Cost Benefit Analysis of Autism Code of Practice

Final Report for the Welsh Government
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LE Wales
CBA of Autism Code of Practice
Executive Summary

The Welsh Government is introducing a Statutory Code of Practice on the Delivery of Autism Services which will come into force in September 2021. The Welsh Government commissioned LE Wales to assess the costs and benefits of introducing the Code compared with the current situation ("business as usual") and with the introduction of primary legislation. The research was undertaken between December 2020 and March 2021.

Health and social care are devolved policy areas, meaning that the legislative context and practices vary across the four UK nations. Two of these (England and Northern Ireland) have primary legislation for autism in place, while in Wales and Scotland there is no autism specific legislation, but each have a national strategy for autism to deliver autism services and support existing legislation (autism bills were discussed and rejected in both Wales and Scotland in the past).

The Code of Practice is designed to underpin the delivery of the current legislation (the Social Services and Well-being (Wales) Act 2014 and the NHS (Wales) Act 2006) and to ensure that the improvements achieved through the delivery of the Autism Spectrum Disorder Strategic Action Plan (first published in April 2008 and updated in 2016) are sustainable for the long term. The main aims of the Code are to promote better awareness of autism amongst statutory services; to secure the long-term provision of autism services which can meet individual needs and provide support for the families or carers of autistic people; to improve integration and collaboration between services to prevent individuals from falling between service responsibilities; and to promote the involvement of autistic people in the design and delivery of the services they receive.

Over the last five years the Welsh Government has provided funding to set up and deliver services specifically targeted at providing support for individuals with autism and supporting the delivery of the ASD Strategic Action Plan: the Integrated Autism Service (IAS), Together for Children and Young People (T4CYP), and continued support for the National Autism Team (NAT). The implementation of the Code is an additional step in supporting continued improvement in the development and delivery of autism services in Wales.

Unfortunately, there is little currently available Welsh specific evidence to assess quantitatively the cost of introducing the Code; nonetheless based on a review of existing evidence, Code documentation and discussion with stakeholders we have identified the following as the main areas where the Code may have an impact.

- Increased expectations for training to be available for all relevant professional figures. This is expected to have an impact on costs, mainly linked to the opportunity cost for relevant professionals undergoing training.
Executive Summary

- Better awareness leading to an increase in the demand for services. However, there is no additional funding associated with the implementation of the Code,¹ so it is potentially conceivable that greater demand could lead to an increase in waiting times (if there is an increased demand but no additional funds).
- On the other hand, the implementation of the Code could contribute to reducing waiting times due to greater efficiency in service coordination and delivery.
- Coordination among different Welsh actors (regional partnership boards, local health boards and local authorities) is expected to improve under the Code.
- Improvements in data collection and data sharing are already occurring for adults and children services and are expected to further develop under the Code. In particular the Code places responsibility on regional partnership boards, local health boards and local authorities to collect information on autism services and on regional partnership boards to oversee local data on autism.

Overall, it is difficult to say exactly what type of impact the Code will have on actual practices and standards; and, given the uncertainty and limited specific data on the current situation and the impact of the Code, it is difficult to quantify the impact on costs.

The introduction of primary legislation was also discussed with stakeholders. They had mixed views about the benefits of introducing the requirements of the Code through primary legislation rather than through a statutory code of practice. Some felt that if the requirements were introduced through primary legislation, then the relevant organisations would be more likely to comply with the requirements and that it would be more likely that the requirements would stay in place in the future. However, other stakeholders felt that the Code has a statutory basis in any case and that the introduction of primary legislation would delay the introduction of the Codes requirements even further.

Moreover, experience from other UK nations (in particular England) suggests that the presence of specific primary legislation alone does not necessarily mean that the autism strategy is fully adequate and fully meets the needs of autistic people and their families. In fact, recent developments suggest that in both Wales and England the current emphasis of the respective autism strategies is similar (e.g. to improve awareness and understanding of autism, to ensure that training is provided to relevant professionals, to further develop data collection and sharing).

¹ Other than a sum of £28,000 for the Regional Partnership Boards to prepare for the implementation of the Statutory Autism Code in 2021/22 (each Regional Partnership Board will receive £4,000 to establish the autism infrastructure which will be required to successfully plan and monitor delivery and outcomes).
1 | Introduction

The Welsh Government commissioned LE Wales to undertake a cost and benefit analysis of three policy options related to providing assessment and services to individuals with autism. The research was undertaken between December 2020 and March 2021.

The three options to be considered in the analysis are the:

- The “business as usual” scenario (option 1), assuming that there is no policy shift compared with the existing situation;
- The introduction of a Code of Practice (option 2);
- Introducing primary legislation (option 3).

This report is structured as follows:

- Chapter 2 provides an overview of the relevant material that we have found in the academic literature;
- Chapter 3 sets out the evidence base in relation to autism prevalence and autism services in Wales;
- Chapter 4 describes the policy options, including the current system, and summarises the views of stakeholder on each option;
- Chapter 5 sets out some early estimates of costs and benefits;

Some supplementary material is provided in the Annexes.

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2 In this report we use the terms “autism” or “Autism Spectrum Condition (ASC)” instead of “Autism Spectrum Disorder (ASD)” based upon the feedback received by the Welsh Government in response to the public consultation of the Code of Practice on the Delivery of Autism Services. The acronym, ASD, is used when referring to the names of specific policies, reports or articles that use that term, such as the ASD Strategic Action Plan.
2 Relevant evidence from the academic literature

2.1 Introduction

Autism is a neurodevelopmental disorder which is associated with difficulties within social interaction and communication, and restricted or repetitive behaviour patterns, interests and activities (Beuscher et al, 2014).\(^3\) The prevalence of autism has increased dramatically over the last 20-30 years and still continues to rise (Dillenburger et al, 2013). In 2016 the Centre for Disease Control Prevention estimated that 1 in 54 children may be somewhere on the autistic spectrum (CDC, 2021).

While it is not possible to identify a single factor behind the increase in prevalence, the literature indicates that a rise in awareness of the disorder is a contributing factor (Idring et al, 2015). In 2015, survey data revealed that 99% of the UK population had heard of the disorder, and just under half of the respondents knew someone who had been diagnosed with it (YouGov, 2015). However, awareness does not necessarily translate into understanding and treating autistic individuals appropriately. Dillenburger et al (2016) found that even among professionals who work within autism services in the UK, many do not have autism-specific training.

Every autistic individual has a unique set of care needs depending on severity and comorbidities, and while some individuals can live relatively independently, most require life-long support across domains such as education, healthcare and social services (Rogge and Jansen, 2019). The economic costs of autism on society can be high depending on the severity of the disorder and whether individuals have coexisting conditions. Knapp, Romeo and Beecham (2009) estimated the direct costs (such as the cost of providing services) and indirect costs (such as lost productivity) of autism and found that the lifetime cost for an autistic individual was £0.8 million, and £1.23 million if that individual also had a learning disability\(^4\).

Roddy and O’Neil (2019) compared the cost of supporting an autistic child for the state to the costs borne by the family. They found that in Ireland the cost of raising an autistic child for parents and caregivers are almost twice as high as the costs to the state. The largest portion of costs borne by parents come from mothers who gave up paid employment to become full-time carers. This could suggest that providing better care services for autistic children may reduce long-run costs to the state if it allows parents to remain in the labour force. Another interesting finding is that the severity of autism is associated with higher costs to the family, but does not have a significant impact on the amount spent by the state.

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\(^3\) The authors refer to ‘Autism Spectrum Disorder’.

\(^4\) Estimates in the report are in 2005/06 prices. The lifetime costs in 2021 prices would be around £1.1 and £1.7 million for an autistic person without and with learning disability respectively.
2 Relevant evidence from the academic literature

In Wales, a Code of Practice for the delivery of autism services has been proposed as a way of ensuring that individuals with autism and their carers receive appropriate care and support. The Code aims to improve the lives of autistic individuals by clarifying the requirements of local authorities, local health boards and NHS trust, and ensuring stability and continuity of service provision. There are four sections to the Code of practice describing the key areas that need to be addressed, namely;

- Autism assessment and diagnosis;
- Access to health and social care;
- Awareness raising and autism training; and,
- Planning and monitoring services, and stakeholder engagement.

The following sections review the literature on the effectiveness of and challenges within the current system and cover the literature on assessment and diagnosis, health and social care, and awareness and training separately.

2.2 Autism assessment and diagnosis

Early intervention programmes for children are imperative for improving overall functioning, social communication, language cognition and adaptive behaviour in autistic individuals (Brett et al, 2016). Behavioural interventions and therapies early on may alter the trajectory of both biological and behavioural development in children (James and Smith, 2020). Being diagnosed at a later age not only means that children are unable to benefit from early interventions but may also become less effective as children get older (Brett et al, 2016).

Autism can be reliably diagnosed as early as 24 months although the median age of diagnosis tends to be around school entry age (Brett et al, 2016). Despite growing awareness about autism, there is limited evidence to suggest that the average age of diagnosis is decreasing. Brett et al (2016) reviewed 2000 children in the UK between 2004 and 2014, and found no evidence to suggest that the mean age of diagnosis decreased over that period.

Although a diagnosis early in life is preferable, there are still many benefits from being diagnosed as an adult. Stagg and Belcher (2019) surveyed adults who had been diagnosed with autism after they turned 50, and found that receiving a diagnosis was a positive experience which allowed them to better understand themselves and their needs. For some individuals, receiving a diagnosis may enable them to access services suited to their needs and to become aware of other conditions that often co-occur, such as mental health issues.

5 However, this should not be interpreted as interventions in older children are not effective: early intervention is important for children and for supporting families, but ongoing intervention is also key. Also important is that intervention needs and support change as a child develops, and change across the lifespan, for both the person and their family.
This is important as autistic individuals have a higher risk of developing psychiatric disorders than the general population (Croen et al, 2015; Burns, Irvine and Woodcock, 2018).

Despite being a neurologically based condition, autistic symptoms manifest as behavioural characteristics (Hyman, Levy and Myers, 2020). Although advances in neurobiology and genetics have improved the understanding of autism, assessments of autistic individuals still rely on identifying behaviourally defined clinical signs. The heterogeneity of the disorder can make autism particularly complex to diagnose both in children (Hyman, Levy and Myers, 2020) and adults (Fusar-Poli et al, 2017). Children may present symptoms differently depending on their age, and cognitive and language abilities. Presence of other co-occurring behavioural and emotional problems or mental health problems can also complicate the diagnostic process, as can environmental factors such as child abuse and neglect, and trauma.

Diagnosing autism in adulthood may be challenging for clinicians for several reasons, including the overlap of symptoms with other conditions such as social anxiety or obsessive-compulsive disorder, difficulties in gaining information about patient’s early development and misleading previous psychiatric diagnoses (Fusar-Poli al, 2017). Even when symptoms of autism are present from childhood, they may only manifest when the patient is faced with a situation that exceeds their restricted social ability.

### 2.3 Access to health and social care

There are many aspects of healthcare visits that may trigger anxiety in autistic individuals, especially those who are hypersensitive to sensory stimulation such as bright lights and crowds (Mason et al, 2019). Environmental and situational considerations such as travelling to appointments and unpredictable waiting times also present significant barriers for autistic adults (Mason et al, 2019). These barriers may often be overlooked because they do not exist for neurotypical individuals. For example, 63% of parents with autistic children report having difficulty with dental care appointments compared to only 13% of parents with typically developing children, and 36% of autistic adults have some form of dental anxiety (Eades et al, 2019).

Nicolaidis et al (2015) categorised these barriers into patient-level factors (e.g., difficulties with verbal communication), provider-level factors (e.g., healthcare staff lack knowledge about autism in adults) and system-level factors (e.g., a lack of informal/formal support). In a survey of autistic adults without learning disabilities, Vogan et al (2017) found that 66% reported not knowing where to find help, 53% reported overwhelming steps to find help and 47% reported previous negative experiences with professionals presented barriers to accessing healthcare services. Health and social care services could reduce the barriers faced by autistic individuals by taking their needs into account, however, there is often a lack of autism-specific training among healthcare professionals (Dillenburg, et al 2016; Zerbo et al, 2015).

Barriers in healthcare systems have tangible consequences for autistic individuals and are likely to result in unmet health needs, higher use of emergency services and lower utilisation...
of preventative support (Southby and Robinson, 2018). Using nationwide population-based registers from Sweden, Hirvikoski et al (2016) found that individuals with autism were at a greater risk of mortality for all recorded categories of disease, other than infection, compared to the general population. The authors linked the higher mortality rates of autistic individuals to higher biological vulnerability to physical conditions, but also insufficient awareness, diagnoses and treatment of co-occurring conditions within healthcare systems. A recent umbrella systematic review (Rydzewska et al. (2021)) confirmed that co-occurring physical health conditions are common amongst autistic people including obesity, epilepsy, sensory impairments, and sleep problems, amongst others.

Despite the strong association between autism and mental health issues, there are also many barriers for autistic individuals who seek mental health support. These barriers are particularly difficult to navigate in the transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) (Crane et al, 2018). Camm-Crosbie et al (2019) conducted in-depth interviews with 200 autistic adults to explore their experiences of treatments and support for mental health problems. The interviews highlight the lack of pathways for autistic individuals, especially those with learning disabilities to access treatment and support in the current system. Almost a quarter of the respondents “fall through the gaps” because mental health services do not feel responsible for individuals with neurodevelopmental disorders.

Access to social care and support is also vital for carers of autistic individuals. Boyd (2002) shows that the level of formal and informal support for families of autistic children are important predictors of depression and anxiety in mothers. This highlights the importance of providing care not only for autistic individuals but also for their families, in the form of advice, signposting and support groups.

Even low-level support for autistic individuals, such as providing information about service pathways, advocacy and referrals to appropriate support services has been shown to improve outcomes for autistic adults. In a small sample of autistic adults without learning disabilities, providing low-level care was seen to qualitatively improve employability, education, access to support and information, social isolation, health and wellbeing, and ability to manage day-to-day activities (Southby and Robinson, 2018).

More research in this area is needed, however, to evaluate the cost effectiveness of low-level support as well as long-term impact on individuals’ health and well-being. In 2016, the Department for Health Reviews Facility conducted a review of evidence about services providing preventative co-ordinated low-level support for autistic adults without learning

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6 Autistic individuals have elevated rates of all major psychiatric disorders, and almost all medical conditions are more common in adults with autism than in the general population (Croen et al, 2015).
disabilities. Out of the eight interventions that they identified\(^7\), only two (job interview training and employment support) had significant positive impacts on autistic individuals (Lorenc et al, 2016). This does not necessarily mean that other interventions are not effective, but there is not enough research to draw conclusions.

### 2.4 Raising awareness about autism and autism training

Prevalence of autism has dramatically risen over the past few decades, one of the reasons for this is thought to be the increase in autism awareness (Idring et al, 2015; Dillenburger et al, 2013). In 2015, a YouGov poll, commissioned by the National Autistic Society (NAS), revealed that over 99% of people in the UK had heard of autism, and almost half knew someone with the disorder. In contrast, according to a survey conducted by nfpSuenergy in 2005, 90% of people had heard of autism and only 33% knew an autistic individual (YouGov, 2015).

Although there has been a rise in awareness of autism, helped by local and international awareness campaigns (De Vilbiss and Lee, 2014), the general population still lacks an understanding of the interventions and support needs of autistic individuals (Dillenburger et al. 2013). Various studies have shown that in most professions, including healthcare and social services (Eades et al, 2019; Dillenburger et al, 2016) and public services (Chown, 2010) there is a conspicuous lack of autism training. Even among professionals such as health, social care and education staff who work within statutory autism services in the UK, there is an “acute lack of autism-specific training” (Dillenburger et al, 2016).

This lack of training not only has a detrimental impact on the autistic individuals who need better support but may also place strain on the professional who are trying to help them. Teachers in primary and secondary education report lack of confidence and feelings of low self-efficacy in working with special education needs (SEN) students including autistic students (Able et al, 2015), and healthcare providers have expressed that they are limited in their ability to provide adequate support for their client (Morris, Greenblatt and Saini, 2019). The lack of confidence that healthcare professionals feel in their ability to deal with autistic individuals results in increasing referrals to specialists and puts pressure on the healthcare system (Morris, Greenblatt and Saini, 2019).

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\(^7\) These interventions were: job interview training, employment support, social skills training and psychoeducation, music and dance, support and mentoring (university students), general support services, peer support groups, and specialist multi-disciplinary teams.
3 Evidence for autism prevalence and services in Wales and the UK

There are no official statistics detailing the number of individuals with autism in Wales or the United Kingdom. Relevant prevalence estimates are based on surveys and estimates from abroad. In this section we briefly present a selection of the estimates for the UK and other relevant countries.

- Baird et al. (2006) looked at children aged 9 and 10 in South Thames (UK) and found an autism prevalence estimate of 1.16%.
- Using 2007 Adult Psychiatric Morbidity Survey (APMS 2007) combined with data from a study of the prevalence of autism among adults with learning disabilities, Brugha et al. (2012) estimated that the overall prevalence of autism was 1.1 per cent in England and that the prevalence of autism was much higher in adult men than women (2% compared to 0.3%).
- More recently, the UK Parliament research briefing on Autism (2020) reported estimates of prevalence of autism of 1.035% across all ages (equivalent to 700,000 autistic people in the UK) and 1.6% for children. The estimate across all ages was developed by MacKay et al. (2017) using a systematic review and meta-analysis of English-language studies of prevalence of autism from across the world to generate a pooled prevalence estimate.
- A recent study by Roman-Urrestarazu et al. (2021) examined the Spring School Census 2017 data from state-funded English schools and focused on more than 7 million pupils aged 5 to 19. The authors estimated an overall standardized prevalence of autism of 1.76% with significant differences by gender (2.81% prevalence rate for male pupils compared with 0.65% for females), ethnic group (with standardized autism prevalence highest in Black pupils (2.11%)) and local authority district (with standardized prevalence ranging from 0.63% to 3.38% across the 326 English LADs);
- In Northern Ireland (Department of Health, 2020), prevalence estimates using the Northern Ireland School Census for children aged between 4 and 15 reported prevalence rate of autism of 4.2% in 2019/20 (rising from 1.2% in 2007/08\(^8\)), with a large variation across males and females (6.4% versus 2% respectively);
- McConkey (2020) also used longitudinal school census data to look at prevalence rates for children across the four UK home nations in the school years 2010/11 to 2018/19. Prevalence rates for school children in Wales were estimated at around 0.75% in 2010/11, rising to 1.8% by 2018/19 (however with a break in the series in 2017, more detail in the next section)\(^9\). For the other UK home nations, prevalence

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\(^8\) However, it should be noted due to a change in the data collection, the years up to and including 2018/19 are not directly comparable with 2019/20

\(^9\) Wales only reported on autism as a primary condition up to 2015/16; as a consequence rates leaped from around 1.1% to 1.5% between 2015/16 and 2016/17
rate using this metric rose from 1% to 2.25% in England, from 1% to 2.5% in Scotland and from 1.4% to 3.2% for Northern Ireland in the period considered (2010/11 to 2018/19). However, these estimates are based on school assessment of pupils with special educational needs and do not necessarily reflect a clinical diagnosis of ASC.

In the US, the Centre for Disease Control Prevention estimated that in 2016, around 1.9% of children (1 in 54) was identified with autism spectrum condition. For adults, the prevalence rate was estimated at 2.21% in 2017.

3.1 Additional Learning Needs, pupil data and autism in Wales

Additional Learning Needs

In 2018 the National Assembly for Wales passed the Additional Learning Needs and Education Tribunal (Wales) Bill, creating the legislative framework to improve the planning and delivery of additional learning provision. The Act replaced the terms ‘special educational needs (SEN)’ and ‘learning difficulties and/or disabilities (LDD)’ with the new term ‘additional learning needs (ALN)’ and created a unified system for supporting learners from 0 to 25 with ALN. The main aims of the new system are to ensure that all learners with ALN are supported to overcome barriers to learning and achieve their full potential; improve the planning and delivery of support for learners from 0 to 25 with ALN, placing learners’ needs, views, wishes and feelings at the heart of the process; focus on the importance of identifying needs early and putting in place timely and effective interventions which are monitored and adapted to ensure they deliver the desired outcomes.

The ALN Act will be supported by an ALN code providing statutory guidance and mandatory requirements to help people and organisations work within the law. The new ALN system is due to come into force in September 2021.

School census data on Special Educational Needs and Autism

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10 The fact that pupils are receiving additional support for autism does not mean they have received a clinical diagnosis: as the author notes: ‘Pupils with special educational needs are identified by school personnel based on the Code of Practice relevant to that country. This includes those pupils who have undergone a formal process of assessment and received a statement of their special education needs (called ‘additional support needs’ in Scotland) and those who receive additional support for the special educational needs based on an assessment by school personnel. In neither case would these assessments constitute a clinical diagnosis of autism, although a proportion of pupils will have received one; although a formal diagnosis of autism is not recorded in the census.’

11 For more information from the CDC see Data & Statistics on Autism Spectrum Disorder and first release CDC data.

12 For more information see the Additional learning needs (ALN) transformation programme summary and frequently asked questions.
Children with Special Educational Needs in Wales are identified and supported following the SEN Code of Practice for Wales. As outlined in the current SEN Code of Practice there are three different levels of intervention, depending on the child’s need and progress over time: Early Years/ School Action\textsuperscript{13}, Early Years/ School Action Plus\textsuperscript{14} and Statutory Assessment\textsuperscript{15} (in early years setting help provided to children with Special Educational Needs is called Early Years Action, while in schools it is called School Action). Reports of Special Educational Needs is returned in the Pupil Level Annual School Census (PLASC) and published by the Welsh Government on StatsWales\textsuperscript{16}.

As already mentioned, from January 2017 maintained schools were allowed to report as many types of special educational need for a pupil as required and the ranking of those needs was removed (before only ‘Major need’ was identified). As a result, figures are not directly comparable with previous years and there is a break in the series between 2015/16 and 2016/17.

Also, the identification of a child as having autism for Special Educational Needs does not necessarily mean that they have received a formal diagnosis of autism (although that may be the case for some of them).

The absolute number of Welsh pupils with Special Educational Needs and Autism rose from 1480 in 2003/04 to 5330 in 2015/16 (at an average yearly growth rate of 11%), before leaping by 30\% to 6920 in 2016/17 (primarily due to the change in classification) and rising to almost 9100 by 2019/20 (latest available year), with an average growth rate of 10\% over the last three academic years.

Relatively to the population of all pupils in Welsh schools reported in the Census, the proportion with SEN and autism increased from 0.3\% to 1.1\% between 2003/04 and 2015/16, jumping to 1.5\% in 2016/17 and further increasing to 1.9\% by 2019/20.

\textsuperscript{13} ‘Early Years Providers/School informs parents that their child is considered as having SEN. SEN co-ordinator (SENCO) and colleagues gather information about the child, including parents. SENCO organises additional provision and ensures that an individual education plan (IEP) is drawn up, working with the child’s teachers to devise school-based interventions.’

\textsuperscript{14} ‘SENCO brings in outside specialists to advise on further changes that could be made within the school to meet the child’s needs.’

\textsuperscript{15} ‘Local Education Authorities considers the need for statutory assessment and, if appropriate, makes a multi-disciplinary assessment.’

\textsuperscript{16} Schools’ data are derived from the Pupil Level Annual School Census (PLASC) returns and STATS 1 returns supplied by schools open on Census day in January each year. The returns are authorised by head teachers and validated by Local Authorities.
3 | Evidence for autism prevalence and services in Wales and the UK

3.2 Estimates of Welsh population with autism over the next ten years

As discussed in the previous sections, there are no official estimates for the population living in Wales and having Autistic Spectrum Condition and available estimates may vary to some extent, although they typically indicate prevalence rate slightly above 1%. In this section we provide estimates for the Welsh population with autism using population projections and available prevalence rates.

When generating the projections for the Welsh population with autism, we followed the approach used by MacKay et al. (2017) and assumed a prevalence rate of 1.035% across both the adult and children population and we adjusted for longevity to reflect evidence on life expectancy for the autistic population\(^\text{17}\). Prevalence rates were assumed to stay constant over time, meaning that trends in the number of autistic people in Wales are solely driven by the underlying trends in the population projections for the relevant age band.

\(^{17}\) MacKay et al. used a life expectancy of 67 years old for individuals with autism, following Shavelle & Strauss (1998).
Reflecting projected population trends, the overall number of autistic people is projected to slightly decline over the next decade, from 27,000 in 2022 to 26,600 in 2031, stable for the group aged 18-67 (at 20,400) and slightly decreasing in the group aged under 18 (from 6,600 to 6,200)\(^\text{18}\).

**Figure 2**  Projections for the Welsh population with autism – 2022-2031

![Bar chart showing projected numbers of autistic people by age group from 2022 to 2031.]

Note: Estimates based on a prevalence rate set of 1.035% and a life expectancy of 67 years

*Source: LE Wales projections based on ONS’ 2018-based population projections and assumptions on autism prevalence*

### 3.3 Number of referrals and diagnosis in Wales

The Integrated Autism Service (IAS) recently started to collect data on demand and capacity for services for adults with autism in Wales, gathering information on a variety of indicators, including number of interactions, number of referrals, number of diagnostic assessments, waiting times etc. These statistics are currently available only for 2019/20, but emerging findings from the first three quarters of 2020/21 may soon become available. Information is returned from the seven IASs across Wales and collated at the national level.

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\(^{18}\) It should be noted that if the true prevalence for children is closer to the rate observed in the PLASC data (1.94%), the number of children with autism would be almost double than the figures presented in Figure 2 (around 12,000). However, that figure does not reflect clinical assessments and it is likely to be an overestimate.
In 2019/20 a total of 5,651 interactions with autistic adults were recorded across Wales, with 3,337 referrals\(^{19}\); around 65% of these referrals were related to autistic adults requesting a diagnosis (2,092), while the other 35% were referrals made by adults already with a diagnosis but requesting support (1,151). During 2019/20, 840 adults received a diagnostic assessment and 76% of these (639 adults) received a positive diagnosis of autism.

Looking at characteristics of individuals accessing services, the vast majority of services were accessed by those in the age bands ‘18-25’ and ‘26-45’ (a combined 77%) and around 57% of those accessing services were males. The initial primary reason for referral into the service was ‘Diagnostic assessment’ for about 60% of adults and ‘Post diagnostic support / advice’ for a further 20%. In total, 82% of referrals were accepted in 2019/20, with 8% pending more information and 10% not accepted. In terms of type of intervention received, the most common intervention was support from IAS support workers (30% of interventions) followed by diagnostic assessment (21%), accessing support groups (16%) and providing information (12%).

Finally, average waiting times for autistic adults, measured from referral accepted to start of intervention (which is typically the reference for waiting times standards) was recorded at 48.7 weeks in 2019/20.

Below we recap the headline figures reported from the Integrated Autism Service for adult services in 2019/20, both in absolute terms and as a proportion of the relevant Welsh population\(^{20}\). Unfortunately, equivalent figures are not currently collated for children services (from the T4CYP) and we have no information on referrals or assessments for this group.

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19 ‘Interactions can include informal discussions through e-mail, phone calls or face to face. These may or may not result in a formal referral to the service and may include signposting to other more suitable services. Referrals refer to formal requests for services from the IAS.’

20 IAS also report figures for 16 and 17 year olds. However, there may be an overlap of competences for young people aged 16 and 17 between IAS and T4CYP and we used the adult population (18+) as the relevant population for IAS services.
Evidence for autism prevalence and services in Wales and the UK

Table 1 2019/20 IAS figures for autism services for adults in Wales

<table>
<thead>
<tr>
<th>Measure</th>
<th>Total</th>
<th>Per 1000 population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total interactions</td>
<td>5,651</td>
<td>2.24</td>
</tr>
<tr>
<td>Total referrals*</td>
<td>3337</td>
<td>1.32</td>
</tr>
<tr>
<td>Referrals for existing autistic individuals</td>
<td>1,151</td>
<td>0.46</td>
</tr>
<tr>
<td>New referrals (seeking diagnosis)</td>
<td>2092</td>
<td>0.83</td>
</tr>
<tr>
<td>Number receiving a diagnostic assessment</td>
<td>840</td>
<td>0.33</td>
</tr>
<tr>
<td>Number receiving a positive diagnosis of autism</td>
<td>639</td>
<td>0.25</td>
</tr>
</tbody>
</table>

Note: * note that nine referrals were not initially categorised and are not included in the breakdown of referrals

Source: LE Wales based on figures provided by IAS and ONS’ 2018-based population projections

3.4 Existing evidence for England

The Autism Act was introduced in 2009, which is the only disability-specific piece of legislation in England. The Act requires the Government to introduce an adult autism strategy, which was published in 2010 and refreshed in 2014 and it is currently being reviewed (following a consultation in 2019) and extended to include children and young people for the first time. The accompanying statutory guidance sets out requirements for the NHS and local authorities to implement the strategy, in areas such as training for staff, identification and diagnosis, transition planning when people move from children to adult services, employment and criminal justice.

However, notwithstanding the presence of the Act, relevant stakeholders have called for more help and support for autistic people. In particular, the National Autistic Society reported findings from a survey of 11,000 autistic people and their families in England which showed that more than 70% of autistic adults were not getting the right help and support (covering a range of areas, from independent living to support for day-to-day tasks, support from social groups etc.). In response to this situation NAS launched the Not Enough campaign to demand better support and services for autistic people calling for increased funding for specialist autism teams providing tailored support in every council in England, a reduction in waiting times for diagnosis (and the introduction of a new waiting time standard) and for the funding of an understanding campaign across the UK to improve the general attitude towards individuals with autism.

The other area of recent significant development in England is training on autism. The Government launched a consultation called ‘Right to be heard’ (the response to the consultation was published at the end of 2019) to introduce mandatory training on learning disability and autism for health and care staff. This mandatory training is about awareness and

21 More information about the act, the survey and the Not Enough campaign.
understanding and does not include training about specific interventions; pilot trials are currently being rolled out in England. Content of the training is set out in two different capabilities frameworks (for Supporting People with a Learning Disability and for Supporting Autistic People), each with three tiers, referring to a specified target audience. In particular, all health and care staff need to do at least tier 1, while tier 2 will be for those with substantial contact with autistic people and people with a learning disability and a small number of workers will need tier 3 capabilities in addition to the tier 1 and tier 2 capabilities.

Although the legislative framework is different across Wales and England (as England introduced specific autism legislation), both nations saw recent developments calling for improvement in awareness, understanding and training. Also, in both Wales and England there is a focus on improving data collection and availability, with IAS gathering information on adult services for the first time 2019/20 and with the NHS publishing experimental statistics on autism starting from 2018/19. These experimental statistics on autism cover information on number of referrals, diagnostic assessments and waiting times (both in terms of waiting time between referral and first care contact for patients with suspected autism and waiting time between referral and diagnosis for patients diagnosed with autism). Clearly, these new and experimental statistics have limitations and have been subject to methodological changes, so they should be treated with caution; nonetheless they could provide useful insights on recent trends in demand for services and waiting times in England and compare them, if possible, with the existing situation in Wales.

Although the NHS data for England is broken down by age and covers both the group aged under 18 and 18 and above, NHS Digital warns that ‘the majority of referrals and assessment for autism in children are undertaken in child development service – these services are out of the scope of the dataset and therefore not included in the statistics presented here’. Quarterly data (in Figure 3) show that the number of referrals increased between the financial years 2018/19 and 2019/20 (the first quarter of 2020/21 show a decline but it is affected by the Covid19 crisis) for both age groups (under 18 and 18+), while waiting times were around 39 weeks for adults and 48 weeks for those aged under 18 in the last available quarter (quarter 2 2020/21), generally declining compared to previous quarters.

In Table 2 we compare the number of referrals for autism adult services in Wales and England in 2019/20. As already noted, these figures should be taken with extreme caution as they are

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22 ‘Tier 1 – People who require a general understanding of autism, and learning disabilities, and the support people may need; Tier 2 – People with responsibility for providing care and support (for an autistic person or people, and / or people who have a learning disability) but who could seek support from others for complex management or complex decision-making; Tier 3 - Health, social care staff and other professionals with a high degree of autonomy, able to provide care and support in complex situations and/or may also lead services for autistic people / people who have a learning disability.’

23 Similar calls for mandatory training for health and social care staff working with people with learning disabilities have been made in Wales.
derived from experimental statistics and may refer to different definitions. Due to the lack of data for under 18 in Wales and the limitations for data in England we only look at adult services provided. The number of new referrals received and diagnostic assessments undertaken in 2019/20 per 1000 adult population was higher in Wales compared with England (more than double), while waiting times (from referral to assessment) were slightly higher in Wales (49 weeks compared to 45 weeks).
Figure 3  Number of new referrals and average waiting times in England

Note: Top panel: number of new referrals; bottom panel: average waiting time (in weeks) between referral and diagnosis for patients diagnosed with autism. The majority of referrals and assessment for autism in children are undertaken in child development service – these services are out of the scope of the dataset and therefore not included in the statistics presented here’.

Source: LE Wales based on experimental statistics on Autism Waiting Time from NHS digital
Table 2  Comparison for adult autism services in Wales an England

<table>
<thead>
<tr>
<th>Measure</th>
<th>Wales</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2019/20 total</td>
<td>2019/20 total</td>
</tr>
<tr>
<td></td>
<td>Per 1000 population</td>
<td>Per 1000 population</td>
</tr>
<tr>
<td>New referrals</td>
<td>2092</td>
<td>13175</td>
</tr>
<tr>
<td></td>
<td>0.83</td>
<td>0.30</td>
</tr>
<tr>
<td>Number receiving a diagnostic assessment</td>
<td>840</td>
<td>6970</td>
</tr>
<tr>
<td></td>
<td>0.33</td>
<td>0.16</td>
</tr>
<tr>
<td>Waiting times from referral to assessment (weeks)</td>
<td>48.7</td>
<td>45.3</td>
</tr>
</tbody>
</table>

Note: For England figures for 2019/20 were calculated as total or average across the four quarters. Methodological approach to calculate these figures may vary across England and Wales.

Source: LE Wales based on figures provided by IAS, experimental statistics on Autism Waiting Time from NHS digital and ONS’ 2018-based population projections

Overall, despite the differences between the systems and the data limitations, there are a few interesting considerations:

- The presence of specific primary legislation does not necessarily mean that the autism strategy is fully adequate and fully meet the needs of autistic people and their families;
- There is a strong emphasis in both Wales and England to improve awareness and understanding of autism;
- There is a strong attention on the importance of training for relevant professionals in both Wales and England;
- There is an increased focus on data collection and sharing across different bodies and organisations;
- Experimental statistics for England suggest that this increased focus on autism related issues is associated with an increased number of referrals (in the pre-Covid period) and a similar pattern may also emerge for Wales.
4 Policy options

This chapter describes the three policy options assessed. The “business as usual” scenario (option 1) forms the baseline against which the Code of Practice (option 2) and primary legislation (option 3) are assessed.

4.1 Option 1: Business as Usual

Under option 1 we assume that the current programmes and services will continue to be supported, although neither a Code of Practice nor new legislation will be introduced. This section contains an overview of the current actors involved in providing services for individuals with autism in Wales followed by a description of how these services work in practice. The practical information on autism services was informed by the stakeholder interviews which were conducted with a variety of individuals who are either directly involved in providing support, or have been diagnosed with autism, and are thus users of the services.

4.1.1 Key actors in the provision of autism related services in Wales

The key actors in providing public services for autistic people in Wales are the National Autism Team (NAT), the National Integrated Autism Service (IAS), Neurodevelopmental (ND) Services, the Together for Children and Young People Programme (T4CYP) and Local Authorities. A range of third sector organisations also provide support for autistic people and their families. The schematic in Figure 4 provides an overview of the key actors and their main functions.

Wales was the first country in the UK to develop a national approach and publish an ASD Strategic Action Plan in 2008 (Welsh Government, 2009). Since then, the plan has been refreshed in 2016, and an updated delivery plan was released for the period 2018-2021 in order to reflect the feedback of autistic people, their families and carers (Welsh Government, 2019a). The aim of the Strategic Action Plan is to ensure that individuals with autism and their families are supported by outlining which actions will be and need to be taken in order to improve well-being. The ASD delivery plan explains what will be done (and how) to improve autism services in the key areas of ‘Assessment and Diagnosis’, ‘Meeting Support Needs’, ‘Awareness Raising, Information and Training’ and ‘Delivering the Priorities for the Social Services and Wellbeing (Wales) Act’. The Welsh Government also publish annual reports of the Strategic Action Plan to monitor the progress being made in delivering existing and new policy commitments.

The National Autism Team (NAT) aid the implementation of the ASD Strategic Action Plan by collaboratively working with partners, stakeholders and the Welsh Government. The NAT hosts the website AutismWales.org which provides information and resources to increase the awareness and understanding of autism. The National Autism Team is funded by the Welsh Government and hosted through a partnership between the Welsh Local Government
Association and Public Health Wales. The NAT receives approximately £600,000 per year from Welsh Government to finance core activities and staffing.\(^{24}\)

In 2016 the concept of a **National Integrated Autism Service (IAS)** was launched. There are 7 Integrated Autism Services (IASs) across Wales, and their purpose is to provide diagnoses and post-diagnostic support to adults with autism, who do not have other co-morbidities such as learning difficulties or severe mental health problems. IASs work in partnership with Local Health Boards and Local Authorities to provide support and advice for autistic adults, their families, and professionals.\(^{25}\) The parents of autistic children may also be referred to an IAS for support or guidance. Autistic people who also have a learning disability or a mental health problem usually receive diagnostic assessment and support services through the Health Board mental health or learning disability services.

The first IAS opened in 2017, and the last services in Western Bay and West Wales were operational by mid-2019 (Holtom et al., 2019). Initial interviews with stakeholders suggest that there has been a positive reception of IASs, with feedback regarding the quality of support provided by the IASs improving over time as the services have become more established. The Welsh Government initially invested £13 million to establish the 7 IASs, and in 2019 it was announced that the government would continue to support the services with £3 million a year across the IASs.

The IAS is funded through the seven **Regional Partnership Boards (RPBs)**\(^ {26}\), who are responsible for promoting the integration of local authorities, health boards and third sector organisations. The RPBs were established as part of the Social Services and Well Being Act (2014) to improve the well-being of the population and improve the way health and care services are delivered. RPBs are key actors in developing regional population needs assessments and regional area plans which set out integrated approach to service design and delivery\(^ {27}\). As part of their task, all Regional Partnership Boards must: produce a regional population assessment; produce a regional area plan; provide a regional annual report; demonstrate citizen engagement and co-production. RPBs will receive £28,000 to prepare for the implementation of the Statutory Autism Code in 2021/22.

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\(^{24}\) Around 80% of this is staff costs.  
\(^{26}\) The RPBs receive funding specifically for the IAS via the Welsh Government’s [Integrated Care Fund](https://www.gov.wales/integrated-care-fund).  
\(^{27}\) [Regional Partnership Boards](https://www.gov.wales/about-wales/regional-partnership-boards).
One of the key aspects of the current system is that under the IAS it is possible for individuals to self-refer for an autism assessment or if they need support (Holtom et al., 2019). This removes some of the barriers to accessing autism assessments and services that were observed in previous systems. The first IAS Data Report, which was published in 2020, showed that of the 3,337 referrals made to the services for an autism assessment, 36% were self-referrals from adults (Autism Wales, 2020). Parents and carers of autistic children and adults
made up 680 referrals with 82% being self-referrals. In total, the IAS had over 5,600 interactions with autistic adults in 2018/2019.\textsuperscript{28}

**Neurodevelopmental (ND) Services** are responsible for diagnosing children and young people under the age of 18 with ND conditions, including autism. ND teams are multidisciplinary and can include the following professionals: Clinical Psychologists, Psychiatrists, Specialist Nurses, Speech and Language Therapists, Occupational Therapists, Community Paediatricians, Assistant Psychologists and Specialist Health Care Support Workers.\textsuperscript{29} After accepting a referral, the ND team will work in partnership with other health, education and social care services to gather information about the child’s history and behaviour to build a complete picture of how the child’s difficulties are affecting his/her life. ND teams offer feedback to families and young people to ensure that they understand the outcome of the assessment.

The **Together for Children and Young People (T4CYP)** programme was developed to improve the emotional well-being and mental health services for children and young people in Wales. Although the programme is not specific to autism services, one of the priorities of the programme is to address the needs of children and young people with autism. The NHS led programme was originally launched in 2015 to help establish the Neurodevelopmental Service in Wales, Neurodevelopmental (ND) pathways and Standards.\textsuperscript{30} ND pathways describe how children can access ND services, and how they should be assessed. Under the T4CYP programme, national assessment pathways were developed and waiting time standards have been fully implemented across Wales. The programme was funded by the Welsh Government, and had an annual budget of £2 million from 2016-2019.

In 2018 the Minister of Health and Social Issues announced that the T4CYP programme would be renewed and would receive further annual funding of £2 million between 2019-2022. The new programme, known as **T4CYP (2)**, focuses on three key areas: early help and enhanced support, Neurodevelopmental Services, and Regional Partnership Boards. Part of the T4CYP (2) remit is to develop a framework for early help and enhanced support with a view of addressing the “missing middle”. This framework is planned to be rolled out at an RPB level from 2021 onwards.\textsuperscript{31}

**Local Authorities** are important actors in the provision of autism services. Each local authority employs an **Autism lead** who is responsible for planning services for individuals with autism,

\textsuperscript{28} More information about the types of services the IAS provides can be found [here](#).

\textsuperscript{29} NHS Wales (undated, retrieved 13 Jan 2021) [Neurodevelopmental Services](#).

\textsuperscript{30} NHS Wales Health Collaborative and T4CYP (2020) Together for Children & Young People (2) Programme: A vision for Neurodevelopmental Support and Services in Wales.

\textsuperscript{31} National Assembly for Wales Children, Young People and Education Committee Follow-up on the Mind over Matter report MOM 05. Response from: [Together for Children and Young People (T4CYP)](#).
and often provide autism training in their communities. Their role is generally not to work directly with autistic individuals, but to regularly meet with the IAS, ND services, T4CYP and NAT in order to share information and coordinate services. The collaborative aspect of this setup has been praised by some stakeholders, as meeting with several different service providers can bring to light issues and find better solutions.

Local authorities employ Autism leads with different backgrounds, which may lead to inconsistencies in terms of autism priorities across different areas. For example, in areas where the Autism lead works in education services they may naturally prioritise the needs of children over the social, mental or health care needs of autistic adults.

Third sector organisations such as the National Autism Society (NAS), the Autism Spectrum Connections Cymru (ASCC) and AP Cymru (The Autism Charity) also play an important role in providing a variety of services to the autistic community. These organisations not only provide support and advice to autistic individuals and their families but can also run specialist training, provide one to one support and other support services. Local authorities and the IAS may refer individuals to these organisations when individuals have specific needs.

The National Institute for Health and Care Excellence (NICE) publish guidelines for healthcare professionals, families and individuals about how to recognise, assess, diagnose and manage autism in children and adults. They provide pathways to be followed in the assessment process, pathways that describe the services available post-diagnosis, as well as guidelines on who should make up a neurodevelopmental team. NICE guidelines stipulate that comprehensive assessment should be undertaken by a team of professionals and involve family members, carers and use documentary evidence such as school reports wherever possible.

In 2017 a waiting time standard was introduced to ensure that waiting time data is collected by each ND service and meets certain standards. The waiting time standard includes a requirement for ND teams to cut waiting times to a maximum of 26 weeks (6 months). Waiting times in ND services have been increasing in all areas and the services are struggling to meet the waiting time standard. The reason for the increase in waiting times is the rising demand for assessments in all areas. Four key drivers of increasing demand have identified:

1) An increase in the amount of awareness about ND conditions amongst families and professionals;
2) Changes in the criteria for referrals and diagnoses;
3) Expectations from schools and parents, and a need for a diagnosis to access services and in some cases welfare benefits; and,
4) Unmet demand left by the limited capacity of services in the past (Holtom et al.,2019).

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32 NICE (2019).
33 Welsh Information Standards Board (2017).
4 | Policy options

4.1.2 Features of current system (Option 1)

This section describes how services for individuals with autism function “on-the-ground” and is informed by practical information gathered from stakeholder interviews. From stakeholder interviews, we also learned where there are gaps in the provision of autism services, what works well and where improvements need to be made. The section is organised according to the four sections of the code of practice in order to make comparisons across options easier.

Diagnosis and assessment

The diagnostic pathways are fundamentally different for adults and children, because the services that provide autism assessments, the IAS and ND services, differ in a number of dimensions. These dimensions include who is able to refer individuals for a diagnosis, the type of diagnoses that can be offered and the support that is provided aside from the initial diagnosis. Figure 5 depicts the referral process for children and adults for ND and IAS services respectively. The main differences between the processes are outlined in red.
Figure 5  The referral process for autism assessments for children and adults

- Referred by GP
  - ND (children)
    - Referral accepted
    - Referral not accepted
      - Not enough information
  - Other diagnosis
    - ASD diagnosis
      - Diagnosis is often seen as a “golden ticket” for other services (e.g., education or NAS support), but ND services usually do not provide support themselves.

- Referred by school
  - Parents referred by ND for support

- Referred by other services (e.g., mental health)
  - IAS (adults)
    - Referral accepted
    - ASD diagnosis
      - Post diagnostic support, guidance and advice

- Self-referred
  - Referral not accepted
    - Not enough information
    - Not eligible

Individuals who have cooccurring conditions such as LD or psychiatric conditions may not be eligible for an assessment by IAS and would need to be assessed by LD, or mental health teams.
While adults can self-refer to the IAS for a diagnostic assessment, children must be referred to ND services either through their school or by a General Practitioner (GP). The referral process for children can sometimes cause problems as a lot of detailed information about the child’s behaviour is required. GPs do not necessarily have all of the information on hand which sometimes leads to incomplete referral forms. These forms are often rejected, or returned with a request for additional information, which leads to longer waiting periods for children and their families. Work is underway to improve this process to avoid this problem. In some areas, ND services only accept referrals from schools, but this can also lead to problems when children are home-schooled.

The second dimension in which the pathways differ is that the IAS does not provide support to autistic adults with co-occurring conditions such as learning disabilities or serious mental health problems. For those with more complex needs (where other services such as mental health support is needed), staff from the IAS work with other professionals to ensure they are able to provide ‘autism-friendly’ support. As co-occurring conditions are very common among individuals with autism, the number of autistic adults who are eligible for IAS support is relatively small. This is because individuals with co-occurring conditions (e.g. Learning Disabilities or Mental Health problems) would generally be referred to the specific service for assessment (for both autism and the co-occurring condition). However, practices may vary across Wales and, also, some autistic people with less severe co-occurring conditions may receive assessment and services directly from the IAS team.

The ND services on the other hand provide diagnostic assessments for all neurodiverse children. The ND services’ approach has been praised by the majority of stakeholders as it reflects the complex ways in which ND conditions may present themselves.

Thirdly, the IAS provides diagnostic assessments as well as post-diagnostic support, guidance and advice. The budgetary split between the two services is approximately 60:40 in favour of providing diagnoses. ND services only provide diagnostic assessments, without offering any post-diagnostic support. This has led to a reputation among some of the stakeholders we interviewed of ND services being “diagnosis factories”. According to the stakeholders, the strong focus of ND teams on diagnosis is mainly due to lack of qualified staff and financial constraints meaning that most of the time for qualified professionals is spent providing diagnosis rather than more focussed support.

The transition period for young people between the ND services and the IAS can be difficult. In some areas it has been the case that ND services have accepted referrals for young people

34 Some ND services provide assistance to parents and young people to complete referral forms, but this is not standard practice.

35 Referrals for adults with learning disabilities or mental health problems may be rejected by IAS, as these cases should be handled by learning disability services, or mental health services respectively.

who are 17 years old knowing that the waiting lists are so long that they will not be assessed before they turn 18.\textsuperscript{37} This has led to some individual cases where a young person is on a waiting list for months in the ND services, and must then start at the back of the queue again on the IAS waiting list when they turn 18. In most areas however the ND services and IAS work relatively flexibly together to accommodate those cases and work is ongoing in this area. A number of common principles for this waiting list transition has recently been shared with ND teams and IAS teams and the Code refers to transition and highlights the NICE guidance on this point.

**Waiting times** in autism services refer to the time between the point when a referral has been accepted and the time of an individual’s first assessment. The average waiting times for children between referral and initial assessment for ND services range from between 6 to 24 months (Holtom et al., 2019). The average waiting time for IAS assessment for adults is 48.7 weeks (approximately 11 months).\textsuperscript{38} Due to “gatekeeping” (regulating the number of referrals that are accepted) and periods of “watchful waiting” (periods in which the individual is observed to establish whether symptoms are stable), the process can take considerably longer than these waiting times indicate (Holtom et al., 2019). In some areas, it can take over two years for children to receive a diagnosis.

According to information gathered through conversations with stakeholders, the long waiting times are primarily due to severe capacity constraints in addition to higher than anticipated demand. In some areas, even when there are no barriers in terms of funding, ND and IAS services struggle to find staff who are adequately trained and have enough experience. One stakeholder mentioned that some of the professionals in ND teams feel as though they are not able to provide the support they would like to give children because they are driven by the high demand for diagnoses to provide diagnostic assessments.

**Health and social care**

A number of stakeholders suggested that it should not be necessary to provide specialised health and social care for individuals with autism, as they should be able to receive the care they need within the existing health and social care structures. This requires health and care workers to be adequately trained to recognise the signs of autism and be able to provide additional/appropriate adjustments for them to be able to provide appropriate services for autistic people. Moreover, while the type of care needed may not be different, the way in which care is delivered to different individuals may be crucial.

In practice, health care professionals are not always adequately trained in autism as was pointed out by our stakeholders. Adults with autism often have related mental health issues such as anxiety or depression. A lack of autism training in mental health services may lead

\textsuperscript{37} Individuals older than 17 years and 9 months should be directly referred to the IAS, however, given the long waiting lists of over 2 years in some areas the risk of sitting on ND and then IAS waiting lists is still present.

\textsuperscript{38} Autism Wales (undated, retrieved 13 Jan 2021) Integrated Autism Service.
practitioners to misunderstand the root cause of these mental health problems, resulting in a failure to refer individuals to IAS, and providing sub-optimum support. Furthermore, interventions that generally work for anxiety, depression and other mental health problems may need to be adapted to meet the needs of autistic people. For example, standard programmes such as Cognitive Behavioural Therapy as an intervention for depression will often not be appropriate for people with autism and learning disabilities without adaptation. Mental health professionals without necessary autism training may not be able to make appropriate adaptations to meet the needs of their autistic clients.

**Awareness and training**

One of the priorities for the NAT is to create resources for the general public to learn more about autism and how autistic people should be treated. The NAT is responsible for the maintenance of the AutismWales.org website which contains resources for autistic individuals, their families, and professionals who work with autistic people and require support and guidance. According to stakeholders, although public awareness about autism is relatively high, there is a lack of deeper knowledge and understanding about how to interact with autistic individuals.

One of the issues around the current system is that there is no official framework for training in autism. This means that people either have a general awareness of autism or a master’s degree, and there is no common framework for training levels in between. Although there is no formal budget for autism training for local authorities, Autism leads provide ad hoc training for professionals. The IAS also provides support to professionals who wish to gain knowledge, skills and experience in working with autistic people. This is done through training, consultations, advice and in some cases joint working. The resources provided by NAT include online training videos for professionals in fields where autism training may be needed, such as education, health, housing and employment services. The onus is on professionals to find the resources on the website and take the time to complete the training.

**Planning and monitoring services**

A key struggle for providing autism services is the lack of data on the number of individuals with autism and their needs. Without knowing anything about the specific needs of the autistic community, it is difficult for local authorities to know how to plan services. Although the IASs have recently begun to collect data on the number of referrals, diagnoses and waiting times, and released the first data report in 2020, ND services do not disaggregate their data by condition making it difficult to know how many individuals have autism and what needs they may have.

### 4.2 Option 2: Code of practice for the delivery of autism services

To address some of the gaps in the current system, the Welsh Government proposed the introduction of a [Code of Practice](#) for the delivery of autism services. The first public consultation for the Code of Practice ended in March 2019 (Welsh Government, 2019b). Overall, the responses from the first consultation were positive and individuals were
generally in support of the proposed guidelines. Many of the responses included suggestions for further issues which should be addressed in the Code, as well as requests for clarification. Based on this feedback a second public consultation for an amended version of the Code ran from September 2020 until December 2020. Responses to the second consultation were published in March 2021.

The goal of the Code is to provide clarity about existing guidelines and legislation in order to increase the accountability of health boards, local authorities and NHS trusts and Regional Partnership Boards so that individuals with autism may be supported effectively. The Code assigns responsibility to the different actors individually, and collectively, to provide support to individuals with autism, as well as for continued support for their parents/caregivers. In addition, the Code provides information on the level and range of services and support that need to be provided and is rooted in the NICE Guidelines and existing legislation.

Implementing the code of practice is not expected to incur any additional costs to the Welsh Government who have already planned it into their workstream. This is because the code only reinforces the existing duties of local authorities and local health boards, services are not expected to require any additional funding to be complicit with the code. The purpose of the code of practice is to underpin and strengthen the delivery of the ASD Strategic Action Plan, by reinforcing existing duties placed on Local Authorities and Local Health Boards under the Social Services and Well-being (Wales) Act and the NHS (Act)\(^{39}\). However, the expected increase in training for relevant professionals would place an additional cost on the relevant organisations (e.g. local authorities, local health boards, NHS trusts etc.) and would include at least the opportunity cost of attending training.

**Box 1 Key differences between options 1 and 2:**

- Option 2 could achieve the aims of the current legislation more quickly than option 1
- Greater awareness about autism and the needs of autistic individuals
- Autism training for all health and social care staff working in local authorities, local health boards and NHS trusts, which may lead to better recognition of symptoms and earlier diagnosis
- Increased pressure on local authorities, local health boards and NHS trusts to provide adequate services for autistic individuals

**Assessment and diagnosis**

The Code sets out the correct procedures for identification, referral, assessment and diagnosis, and for support during the assessment process and after diagnosis. This means

\(^{39}\) See the correspondence between the Cabinet Secretary for Health and Social Services and the Chair of the Finance Committee Autism (Wales) Bill: Committee stage 1 report (2018). National Assembly for Wales.
that practitioners should receive training on autism so that they can recognise the signs, as well as guidance on referral pathways for assessment. The supporting guidance of the Code also clarifies which professionals must be part of the multidisciplinary autism assessment teams, and the type of support that should be available both during the assessment period and post-diagnosis.\textsuperscript{40}

The majority of stakeholders do not believe that the Code will have a significant impact on assessment, diagnosis or waiting times. However, the Code will require that a care pathway is outlined after the assessment, which stakeholders believe will be especially beneficial in children’s services so that parents and carers can understand what type of support is available to them.

\textbf{Health and social care}

The second section of the Code describes the arrangements that individuals with autism can follow to access health and social services. Under the Code, health and social services must accommodate the needs of autistic people in their workflow. In addition to ensuring that health and social care services provide the right type of support, the Code also provides clarity for autistic individuals and their families about their rights and what types of services are available for them.

Different stakeholders expressed concern that the Code is too focussed on providing services, as opposed to addressing the needs of autistic individuals. They felt that the Code should be more “outcome-led” and focus on improving individuals’ outcomes by helping them with specific needs, instead of being “service-led” and focussing on providing as many comprehensive services as possible. Other stakeholders expressed the hope that the Code may encourage a more holistic approach in supporting autistic people than the current system as there is an emphasis on the integration of different services.

\textbf{Awareness and training}

The Code specifies which actors are responsible for raising awareness about autism and providing training on autism. Local authorities, local health boards and NHS trusts must ensure that staff working in health and social care must have specific autism awareness training. They must also undertake an autism learning and development needs assessment for all of their staff, and regularly provide opportunities for learning and development. All professionals who work with, assess, care for, or treat autistic individuals should have

\textsuperscript{40} Children’s core autism assessment teams must include paediatricians and/or child psychiatrists, Speech and Language Therapists, and clinical and/or educational psychologists for children. These teams must also have regular access to occupational therapists and other professionals such as specialist health visitors or nurses, specialist teachers or social workers. Adult autism assessment teams must include clinical psychologists, primary care services and nurses, occupational therapists, psychiatrists, social workers and speech and language therapists.
appropriate training to provide adequate care and support. This includes clinicians, health professionals, social workers, teachers, pharmacists, dentists, and emergency services (including fire, ambulance and call handlers).

This section of the code was met with enthusiasm from all stakeholders that were interviewed, although many expressed concerns about how training goals could be reached without additional funding. Greater awareness about autism and the needs of autistic individuals can help to reduce stigma so that individuals are more inclined to seek support. Through generating autism awareness, the Code will also increase awareness about other ND conditions could lead to more holistic support for a greater number of people.

Although training is provided by NAT, local authorities and IAS in the current system attendance for professionals is voluntary, which results in a situation where only those who are interested in autism will seek training. The Code sets out a requirement for professionals to undergo autism training and stipulates which bodies are responsible for providing it. Training professionals to be able to support autistic people may save money in the long-run as the additional needs of autistic individuals are more likely to be recognised by a trained professional and this will lead to steps being taken to prevent escalation and stressful situations.\(^{41}\)

Although stakeholders acknowledged the importance of training, many are concerned that it would not be possible to provide the type of training described in the Code without earmarked funding. The NHS and Social Care Wales have training budgets, but as individuals with autism make up only a small part of the community it is unlikely that training in this condition will be prioritised over other types of training.

**Planning and monitoring services**

The Code stipulates which bodies are responsible for monitoring services and collecting data, as well as the type of data which needs to be collected and the format. The Code also requires regional partnership boards to select an “autism champion” to ensure that the needs of autistic individuals are being met. The purpose of this is to enable the Welsh Government to develop policies and make provision for services which can improve the outcomes for autistic individuals.

The Code is expected to support data collection and data sharing between different autism actors. In particular, regional partnerships boards should oversee local data on autism which informs the population needs assessment and assists in monitoring delivery of the area annual plan, while Local health boards and local authorities are required to collect

\(^{41}\) For example, autistic individuals have additional housing needs that are easily overlooked. In one such case, an autistic individual was placed in a flat opposite a noisy neighbour, this created a lot of tension and eventually led to a confrontation in which the police were called to intervene. Appropriate autism training on the part of the housing officer may have prevented escalation.
information on autism services at a local level to support the population needs assessment. Moreover, the Code places responsibility on regional partnership boards, local health boards and local authorities to collect information on the extent to which individual outcomes are improved and the quality of services provided for autistic people and their family or carers. In particular RPBs are expected to undertake a series of actions to support monitoring and service improvement for autism, (e.g. to identify a board member to lead on autism monitoring and service improvement; to discuss autism services at least annually to ensure area plans are being achieved etc.).

Stakeholders from local authorities specifically thought that the aspect of having access to data about the number of diagnosis and referrals in their area would help them to plan services. Stakeholders were also enthusiastic about there being an autism champion in each area.

4.3 **Option 3: Introduction of Primary Legislation on Autism**

Third option under consideration is to introduce primary legislation on Autism such as the proposed Autism (Wales) Bill which was introduced to the Senedd in 2018 (but rejected by the Assembly) or existing legislation in England and Northern Ireland (Autism Act 2009 and Autism Act (Northern Ireland) 2011). The rationale for creating a legal requirement is that it would ensure a measure of permanence and sustainability in the delivery of services for autistic individuals (National Assembly for Wales, 2018). Primary legislation would also ensure a continued focus on meeting the needs of children and adults with autism, irrespective of the financial or political climate. Stakeholders also pointed out that if legislation was in place, autistic individuals and their families would be able to take legal action if they did not receive adequate support. In addition, primary legislation is generally accompanied with a dedicated funding stream which would ensure that the measures introduced in legislation could be sustained.

**Box 2  Key differences between option 3 and option 1**

In hypothetical terms, primary legislation would differ from option 1 in the following ways:

- Introducing primary legislation is costly and time consuming
- Autistic individuals and their families will be able to appeal if service provision is inadequate
- Primary legislation would ensure that a focus on autism is sustained regardless of financial or political climate
- Primary legislation could come with a dedicated funding stream

Furthermore, the main differences between the specific Autism (Wales) Bill proposed in 2018 and option 1 would have been the following:

- Waiting times target outlined in option 3 are 13 weeks, while in the current system the standard is 26 weeks for children, and there is no equivalent standard for adults
Introducing the bill would have been costly and time consuming
Welsh ministers would be made responsible for raising public awareness
Welsh ministers would be made responsible for procuring, updating and publishing data on autism and autism services on an annual basis

The Autism (Wales) Bill required the Welsh Government to publish an autism strategy and review it at minimum every 3 years. The Bill also required Welsh Ministers to publish guidance along with the autism strategy, to raise awareness about autism through public awareness campaigns, and to obtain, produce and publish data about autism on an annual basis. Box 3 presents a short summary of the bill as it is on the Senedd website.

Box 3  About the Autism (Wales) Bill

“The Bill delivers its purpose by seeking to:

- Introduce a strategy for meeting the needs of children and adults in Wales with ASD conditions.
- Require the Welsh Ministers to issue guidance to the relevant bodies on implementing the strategy.
- Require the Welsh Ministers to collect suitable data to facilitate the implementation of the Bill.
- Require the Welsh Ministers to undertake a campaign to raise awareness and understanding of ASD”.

Although the Autism (Wales) Bill was rejected after it was found that there was not sufficient evidence to support its implementation, the following section will draw on the requirements set out in the proposed bill to outline the potential differences between a business as usual scenario and introducing primary legislation.

Assessment and diagnosis

Section 2 of the Autism bill states that the autism strategy must provide for diagnostic assessments and post-diagnostic meetings to be commenced within any timescales set out in the relevant quality standards. The quality standards referred to is the NICE clinical guideline 128 which recommends a maximum waiting time of 3 months for children and young people, and the NICE quality standard 51 on Autism which recommends a 3 month waiting period for children and adults.

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42 Welsh Parliament (Undated, retrieved 13 Jan 2021) Autism (Wales) Bill.
43 From VWCPS Specification: Annex 3
In order to meet these targets, ND services and the IAS would have to reduce their waiting times to a maximum of 13 weeks. A variety of stakeholders believed that the bill was too heavily focussed on waiting times and if implemented would result in lower quality assessments and come at the expense of providing post-diagnostic support.

**Awareness and training**

Under section 2 of the bill the autism strategy which should be prepared by Welsh Ministers should identify key professionals and provide appropriate, but not mandatory, training for them. Under section 7 of the Bill, Welsh Ministers would be responsible for initiating and maintaining campaigns to raise awareness and understanding of the needs of people with autism.

The section of the bill about raising awareness positively received by some stakeholders as the government are in the best position to reach the general population and should therefore take responsibility for raising awareness. Greater awareness about autism in the general population could make daily tasks such as going to the shops or riding the bus less stressful for autistic people.

**Health and social care services**

The Autism (Wales) Bill did not specifically address any issues around health and social care services.

**Planning and monitoring services**

The key aspect of the Autism (Wales) Bill is that the Welsh Government is responsible for publishing an autism strategy and reviewing it at intervals of no more than three years. This includes commissioning independent reports on the strategy’s implementation, and regularly making revisions and recommendations where necessary. Welsh ministers are also responsible for obtaining, producing and updating reliable data on autism, which should be anonymised and published annually.
5 | Costs and benefits of the different options

In this section we review the available evidence on costs associated with autism and potential benefits arising from effective interventions. There is very little evidence specific to Wales in terms of services provided, existing costs and potential benefits of different interventions. Moreover, it is unclear to what extent the introduction of the Code or new legislation would affect expenditure on autism related services in practice.

5.1 Estimates for the Business-as-usual scenario

Previous estimates contained in the Regulatory Impact Assessment published with the Autism (Wales) Bill: Explanatory Memorandum (2018) and also discussed in the Financial implications of the Autism (Wales) Bill (2018) outline costs for Option 1 and Option 3 and also discuss potential implications of Option 2. These estimates are mainly based on the work undertaken for Scotland by MacKay et al. (2017) and adjusted for Wales.

In the table below we present the estimates for Wales for the next decade, developed following the same methodology used in the previous studies, but looking at the period 2022-2031, uprating the cost data to 2021 prices and taking into account the revised ONS population projections.

Table 3 ‘Costs of autism’ over 2022-2031 under option 1 (business as usual)

<table>
<thead>
<tr>
<th></th>
<th>Average annual cost in 2021 prices</th>
<th>NPV (2021, £)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autistic individuals with LD</td>
<td>£550mn</td>
<td>£4.58bn</td>
</tr>
<tr>
<td>Autistic individuals without LD</td>
<td>£640mn</td>
<td>£5.32bn</td>
</tr>
<tr>
<td>Combined</td>
<td>£1,191mn</td>
<td>£9.90bn</td>
</tr>
</tbody>
</table>

Note: LD: Learning disabilities. Average annual cost calculated over the 10 years in constant 2021 prices. Net Present Value calculated using a 3.5% discount rate. Total costs for children and adults (assuming a life expectancy of 67 years). Area of costs included in the estimates are education, health and social care, accommodation, and productivity loss for individuals with autism and their parents. Cost figures have been rounded.


Average annual cost over the 10 years was estimated to be around £1,191 million across the entire autistic population, with a Net Present Value of almost £10 billion. An indication

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45 For the Autism (Wales) Bill version of Option 3.

46 In the memorandum the cost of the Business as usual scenario was estimated to be around £1,125 mn in the first year (in 2017 prices).
of the types of costs included in these estimates of the ‘cost of autism’ is provided in the Box below.

### Box 4 Costs included in the ‘cost of autism’ estimates

<table>
<thead>
<tr>
<th><strong>Accommodation</strong></th>
<th>e.g. supported living accommodation;</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Education</strong></td>
<td>e.g. education received in special units within mainstream schools, special day schools or residential schools; support received from a classroom assistant, special teacher, speech and language therapist, occupational therapist etc.; school extra-educational support received from an educational psychologist or a school family worker;</td>
</tr>
<tr>
<td><strong>Health and Social Care</strong>: type of care</td>
<td>costs for inpatient, outpatient and community care, respite care. Healthcare professionals: visits to GP, support received from a speech and language therapist, a psychiatrist, psychologist, community paediatrics, social worker or some other healthcare professional;</td>
</tr>
<tr>
<td><strong>Productivity loss (individual with ASD)</strong></td>
<td>e.g. lower employment rates, higher incidence of part-time working;</td>
</tr>
<tr>
<td><strong>Productivity loss (parents)</strong></td>
<td>e.g. lower employment rates, higher incidence of part-time working.</td>
</tr>
</tbody>
</table>

Although these estimates are based on information currently available for Wales, they are based on a methodological approach developed for Scotland (and using Scottish microdata), so may not adequately reflect the Welsh situation. As such, they should be considered as providing an indication of costs under the BAU scenario, rather than accurate estimates.

### 5.2 Costs of newer autism specific services

Over the last five years the Welsh Government has provided funding to set up and deliver services specifically targeted at providing support for individuals with autism and supporting the delivery of the ASD Strategic Action Plan.\(^{47}\) In particular, the Welsh Government provided\(^{48}\) £13m to deliver the Integrated Autism Service up to March 2021 (£3 million per year) and £2m annually to support improvements in children’s neurodevelopmental services (however covering not just autism but a wider range of ND services). Funding for these services has been confirmed for 2021/22. To provide an indication of the overall costs associated with these services over the next decade we have assumed that funding will

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\(^{47}\) This is in addition to the pre-existing learning disability and mental health services available to people with autism.

\(^{48}\) Also, the Welsh Government provided funding of £730k to deliver the work programme.
continue at current levels (i.e. staying constant in real terms); however this was done for illustrative purposes only as there is currently no confirmation of funding after 2021/22.

Below we present the costs for autism specific services (Integrated Autism Services, Neurodevelopmental children services and the National Autism Team) over the period 2022-2031 (we have included all costs associated with the ND children services as it was not possible to disaggregate between autism and other ND conditions). The average annual cost is equal to £5.6mn (reflecting the cost in 2021/22 as we assumed that all costs rise in line with inflation), while the Net Present Value is almost £47mn over the 10-year period.

Table 4  Costs of newer autism specific services during 2022-2031

<table>
<thead>
<tr>
<th>Service</th>
<th>Average annual cost in 2021 prices</th>
<th>NPV (2021, £)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integrated Autism Services (IAS)</td>
<td>£3mn</td>
<td>£24.9mn</td>
</tr>
<tr>
<td>Neurodevelopmental services (ND)</td>
<td>£2mn</td>
<td>£16.6mn</td>
</tr>
<tr>
<td>National Autism Team (NAT)</td>
<td>£0.6mn</td>
<td>£5.0mn</td>
</tr>
<tr>
<td>Total</td>
<td>£5.6mn</td>
<td>£46.6mn</td>
</tr>
</tbody>
</table>

Note: Average annual cost calculated over the 10 years in constant 2021 prices. Net Present Value calculated using a 3.5% discount rate. For illustration only as funding for these services has not been confirmed beyond 2021/22. Cost figures have been rounded.

Source: LE Wales based on data provided by the Welsh Government

5.3  Potential impacts of implementing the Code of Practice

From a review of existing evidence, Code documentation and discussion with stakeholders the main areas where the code may have an impact are the following:

- Increased expectations for training to be available for all relevant professional figures (discussed in greater detail overleaf): some stakeholders have raised concerns about funds being diverted from other activities if training becomes mandatory or similar (e.g. for all local authority staff);
- Better awareness leading to an increase in the demand for services. However, there is no additional funding associated with the implementation of the Code, so some stakeholders pointed out that greater demand could lead to an increase in waiting times (if there is an increased demand but no additional funds), although others had a more neutral view;
- On the other hand, the implementation of the Code could contribute to reducing waiting times due to greater efficiency in service coordination and delivery;
- Improvements in data collection and data sharing. Data on adult services are already being collected by the IAS teams (and thus are already part of the existing budget allocation), while information on children services is currently not published specifically for autism services (and again, it is accounted for by existing budget allocation). It is possible that other professionals (e.g. local authority staff) are involved in the data collection and sharing, but it was not possible to quantify their involvement in terms of time or costs;
5 | Costs and benefits of the different options

- There are also some **small transitional costs** associated with the implementation of the Code: in particular, Regional Partnership Boards will receive £28,000 to prepare for the implementation of the Statutory Autism Code in 2021/22 (each Regional Partnership Board will receive £4,000 to establish the autism infrastructure which will be required to successfully plan and monitor delivery and outcomes).

Overall, it is difficult to say exactly what type of impact the Code will have on actual practices and standards; and, given the uncertainty and limited specific data on the current situation and the impact of the Code, it is difficult to quantify the impact on costs.

In terms of **benefits**, the main expected benefits from the Code (as already discussed in section 4.2) are related to:

- Greater awareness and an increase in autism specific training for relevant professionals, potentially leading to better recognition of symptoms and earlier diagnosis;
- Increased pressure on local authorities, local health boards and NHS trusts to provide adequate services for autistic individuals;
- Achieving the aims of current legislation more quickly than the business-as-usual scenario;
- Being easier, quicker and less expensive to implement compared to new primary legislation;

**Potential impact on training - illustrative example**

To provide an illustrative example of how the Code may have in impact on training we present below the potential costs of providing training to all professional figures listed in the code. This is provided for illustration only as current rates of training for different professionals are unclear (as training may be provided by a variety of subjects, including the NAT, IAS team, local authority staff providing internal training, external providers etc.) and also there is uncertainty on the proportion that will receive training (as training is not mandatory, although professionals are expected to undertake it). Our understanding is that, currently, plans for future training to meet the requirements of the Code are not fully developed.

For the purposes of constructing this illustrative estimate we have used the following assumptions:

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49 i. clinicians – psychiatrists, paediatricians, psychologists (clinical and educational); ii. medical, nursing and allied health professionals; iii. social workers; iv. teaching workforce; v. therapists – occupational speech and language, physio; vi. pharmacists vii. podiatrist; viii. dentists; ix. general practitioners; x. emergency service – fire, ambulance (including call handlers); xi. first point of contact.
• Level 1 training will be provided to all staff working in Education, Health and Social Care and Protective Services;
• Current levels of training are unknown, but based on NAT data we estimated that at least 5.8% of the education workforce in Wales received training in the latest academic year (we considered both 2018/19 and 2019/20 to take into account of the COVID-19 effect after March 2020). Due to the lack of comprehensive information for other categories we assumed that the same rate of training was also provided to other workforce types;
• One fifth of the workforce in the specified categories is assumed to undertake training in each year – costs associated with training are assumed to become recurring due to new joiners and refresher courses;
• Length of training is assumed to be equal to 1 hour of working time for the specified professionals and the associated opportunity cost was estimated using ASHE data on hourly pay (and the number of employees in each category)\(^{50}\);
• For the purposes of the analysis we only considered the opportunity costs of training as we assumed that training would be delivered online (using existing resources);
• The additional cost associated with the implementation of the Code was calculated based on the proportion of the relevant workforce attending level 1 training in each year (20%) compared to the proportion attending training in the BAU scenario (5.8%);
• For this illustrative example, we did not assess the costs of more specialised training (beyond level 1), as the number of professionals currently receiving training (and how things will change with the code) is unclear. Nevertheless, higher levels of training are likely to play an important role in making services more accessible for people with autism.

The indicative additional costs of training calculated using this approach was estimated to be slightly below £1mn per year, with a total NPV of £8.3mn over the decade.

\(^{50}\) Median gross hourly pay was £18.74 for education professionals, £14.85 for health and social care staff and £16.39 for protective services (data referring to 2020). On top of that we considered 30% on-costs (based on figures reported by UKHCA and PSSRU). Relevant workforce size was 116,500, 187,700 and 14,000 for education, health and social care, and protective services respectively (Oct 2019-Sep 2020). It is assumed that the workforce grows at the same rate of population aged 16 to 66 over the next decade.
Table 5  Illustrative additional training costs incurred over 2022-2031 under option 2

<table>
<thead>
<tr>
<th></th>
<th>Average annual cost in 2021 prices (£)</th>
<th>Net Present Value (NPV) (2021, £)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>£419,000</td>
<td>£3.5mn</td>
</tr>
<tr>
<td>Health and social care</td>
<td>£530,000</td>
<td>£4.4mn</td>
</tr>
<tr>
<td>Protective services</td>
<td>£43,600</td>
<td>£0.4mn</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>£992,000</strong></td>
<td><strong>£8.3mn</strong></td>
</tr>
</tbody>
</table>

Note: Average annual cost calculated over the 10 years in constant 2021 prices. Net Present Value calculated using a 3.5% discount rate. For illustration only as current levels of training are unknown. Cost figures have been rounded.

*Source: LE Wales calculations based on NAT training data, hourly wage data from ASHE population projections from ONS and inflation data from OBR.*

5.4  Potential impacts of primary legislation

In this section we briefly review the potential impacts of introducing primary legislation – first the introduction of the Code requirements in the form of primary legislation, rather than a statutory code; and second the Autism (Wales) Bill of 2018.

**Costs and benefits of introducing primary legislation**

The stakeholders we spoke to had mixed views about the benefits of introducing the requirements of the Code through primary legislation rather than through a statutory code of practice. Since this is about the way in which the requirements are imposed, rather than the nature of the requirements themselves, then the costs and benefits relative to the baseline are similar to the costs and benefits of Option 2, but with additional impacts linked to the specific method of introducing the requirements (i.e. primary legislation).

Some felt that if the requirements were introduced through primary legislation then the relevant organisations would be more likely to comply with the requirements; that the penalties for non-compliance might be tougher; and that there might be more scope for interested parties to take action if the requirements of the legislation were not being met. It was also argued that since primary legislation would be harder to amend, then it would be more likely that the requirements would stay in place in the future.

Other stakeholders felt that there was little reason to introduce the requirements through primary legislation rather than through a statutory code of practice, arguing that the Code has a statutory basis in any case and that the introduction of primary legislation would delay the introduction of the Codes requirements even further.

**Estimated costs associated with the 2018 Autism (Wales) Bill**

The Explanatory Memorandum to the 2018 Autism (Wales) Bill provided an estimate of the costs of implementing the proposed Bill. Total costs of delivering the 2018 Autism (Wales) Bill for all organisations involved (Welsh Government, Local Health Boards, Public Sector Organisations) were estimated to be around £1.73mn in the first year and £7.39mn over
five years (in 2017 prices). In 2021 prices that would correspond to an average cost of £1.6mn per year (over the first five years). Although the Memorandum reported that the Bill would result in considerable benefits, these were not directly quantifiable.\(^5\)

However, the National Assembly for Wales Finance Committee when scrutinising the financial implications of the proposed Bill concluded that they were unable to make a decision on the validity of the RIA due to the lack of financial information, and all these estimates should be considered with care.

Some of the expected benefits of the Bill are outlined in Section 4.3.

### 5.5 Summary of the three scenarios

In Table 6 we summarise the main costs and benefits associated with each option. The costs and benefits of Option 1 reflect anticipated changes over time in that Business-as-Usual scenario. Those impacts are also relevant to Option 2 (Code of Practice) and Option 3 (new primary legislation), though the costs and benefits indicated for Options 2 and 3 are the additional costs and benefits relative to the Business-as-Usual scenario. For options 2 and 3, costs and benefits are the result of the stakeholder consultation and our own assessment, but cannot be anticipated with certainty.

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\(^5\) ‘There is evidence that the Bill will result in considerable benefits, both direct and indirect, but these are not possible to quantify and hence unknown’.

\(^5\) ‘Conclusion 4. The Committee is unable to make a decision on the validity or not of this Regulatory Impact Assessment. Members have not received any substantial financial reason for the legislation not to go forward, but we have been unable to ascertain whether there is any value for money in this legislation due to the lack of financial information.’
Table 6 - Summary of main costs and benefits associated with the 3 options

<table>
<thead>
<tr>
<th></th>
<th>Business-as-usual</th>
<th>Code of practice</th>
<th>New primary legislation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Main costs</strong></td>
<td>• Health and social care</td>
<td>• Transitional costs of implementing the code for all organisations involved</td>
<td>• Longer time and higher costs to discuss and pass legislation</td>
</tr>
<tr>
<td></td>
<td>• Education</td>
<td>• Further costs for data sharing</td>
<td>• Higher transitional costs to comply with new legislation</td>
</tr>
<tr>
<td></td>
<td>• Accommodation</td>
<td>• Increased demand on services</td>
<td>• Higher costs to meet reduced waiting time targets</td>
</tr>
<tr>
<td></td>
<td>• Productivity loss for individuals with ASD and their parents</td>
<td>• Training costs</td>
<td>• Higher costs for mandatory training</td>
</tr>
<tr>
<td></td>
<td>• Funding of recent ASD specific services (IAS, NAT, ND services)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Data collection and sharing</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Main benefits</strong></td>
<td>• Better health conditions and higher quality of life for autistic patients and their families</td>
<td>• Greater efficiency in service coordination and delivery</td>
<td>• Reduced waiting time targets enshrined in legislation</td>
</tr>
<tr>
<td></td>
<td>• Lower costs of subsequent interventions linked to early intervention</td>
<td>• Improvements in awareness and training</td>
<td>• More stringent requirements</td>
</tr>
<tr>
<td></td>
<td>• Better education outcomes due to ALN interventions</td>
<td>• Potential reduction in waiting times</td>
<td>• Higher compliance due to more stringent penalties</td>
</tr>
<tr>
<td></td>
<td>• Reduction in productivity loss</td>
<td>• Increase data sharing and availability</td>
<td>• Improvements in awareness and training</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Quicker and easier to implement</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Better planning and monitoring</td>
<td></td>
</tr>
</tbody>
</table>

Note: Based on stakeholder legislation, review of available evidence and authors’ own assessment
6 Conclusions

The Code of Practice is designed to underpin the delivery of the current legislation (the Social Services and Well-being (Wales) Act 2014 and the NHS (Wales) Act 2006) and to ensure that the improvements achieved through the delivery of the Autism Spectrum Disorder Strategic Action Plan (first published in April 2008 and updated in 2016) are sustainable for the long term. The main aims of the Code are to promote better awareness of autism amongst statutory services; to secure the long-term provision of autism services which can meet individual needs and provide support for the families or carers of autistic people; to improve integration and collaboration between services to prevent individuals from falling between service responsibilities; and to promote the involvement of autistic people in the design and delivery of the services they receive.

Over the last five years the Welsh Government has provided funding to set up and deliver services specifically targeted at providing support for individuals with autism and supporting the delivery of the ASD Strategic Action Plan: the Integrated Autism Service (IAS), Together for Children and Young People (T4CYP), and continued support for the National Autism Team (NAT). The implementation of the Code is an additional step in supporting continued improvement in the development and delivery of autism services in Wales.

Unfortunately, there is little Welsh specific evidence currently available to assess quantitatively the cost of introducing the Code; nonetheless based on a review of existing evidence, Code documentation and discussion with stakeholders we have identified the following as the main areas where the Code may have an impact.

- Increased expectations for training to be available for all relevant professional figures. This is expected to have an impact on costs, mainly linked to the opportunity cost for relevant professionals undergoing training.
- Better awareness leading to an increase in the demand for services. However, there is no additional funding associated with the implementation of the Code, so it is potentially conceivable that greater demand could lead to an increase in waiting times (if there is an increased demand but no additional funds).
- On the other hand, the implementation of the Code could contribute to reducing waiting times due to greater efficiency in service coordination and delivery.
- Coordination among different Welsh actors (regional partnership boards, local health boards and local authorities) is expected to improve under the Code.
- Improvements in data collection and data sharing are already occurring for adults and children services and are expected to further develop under the Code. In particular the Code places responsibility on regional partnership boards, local health boards and local authorities to collect information on autism services and on regional partnership boards to oversee local data on autism.

Overall, it is difficult to say exactly what type of impact the Code will have on actual practices and standards; and, given the uncertainty and limited specific data on the current situation and the impact of the Code, it is difficult to quantify the impact on costs.
The introduction of primary legislation was also discussed with stakeholders and they had mixed views about the benefits of introducing the requirements of the Code through primary legislation rather than through a statutory code of practice. Some felt that if the requirements were introduced through primary legislation then the relevant organisations would be more likely to comply with the requirements and that it would be more likely that the requirements would stay in place in the future. However, other stakeholders felt that the Code has a statutory basis in any case and that the introduction of primary legislation would delay the introduction of the Codes requirements even further.

Moreover, experience from other UK nations (in particular England) suggests that the presence of specific primary legislation alone does not necessarily mean that the autism strategy is fully adequate and fully meet the needs of autistic people and their families. In fact recent developments show that there is a strong emphasis in similar areas in both Wales and England to improve awareness and understanding of autism, to ensure that training is provided to relevant professionals, to further develop data collection and sharing.
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UK Parliament POSTNOTE 612 January 2020 *Autism*.


Welsh Government (2016) *ASD Adult Diagnostic task and finish group report*


Welsh Information Standards Board (2017) *Data standards change notice*.


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Annex 1 | Cost-benefit framework

The theoretical framework for impact assessment is presented in Box 5 below, while in Table 7 we summarise the key areas of costs associated with having autism and the potential benefits stemming from effective and timely service provision. The areas and examples of cost estimates are derived from an initial exploration of the available literature and refer to the United Kingdom (when available). They relate to the costs and benefits of providing autism services, rather than specifically on the cost and benefits of the Code or the Bill.

Box 5 | Costs and benefits – theoretical framework

**Areas of costs**

The main areas of costs identified in the literature are the following:

- Costs for direct medical services, including assessment and diagnosis costs, expenses for healthcare professionals, costs for interventions and therapies, hospital costs etc.;
- Costs for social care services, covering assessment and diagnosis costs, costs of service provision, costs of hiring additional staff and providing specialised training etc.;
- Costs of providing special education services to individuals with autism;
- Employment and earnings loss for adults with autism;
- Employment and earnings loss for parents/carers of individuals with autism;
- Accommodation costs both in private households and in accommodations arranged for by the healthcare services (e.g. residential care);

**Potential benefits**

The effect of providing timely and appropriate services to individuals with autism may potentially induce benefits in a series of areas:

- Non-monetary benefits, including better education, health and well-being for autism patients and their families (although an improvement in these areas may also lead to monetary benefits as discussed below);
- Lower future costs for the healthcare system due to early and appropriate interventions following a timely diagnosis;
- Increased earnings for adults with autism and their parents/carers due to better education and health conditions;

**Intervention channels**
When assessing the effect of each option it needs to be considered how the effect of the intervention could lead to different costs and benefits under the scenarios considered. In particular, we have identified the following channels:

- **Increased take-up**: introducing the Code of Practice or new legislation may increase awareness and the number of referrals, leading to a higher number of diagnosis;

- **Early interventions**: increased awareness may also lead to individuals requesting an assessment (or being referred to) at an earlier stage compared to the business-as-usual scenario;

- **Reduction in waiting times** due to the introduction of a Code of Practice or legislation defining the maximum length of time elapsing between referral and diagnosis;

- **More tailored services** delivered to autism individuals currently receiving services, but without being diagnosed with autism (e.g. receiving support for learning disability);

Although these factors may lead to higher costs they may also have positive effects on patients’ (and carers’) health, education and well-being and employability.

**Risks and limitations**

- There may be overlap between cost areas and it may be difficult to identify separately some of the costs. Also, information on costs may not be available in the Welsh context, meaning that UK or other estimates may be used.

- Non-monetary benefits (e.g. better health and well-being) may be difficult to quantify and monetary benefits (e.g. increased earnings), may rely on high level assumptions;

- The likely presence of confounding factors, in particular it is likely that a number of autistic patients are currently already receiving health and care services although without a formal diagnosis of autism (this is especially relevant for patients with learning disabilities).

- Even if we were able to quantify accurately the number of people with autism in Wales and the number currently with an autism diagnosis, it would be very difficult to quantify how many of those not receiving any services will refer to the Welsh healthcare system and ask for a formal diagnosis; in other words, it is highly challenging to estimate the magnitude of the additional demand for services stemming from increased awareness under options 2 and 3 and any estimate should be seen as providing an indication only.

- An increase in take-up due to greater awareness may potentially lead to longer waiting times for an assessment due to increased demand for healthcare services and pressure on staff. However, under the Code of Practice we expect there to be a greater incentive for ND services to meet existing waiting times standard (26 weeks between referral acceptance and start of the intervention for children, while there is no set standard for adults), while under the proposed legislation there would be a legal requirement of maximum waiting times of 13 weeks (for both adults and children). The
two effects lead in different directions, but if both are implemented as a consequence of options 2 and 3, we would expect costs to increase and waiting times to decrease (although that may be difficult to implement in practice in the short term due to limited availability of additional staff with the right skills).

Figure 6 shows a summary diagram of the framework for impact assessment highlighting the key steps and limitations.

**Figure 6  Framework for impact assessment – summary diagram**

**Source: LE Wales based on available information and own assumptions**
### Table 7  Example of costs and benefits of Autism Spectrum Conditions from the literature

<table>
<thead>
<tr>
<th>Cost/benefit area</th>
<th>Description</th>
<th>Initial cost estimates from the literature for Children with autism (2011 prices)</th>
<th>Initial cost estimates from the literature for Adults with autism (2011 prices)</th>
<th>Main risks/limitations for Welsh analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical services</strong></td>
<td>Costs: costs for medical professionals, costs related to hospital and A&amp;E admissions, pharmaceutical and therapeutical costs. Benefits: better health conditions and higher quality of life for autistic patients and their families. Potential lower costs of subsequent interventions linked to early intervention.</td>
<td>With LD**: £276 - £1,818</td>
<td>With LD: £5,142</td>
<td>Need to explore whether these costs are collected separately for autistic patients. May be difficult to identify benefits</td>
</tr>
<tr>
<td></td>
<td>With LD: £267 - £890</td>
<td>Without LD: £16,044</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Without LD: £267 - £890</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Social care services</strong></td>
<td>Costs: costs of service provision for day care, child-care, special programmes, after-school care, transport, respite care etc.. Costs of arranging and providing assessment (including costs for healthcare professionals and administrative costs). Cost of training staff. Benefits: better health conditions and higher quality of life for autistic patients and their families. Potential lower costs of subsequent interventions linked to early intervention.</td>
<td>With LD: £0 - £7936</td>
<td>With LD: £2,871</td>
<td>Identify separately these costs for autistic patients. The fact that some autistic patients are already receiving some of these services with no formal diagnosis.</td>
</tr>
<tr>
<td></td>
<td>With LD: £0 - £1,561</td>
<td>Without LD: £3,610</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Without LD: £0 - £1,561</td>
<td></td>
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<tr>
<td><strong>Special education</strong></td>
<td>Costs: costs of provision for special education services (including early intervention costs and costs for dedicated teachers).</td>
<td>With LD: £0 - £32,774</td>
<td>With LD: £2,619</td>
<td>Some autistic individuals may already be</td>
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</table>
### Annex 1 | Cost-benefit framework

<table>
<thead>
<tr>
<th><strong>Costs</strong></th>
<th><strong>Benefits</strong></th>
<th><strong>Without LD</strong></th>
<th><strong>With LD</strong></th>
<th><strong>Note</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Employment prospects for adults with autism</strong></td>
<td><strong>Costs:</strong> Loss in employment and earnings for adults with autism. Costs for employment support programmes. <strong>Benefits:</strong> potential increase in productivity due to specific intervention received.</td>
<td>N/A</td>
<td>With LD: £25,644</td>
<td>Measuring the loss in earnings and potential effect of interventions.</td>
</tr>
<tr>
<td><strong>Employment prospects for parents/ carers of individuals with autism</strong></td>
<td><strong>Costs:</strong> Loss in employment and earnings for parents and carers of individuals with autism. <strong>Benefits:</strong> increase in parental productivity</td>
<td>With LD: £608 - £5,314</td>
<td>With LD: £1,477</td>
<td>Measuring the loss in earnings and potential effect of interventions.</td>
</tr>
<tr>
<td><strong>Accommodation</strong></td>
<td><strong>Costs:</strong> for autistic individuals living at home costs related to adaptations and equipment and other out-of-pocket expenses (e.g. damages, extra laundry, special dietary requirements). For autistic individuals not living at home, costs for residential care, supported living accommodation etc. <strong>Benefits:</strong> better quality of life for autistic individuals and their families</td>
<td>With LD: £0 - £1,240</td>
<td>With LD: £41,512</td>
<td>Difficult to identify accommodation costs for individuals living at home.</td>
</tr>
</tbody>
</table>

Note: all figures are in 2011 prices (£) * Cost data for medical services is not separated from residential care in the UK. The cost of residential care therefore includes medical costs for individuals who are frequently in government sponsored residential care, while adults without receiving special education and other services for learning disabilities, but with no formal autism diagnosis...
Annex 2  Research methods

A2.1  Stakeholder interviews

The original aim of the research was to undertake 10-15 interviews. Over the period mid-January to early February 2021 we undertook 16 interviews.

We spoke to a range of people across a number of different organisations, including Welsh Government, the National Autism Team, Integrated Autism Service, local authorities, academics working in this field, and an autism charity. A small number of the people that we have interviewed have been people with autism or people who are parents of people with autism.

Interviewees were sent an Interview Guide – in English and Welsh – before the interview and this was used to structure the discussions, which generally lasted about an hour. We were flexible in giving interviewees the freedom to focus on the issues of particular interest to them. One interview was conducted in Welsh and the rest were conducted in English. Interviews were all undertaken using an online video facility. Interviewees were also offered a telephone call as an alternative. Most interviews were conducted with one interviewee and two interviewers, though one interview included several interviewees. To maintain consistency, one interviewer took part in all of the interviews and an additional interviewer took part in most of the interviews, taking notes during the interview. Interviews were not audio recorded.

Given the limited nature of the stakeholder engagement, it clearly does not provide a representative view of the impact of the Code or other policy options in any way, but it has enabled us to gain a clearer understanding of a range of views about how the current system works; and how the Code and primary legislation (a hypothetical Bill) might change that. Some interviewees were able to help us with data and we had some follow up e-mail exchanges with these interviewees.

A2.2  Desk research

Our desk research included searches for written qualitative and quantitative evidence. We undertook:

- a short review of relevant parts of the academic literature with guidance from our partners at the University of Warwick;
- reviews of reports produced by relevant organisations in Wales (e.g. NAT, IAS etc) – some of these were found by us online and some were provided by the stakeholders that we engaged with;
- searches for data relevant to describing the system as it currently is and to the costs and benefits of introducing the Code and primary legislation for Autism. These searches have included online searches and discussions with stakeholders, both during and after our interviews with them.
Whilst we were able to find plenty of qualitative information about the current provision of services to people with autism in Wales, quantitative information was much more limited, particularly in relation to services for children and young people and their families. The amount of evidence relating directly to the potential impacts of the Code and introducing primary legislation (the hypothetical Bill) is also limited.
Annex 3 Stakeholder interview guide – English

Interview guide for LE Wales discussions with stakeholders on the proposed statutory Code of Practice on the provision of autism services in Wales

LE Wales are currently undertaking research for Welsh Government on the costs and benefits of the proposed statutory Code of Practice on the provision of autism services. Our research will feed into the Welsh Government future policy development work for neurodevelopmental services.

We are hoping to have a discussion with you about issues relevant to the Code. In particular we would like to understand your views on some of the following:

1. Current services
   - What works well and what doesn’t work so well? e.g. in the areas of:
     - Assessment/diagnosis
     - Service provision
     - Integration of care/health/other services
     - Current capacity, staff availability
     - Services for protected characteristics and for Welsh Language provision
   - How do you see things changing in the future (without the introduction of a Code of Practice)?

2. Autism awareness and training
   - How has awareness of the needs of people with autism changed over time? Are improvements needed?
   - Could more awareness lead to greater demand for services?
   - Is training for professionals adequate? How could it be improved?
   - What impacts could better training have?

3. Statutory Code of Practice
   - What are the main improvements that the Code of Practice will achieve? How?
   - What are the problems/barriers for the implementation of the Code’s requirements?

4. New legislation
   - An autism bill was proposed in the Senedd in 2017, did you see any merit in this approach?

53 The Welsh Government recently consulted on this code.
• What do you see as the main advantages/disadvantages of using primary legislation rather than a statutory Code of Practice as a mechanism for improving services?

5. **Data**

• We would like to understand what data (if any) your organisation holds in relation to the demand, provision and costs of autism services in Wales and whether any of that data would be available to us in our current research.
Annex 4 Stakeholder interview guide – Welsh

Canllaw cyfweliad ar gyfer trafodaethau LE Wales gyda rhanddeiliaid ar y cod ymarfer arfaethig ar gyflenewi gwasanaethau awtistiaeth yng Nghymru

Ar hyn o bryd mae LE Wales yn cynnal ymchwil i Lywodraeth Cymru ar costau a buddion y cod ymarfer arfaethig ar gyflenwi gwasanaethau awtistiaeth. Bydd ein hymchwil yn bwydo i mewn i waith datblygu polisi Llywodraeth Cymru yn y dyfodol ar gyfer gyflenwadiadau a gyflawniadau gwasanaethau awtistiaeth.

Rydym yn gobeithio cael trafodaeth gyda chi am faterion sy’n berthnasol i'r Cod. Yn benodol, hoffem ddeall eich barn ar rai o’r canlynol:

1. Gwasanaethau cyfredol
   • Beth sy’n gweithio’n dda a beth sydd ddim yn gweithio cystal? e.e. ym meysydd:
     o Asesu / diagnosis
     o Darparu gwasanaeth
     o Integreiddio gofal / gwasanaethau iechyd / gwasanaethau eraill
     o Cyflenwad presennol, argaeledd staff
     o Gwasanaethau ar gyfer nodweddion gwarchodedig ac ar gyfer darpariaeth Gymraeg
   • Sut ydych chi’n gweld pethau’n newid yn y dyfodol (heb gyflwyno cod ymarfer)?

2. Ymwybyddiaeth a hyfforddiant awtistiaeth
   • Sut mae ymwybyddiaeth o anghenion pobl ag awtistiaeth wedi newid dros amser? A oes angen gwelliannau?
   • A allai mwy o ymwybyddiaeth arwain at fwy o alw am wasanaethau?
   • A yw hyfforddiant i weithwyr proffesiynol yn ddigonol? Sut y gellid ei wella?
   • Pa effeithiau y gallai gwell hyfforddiant eu cael?

3. Cod ymarfer statudol
   • Beth yw’r prif welliannau y bydd y cod ymarfer yn eu cyflogi? Sut?
   • Beth yw’r problemau / rhwystrau ar gyfer gweithredu gofynion y Cod?

4. Deddfwriaeth newydd
   • Cynigiwyd bil awtistiaeth yn y Senedd yn 2017, a welsoch chi unrhyw rinwedd yn y dull hwn?

54 Ymgynghorodd Llywodraeth Cymru ar y cod hwn yn ddiweddar.
• Beth yn eich barn chi yw prif fanteision / anfanteision defnyddio deddfwriaeth sylfaenol yn hytrach na chod ymarfer statudol fel mecanwaith ar gyfer gwella gwasanaethau?

5. **Data**

• Hoffem ddeall pa data (os o gwbl) sydd gan eich sefydliad mewn perthynas â galw, darpariaeth a chostau gwasanaethau awtistiaeth yng Nghymru ac a fyddai unrhyw ran o’r data hwnnw ar gael inni yn ein hymchwil gyfredol.
# Annex 5  Summary of stakeholder responses

<table>
<thead>
<tr>
<th>Referrals</th>
<th>Business as usual</th>
<th>Code of practice</th>
<th>Autism (Wales) Bill/ Primary Legislation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stakeholders</td>
<td>Stakeholders were generally satisfied with the fact that adults are able to self-refer for an autism assessment, but lamented the fact that children must be referred by a GP or an educator. Stakeholders noted that some ND services will only accept referrals from GPs (this has led to problems as GPs don’t always have all of the information they require), while others only accept referrals from schools (also problematic as children with behavioural problems are often home-schooled).</td>
<td>The code will provide clarity so that NICE guidelines will no longer be interpreted differently by the different areas- this will prevent areas from only accepting referrals from schools/GPs. The training described in the code will ensure that professionals are able to recognise the signs of autism, and therefore better able to refer individuals who have autism.</td>
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</tbody>
</table>

| Waiting times   | Stakeholders all agreed that waiting times for child and adult services were too long, and attributed the long waiting lists to a combination of poor planning (services were not | Raising awareness about autism and autism services could lead to higher demand and therefore longer waiting times, however, most of the stakeholders interviewed did | The bill has a heavy focus on the waiting times, and many stakeholders believe that if the target of 13 weeks was to be |
|                 | waiting times |                                                                 |                                                                                            |
## Summary of stakeholder responses

<p>| | |</p>
<table>
<thead>
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<tbody>
<tr>
<td><strong>aware of the demand for autism assessments when they were conceived</strong> and lack of staff availability (there simply aren't enough professionals in Wales who are willing and able to work in the autism services).</td>
<td><strong>not believe this would be the case. Many believe that families are already sufficiently aware and that the upswing in demand for diagnoses has already happened.</strong></td>
</tr>
<tr>
<td></td>
<td><strong>achieved it would result in lower quality assessments and services.</strong></td>
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<tr>
<td>One stakeholder made the point that there was a lack of communication to patients about where they were on the waiting lists. Referrals are accepted and then families don’t hear from the service again for a year.</td>
<td>One stakeholder pointed out that if people are eligible for services they are probably already on the waiting list so an increase of awareness would not make a big impact.</td>
</tr>
<tr>
<td>No support is offered to individuals while they are on the waiting lists.</td>
<td></td>
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<tr>
<td><strong>Diagnosis</strong></td>
<td><strong>Diagnosis</strong></td>
</tr>
<tr>
<td>A diagnosis is often believed to be a “golden ticket” by parents who have autistic children. Through the diagnosis they hope to be able to get additional support from schools and other services.</td>
<td><strong>Stakeholders generally believe that the code will not have any impact on diagnoses as it “just reinforces what is already happening”.</strong></td>
</tr>
</tbody>
</table>
### Assessment process

- The code will ensure that individuals receive more information when they first make contact with services so that they are aware of the types of support they can access (even without a diagnosis).

### Health and social care services

- ND services are too health orientated (medical), ideally they should have a broader focus and include educational and social care considerations.
- Individuals slip through gaps when they do not fit neatly into a specific diagnosis. This is the case with many autistic individuals who have co-occurring conditions. It is really difficult for them to cross over to different care pathways.
- The Code is very focussed on “autism services”, and while it is important to have specialist services, a better strategy would be to integrating autistic individuals so that they are part of the community- updating existing services to be autism friendly rather than creating services specifically for autistic individuals.
- Stakeholders hope that the code will even out the “patchy” nature of autism service provision across regions.
## Annex 5 | Summary of stakeholder responses

<table>
<thead>
<tr>
<th>Autism awareness</th>
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<tbody>
<tr>
<td>General awareness training is provided by the NAT who have a lot of resources on their website. Stakeholders were positive about the NATs efforts, and reported that the majority of the population had a good understanding of what autism is.</td>
<td>The Code (despite being autism specific) will help to bring other ND conditions to light.</td>
<td>Under the bill, Welsh ministers would be responsible for raising awareness. Some stakeholders were in favour of this, as they believe the Welsh government to be in the best position to address this issue in the general population.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Awareness of autism services</th>
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<tbody>
<tr>
<td>The code is not only a guide for service providers, but also for individuals with autism and their families. The Code can help individuals get clarity about the types of services that they can receive, and what their rights are.</td>
<td>The Code may help bring issues in service provision to the forefront.</td>
<td></td>
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<thead>
<tr>
<th>Training</th>
<th></th>
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<tbody>
<tr>
<td>Training for professionals is completely voluntary. Stakeholders who were involved in providing training</td>
<td>Stakeholders were generally pleased with this section in the Code, however most expressed some concern</td>
<td>Some stakeholders were of the opinion that the bill would have the largest impact on</td>
</tr>
</tbody>
</table>
### Annex 5 | Summary of stakeholder responses

<table>
<thead>
<tr>
<th>Data collection</th>
<th>Data Sharing</th>
</tr>
</thead>
<tbody>
<tr>
<td>report that while it is easy to train those who are interested, it is difficult to reach those who are uninterested.</td>
<td>Not enough data is currently being collected across regions, although this has been improving over the last year or two.</td>
</tr>
<tr>
<td>Training largely depends on “good will” of individuals in local authorities and IAS.</td>
<td>It is difficult to share information between different actors, partly due to privacy concerns, but also because different services use different</td>
</tr>
<tr>
<td>about how training would be funded.</td>
<td>The code is expected to improve information sharing between different service providers. This could lead to better integration between</td>
</tr>
<tr>
<td>■ If training becomes mandatory there will be costs for local authorities, which may result in funds being diverted away from other issues</td>
<td></td>
</tr>
<tr>
<td>■ Training for professionals would not only benefit autistic individuals but professionals themselves. Providing training enables staff to deal with difficult situations with greater confidence and also makes them feel valued.</td>
<td></td>
</tr>
<tr>
<td>training, as primary legislation would come with a dedicated financial stream. The Code does not come with additional training budget.</td>
<td></td>
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</table>
systems to collect and store data. Stakeholders from local authorities mentioned that they often struggle to get information about the number of diagnoses from ND services, making it difficult to plan.

<table>
<thead>
<tr>
<th>Inclusivity</th>
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</thead>
<tbody>
<tr>
<td>It is difficult to share information between different actors, partly due to privacy concerns, but also because different services use different systems to collect and store data. Stakeholders from local authorities mentioned that they often struggle to get information about the number of diagnoses from ND services, making it difficult to plan.</td>
</tr>
<tr>
<td>Some stakeholders mentioned that there is a lack of representation of autistic people when it comes to decisions about autism services. Although this has been improving, autistic people still feel as though they are often</td>
</tr>
<tr>
<td>The Code is thought to acknowledge the complexities of supporting individuals with autism a bit more than the Bill.</td>
</tr>
<tr>
<td>Some stakeholders even see the Code as a first step towards a more holistic approach. These stakeholders believed that the Code would encourage ND services to start providing more post-diagnostic support (like the IAS), and encourage the IAS to provide support to other neurodevelopmental conditions (as the ND services do).</td>
</tr>
<tr>
<td>Many stakeholders felt that the proposed Bill was too autism specific—there are many other neurodevelopmental conditions that also need attention—“Why focus on autism, and not on learning/physical disabilities?”</td>
</tr>
</tbody>
</table>
### Annex 5 | Summary of stakeholder responses

<table>
<thead>
<tr>
<th>Implementation and enforcement</th>
<th>shut out of the conversation, and often organizations are biased towards the views and opinions of parents.</th>
<th>Other stakeholders thought that the focus on autism would lead to fragmentation in the provision of ND services, and considered the code “a step backwards”.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The Code should technically be less time consuming to implement than the Bill, but in practice it has taken much longer.</td>
<td>Some stakeholders stated that primary legislation such as the bill should be easier to enforce than a Code, and therefore believed that the Bill would be more impactful. The Bill would also provide more clarity about whether something is a “must” or a “should”.</td>
</tr>
<tr>
<td></td>
<td>One stakeholder commented that the code has taken so long to be implemented that by now it is a bit irrelevant—the pathways and standards have already been developed, and a lot of what was set out in the Code has already been set in motion.</td>
<td>Other stakeholders, however, believed that the necessary legislation already exists (NICE guidelines, Social Care Wales Act, etc.), and if actors are not following current legislation they are unlikely to follow</td>
</tr>
<tr>
<td></td>
<td>The Code is more “future proof” than the Bill as it can be amended more easily. We are still learning a lot about autism and it reasonable to expect that these advances</td>
<td></td>
</tr>
</tbody>
</table>
will have an impact on how autism is diagnosed and treated in the future.  

- If an autistic individual feels that they are not getting support in line with what the Bill prescribes, then they would be able to appeal - this is an advantage of the Bill over the Code and the status quo.
Mae’r ddogfen yma hefyd ar gael yn Gymraeg.
This document is also available in Welsh