives so that they are able to have the same chosen level of privacy as other citizens;
- **Choice**: care and support should be personalised and based on the identified needs and wishes of the individual;
- **Safety**: people should be supported to feel safe and secure without being over-protected;
- **Realising potential**: people should have the opportunity to achieve all they can;
- **Equality and diversity**: people should have equal access to information assessment and services; health and social care agencies should work to redress inequalities and challenge discrimination.

Goals

The strategy sets a series of short-term (2 year); medium-term (5 year); and long-term (10 year) goals.

**Short-term goals (foundations)** focus on: improving access to existing services; implementing existing guidelines; acting on “unaddressed diagnoses and delayed intervention”; and improving access to “post-diagnostic support for families and individuals”.

**Medium-term goals (whole life journey)** focus on: ensuring that services for people with Autism reflect the needs of people with ASD at different stages in their lives, and building awareness of Autism across mainstream services.

**Long-term goals (holistic personalised approaches)** are concerned with: planning and delivering personalised services and indicate: “meaningful partnership between central and local government and the independent sector”; “creative and collaborative use of service budgets to meet individual need”; and access to assessment and appropriate support at all stages of an individual’s life (Scottish Government 2011, p.10-11).

Indicators

To help service providers identify future actions, the strategy outlines 10 indicators for best practice in the provision of effective ASD Services. The indicators stress co-operation with people with ASD, their families, carers and relevant professionals when planning services, seeking feedback and encouraging engagement. They emphasise multi-agency approaches to assessing and supporting people with ASD. They specify the need to plan training for relevant professionals. They also stress the need to ensure useful data collection to inform service provision, and ensure access to “useful and practical information about ASD” (Scottish Government, 2011, p.12).
Aims and Recommendations

The strategy’s 26 aims and recommendations are grouped around 6 themes:

- **Theme 1: Strategic Leadership from the Scottish Government**: Recommends that the ASD Reference Group be reconvened, and works collaboratively with COSLA, the NHS, and other public bodies to support Local Authority implementation of the strategy. COSLA should oversee this process. The Reference Group and partners will investigate the benefits of “ASD Lead Officers”.

- **Theme 2: Achieving best value services**: Recommendations in this area relate to research and evaluation. They include: evaluating the economic costs of autism; identifying gaps in research relating to ASD services; assessing current outcomes for people with ASD and their quality of life and; developing a “menu of interventions” which identifies the support available to individuals with ASD, their families and carers.

- **Theme 3: Involving people with autism, their families and carers with decision making**: Recommends that the ASD reference group explores options to improve user and carer involvement in service planning, and that the Self-Directed Support Strategy Implementation Group ensures representation from the autism community.

- **Theme 4: Improved cross-agency working**: Recommendations include: developing good practice guidelines to support people with ASD as they transition between services at different points in their lives; the ASD reference group should contribute to a review of existing SIGN guidelines in consideration of adult services; an audit of existing services should identify gaps in provision; assessing the impact of the Scottish Autism Services Network.\(^9\)

- **Theme 5: Improving diagnosis**: These recommendations focus on steps that might be taken to improve guidelines and training on diagnosis of ASD, including that “a request is made to NHS QIS […] to develop guidelines for evidence-based approaches to the diagnosis and management of ASD in adults”;\(^10\) and that “approaches are made to the Royal College of Physicians and Surgeons” on the subject of developing e-learning resources for medical practitioners. Other recommendations relate to assessing waiting lists for diagnosis and improving existing data.

- **Theme 6: Improving Access to the Workplace**: Recommends evaluating the impact of the “supported employment framework for Scotland” (Scottish Government 2011).

The strategy then reflects on the needs of people with ASD at different stages of their life. It stresses that effective services should support people with ASD to make transitions throughout their lives. It highlights issues including:

- The importance of early intervention and the need to ensure children who are identified as requiring additional support are provided with that support when they enter nursery, primary school and secondary education.

- Education authorities have statutory duties to ensure pupils with additional support needs who are due to leave secondary school are supported in making this transition.

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\(^9\) The Scottish Autism Services Network has been succeeded by Autism Network Scotland, which acts as an information hub and supports some projects more directly.

\(^10\) NHS Quality Improvement Scotland (QIS) (now Healthcare Improvement Scotland) is an NHS Board with responsibility for improving the quality of care in Scotland and providing guidance on effective clinical practice.
• Access to appropriate assessment of needs is required throughout the lifetime of a person with ASD.

IMPLEMENTATION OF THE STRATEGY

Related Funding

In November 2011, the Minister for Public Heath announced funding of £13.4 million to be invested over four years to improve autism services and access to services for people with ASD and their carers (Scottish Government 2014). Details of spending include:

• £1.12 million allocated to supporting the development of Local Authority Action Plans, with £35,000 awarded to each of Scotland’s 32 local authorities.

• £6 million committed to an Autism Development Fund. By the end of 2015, a total of £2,727,383 had been disbursed to projects supporting people with ASD and their carers. Full details of projects funded can be viewed on the Scottish Strategy for Autism website.

Autism Mapping Project

The Autism Mapping project aimed to identify and locate existing ASD services and provide local authorities a ‘Service Map’ of their area. The final report was published in April 2013. 16 local authority service maps are available to view online at Autism Strategy Scotland.

Menu of Interventions

In November 2013, the Scottish Government published a Menu of Interventions which outlines advice and support available to people with ASD. Its guidance notes that, according to NICE (2012), the evidence base for many ASD interventions is not well developed. The list of interventions is therefore based on the experience of clinicians, researchers, other relevant professionals and carers. They include clinical, educational and social interventions.

ASD Reference Group

ASD Reference Group overlooks the input of robust arrangements in order to ensure the delivery of the Scottish Strategy for Autism recommendations. It was reconvened to help lead implementation of the strategy. In May 2014, the Reference Group was succeeded by a Governance Group, overseeing strategy and direction of ASD service delivery and access. Further work groups were established to draw on professional expertise and allow greater co-production with service users. Details of these changes and minutes of the Governance group are available at the Autism Strategy for Scotland website.

Waiting Times for Diagnosis

In August 2014, Autism Achieve Alliance published Autism Spectrum Disorders: Waiting for Assessment: a report on Autism Diagnosis waiting times commissioned by the Scottish Government. It found that waiting times among children and young people was highly variable. The average total waiting time between being referred for diagnosis and receiving a diagnosis was almost a year (331 days). Recommendations issued in England, in the National Autism Plan for Children (2003), advised a maximum waiting time of 119 days. The average waiting time for adults in Scotland was 162 days, and there was also a wide range of waiting times (Autism Achieve Alliance 2014).

11 The Autism Development Fund originally provided £1m per year but was increased to £1.5m in June 2012 (Autism Strategy Scotland online)
Autism Achieve Alliance trialled a “wait reduction intervention” which involved leading workshops with participating services and developing local action plans for reducing waits. Their results concluded that waiting times across the services they collaborated with reduced by an average of 29.9 days.

Training

In May 2015, NHS Education for Scotland published a Training Plan for ASD which scoped the training needs of all NHS practitioners, and matched these to existing resources and highlighted gaps. It indicated further training was needed in many areas, including:

- Continuing to raise staff awareness of ASD
- Training that informs people about local pathways and procedures
- Training focused on staff with a particular role in screening people for ASD
- Developing understanding of how people with ASD may be more likely to have negative life experiences, which can contribute to developing conditions such as anxiety, depression and post-traumatic stress disorder
- More training in specialist assessment of people who have complex presentations of ASD, multiple health problems or conditions which are difficult to distinguish from ASD
- Improving outcomes for people with ASD including post-diagnostic support for individuals, families and carers

RECENT POLICY DEVELOPMENTS

Strategic Priorities for 2015 - 2017

In December 2015, the Scottish Government published Strategic Priorities for 2015 - 2017. These are provided in full in Annex C. Four strategic priorities and range of actions were outlined including: improving access to services and advice; ensuring ‘Good Autism Practice’ across public services; developing public and professional awareness of ASD; and improving access to “appropriate transition planning” at all stages of people’s lives. Transition planning can help people with ASD when, for example, they move on from secondary education. Future actions in this area include working with partners to improve employment opportunities for people with ASD. For further information about transition planning see Principles of Good Transitions 2 (2014), produced by the Scottish Transitions Forum.

Other actions include:

- Promoting “personal outcomes approaches” for people with ASD by “working to influence the choice of self-directed support providers and support available for people with autism” (p.4).
- Encouraging innovative Autism services and exploring ways of evaluating and sharing successful services.
- Exploring “alternative solutions to out of area bed placements for people with complex care needs” (p.8).

Blue Badge Scheme

In April 2016, a pilot extension of the “blue badge” Disabled Persons Parking Badge scheme was launched in Scotland, making this facility available to some people with ASD. The extension is afforded to “people, who as a result of a diagnosed mental disorder or cognitive

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13 The Scottish Transitions Forum is an organisation for people with additional support needs, their carers, and professionals working with people with additional support needs, focused on developing best practice.
impairment, have no awareness of danger from traffic and are likely to compromise their safety or the safety of others” (Transport Scotland online). This must be confirmed by evidence from a healthcare professional or social worker. Applicants must also receive certain disability related benefits or provide evidence that they meet certain criteria in their application for Personal Independence Payments. Further information is available from the National Autistic Society.

Review of Autism Network Scotland

An independent review of Autism Network Scotland was led in 2016, in the context of an anticipated retendering exercise. The final report (September 2016) found that Autism Network Scotland “has achieved a range of positive impacts” and that its main strengths lay in its Scotland-wide “overview of Autism practice and strategy development” (para 20) and “independence”, particularly independence from service provision. The model’s main weaknesses were identified as a “lack of clarity about the remit of ANS and its relationship to the Scottish Strategy for Autism, the Governance Group and the Scottish Government” and “the insufficient delineation of leadership roles” (para 22).

WIDER POLICY CONTEXT

As many people with ASD may have additional learning disabilities or health needs, many other policies can affect their care and support. The most recent overarching policy shaping support for people with disabilities is A Fairer Scotland for Disabled People: Scottish Government Delivery Plan for The United Nations Convention on the Rights of Persons with Disabilities (2016a).

Some people with ASD may use augmentative and alternative communication (AAC) to help them interact with others. AAC could include electronic devices or picture and symbol boards. The main policy supporting AAC users in Scotland is A Right to Speak: Supporting Individuals who use Augmentative and Alternative Communication (2012).

Many people with ASD may also have a learning disability. Scotland’s learning disability strategy, The Keys to Life, published in June 2013, promotes more choice and control for people with learning disabilities over the support they receive. It aims to help people with learning disabilities live as independently as they would like. It also aims to reduce health inequalities between people with learning disabilities and the general population.

Many people with ASD may also have one or more mental health conditions. The most recent mental health strategy, the Mental Health Strategy for Scotland 2012-2015 noted the need to cross “traditional boundaries between health and social care services” in order to support people with ASD and other mental health conditions, particularly for the “small number of people with ASD within Scotland who have particularly high levels of need” (p.49). A new 10-year mental health strategy is due to be published in early 2017. A proposed framework for the new strategy, Mental Health in Scotland – a 10 year vision, published in July 2016 indicated that by April 2017, the Scottish Government would begin a review of autism in the definition of “mental disorder” in current mental health legislation (2016b p.8). An analysis of responses to the proposed framework found support for this review. Respondents also raised other issues the draft strategy might address including: healthcare inequalities experienced by people with ASD; the particular mental health needs of children and young people with ASD (Scottish Government 2016c).

14 The review will also relate to learning disability and dementia.
INVESTIGATIONS AND RECOMMENDATIONS OF THE MENTAL WELFARE COMMISSION

The Mental Welfare Commission for Scotland (MWC) is the statutory body which monitors and safeguards the rights of people with mental health problems, learning disabilities, dementia and related conditions.

In 2016, the MWC published a report on their investigation into the death of Ms MN, a 44 year old woman diagnosed with Asperger Syndrome, who died as a result of suicide. It found that Ms MN did not have access to specialist ASD services, and states that many people who require a high degree of care due to ASD are not appropriately supported.

The MWC’s report states that many people diagnosed with ASD who are not also diagnosed with a learning disability or a mental health problem “fall into a wholly unacceptable gap between two services inappropriate for their needs” (p.39). Ms MN had never had a specialist assessment relating to Asperger Syndrome and “struggled to access any specialist autism services, leaving mental health or learning disability services to manage as best they could” (p.40).

The report recognises that “by developing specialist services for one condition other conditions may end up neglected” and that expecting “general adult psychiatry and learning disability services to obtain lengthy specialist assessments for people with autistic spectrum disorders” would be “associated with other opportunity costs” (p.40). It notes that balance is therefore required between “adequately resourcing specialist services” and increasing the skills and experience of practitioners in general services (p.40). It acknowledges that the Scottish Autism Strategy aspires to develop the skills and experience of health professionals in diagnosing and managing people with autistic spectrum disorders, but criticises its “piecemeal” implementation and concludes that:

As the strategy makes clear, it will take years before we can be satisfied that all people with autistic spectrum disorders are receiving appropriate support across the lifespan, using holistic and personalised approaches […] In the meantime, though, we cannot accept that people with autistic spectrum disorder and complex needs should expect to be fitted into services designed for very different client groups, with a tacit acknowledgment that, while people are doing what they can, it is unlikely to succeed (p.41).

The report makes a range of related recommendations, including that the Scottish Government should audit the availability of specialist services for people with “highly complex needs who are not appropriately accommodated” (p.44).
LEGISLATIVE FRAMEWORK

In Scotland there is no existing legislation focusing exclusively on the rights and needs of people with ASD, their families and carers. Legislation which determines the rights of people with ASD and underpins the provision of relevant services includes legislation focused on the needs of people with a ‘mental disorder’, legislation focused on equalities, and legislation relating to wider services such as health, social care and education.

EUROPEAN CONVENTION ON HUMAN RIGHTS

Devolved legislation and policy is required to reflect the European Convention on Human Rights (ECHR). In recent years the degree to which legislation in Scotland intended to protect people with a ‘mental disorder’ complies with Article 5 (The Right to liberty and security) and Article 8 (Right to respect for private and family life) of the ECHR has been questioned. The Scottish Government has announced intentions to review aspects of mental health legislation and incapacity legislation.

UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Scotland is required to respect ‘international obligations’ including the United Nations Convention on the Rights of Persons with Disabilities, which the UK ratified in 2009. This international agreement aims to promote and protect disabled people’s rights, and help ensure that people with disabilities can participate fully in society on an equal basis with others. The convention is not enforceable in UK courts, rather, implementation is monitored by the Committee on the Rights of Person with Disabilities. The Committee recently led an inquiry into the impact that welfare reforms had upon disabled people’s rights. Its report was published in November 2016.

EQUALITY ACT 2010

The UK-wide Equality Act 2010 extended protection against discrimination related to nine ‘protected characteristics’, including disability. The Equality Act 2010 (Specific Duties) (Scotland) Regulations 2012 placed specific equality duties on public authorities in Scotland. The Equality Act defines disability as “a physical or mental impairment” which has a “substantial and long-term adverse effect” on that person’s “ability to carry out normal day-to-day activities” (6.1). ASD is a developmental disorder and meets the criteria of “a physical or mental impairment”. However, whether or not a person is protected by the Equality Act does not generally depend on the nature or cause of such an impairment but the extent of its effects.

ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000

The Adults with Incapacity (Scotland) Act 2000 (AWI Act) relates to people aged 16 or over who lack the capacity to act or to make some (or all) of their own decisions due to a mental disorder or inability to communicate, which may include some people with ASD. It allows people to apply for certain powers to make some decisions on behalf of adults with incapacity, in relation to their welfare and finances, subject to safeguards. They may also be authorised to act as the adult’s legal representative on related matters. The AWI Act also places a duty on local authorities to supervise people who have been granted guardianship of an adult’s welfare, and to provide them with advice. More information on the scope of the Act is available from the Mental Welfare Commission. It is expected that the Scottish Government will lead a review of the Act and develop changes by 2018 (Scottish Government, 2016a).
In October 2014, the Scottish Law Commission (SLC) published a report on Adults with Incapacity legislation which focused on safeguards around the “deprivation of liberty” of adults who may be subject to the AWI Act. The report relates to adults who are considered unable to give consent to care or treatment which places restrictions on their freedom of movement. It outlines proposed reforms and includes a draft Bill.

The report concluded that aspects of the way in which some adults have their liberty restricted in practice, while in hospital or in residential care (among other settings) do not comply with Article 5 of the European Convention on Human Rights, which provides that:

1. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:

   (e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts, or vagrants;

4. Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.

The report recommended a range of amendments to the AWI Act, including:

- That there should be a legal process authorising measures to prevent an adult with a cognitive impairment from leaving a hospital, if they have been hospitalised in order to be treated for a physical health condition or assessed for treatment. The process should include rights to challenge the decision to take such measures.

- That there should be a process to authorise a “significant restriction of liberty” if this is thought necessary for adults with incapacity who are cared for in a community setting. The draft Bill defines a “significant restriction of liberty” as occurring when a person in these circumstances is regularly subject to more than one of the following measures:
  - They are either not allowed to leave the premises unaccompanied or are unable to leave the premises without assistance due to a physical impairment.
  - Barriers are used to limit them to particular areas of the premises
  - Their actions are controlled, whether inside or outside the premises, by physical force, the use of restraints or medication administered for this purpose.

- That a “relevant person” (typically the manager of the care facility or a social worker with some responsibility for the adult’s care) may, if they think it necessary, prepare a “Statement of Significant Restriction” outlining the measures necessary and then obtain a report from a Mental Health Officer and an appropriately qualified medical practitioner confirming that the proposed restrictions are appropriate (Appendix A, Draft Bill, 52C, 52D). Authorisation to implement the restrictions must then be sought from the person’s welfare guardian, attorney with welfare powers, or guardian appointed by the local authority.

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15 A Mental Health Officer is a social worker with specialist training in mental health; in the draft Bill, the relevant medical practitioner may be practitioner primarily responsible for the person’s medical treatment or a practitioner with particularly relevant expertise who is also personally familiar with the person’s circumstances.
• It recommends that people who are unlawfully detained in a community setting, or people claiming an interest in the detained person’s welfare, may apply for an order to end their placement.

Further discussion of the issues raised in the SLC’s report is contained in the Mental Welfare Commission’s advice notes on the deprivation of liberty in the context of medical and social care and treatment (Stavert 2015). These offer a discussion of the definition of “deprivation of liberty”, interpretations of Article 5 of the ECHR, summaries of relevant case law, and discussion of the types of controls on people’s movement and behaviour which may amount to a deprivation of liberty or significant restriction of liberty.

Consultation on the Scottish Law Commission Report on Adults with Incapacity

In December 2015 the Scottish Government opened a consultation on the Scottish Law Commission Report, summarising the SLC’s report seeking views on the draft Bill and “wider aspects” of the AWI Act that “may benefit from review” (para 3). An analysis of responses was published in July 2016.

MENTAL HEALTH LEGISLATION

The key pieces of mental health legislation in Scotland are Mental Health (Care and Treatment) (Scotland) Act 2003 (‘the 2003 Act’) and the Mental Health (Scotland) Act 2015. The 2003 Act led from the recommendations of the Millan Committee, which reviewed previous mental health legislation, specifically the Mental Health (Scotland) Act 1984. The 2003 Act applies to all those with a mental disorder, and takes a rights-based approach to people’s care and treatment, emphasising that interventions should be the least restrictive possible and people should be enabled to participate as fully as possible in their care. More information is available from the Mental Welfare Commission.

The McManus Review (2009) reported on the implementation and operation of the 2003 Act. It presented recommendations which formed the basis of the Mental Health (Scotland) Act 2015 (‘the 2015 Act’). The 2015 Act sought to improve access to mental health care and treatment, making the mental health system more efficient.

The Inclusion of Autism Spectrum Disorder in Mental Health Legislation

Mental disorder is broad term. As defined in the 2003 Act it includes any mental illness, personality disorder, or learning disability “however caused or manifested” (asp 13 s 328.1). Although ASD is a developmental condition rather than a mental illness or learning disability the term ‘mental disorder’ has in practice included people with ASD.

The Millan Report (2001) took the view that new mental health legislation should use a “broad and inclusive term” to establish who the Act applies to (para 11). It acknowledged that including conditions such as autism under the act was “problematic” since they are “lifelong conditions which manifest themselves in childhood, and are not normally considered as mental illnesses” (para 10). It concluded the new Act should apply to people with learning disabilities and that “learning disability should include autistic spectrum disorders” (recommendation 4.9). Reasons presented for including learning disability within the Act were concerned with safeguarding people’s care and support. It called for further consideration of legislation specifically concerned with learning disability, and for a review to take place at “an early date” (para 62). It also recommended that mental health legislation should be “consistent with” the AWI Act and that “In due course, mental health and incapacity legislation should be consolidated into a single Act” (recommendation 2.1).
In January 2015, the Health and Sport Committee’s [Stage 1 Report](#) on the Mental Health (Scotland) Bill noted that a number of witnesses and written submissions to the Committee questioned the ongoing inclusion of learning disabilities and ASD in mental health legislation. Some called for a wider review of mental health and learning disability legislation. The Committee recognised this was not the ambition of that Bill, and did not call for such a review at that time, but invited the Scottish Government to “set out its views” on whether this was needed (SPP 663 para 222).

During the [Stage 3](#) debate on the Bill, the Minister for Sport, Health Improvement and Mental Health made a commitment to reviewing the place of learning disability and ASD within the 2003 Act.

**Review of Learning Disability and ASD in Scottish Mental Health Legislation**

In May 2016, the Mental Welfare Commission and the Scottish Council for Learning Disability opened a [scoping consultation](#) on the format of the forthcoming review of learning disability and autism in Scottish mental health legislation. The review considered views and evidence for removing autism and learning disability from the definition of ‘mental disorder’ under the 2003 Act.

The scoping consultation acknowledged that as ASD is not explicitly listed as a category of mental disorder in the 2003 Act there has been “some confusion among professional care providers about how the 2003 Act should be used for people with ASD” (2.2). It outlined the following arguments for and against including learning disabilities and ASD in mental health legislation:

**Reasons for:**

- It is “not uncommon for people with learning disability and autism to also have some form of mental illness. Diagnosis in such cases can be difficult and may require close observation in a controlled setting over an extended period of time.”
- It may be “appropriate to give medication to manage stressed and distressed behavior” or “provide restrictive care”, even if no mental illness is present. These interventions “require safeguards beyond those available in common law or under incapacity law.”
- If they are removed from the Act, people with these conditions whose “behaviour is inappropriate or illegal” could potentially be imprisoned. This outcome “was seen to be inhumane, as well as unhelpful, since it would make it harder to address the causes of the offending behavior” (2.7)

**Reasons against:**

- They are “lifelong conditions which cannot be cured or ‘treated’ with medication (unlike mental illness)”
- “The Mental Health Act is based on the idea that people who require treatment, but who do not accept the need for it, may be detained in hospital, under the care of a psychiatrist, to receive such treatments”. People with learning disabilities or ASD who also have a mental illness can be detained under mental health law “without any reference to their learning disability or ASD.”
- People with learning disabilities or ASD are “more likely to receive support from a psychologist rather than a psychiatrist, to address any problems related to these conditions such as problems with aggression, or distressed behaviour (sometimes referred to as ‘challenging behaviour’). However, the Mental Health Act contains no specific safeguards in relation to such interventions.”
• Distressed behavior could “reflect inappropriate or inadequate services. In this case, the correct response is to provide the appropriate services, rather than place the individual under greater constraints. Concerns were voiced that the Act can result in people being detained for lengthy periods because the right services are not available”.

• Their inclusion in mental health legislation “contributes to the marginalization” of people who have learning disabilities or ASD (2.6)

Findings from this consultation were published on the 12 January 2017. It is expected that a review of the place of ASD, dementia and learning disability in mental health legislation will begin in April 2017.

ADULT SUPPORT AND PROTECTION (SCOTLAND) ACT 2007

The Adult Support and Protection (Scotland) Act 2007 applies to people aged 16 “at risk from harm”. The Act defines “adults at risk” as those who “are unable to safeguard their own well-being, property, rights or other interests”; and “are at risk from harm”; and “because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than others who are not so affected (asp 10 s 3.1). The Act requires local authorities and various public bodies to work together to protect adults in these circumstances. More information is available from the Mental Welfare Commission.

EDUCATION (SUPPORT FOR ADDITIONAL LEARNING) (SCOTLAND) ACT 2004 AND 2009

The Education (Additional Support for Learning) (Scotland) Act 2004 established duties on education authorities to make suitable provisions for children with “additional support needs” (ASN): a broad category defined as circumstances, “where, for whatever reason, the child or young person is, or is likely to be, unable without the provision of additional support to benefit from school education” (asp 4 s1). For more detailed discussion of the wider legislative framework and policy context into which the Acts were introduced, see SPICe Briefing Additional Support for Learning (Georghiou and Kidner 2008).

SOCIAL CARE (SELF-DIRECTED SUPPORT) (SCOTLAND) ACT 2013

The Social Care (Self-directed Support) (Scotland) Act 2013 places a duty on local authorities to offer people eligible for social care a range of choices over how they receive their support (Scottish Government online). This is intended to give people eligible for social care and their families more control over how support is provided. It includes the option to allocate funding directly to the supported person or someone acting on behalf of a supported person.

PARLIAMENTARY CONSIDERATION

THE AUTISM (SCOTLAND) BILL

The Autism (Scotland) Bill was introduced to Parliament on 26 May 2010, by Hugh O'Donnell MSP. This Members Bill was intended to place a statutory duty on the Scottish Government to produce an autism strategy focused on the needs of adults and young people with ASD, and issue guidance to local authorities and NHS bodies.

The Bill reflected the overarching aims of similar legislation in England. The Autism Act (2009) placed a duty on the Secretary of State to produce an Autism strategy for England and issue related guidance to local authorities and NHS bodies. Similarly, the Autism Act (Northern
Ireland) 2011 now requires the Northern Ireland Executive to publish an Autism Strategy and report on its implementation every three years (Parkin 2016).

Following the Bill’s introduction, the Scottish Government opened consultation on a draft autism strategy in September 2010 and presented the view that new legislation was not required to underpin an autism strategy. The Bill was considered at Stage 1 by the Parliament’s Education, Lifelong Learning and Culture Committee. Evidence presented to the Committee is summarised in the Committee’s 11th Report. The Committee agreed that an autism strategy would “help focus the delivery of services to people with autism more effectively” (3). However, the Committee concluded that ineffective implementation of existing legislation was a more pressing concern for people with autism and their families than the introduction of legislation specifically focused on autism. It noted that “significant pieces of relevant legislation, such as the Education (Additional Support for Learning) (Scotland) Act 2009 and the Equality Act 2010 have not been in force for sufficient time to evaluate their impact”. The Committee therefore did not find that “there is a need for a strategy to be underpinned by legislation at this time” (4).

At the Stage 1 debate on 12 January 2011, the Parliament disagreed to the general principles of the Bill and the Bill therefore fell at the Stage 1 debate on 12 January 2011. For more information see the Autism (Scotland) Bill Summary.

HEALTH AND SPORT COMMITTEE

On 19 March 2013, the Scottish Parliament Health and Sport Committee heard evidence on the implementation of the Scottish Strategy for Autism. Witnesses indicated that good progress was being made on local initiatives but indicated that it was too early to evaluate the strategy’s overall implementation.

EDUCATION AND SKILLS COMMITTEE

On the 1 March 2017, the Education and Skills Committee held a round-table discussion on additional support needs with representatives from Enquire, Glasgow City Council, Scottish Children’s Services Coalition, Glasgow City Council, Director of the Centre for Education Inclusion and Diversity, a Principal Teacher and parents.

PETITIONS

In January 2016, Petition PE01597 was lodged with the Scottish Parliament. The petition called for the Scottish Government to commission a study into the relationship between Mycoplasma Fermentans (a very small bacterium) and regressive autism. The petitioner had previously submitted four petitions related to ASD to the Parliament. The Public Petitions Committee took evidence from the petitioner and agreed to write to the Chief Scientist’s Office, the Scottish Government, the European Commission and the UK Government. The view of the Scottish Government, based on scientific advice available, was that there is no evidence to support the theory that regressive autism may be caused by Mycoplasma fermentans contamination (Public Petitions Committee 2016). The petition was therefore closed on 8 March 2016.
RECENT DEVELOPMENTS IN ENGLAND, WALES, NORTHERN IRELAND AND THE EUROPEAN PARLIAMENT

ENGLAND

The Autism Act (2009) was followed by the first Autism strategy for England, Fulfilling and Rewarding Lives (2010). This was superseded by Think Autism in 2014 which focused on building awareness of ASD in communities, providing innovative services and integrated care. A progress report on the strategy’s implementation was published in January 2016.

Recent relevant legislation in England includes the Care Act 2014 “which provides that all staff who undertake autism assessments must have appropriate training” and the Children and Families Act 2014 “which provides for a new special educational needs and disability support system, covering education, health and social care” (Parkin 2016, p.3).

WALES

In May 2015, the Welsh Government announced a one-year plan for ASD, supported with over £600,000 in funding. £2m was to be invested in developing services relating to diagnosis and support for young people with ASD, and cut waiting times for specialist child and adolescent mental health services. Other priorities identified by an advisory group include developing more integrated services; improving education and employment opportunities for people with ASD; and promoting awareness and developing further training resources for professionals (Parkin 2016).

NORTHERN IRELAND

Autism policy and strategy in Northern Ireland is underpinned by the Autism Act (Northern Ireland) 2011, which requires the Northern Ireland Executive to publish an Autism Strategy and report on its implementation every three years (Parkin 2016).

In January 2014, the Northern Ireland Executive published the Autism Strategy (2013 – 2020) and Action Plan (2013 – 2016) which established eleven themes and strategic priorities, and 34 actions. A progress report was published in September 2015 (Parkin 2015).

EUROPEAN PARLIAMENT

In September 2015, the European Parliament adopted the Written Declaration on Autism, calling for a European strategy for autism aimed at, “encouraging research on autism, prevalence studies and exchange of best practices” (5).

ANNEX A: DIAGNOSING AND ASSESSING ASD

The Scottish Intercollegiate Guidelines Network (SIGN) published new clinical guidelines on assessment, diagnosis and interventions for ASD in June 2016. (SIGN 145). These new guidelines follow the diagnostic criteria and terminology in the most recently published diagnostic classification system. There are two diagnostic classification systems in general use: the Diagnostic Statistic Manual of Mental Disorders (DSM-5), last published in 2013; and the

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16 Written declarations of the European Parliament represent the views of signatories, not the Parliament as a whole, they do not call for legislative change and are not enforceable.  
International Classification of Diseases (ICD-10), last published in 1993. ICD-10 is more commonly used in the UK. Previous SIGN guidelines referred to ICD-10 and much of the recent literature on ASD in the UK incorporated aspects of both classification systems.

A key difference between these diagnostic classification systems is that ICD-10 presented a number of different disorders including ‘Childhood Autism’, ‘Atypical Autism’ and ‘Asperger syndrome’. These are described as “pervasive developmental disorders”, indicating that they affect all aspects of people’s lives. DSM-5 replaces this group of distinct disorders with the collective term ‘Autism Spectrum Disorder’, and streamlines diagnostic criteria, reflecting a range of difficulties which people may experience to different degrees.

Another significant difference between the two systems is that whereas ICD-10 referred to a “triad of impairments” (social communication, social interaction and repetitive or restricted behaviour) to diagnose and assess childhood autism and Asperger syndrome, DSM-5 refers to a “dyad” of impairments: specifically to “persistent deficits in social communication and social interaction across multiple contexts” reflecting “the view that problems with reciprocal social interaction and social communication overlap and cannot be reliably distinguished” (SIGN 145, p.1).

The new SIGN guidelines reflect recent evidence on assessment, diagnosis and clinical interventions for children and young people, adults and older people with ASD. They update previous SIGN guidelines (SIGN 98) published in 2007, which related exclusively to children and young people with ASD. This follows “increasing understanding that autism spectrum disorder (ASD) is a lifelong condition in which the core features of ASD persist while manifesting differently according to different age stages”. The likelihood of the signs and symptoms of ASD being recognised in childhood or early adulthood can depend on a range of factors such as classroom size and family support and there is “therefore a need for a guideline which reflects the whole age range” (SIGN 145, p.1).

ANNEX B:

AUTISM STRATEGY FOR SCOTLAND GOALS

<table>
<thead>
<tr>
<th>Foundations</th>
<th>By 2 Years</th>
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<tbody>
<tr>
<td>1</td>
<td>Access to mainstream services where these are appropriate to meet individual needs.</td>
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<tr>
<td>2</td>
<td>Access to services which understand and are able to meet the needs of people specifically related to their autism.</td>
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<tr>
<td>3</td>
<td>Removal of short-term barriers such as unaddressed diagnoses and delayed intervention.</td>
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<tr>
<td>4</td>
<td>Access to appropriate post-diagnostic support for families and individuals (particularly when there is a late diagnosis).</td>
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<tr>
<td>5</td>
<td>Implementation of existing commissioning guidelines by local authorities, the NHS, and other relevant service providers.</td>
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<tr>
<th>Whole Life Journey</th>
<th>By 5 years</th>
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<tbody>
<tr>
<td>1</td>
<td>Access to integrated service provision across the lifespan to address the multidimensional aspects of autism.</td>
</tr>
</tbody>
</table>

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18 Pervasive developmental disorders are defined as “A group of disorders characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual’s functioning in all situations” (ICD-10, F84).
Ten Indicators for current best practice in the provision of effective Autism Spectrum Disorder (ASD) services

ASD provision should include:

1. A local Autism Strategy developed in co-operation with people across the autism spectrum, carers and professionals, ensuring that the needs of people with ASD and carers are reflected and incorporated within local policies and plans.

2. Access to training and development to inform staff and improve the understanding amongst professionals about ASD.

3. A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication.

4. An ASD Training Plan to improve the knowledge and skills of those who work with people who have ASD, to ensure that people with ASD are properly supported by trained staff.

5. A process for data collection which improves the reporting of how many people with ASD are receiving services and informs the planning of these services.

6. A multi-agency care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.

7. A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.

8. Services that can demonstrate that service delivery is multi-agency in focus and coordinated effectively to target meeting the needs of people with ASD.

9. Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.

10. A self-evaluation framework to ensure best practice implementation and monitoring.
## ANNEX C: SCOTTISH STRATEGY FOR AUTISM OUTCOMES
### APPROACH: PRIORITIES 2015 – 2017

<table>
<thead>
<tr>
<th>Priority</th>
<th>Improve access to integrated service provision across the multi-dimensional aspects of Autism</th>
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<tbody>
<tr>
<td><strong>Next Steps</strong></td>
<td>Take steps to improve how people with autism are captured in health and social care data to better understand and evidence their needs</td>
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<td>Share best practice in the use of the menu of interventions</td>
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<td>Provide leadership for an improvement programme across NHS Boards to improve diagnostic services and increase diagnostic capacity</td>
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<td></td>
<td>Support One Stop Shops to become sustainable by embedding the service in local strategic delivery plans</td>
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<td></td>
<td>Continue to support implementation of local action plans ensuring that local authorities and third sector organisations can identify local autism needs and commission the appropriate services to meet those needs.</td>
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<td></td>
<td>Promote personal outcomes approaches for people with autism by working to influence the choice self-directed of support providers and support available for people with autism.</td>
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<td></td>
<td>Encourage innovation and improvement in autism services through Autism Funded projects and explore how learning from these projects can be evaluated and shared wider.</td>
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<tr>
<td><strong>Priority</strong></td>
<td>Consistent adoption of best practice in key areas of education, health and social care across local authority areas</td>
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<tr>
<td><strong>Next Steps</strong></td>
<td>Explore how research on autism can be shared and translated into practice. Further develop opportunities to take forward gaps in autism research.</td>
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<td></td>
<td>Continue to work across all sectors to improve autism practice through networks, good autism practice events and annual national events. Explore how these networks can work collaboratively to improve services.</td>
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<td></td>
<td>Promote the use of a person centred approach to identify and improve personal outcomes for people with autism.</td>
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<tr>
<td><strong>Priority</strong></td>
<td>Capacity and awareness building in mainstream services</td>
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<tr>
<td><strong>Next Steps</strong></td>
<td>Work in partnership with policy colleagues across wider government to identify joint objectives and develop shared outcomes.</td>
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<td></td>
<td>Develop the skills and competency of the health and social care workforce through implementing the NHS NES autism training framework and further develop training opportunities where gaps in provision have been identified.</td>
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<td></td>
<td>Support access to the community for people with autism by increasing an</td>
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understanding of autism in mainstream services and breaking down barriers to access.

Explore alternative solutions to out of area placements for people with complex care needs drawing from the data obtained in the Mental Health Day Bed Audit.

Understand the level of autism alert card schemes across Scotland and consider the benefits and any risks.

Explore the impact of Open University and University of Strathclyde free autism modules schemes to determine how training is building professional capacity, in order to identify future need and prioritise further funding.

Work in partnership to continue to promote the use of the Autism Toolbox in schools and teacher training colleges.

Encourage innovation and improvement through Autism Funded projects to enable people with autism to live independently and explore how these can be shared wider.

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<tr>
<th>Priority</th>
<th>Improve access to appropriate transition planning across the lifespan</th>
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<td>Next Steps</td>
<td>Work in partnership with Association for Real Change and statutory bodies to embed the Principles of Good Practice Transitions into practice.</td>
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<td>Promote personal outcomes approaches for people with autism by working to influence the opportunities for people with autism in opportunities for all, young workforce strategy and employment.</td>
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<td>Encourage innovation and improvement through Autism Funded projects that enable people with autism to be better socially connected and explore how these projects can be shared wider.</td>
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<td>Work with partners to improve Modern Apprenticeship opportunities for young people with autism.</td>
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<td></td>
<td>Promote further positively evaluated models of supported employment.</td>
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</tbody>
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SOURCES


Autism Scotland Bill Summary. Available at: http://www.parliament.scot/S3_Bills/Autism(Scotland)Bill/AutismBillSummary.pdf

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RELATED BRIEFINGS
SB 10/72 Autism (Scotland) Bill
SB 08/66 Education (Additional Support for Learning) (Scotland) Bill 2008

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Published by the Scottish Parliament Information Centre (SPICe), The Scottish Parliament, Edinburgh, EH 99 1SP

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