

About NAS Cymru

We are the leading charity for people on the autism spectrum, including Asperger syndrome, and their families. Since we began more than 50 years ago, we have been pioneering new ways to support people and understand autism. We continue to learn every day from the children and adults we support in our schools and care services. Based on our experience, and with support from our members, donors and volunteers, we provide life-changing information and advice to millions of autistic people, their families and friends. And we support professionals, politicians and the public to understand autism better so that more autistic people of all ages can be understood, supported and appreciated for who they are. NAS Cymru works across Wales alongside our 14 volunteer-led branches and members. We also provide support and specialist services for adults across Wales in a number of settings including residential care, supported living, community-based resource centres, at university and in people's own homes

Around 34,000 people in Wales are autistic. Together with their families and carers, they make up around 136,000 people for whom autism is a part of their daily lives.

About Autism

Autism is a lifelong developmental disability that affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people on the autism spectrum share three main areas of difficulty, their condition will affect them in different ways. The three main areas of difficulty are:

- Social interaction: autistic children and adults can have difficulties recognising and understanding their own and other people's feelings. They may sometimes find it hard to manage stress and frustration in ways that are socially appropriate. They may not always understand the 'social rules' and how to interact appropriately with their peers. This can make it hard to form friendships.

- Social communication: autistic people may have difficulties understanding both verbal and non-verbal language, such as people's gestures, facial expressions and tone of voice. They may need support to express themselves and, equally, to understand what is happening during lessons, or what is being asked of them by school staff.
- Social imagination: this affects the ability to imagine situations outside of their normal daily routine, to plan ahead and to cope with change. Many autistic people like set routines, familiar people and environments, and they may have very strong special interests and repetitive behaviours.

Some people on the autism spectrum are able to live relatively independent lives but others may need a lifetime of specialist support. Autistic people may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds touch, tastes, smells, light or colours. This might mean that sensory input such as a ticking clock or screaming in the playground can be highly stressful. Asperger syndrome is a form of autism.

Background

The National Autistic Society Cymru (NAS Cymru) welcomes the opportunity to respond to this consultation which in our view seeks to shape a clear 'made-in-Wales' piece of legislation for autistic children and adults.

NAS Cymru, its members and supporters, and members of the National Assembly for Wales' Cross Party Autism Group have supported the introduction of specific autism legislation to be introduced in Wales since 2014 in order to strengthen the support and provision available and improve the lives of autistic children and adults in Wales.

In January 2016 we launched our 'Act Now' report which set out the need for autism legislation based on responses to an online survey held between May and June 2015. Nearly 90 per cent of the people who responded to our survey said that specific autism legislation was needed in Wales.

We support the need for autism legislation underpinned by a mandatory code or statutory guidance that explains how the legislation must be implemented so that local authorities, health boards and public services are clear on their duties and that autistic people, their parents and carers know what to expect.

Context

NAS Cymru worked with Welsh Government and other stakeholders on the Welsh Government's original autism strategy published in 2008. We were glad to be a member of the Stakeholder Advisory Group working with Welsh Government on its refreshed strategy during 2013 and are currently members of its Implementation Advisory Group. The Group was established in 2017 and held its first meeting in March.

We recognise that the Welsh Government's autism strategy was the first of its kind in the UK, and set out in detail how it would meet the needs of autistic people of all ages in Wales. While some progress has been made, we believe that a non-binding and voluntary strategy alone is not sufficient in securing the change that we all want to see for autistic children, adults and their family members.

Wales is currently at a disadvantage to other UK nations as it doesn't have primary legislation that requires the Government to publish an autism strategy and places legal duties public bodies. It is approaching 10 years on since the publication of the original strategy and there are still such substantial challenges in autism services that we think the time is now right to turn some of the aims and objectives of the strategy into legal requirements.

We have worked with lawyers on a draft Bill that we have attached that we think would help address the significant challenges autistic people and their families face in Wales in getting the support they need. We further clarify below some of the points made in that draft Bill.

Clarity on pathways to diagnosis

We note the Welsh Government's recognition in its refreshed autism strategy that diagnosis of autism remains an issue.

This is one of the key areas of concern among our volunteer-led branches, members and supporters. According to a survey that we published in 2016, six out of ten people had waited more than a year for a diagnosis with a third waiting more than two years. While waiting, people are likely to develop mental health problems and fall into crisis. For children, this can mean being excluded from school and missing out vital years of education. For adults, it may mean missing out on support and information that could help them stay in the workplace and reduce their social isolation.

We welcome the Welsh Government's commitment to improving the diagnosis waiting times for children through the Together for Children and Young People work programme and the introduction of a new 26 week waiting time from referral to first assessment appointment alongside extra recurring funding. We believe this could have a transformative effect on the lives of thousands of autistic children, their parents and siblings.

We also note that a similar 26 week waiting time for diagnosis of autistic adults has been introduced by the Welsh Government for adults and the new integrated autism service which adults can self-refer for diagnostic and assessment services.

However it's unclear if those targets are being met across the country and we believe that more needs to be done to improve the diagnosis process for both children and adults and reduce the waiting time. We would like to see data that records the time from which autistic people or parents first raise concerns with a professional so that there is more clarity around how long people wait for a diagnosis and how this can be reduced.

In England, for example, there is now a legal duty around diagnosis for adults. Adults who suspect they are autistic have been able to use this duty to secure an assessment locally. We have provided draft letters to send to local health bodies to help them to secure their assessment. There are still ongoing challenges around diagnosis in England, but it should be remembered not only that the requirements are adults only in England, but also this legal requirement sets a clear steer for public services and for individuals about what the requirements are.

Under the legislation we would want to see a single point of referral for a diagnosis for children and adults with a clear diagnostic assessment pathway in each local area. Furthermore we would want to ensure that information on the pathway to diagnosis is published regularly and should include the steps that Health Boards and Local Authorities are taking to reduce the waiting times to ensure transparency.

We also believe that the waiting times from referral to assessment should take no longer than three months, in line with NICE guidelines, and that Health Boards should be clear about how they are implementing these guidelines.

In addition, appropriate pre- and post-diagnostic support should be in place for both children and adults. Once a diagnosis has been made, that should trigger a

process of support from relevant bodies, including signposting to services, training opportunities, information on low-level support and a named contact within the local area.

We believe that an autism bill, statutory guidance published alongside it, and any future strategies for autism should:

- place duties on every health board to ensure that there is a clear pathway to diagnosis in every area for children and adults, with a single point of referral;
- ensure each local area publishes its diagnosis pathway;
- ensure that staff are appropriately trained to identify signs of autism for referral and that there are sufficiently trained clinicians to carry out the diagnosis;
- ensure waiting times for a diagnosis are published in each area;
- waiting times for a diagnosis do not exceed NICE guidelines of three months and that there is a way to hold services to account for this; and
- ensure pre- and post-diagnostic support is in place in every local area.

Delivery of services and support

We believe that autism legislation is required to bring about the change we all want to see for autistic people, their families and carers. An autism act should set out how primary legislation will meet the needs of autistic children and adults in Wales, that Welsh Ministers must publish an autism strategy with a mandatory code or statutory guidance.

The strategy and guidance should make clear what is required from local authorities, health boards and other public services and should include:

- implementing a clear pathway of diagnosis for both adults and children in line with NICE guidelines;
- collecting data on the numbers of autistic people through GP surgeries to ensure that local authorities and health boards can plan their support services properly;
- ensuring that local autism plans developed for services and support are

based on need;

- ensuring that local autism plans include a named contact that can provide information and advice;
- statutory local infrastructure groups are established with a named lead officer to ensure that services and support are improved;
- ensuring that access to health and social care services are based on need and not IQ related criterion; and
- awareness and understanding training for key individuals

We would expect the strategy, statutory guidance or a mandatory code to be kept under review every three years initially, with a report on progress of implementing the strategy to be laid and debated in the National Assembly for Wales alongside the steps needed to take to address areas of concern.

In its original autism strategy the Welsh Government stated that ‘access to health and social care services for adults must not be based on IQ criterion’. We have called on the Welsh Government to provide clearer leadership in this area to prevent autistic adults falling between mental health and learning disability teams when trying to access the support they need after a diagnosis. We would therefore support legislation that is explicit that eligibility for services cannot be denied on the grounds of IQ. Having this in law would make absolutely clear that this cannot and should not be happening and give parents and autistic people something to point to if they are being turned away from services on the basis of IQ.

An autism bill should:

- require the Welsh Government to publish an autism strategy with a mandatory code or statutory guidance;
- place specific duties on local authorities, health boards and other public services including:
 - implementing a clear pathway of diagnosis for both adults and children in line with NICE guidelines
 - collecting data on the numbers of autistic people through GP surgeries to ensure that local authorities and health boards can plan their

support services properly

- ensuring that local autism plans developed for services and support are based on need
 - ensuring that local autism plans include a named contact that can provide information and advice
 - statutory local infrastructure groups are established with a named lead officer to ensure that services and support are improved
 - ensuring that access to health and social care services are based on need and not IQ related criterion
 - awareness and understanding training for key individuals
- ensure the autism strategy, mandatory guidance or statutory guidance are kept under review; and
 - ensure that access to health and social care services for adults are based on need and not IQ related criteria.

Training

We know that an increase in awareness and understanding, especially among professionals would help autistic people in Wales get the support they need. We welcome the training resources that have been produced by the Welsh Government in recent months to improve awareness within the education sector in particular. However we also know that these resources are voluntary and therefore take-up across Wales has been patchy.

We would support the development of statutory guidance which sets out which professionals need what levels of autism training to ensure that autistic children and adults are supported by professionals that understand their needs. This would include professionals across health and social care sectors as a priority, especially GPs and community care assessors.

There are more than 6000 children and young people of school age with autism in Wales. Every teacher can expect to teach children and young people with autism during their career and school staff who come into contact with autistic pupils should have an understanding of the condition. Autism training for trainee teachers and teachers who have already qualified but who have not received autism

training should also be included.

In England, there is a model of continued professional development that exists for teachers. The Autism Education Trust [AET] is supported by the Department for Education and provides three levels of training for teachers at school, with the basic training provided free of charge. A similar model could work in Wales. Moreover, from 2018, all teachers in England will learn about autism as part of their initial training.

In our consultation events with our branches, parents were keen for professionals to be given autism training highlighting paediatricians, personal assistants and social workers in particular.

We would also support making a range of training and workshops available to parents and carers across Wales.

An autism bill should

- specify which professionals need what levels of training to ensure that autistic people are supported by professionals who understand them

Employment

More than half [55 per cent] of those who responded to our ‘Act Now’ report said that they’d like more support in getting employment. We also know that that employment rates among autistic adults are much lower than in the general population. Our research suggests that only one in 10 autistic adults are in full time employment.

We believe that there are opportunities within programmes such as Getting Ahead 2 and Working with Autism to increase the levels of employment among autistic adults. We believe that autism apprenticeships schemes be established with employers who take part being supported through Welsh Government.

In our ‘Autism Employment Gap’ report published in 2016, we made a number of recommendations to Welsh Government to help increase the number of autistic people into employment. These included:

- maintain the role of the Autism Employment Ambassador and look at enhancing the role as the autism strategy for Wales is refreshed;
- make sure that support for finding work is included in its Additional

Learning Needs reforms;

- ensure the new £6 million integrated autism service, announced by Welsh Government in March 2016 as part of its refreshed strategy, includes employment support;
- note the recommendations of the England taskforce on apprenticeships and look at the scope for implementing them as part of the apprenticeships programmes in Wales; and
- set a target as part of a wider action plan to boost the number of autistic apprenticeships within the commitment to creating at least 100,000 apprenticeships.

We believe that these recommendations should be considered as the part of the work around developing the bill.

Definition of autism

Our understanding of autism has developed greatly over the decades and we welcome the fact that further research into the condition is being undertaken across the globe. NAS Cymru would support the definition of autism to be included in the supporting guidance rather than on the face of the bill so that it can be updated from time to time.

Costs / Savings

We recognise that there is always some cost in introducing new legislation, however we believe that the costs would not result in significant new burdens on Local Authorities, Health Boards and public services. In fact we believe that over the long term money could be saved by making clear what the duties on them will be.

Local Authorities, Health Boards and public services already have to provide care and support services, including preventative services for people under the Social Services and Well-being Act 2014. Failure to adequately provide these services can have costly consequences for individuals and the state, through people falling into crisis situations, needing expensive services such as residential care and through not being able to work.

We would support the evidence in the report by the National Audit Office (NAO) which states that: 'Beside the negative impact of such crises on a person's life,

acute services are also expensive, with inpatient mental health care costing between £200–£300 per day.’

As a result, the NAO report found that if local services identified and supported just four per cent of autistic adults, the outlay would become cost neutral over time. If they did the same for just eight per cent it could save £67 million each year.

According to ‘The Autism Dividend’ a report published by the National Autism Project, based at the London School of Economics, there is a UK economic impact of £32 billion per annum while the needs of autistic people remain unmet.

Other Issues

In February 2016, the Welsh Government published its independent report on the Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan. It made 21 recommendations that it thought would improve the lives of autistic people. We strongly support these recommendations and would urge them to be given full consideration as part of the consultation process.

Conclusions

In conclusion, we believe that the need for an autism bill is clear. It’s almost a decade on from the publication of the Welsh Government’s original autism strategy, which was the first of the UK’s nations to outline how it would meet the needs autistic people, their families and carers. However, families are still facing lengthy waiting times, provision across the country is patchy and professionals are unable to support autistic people properly as they don’t have sufficient training and understanding.

In the last decade, both Northern Ireland and England have introduced autism acts for their nations. The Dáil Éireann is also currently considering passing legislation in this area. As we look to the next decade, it’s time for Wales to show leadership again and introduce autism legislation to bring about positive, sustainable change that will benefit autistic people.

Summary of recommendations

An autism bill should:

- place duties on every health board to ensure that there is a clear pathway to diagnosis in every area for children and adults, with a single point of referral;

- ensure each local area publishes its diagnosis pathway;
- ensure that staff are appropriately trained to identify signs of autism for referral and that there are sufficient trained clinicians to carry out a diagnosis
- ensure waiting times for a diagnosis are published in each area;
- ensure waiting times for a diagnosis do not exceed NICE guidelines of three months and that there is a way to hold services to account for this;
- ensure pre- and post-diagnostic support is in place in every local area;
- require the Welsh Government to publish an autism strategy with a mandatory code or statutory guidance;
- place a duty to collect data on the numbers of autistic people through GP surgeries to ensure that local authorities and health boards can plan their support services properly;
- local autism plans developed for services and support are based on need;
- local autism plans include a named contact that can provide information and advice;
- statutory local infrastructure groups are established with a named lead officer to ensure that services and support are improved;
- ensuring that access to health and social care services are based on need and not IQ related criterion;
- awareness and understanding training for key individuals; and
- ensures the autism strategy, mandatory guidance or statutory guidance are kept under review.

DIAGNOSIS

During September October and November NAS Cymru held a number of events to gather the views of people across Wales on the proposals in the consultation on an autism bill for Wales. These included a meeting of the Cross Party Autism Group in Bangor, four consultation events with representatives from our Merthyr Tydfil,

Caerphilly, Blaenau Gwent, Wrexham and Bridgend branches, as well as other local stakeholders. We also sought the views of people that we support through our adult services.

Some of the views expressed are summarised below.

Getting a diagnosis was a key issue for most contributors. Some contributors said that the diagnosis service from the new neurodevelopmental team was a positive development. However, people spoke of 'fighting for a diagnosis' and that the process was taking far too long.

Contributors found the process inflexible with the appointments based on the availability of the professionals rather than the needs of parents or autistic people, and as a result were 'kicked off the [waiting] list.'

People sought an open referral process for diagnostic assessment, as too often barriers are put up by those without the necessary understanding. Parents felt like they weren't listened to when seeking a diagnosis for their child. One said "Our knowledge base is often wider than the professionals who are supposed to be helping but we are met with a 'You're only a parent, what do you know' attitude".

A person that we support said: 'Discussing the problems I had when I was younger with the professional that diagnosed me was difficult.'

Contributors in north Wales in particular spoke of having to get a private diagnosis that subsequently wasn't recognised by professionals.

Contributors said that they would value a clear process that set out how long the process for a diagnosis will take. They also wanted to know who would be part of the diagnostic process and what would happen after a diagnosis was made and what support would be available. Contributors said that waiting times for a diagnosis of autism should be published.

Contributors felt that there was a lack of clarity surrounding the diagnostic process for both children and adults.

A person that we support said: 'Getting someone to listen to my concerns and piecing it together' was most difficult part of getting a diagnosis.

One parent spoke of a 'fantastic' process, which took six months from the time at which the possibility of autism was first raised. The parent was proactively offered

counselling support to cope with the diagnosis which was greatly valued. It was said multiple times that a diagnostic assessment should take into account the needs of the whole family.

GENERAL COMMENTS

During September October and November NAS Cymru held a number of events to gather the views of people across Wales on the proposals in the consultation on an autism bill for Wales. These included a meeting of the Cross Party Autism Group in Bangor, four consultation events with representatives from our Merthyr Tydfil, Caerphilly, Blaenau Gwent, Wrexham and Bridgend branches, as well as other local stakeholders. We also sought the views of people that we support through our adult services.

Some of the views expressed are summarised below.

Transport to and from school was raised as an issue with a number of parents expressing concerns that when a different provider was chosen by a local authority, that decision wasn't communicated early enough with parents so that their autistic children could better deal with the change in routine. Parents felt that giving advance notice would be a fairly simple process that would be hugely beneficial.

Contributors highlighted a lack of planning around transitions points. Some parents felt that technologies could help with this especially when transitioning from junior to secondary school. One suggestion was that autistic pupils could visit their new school and take a camera with them so that they could replay the footage to help get used to the new environment and reduce their anxiety.

Transition to adulthood was also a significant factor with one parent saying that their child 'needs some help with being an adult.'

More employment opportunities, including apprenticeships for autistic adults would also be welcomed by the contributors.

A person that we support said: 'Get employers to realise the skills that people with autism have.'

One parent suggested businesses should exclusively recruit autistic people for some roles. It was generally agreed that employers should be given support and

training to help them understand the value that autistic employees can bring to a business.

At the meeting of the Cross Party Autism Group meeting in Bangor, the issue of ensuring that autistic children and adults could access support and services through the Welsh-language was raised and should be specifically addressed in the bill.

SUPPORT

During September October and November NAS Cymru held a number of events to gather the views of people across Wales on the proposals in the consultation on an autism bill for Wales. These included a meeting of the Cross Party Autism Group in Bangor, four consultation events with representatives from our Merthyr Tydfil, Caerphilly, Blaenau Gwent, Wrexham and Bridgend branches, as well as other local stakeholders. We also sought the views of people that we support through our adult services.

Some of the views expressed are summarised below.

Contributors said that after receiving a diagnosis, they felt there was little or no contact made by professionals to explain the next steps. Having a single point of contact was another common theme, with members from the Blaenau Gwent branch suggesting a family liaison or pastoral care type role which would coordinate the support a family needed during and after a diagnosis. In the words of some parents: 'Nobody tells you what happens next' and 'There's no port of call to go to.' There was a clear emphasis on all professionals involved in providing support services were key partners alongside the families – and not 'merely a tick-box exercise.'

"Time-consuming and stressful" to call around and chase up support. Many said that, following a diagnosis, they would like services to be proactively offered.

Support for integrated teams however crucial that they are fully integrated and encompass health, social care and education.

Many families said that there was little or no support available after a diagnosis was received, and many found themselves falling between the Learning Disabilities and Mental Health teams.

Social services eligibility criteria under Social Services and Well-being Act is denying services to autistic people. Parents having to tell LAs that they 'are not willing and able' to support their own child is emotionally traumatic but often the only way to access support. IQ is still a barrier to services which is having a disproportionately negative effect on autistic people.

Where support was in place, it was often because of the commitment by individual people rather than having a robust system in place. One parent commented that while 'good things are run by good people' there were gaps in provision because positions weren't backfilled and local authorities were unable to adequately plan their services.

Concerns were raised that autistic adults can be vulnerable and find themselves in difficult situations. One branch suggested that there were dedicated services day centres for autistic adults where they could learn life and social skills or given opportunities to volunteer in the community. Many parents commented that services finished arbitrarily at 18 years of age, pointing out that there is a difference between someone's actual age and their developmental age.

Contributors also suggested that support for parents was more readily available, including support for their own wellbeing as well as their mental health needs. Reference was also made to the fact that in England, autistic adults can access healthcare checks. This is particularly relevant to people living close to the English border, who may already access some services in England.

There was a general support for collection of data providing people have the opportunity to have a say on how it's used. It was suggested that autism teams could take on the responsibility for capturing this data.

Contributors felt that better communications among professionals would also be of benefit for autistic people and their families.

The issue of access to health care for autistic adults was also raised, with people reporting difficulties in visiting their GPs, hospital settings and dentists in particular.

There was a recognition that money was being spent, but not always wisely: "My son is in a very expensive placement but it's failing him."

TRAINING

During September October and November NAS Cymru held a number of events to gather the views of people across Wales on the proposals in the consultation on an autism bill for Wales. These included a meeting of the Cross Party Autism Group in Bangor, four consultation events with representatives from our Merthyr Tydfil, Caerphilly, Blaenau Gwent, Wrexham and Bridgend branches, as well as other local stakeholders. We also sought the views of people that we support through our adult services.

Some of the views expressed are summarised below.

A lack of understanding of autism among professionals was highlighted by all branches. Contributors felt that a number of professionals should receive mandatory autism training not only to provide better support for autistic people but also as something that professionals could highlight on their CVs, as part of their continuous professional development. Many people noted a particular lack of expertise in identifying the sensory profile of autistic people.

The types of professionals who should receive mandatory training included:

- General Practitioners
- Paediatricians
- Personal Assistants
- Health Visitors
- Social Workers
- Head teachers
- Teachers
- Teacher Assistants
- SENCOs
- Educational Psychologists
- Dentists
- Police
- Ambulance Service
- School bus drivers / school taxi drivers
- Care home workers

Proposed Draft Bill



AUTISM BILL (WALES) [2016]

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AUTISM BILL (WALES) [2016]

A Bill of the National Assembly for Wales to make provision for meeting the needs of children and adults with autism spectrum conditions in Wales with the aim of protecting and promoting the rights of both adults and children with autism in Wales and connected purposes.

[Having been passed by the National Assembly for Wales and having received the assent of Her Majesty, it is enacted as follows].

PART 1 INTRODUCTION Overview

1 Overview of this Bill

1. This Bill has 3 parts.
2. This Part provides an overview of the whole Bill.
3. Part 2 deals with the general functions and covers the autism strategy, guidance by the Welsh Ministers and imposes a duty on local authorities and NHS bodies to act under guidance. Part 2 also sets out a requirement for local authorities to prepare and maintain a register of children and adults with autism.
4. Part 3 deals with the miscellaneous and general provisions including definitions, how expenses shall be dealt with and the extent, commencement and short title of the Bill.

PART 2
GENERAL FUNCTIONS

2 Autism strategy

- (1) The Welsh Ministers must prepare and publish a document setting out a strategy for meeting the needs of children and adults in Wales with autistic spectrum conditions by:
 - (a) improving the provision of relevant services to such children and adults by local authorities and NHS bodies through the following:
 - (i) the identification of children and adults with such conditions including in every local area the NHS shall have a clear pathway to diagnosis and every local authority shall have a clear framework for assessing the care and support needs of children and adults with autism; and
 - (ii) the assessment of the needs of children and adults with such conditions for relevant services and in particular, local authorities and NHS bodies should develop commissioning plans for services for children and adults and review them annually.
- (2) That document is referred to in this Bill as “the autism strategy”.
- (3) The autism strategy must be published no later than [·].
- (4) The Welsh Ministers —
 - (a) must keep the autism strategy under review, and
 - (b) may revise it.
- (5) If the Welsh Ministers revise the autism strategy the Welsh Ministers must publish it as revised.
- (6) The Welsh Ministers must consult and seek the participation of such persons as the Welsh Ministers considers appropriate:—
 - (a) in preparing the autism strategy, or
 - (b) in revising it in a way which would, in the opinion of the Welsh

Ministers, result in a substantial change to the strategy.

- (7) A document prepared and published by the Welsh Ministers before this section comes into force is as effective for the purposes of this section as a document prepared and published after that time.
- (8) Consultation and steps to seek participation undertaken by the Welsh Ministers before this section comes into force are as effective for the purposes of this section as consultation and steps to seek participation undertaken after that time.

3 Guidance by the Welsh Ministers

- (1) For the purpose of securing the implementation of the autism strategy, the Welsh Minister must issue guidance:–
 - (a) to local authorities about the exercise of their social services functions within the meaning of the Local Authority Social Services Act 1970 (c. 42) (see section 1A of that Act), and the Social Services and Well-being (Wales) Act 2014 (section 143), and
 - (b) to NHS bodies about the exercise of their functions concerned with the provision of relevant services
- (2) Guidance must be issued under this section no later than [●].
- (3) Guidance issued under this section must in particular include guidance about:–
 - (a) the provision of relevant services for the purpose of diagnosing autistic spectrum conditions in children and adults;
 - (b) the fact that assessment of the eligibility of children and adults for relevant services cannot be denied on the grounds of the persons IQ;
 - (c) planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults;
 - (d) other planning in relation to the provision of relevant services to children and adults with autistic spectrum conditions;

- (e) the training of staff who provide relevant services to children and adults with such conditions;
 - (f) local arrangements for leadership in relation to the provision of relevant services to children and adults with such conditions.
- (4) The Welsh Ministers must consult and seek the participation of local authorities and NHS bodies before:—
- (a) issuing guidance under this section, or
 - (b) revising it in a way which would, in the opinion of the Welsh Ministers, result in a substantial change to the guidance.
- (5) Consultation and steps to seek participation undertaken by the Welsh Ministers before this section comes into force are as effective for the purposes of this section as consultation and steps to seek participation undertaken after that time.

4 Duty to review the autism strategy and guidance

Strategy

- (1) Not more than three years after the publication of the autism strategy, and at intervals of no more than five years thereafter, the Welsh Ministers must prepare a report on the progress of implementing the autism strategy..
- (2) The Welsh Ministers shall lay a report prepared by the Welsh Ministers under subsection (1) before the National Assembly for Wales as soon as possible after its preparation.
- (3) The autism strategy shall be revised in accordance with the report within [●] months of the publication of the report. [Note: is it useful to have a time frame here for updating the autism strategy?]

Guidance

- (4) The Welsh Ministers:–
 - (a) must keep the guidance under review, and

- (b) must publish revised guidance at intervals of not more than seven years.
- (5) In keeping the guidance under review the Welsh Ministers must in particular consider the extent to which the guidance has been effective in securing the implementation of the current autism strategy.

5 Local authorities and NHS bodies: duty to act under guidance

- (1) This section applies to guidance or revised guidance issued under section 3 to a local authority or an NHS body.
- (2) Guidance or revised guidance is to be treated as if it were general guidance of the Welsh Minister under section 7 of the Local Authority Social Services Act 1970 (c. 42) (local authorities to exercise social services functions under guidance of Welsh Minister) and as if it were a code under section 144 of the Social Services and Well-being (Wales) Act 2014.
- (3) For the purposes of guidance or revised guidance—
 - (a) an NHS body is to be treated as if it were a local authority within the meaning of the 1970 Act (see section 1 of that Act) and within the definition of local authority under section 197 of the Social Services and Well-being (Wales) Act 2014, and
 - (b) the functions of an NHS body mentioned in section 3(1)(b) are to be treated as if they were its social services functions within the meaning of that Act (see section 1A of that Act) and within the meaning of Social Services and Well-being (Wales) Act 2014 section 143.

6 Register of persons with autism

- (1) A local authority must establish and maintain a register of adults with autism in its area and the local authority must keep the register under review.
- (2) The Welsh Ministers are obliged to develop regulations on the register of adults with autism including but not limited to the following:
 - (a) outlining what the register of adults with autism will contain;

- (b) where a local authority includes a person in a register maintained under the regulations, the authority:
 - (i) must inform the person that he or she has been so included, and
 - (ii) if a request is made by the person or on the person's behalf, must remove from the register any personal data (within the meaning of the Data Protection Act 1998) relating to that person.
- (c) making it clear that nothing in the regulations requires a local authority to include any person in a register maintained under the regulations unless –
 - (i) the person has applied to be included in the register, or
 - (ii) an application to be so included has been made on the person's behalf.
- (3) NHS bodies must co-operate with local authorities in providing information required for the preparation of the register.
- (4) In preparing an assessment of relevant needs under and section 19, Social Services and Well-being (Wales) Act 2014, local authorities and partner Primary Care Trusts must have regard to the requirements of persons with autism in their area, as identified by the register.

7 Register of children with autism

- (1) Children Act 1989, schedule 2, clause 2 insert:
 - “(3) Every local authority shall take reasonable steps to ensure that the register includes an accurate record of children with autistic spectrum conditions within their area
 - (4) Every local authority shall ensure the register contains sufficient information to effectively plan services for children with autistic spectrum conditions
 - (5) Nothing in this section requires a local authority to include any child in a register maintained under this section unless an application to be so included has been made on the child's

behalf.”

- (2) Where a local authority includes a child in a register maintained under this section, the authority –
- (a) must inform the [appropriate] person that he or she has been so included, and
 - (b) if a request is made by the child or on the child’s behalf, must remove from the register any personal data (within the meaning of the Data Protection Act 1998) relating to that person.

PART 3 MISCELLANEOUS AND GENERAL

7 Interpretation

- (1) In this Bill:–

“adult” means a person who is aged 18 or over (and, accordingly, “child” means a person who is under the age of 18);

“autism strategy” means the strategy required to be published under section 2(2);

“local authority” means—

- (a) each of the 22 county, borough, city and district councils in Wales;
- (b) a county council;
- (c) a borough council;
- (d) a city council;
- (e) an NHS body;

“NHS body” means:–

- (a) NHS Wales;
- (b) NHS (Wales) Trusts;
- (c) a Local Health Board;

- (d) [a Special Health Authority] performing functions only or mainly in respect of Wales;

“relevant services” means:–

- (a) in relation to an NHS body, means health services provided for the purposes of the health service continued under section 1(1) of the National Health Service Act 2006 (c. 41);
 - (b) in relation to a local authority, means services provided in the exercise of the authority's social services functions within the meaning of the Local Authority Social Services Act 1970 (see section 1A of that Act).
- (2) In this Bill references to the provision of services include references to arranging for the provision of services (and references to services provided are to be construed accordingly).

8 Expenses

There shall be paid out of money provided by the Welsh Ministers:–

- (a) any expenditure incurred under or by virtue of this Bill by the Welsh Ministers, and
- (b) any increase attributable to this Bill in the sums payable under any other Act out of money so provided.

9 Extent, commencement and short title

- (1) This Bill extends to Wales only.
- (2) This Bill comes into force at the end of the period of 2 months beginning with the day on which it is passed.
- (3) This Bill may be cited as the Autism Bill (Wales) 2016.