



HM Government

# Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update.

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Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update.

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## Ministerial Foreword

Since the ground-breaking 2009 Autism Act<sup>1</sup> and the publication of the autism strategy, *Fulfilling and Rewarding lives*,<sup>2</sup> that followed in 2010, a lot of progress has been made in improving support for adults with autism in England. In this update, rather than producing a replacement for *Fulfilling and Rewarding lives* we stand firmly behind the vision and direction of travel that the strategy set in train.

Strong foundations for change have been laid. Local authorities have, in line with the strategy, appointed leads with responsibility for mapping local need and developing plans and, increasingly, people with autism have been engaged locally in planning and designing services. A comprehensive suite of clear national guidance has been issued on the care, management and diagnosis of autism. We have heard about some great experiences people have had in further education or with particular employers and the Children and Families Act 2014 will improve transitions from adult life, provide new protections for those with special educational needs in further education and support pathways into employment for young people. In some areas there are great local autism teams and excellent diagnostic services.

But, we know that we are just at the beginning of this journey. It was only 5 years or so ago, that very low levels of awareness and a lack of services were what led to the Autism Act. So, although we know there are

some real successes, we also know there is much more to do to see those foundations translated into making a greater difference to peoples' lives. As we have reviewed the strategy over the past year, we have also sadly heard from many people with autism and their families and carers who say that things have not yet changed enough for them.

For example, some people with autism, and those that support them, continue to report gaps in provision or waits for diagnostic services. Many people have told us that they have skills to offer employers that are not being put to good use. This is a waste for the individual and for the economy and we must do more to ensure that people with autism have the opportunity to achieve their aspirations in employment. Some have told us that services like the NHS, criminal justice system, or the benefits system could have made better adjustments for their needs. We appreciate the problems that people face, and this strategy sets out some of the real progress we are making and will continue to make in improving services.

With well over half a million people on the autism spectrum, all our everyday services – colleges, social services, health services, employment services and beyond – will already be seeing or in contact with many people who have autism. This is about people's lives – where they live, where they work and the communities they live within.

1. Autism Act 2009, <http://www.legislation.gov.uk/ukpga/2009/15>
2. "Fulfilling and rewarding lives" The strategy for adults with autism in England (2010) [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_113405.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf)

Our society is becoming more aware of autism. We have seen more positive and balanced coverage in art, in literature and in the media of people with autism. We hear about innovative local schemes to make parts of the community more accessible and welcoming to people with autism. The dedicated work of national charities and organisations like the National Autistic Society (NAS), Autism Alliance UK, Autism Plus, Ambitious about Autism and the many smaller local and national organisations and groups who work tirelessly to raise awareness day in and day out makes a real difference. But we know there is much more to be done. We still hear too many stories of what is, at best, clumsy stereotyping, and, at worst, discrimination. People with autism have an equal right to a fulfilling life, just like anyone else.

Working together to improve outcomes for people with autism crosses many government departments; from health and social care to employment, education and criminal justice. We need to continue with concerted action and commitment across Government nationally and locally to make a difference. This update to the 2010 strategy sets out the new challenges people with autism and other stakeholders have set for us. They have identified 15 priority challenges for action where they wanted to see further change. This is an area where we can all make a difference. Each of us should ask ourselves what we know about autism, what we could do in our work and in our communities to make them more accessible to people with autism. It is time for all of us to think autism.



**Norman Lamb**  
Minister for Care  
and Support



**Mike Penning**  
Minister for  
Disabled People



**Edward Timpson**  
Minister for Children  
and Families



**Jeremy Wright**  
Minister for Prisons  
and Rehabilitation

# 1. Introduction

## About Autism

1.1 It is estimated that more than half a million people in England have autism. This is equivalent to more than 1% of the population and similar to the number of people that have dementia.

1.2 Autism is neither a learning disability or a mental health problem, although mental health problems can be more common among people with autism and it is estimated that one in three of adults with a learning disability also have autism<sup>3</sup>.

1.3 Autism 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 of different needs – so it is essential to look at the individual.

1.4 Everyday life for people with autism can be confusing, frightening and lack meaning. People with autism can often find understanding and communicating with others particularly difficult, which can leave them feeling isolated. People with autism may also experience some form of hypersensitivity or lack of sensitivity, for example to sound, touch, taste, smell, lights or colours. Autism is a lifelong condition and people may need to use services at any time in their life.

**Appendix A** gives more information on autism and some further sources of information.

1.5 However, every day we hear stories of people with autism who are living successful and rewarding lives: achieving at college, working in fulfilling jobs, and leading training to improve others' awareness.

## Staying true to the vision of *Fulfilling and Rewarding Lives*

1.6 Some people may manage well with the support of friends and family. Others – of all ages – may be struggling to manage with autism and may need support from services. Everyone, whatever their support needs, should be “able to live fulfilling and rewarding lives within a society that accepts and understand them.” This overarching ambition was at the heart of the 2010 Adult Autism Strategy *Fulfilling and Rewarding Lives*: treating people fairly so they are able to participate equally.

1.7 The clear vision is that:

“All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.”

3. Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey, The NHS Health and Social Care Information Centre (2012) <http://www.hscic.gov.uk/article/1733/New-study-estimates-autism-prevalence-among-adults-with-learning-disability>

1.8 We remain committed to the requirements for local areas from the 2010 Adult Autism Strategy and guidance. A summary of what this means for local authorities and the NHS is in **Appendix B**.

1.9 This update to *Fulfilling and Rewarding Lives* builds on rather than replaces these themes. It is issued pursuant to the Secretary of State for Health's powers under section 1 of the Autism Act 2009. We will continue to monitor progress in an annual self-assessment exercise.

## So, why are we updating the 2010 Adult Autism Strategy?

1.10 There are three reasons why we are publishing an update to the 2010 strategy now:

- Firstly, in line with the requirement in the Autism Act, we have undertaken a review of the Autism Strategy in 2013/14 and we need to reflect what we heard from people with autism, their families and from services in this update.
- Secondly, because a huge amount has been done to deliver the strategy and we need to take stock of this and then move forward
- Thirdly, because many things have changed in key services since 2010. Widespread transformation programmes have been set in place across public services and new organisations have been set up who need to take action to improve the lives of people with autism. We need to take

account of these reforms and how we can use them to improve people's lives.

## Progress Since 2010

1.11 Since 2010, in line with commitments in *Fulfilling and Rewarding Lives*, we have worked with a range of organisations to produce a comprehensive set of resources for staff in the health and care sector. These can be found in **Appendix C** along with other related materials.

1.12 The two local area self-evaluations also provide information on progress locally. These can be accessed at: [www.improvinghealthandlives.org.uk/projects/autism2013](http://www.improvinghealthandlives.org.uk/projects/autism2013)

1.13 This update provides an opportunity to:

- re-state the importance of issues like health and care staff training and awareness-raising which were central to *Fulfilling and Rewarding Lives* while recognising we still have further to go;
- highlight and update the resources that have been produced since 2010 which will help people to make a difference.

## Changes since 2009/10

1.14 There have been major changes to many parts of the system since the 2009 Autism Act and the 2010 Autism Strategy as part of the important programme right across Government to reform public services. We need to ensure the autism strategy and statutory guidance<sup>4</sup> are updated to take account of these reforms.

4. Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy (December 2010) <https://www.gov.uk/government/publications/implementing-fulfilling-and-rewarding-lives>



1.15 For example, locally, NHS commissioning is now led by Clinical Commissioning Groups (CCGs), supported nationally by NHS England. Local authorities have taken on important public health responsibilities for their local communities. Subject to Parliament, the Care Bill will make major transformations to local care and support. There is a much stronger focus on personalised care and on choice throughout health and care with the individual more in control of their own lives. At a local level the NHS and local government already come together through Health and Wellbeing boards to understand their local health and care needs and discuss together the priorities for their local communities. For young people, there are radical new provisions in the Children and Families Act 2014 for special educational needs and disability support and the health and social care support young people with special educational needs and disabilities (SEND) receive.

1.16 Many of these changes emphasise increased personalisation, choice and control for individuals. This is really significant for people with autism for whom personalised support that properly reflects what will make a difference to their lives is likely to be much more beneficial than one size fits all solutions designed in Whitehall.

1.17 Since *Fulfilling and Rewarding Lives* was published in 2010, all public services have had to look at delivering transformational changes to improve efficiency and value for money for the taxpayer and local communities. This means new models of delivery, building new partnerships and using technology more effectively.

## Reviewing the 2010 strategy

1.18 One of the requirements of the Autism Act is that we review the Autism Strategy, so, over the past year, we have run a comprehensive exercise to listen and learn about how the strategy is working. Nearly 2,000 people, including many people on the autism spectrum as well as those involved in planning, commissioning and providing services took part in focus groups, events and conferences. Over 1,100 people with autism took part in an on-line survey. Local authorities have also worked with their partners and local people to complete two annual self-evaluation exercises looking at the progress they are making for their local populations.

1.19 This update also brings renewed emphasis on involvement and awareness within the local community and on ways to look differently at support and engagement. Updated statutory guidance will follow later this year. **[Action 1]**

## Priority Challenges for Action

1.20 From this 2013/14 review, fifteen priority challenges for Action have been identified by people with autism, carers, professionals and others who work with people with autism for this update. These are listed on page 7.



## **An equal part of my local community**

1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.

2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.

3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support.

4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.

5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.

6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

## **The right support at the right time during my lifetime**

7. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.

8. I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism.

9. I want staff in health and social care services to understand that I have autism and how this affects me.

10. I want to know that my family can get help and support when they need it.

11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.

12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.

13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

## **Developing my skills and independence and working to the best of my ability**

14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.

15. I want support to get a job and support from my employer to help me keep it.

## 2. How we will check progress

2.1 **Appendix D** summarises the actions we will take to help the local implementation of the adult autism strategy. The cross-Government Autism Programme Board, chaired by Norman Lamb MP the Minister of State for Care and Support, has played an important role since 2010 in overseeing progress on the strategy and it will continue to do so. We will also continue to operate transparently ensuring that all papers from the Programme Board are publicly available on the gov.uk website.

2.2 Later in 2014/15, we will be advertising for new members to join the Board to take us into this next phase. **[Action 2]** The Board will receive regular reports on progress against the actions in **Appendix D** and will hold those responsible for Action to account for delivering these commitments. We will publish a summary of progress against these actions by August 2015 **[Action 3]**

2.3 Locally, we intend to continue to run the Local area self-evaluation exercise and to make public the responses. As set out later in this document, we will look at ways to strengthen the way this information is brought together with other sources and made available for local people and autism groups to enable them to hold their local areas to account on their reports of progress.

2.4 The Autism Act requires us to review the Autism Strategy periodically and we propose that the next review of the strategy should take place within the next 5 years.

It is central to the strategy that all actions, nationally and locally, should be taken forward in a co-productive way that involves and engages people with autism and their families and carers as partners, respecting the insight and expertise that their experience and lives bring.

## 3. Promoting Innovation and Awareness

3.1 There are three key areas in this update where we want to bring a particular drive and focus to deliver change.

3.2 Firstly, we want to enable people with autism to really be included as part of the community. This means looking beyond statutory services at how we **build communities that are more aware of and accessible to the needs of people with autism**, bringing together champions for change. The successful approach taken to dementia in response to the Prime Minister's Dementia Challenge provides an exciting and innovative model from which we can learn. This is explored in more detail under Priority Challenge for Action 1.

3.3 Secondly, to promote **innovative local ideas, services or projects which can help people in their communities** through new models of care, particularly for "lower level" support for those not meeting eligibility criteria for statutory support. This includes models which will support early intervention or crisis prevention or which support people to gain and grow their independence, or to find employment. This will also improve our understanding of the cost effectiveness involved and help local authorities get more for their local populations.

3.4 Thirdly, the need to focus on **how advice and information on services can be joined up better** for people (see Action 8).

3.5 In 2014/15, we are pleased to announce that we have available revenue and capital funding of £4.5 million to

support the delivery of some of the key themes set out in this update, including local innovation and awareness.

3.6 As part of this, we will launch a time limited Autism Innovation Fund to help drive creative and cost effective solutions, and identify new models of good practice that could be replicated in other areas. We will be exploring with other partners, for example in social finance, whether additional funding can be added to the national funding.

3.7 There are four areas, aligned with the priority challenges in this report, where we will invite proposals:

- Advice and information;
- Gaining and growing skills for independence;
- Early intervention and crisis prevention; and
- Employment, particularly involving the use of apprenticeships.

3.8 We will be looking for proposals that demonstrate the following core characteristics:

- Involvement of people with autism;
- Innovation, including either technology or innovative service design or provision;
- Partnership: an integrated approach to local services and/or partnership with local businesses, employers or other services.

3.9 We will also be looking for proposals that seek to identify match funding from other innovative non-Government sources, for example, businesses clubs, social enterprise or crowd funding.

3.10 All proposals will be expected to evaluate and evidence outcomes, including cost-benefit or cost-comparators. The Department of Health (DH) will also work with the Association of Directors of Adult Social Services (ADASS) and the Local Government Association (LGA) to develop a resource of innovative practice.

3.11 We will provide further information about this scheme by the end of June 2014. **[Action 4]**

## 4. The 15 Priority Challenges for Action

## An equal part of my local community

### ***1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.***

1.1 Many local services provide support for people with autism which is vital for helping them to be part of their local communities. But whilst we need to continue to strengthen statutory services, we also need to look beyond this important work, to spread autism awareness to a wider range of people. As a society, we need to **think autism**.

1.2 There are examples from around the country of local businesses and services that have made adjustments so that people with autism can access their community in the same way as anyone else.

#### **Autism Friendly Screenings**

*Dimensions* offer Autism Friendly Screenings at over 250 cinemas in partnership with Cineworld, ODEON, Showcase and Vue cinemas. Every month, each participating cinema shows a different film from a selection of new releases and classics. They make the screenings autism friendly by simple adjustments like having the lights on low, the volume turned down and allowing people to bring their own food and drinks. Some gyms and swimming pools offer special sessions for people with autism and a small number of theatres have started putting on autism friendly performances.

1.3 During 2014/15 we will launch a new community based *Think Autism* awareness and champions programme. The aim is for people with autism, parents/carers and autism workers to be supported to increase awareness and understanding of autism in their local areas, working in partnership with other local community groups, services and businesses. Local groups will come together to identify the key local priorities and Action needed to increase awareness of autism in their communities.

1.4 DH with colleagues across Government, will also work with third sector organisations to support them to develop a voluntary award or pledge for public and private organisations which have demonstrated their commitment to becoming more autism aware. Local people could help identify and work with key organisations and groups in their community; or organisations could work towards it directly themselves.

1.5 We will also identify and bring together a network of champions from different sectors to act as catalysts for change. We will issue further information on the autism awareness and champions programme by the end of June 2014, including how organisations and groups could tender to help provide co-ordination for this work. **[Action 5]**



## **2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.**

2.1 The 2010 Autism Strategy and statutory guidance set out that every local area is expected to have an Autism Partnership Board (APB) in place or a similar mechanism to ensure that all relevant stakeholders, including people with autism and their families and senior commissioners of health and care services help identify local need and plan appropriate services and support. Later this year, we will emphasise in the updated statutory guidance the need for strong local partnership working with people with autism and their families.

2.2 Effective APBs or similar mechanisms can play an important role in engaging people with autism and family members in the development of local plans.

Supplementing and working with other statutory local groups, such as Health and Wellbeing Boards, APBs (or similar partnership mechanisms) should have the sign-up of key lead individuals across public bodies – social services, health, education, housing and criminal justice. They should be able to demonstrate their positive involvement and achievement against the strategic strands in which they are involved. Effective APBs establish clear goals and monitor progress. DH has funded NAS to provide a guide for local authorities on how best to involve people with autism in APBs as well as how to involve people more widely – *It involves us: Enabling meaningful inclusion of adults with autism in the development of local autism plans* (via the NAS website in **Appendix C**).

### **Communication in Hampshire**

Early in 2010, Hampshire County Council developed close working partnerships with autism commissioning leads from health and local unitary authorities within Southampton, Hampshire, Isle of Wight and Portsmouth (acronym SHIP). Meeting monthly the leads explored commonalities and adopted approaches that supported the development of their four closely mirrored local Autism Strategies. The Hampshire Autism Programme Board (HAPB) was established to improve access to better local services by people with autism and their families. The Hampshire autism communication strategy was developed by setting up Hampshire Autism Voice (HAV) at the same time as the APB. HAV is a resource of the Board whose membership comprises people with autism, parents and carers. HAV and the communication strategy connected the Board to the local autism community. A HAV communication workshop highlighted the approaches required to engage with local people with autism, especially those hard to reach. The communication strategy enabled extensive participation and consultations with the autism community which took place from 2011 to 2012.

HAPB's web pages and SHIP wide developed introduction to Autism e-learning (found via Hampshire County Council's website):

<http://www3.hants.gov.uk/adult-services/carechoice/disability/as-autism.htm>

For further information contact – [Linda.burgess@hants.gov.uk](mailto:Linda.burgess@hants.gov.uk)

2.3 Subject to Parliament, the Care Bill will place a new duty on local authorities to involve adults in care and support assessment, planning and review. Many people will be able to do this on their own and many others will have someone (usually a friend or family member) who is able to act on their behalf. However, the Bill also stipulates that an independent advocate must be provided where this is required to facilitate the involvement of the individual concerned.

2.4 The Children and Families Act 2014 requires local authorities to publish details of the education, training, children’s and young people’s services which people can expect to be available in their areas. The Act sets out the expectations that parents and young people (up to 25) will be consulted about the services in this “local offer”. During 2014, NAS will issue a guide, developed with funding from DfE, on how to include young people with autism in the development of the local offer. **[Action 6]**

2.5 DH, Public Health England (PHE), ADASS and the LGA will use their respective communication routes to emphasise that local authorities are aware that the involvement of self-advocates with autism and carers of people with autism should now be a central component in the regular self-assessment exercise for local authorities and their partners. This should provide a clear channel for users and potential users of local services to contribute their views on, and experiences of local services, which will in turn inform local priorities. DH will make Healthwatch England aware of this work. The next self-assessment exercise will be issued in November 2014. **[Action 7]**

2.6 DH with PHE and partners like NAS will also look at how information on local progress, including the self-evaluation exercise, can be brought together in a single place digitally so that it is easily accessible to people on APBs, to young people and their families and to their local communities. This empowers local communities to hold their local authorities and other local services to account as part of the local democratic process and ensures that they have the right tools to engage with important groups like the Health and Wellbeing Board. We aim to bring together the 2014/15 local self-evaluation responses with other available data. **[Action 8]** This will allow a ready comparison of local offers and experiences. The local offer under the Children and Families Act will also cover health and care services for those aged 18 to 25. It is critical this links with wider work on supporting adults with autism.

### **3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support.**

3.1 Many adults with autism find it difficult to make friends. User-led and voluntary support groups help adults with autism build relationships with peers, friends, partners and colleagues and support independent living and being part of the community. It is important that all people with autism, whatever their level of need, can easily access information in their local area about what support from peers, charities or other community groups is available. This is a core part of the Care Bill currently before Parliament.

#### **Eligibility for adult social care**

3.2 The *Prioritising need in the context of Putting People First*<sup>5</sup> guidance sets out the framework for eligibility to adult social care. If a person does not meet the eligibility criteria set out, the local authority is not required to arrange services for that person (known as Fair Access to Care Services or FACS)<sup>6</sup>, that person will not receive publicly funded social care services. The Care Bill will replace the current system with a new national minimum eligibility threshold for access to on-going care and support. Local authorities will not be able to tighten the criteria but they can decide to meet needs that are not eligible. This will provide more transparency and clarity for people on whether or not they are eligible for local authority funded services. Of those people with autism who do not meet eligibility criteria, many will still benefit from being connected with peers and with other local

groups and other “lower level” preventative support. The Care Bill will place a duty on local authorities to prevent, delay or reduce adults or carers’ needs for care and support.

#### **Low level interpersonal support**

3.3 Services based around low level interpersonal support, such as buddying schemes, have enabled adults with autism to participate in different social and leisure activities, and promoted social inclusion and wellbeing. Access both to these networks and to advice and information is vital to help people access the communities in which they live. It can also help to prevent people going into crisis situations, which is bad for them as individuals and can be very costly for services.

3.4 People with autism and their families have also told us that it can be hard sometimes to know where to go for advice and information locally as they do not fit into local “boxes” such as learning disability or mental health.

3.5 Autism strategies developed by local authorities should ensure that they include plans for meeting the needs of adults with autism in their local population, as identified in local needs assessments. We would expect services such as those already described to be considered in those strategies.

5. *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care- Guidance on Eligibility Criteria for Adult Social Care, England 2010* [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_113155.pdf](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113155.pdf)
6. Fair Access to Care Services (FACS): prioritising eligibility for care and support (December 2013) <http://www.scie.org.uk/publications/guides/guide33/files/guide33.pdf>

### A one-shop stop in Hull

FIND (Families for Individual Needs and Dignity) is a charity set up in 2000 by parents of young people with learning disabilities and autism. Matthew's Hub has been developed to meet the needs of people with high functioning autism and Asperger's syndrome and is named after a young man with Asperger's syndrome who committed suicide. It provides support to access services, and offer a range of opportunities including:

- Social networking;
- Volunteering and work;
- Training and learning;
- Advice;
- Advocacy.

The service works with its members to build confidence and self-esteem, and develop real skills to enable them to take up volunteering and work opportunities. The approach is to encourage individuals to move from doing things alongside others to doing things for themselves, and promoting independence. The project began with the development of a website which includes a social networking forum. Matthew's Hub has a base in the heart of the city of Hull, where people with autism are welcome to drop in. Individuals and families can self-referral. The service welcomes referrals from social services, GPs, Health services and any other agency whether or not there is a formal diagnosis. Matthew's Hub works closely with individual's families, advocates, social services and Health so that people with high functioning autism and Asperger's syndrome can access statutory services as appropriate.

For further information contact: [hello@matthewshub.org](mailto:hello@matthewshub.org)

Website link: <http://matthewshub.org/>

3.6 We are also keen to encourage proposals for the Autism Innovation Fund which are based on innovative models for these sorts of services, such as crisis prevention, or for the better provision of advice and information, for example, exploring different models for "one-stop shops". DH is also exploring the feasibility of research to review the effectiveness of low level interventions aimed at adults with autism who do not meet FACS social criteria. **[Action 9]**

#### ***4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.***

4.1 For many people with autism, mainstream public services can be hard to access. Some of this is due to a lack of understanding of autism among staff but this is not the only factor. Many people with autism are hypersensitive to light and noise; they can have significant difficulties with communication and can struggle with the formats, language or instructions in forms or standard letters. Yet people with autism have a right to access mainstream services just like anyone else. This is, at its heart, about equal rights. Under the Equality Act 2010<sup>7</sup>, all public sector organisations are required to make reasonable adjustments to services to ensure they are accessible to disabled people, including to people with autism.

#### **Reasonable adjustments**

4.2 Adults with autism should be able to benefit fully from mainstream public services to live independently and healthily, including access to appropriate housing to meet individual needs. Without reasonable adjustments many services can be inaccessible for adults with autism.

Reasonable adjustments can include:

- premises – taking account of hypersensitivities and providing quiet or lower-light areas;
- processes – scheduling appointments at less busy times, allocating extra time to adults with autism and being flexible about communication methods, for example, less reliance on telephone-based services;
- communications – avoiding ambiguous questions, not pressurising adults with autism in conversation and being aware of sensitivity to touch; ensuring essential documents and forms are available in accessible formats, in particular, easy read versions and formats that take account of sensory issues in their choice of colours;
- planning and preparation – offering opportunities for adults with autism to visit settings in advance to familiarise themselves with what to expect, for example visiting a court prior to giving evidence or an optician's prior to an eye test.

4.3 Since 2010, a number of guides have been published on making reasonable adjustments, including making GP practices and mental health services accessible. The Green Light toolkit example is found at **Appendix C**.

4.4 Reasonable adjustments may also include using new technology to help increase and maintain independence. This includes equipment to help people who have problems with speaking, hearing, sight, moving about, getting out and about, socialising, memory, cognition (thought processes and understanding) and daily living activities such as dressing and preparing meals. All service providers have an Equality Act duty to make reasonable adjustments and should think about technological enablers as part of this. Providers of specific specialist services to people with autism should be exploring the use of assistive technologies with the

7. Equality Act 2010, <http://www.legislation.gov.uk/ukpga/2010/15/contents>



people they support to help develop their confidence, sense of achievement and independence. We would encourage applications for the Autism Innovative Fund which include innovative uses of technology.

4.5 One of the things many people find both frustrating and distressing is having to tell their story and explain what adjustments make a difference to them over and over again. Autism Passports are a simple adjustment which allow people to carry with them information about themselves. They can play a very important role in enabling a person to share with services what adjustments they need. DH will work with Baroness Angela Browning<sup>8</sup>, NAS and others to look at how to promote Autism Passports and will report to the Autism Programme Board by the end of 2014/15. **[Action 10]**

### Claiming social security benefits

4.6 The Department for Work and Pensions (DWP) is ensuring that reasonable adjustments are made to the process for claiming social security benefits for people with autism. The claims process for Personal Independence Payments (PIP) has been developed through extensive engagement with disabled people and disability organisations and has been designed to reflect their views. DWP recognise that for some individuals, for example, those with conditions like autism, attending a consultation in an unfamiliar place could cause anxiety. So, when attending a face-to-face consultation, people can bring a relative, friend or a professional who

supports them to help manage any anxiety they may feel and who can provide additional information and explanations about the person's difficulties. Key staff involved in making assessments for benefits should also receive training to ensure they understand the needs of people with autism. DWP also keeps the process for claiming Employment and Support Allowance under constant review to ensure it is as fair and effective as possible. The most recent independent review<sup>9</sup>, conducted by Dr Paul Litchfield, made a number of recommendations about simplifying the claims process and improving the forms and letters used. When making changes to policy or processes that are likely to have a particular impact upon disabled people, a full equality analysis is undertaken. DWP will, in addition, continue to ensure that reasonable adjustments are made to the benefits processes so that they are accessible to people with autism.

### Education settings

4.7 Adjustments in education settings, such as providing quiet or low-light areas, can benefit people with autism. The Disabled Student Allowance supports people with autism with the academic aspects of university life. This includes funding a note-taker for lectures, electronic equipment and software, social skills training, travel training, and 1:1 support.

4.8 As well as making reasonable adjustments to the physical environment, service providers should look at providing awareness training for all frontline staff to enable them to make reasonable

8. Baroness Angela Browning, [http://www.conservatives.com/People/Peers/Browning\\_Angela.aspx](http://www.conservatives.com/People/Peers/Browning_Angela.aspx)

9. An Independent Review of the Work Capability Assessment – year four (December 2013) [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/265351/work-capability-assessment-year-4-paul-litchfield.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/265351/work-capability-assessment-year-4-paul-litchfield.pdf)



adjustments to their services and behaviour. This will increase the accessibility of mainstream services for people with autism, and lead to better understanding of the condition. We recommend that quality autism awareness training should be included within general equality and diversity training programmes across all public services.

### **Equality and diversity training**

4.9 DH will lead the way by ensuring that its equality and diversity training includes autism. Many people with autism feel that training should focus less on the theory of autism and more on giving staff an insight into how autism can affect people, drawing directly on the experiences and input of adults with autism and their families. This would better enable staff to understand the potential behaviours of adults with autism in different settings. Good quality autism awareness training is developed and delivered in partnership with people with autism themselves.

We will aim that, by the end of 2014, staff in all Directorates in DH have had access to training on autism and will also work with DH's arm's length bodies on including autism in their equality and diversity training. **[Action 11]** We will ensure that guidance and e-learning products developed as a result of the autism strategy are publicised across other Government Departments. **[Action 12]**

## ***5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.***

### **Code of Practice for Victims**

5.1 The Government brought into force a new Code of Practice for Victims of Crime in December 2013, which sets out the information and support provided to victims of crime by criminal justice agencies in England and Wales.

5.2 The new Code provides an enhanced level of service to victims of the most serious crime, persistently targeted and vulnerable or intimidated victims to make sure they get the right support at the right time. Victims suffering from a mental disorder within the meaning of the Mental Health Act 1983, a physical disability or that have a significant impairment of intelligence or social functioning will be entitled to an enhanced service under the Code as a vulnerable victim. This includes quicker updates on the status of their case and referral to pre-trial therapy or counselling where appropriate and available.

5.3 To ensure that people who need this enhanced support get it, the police have a duty under the Victims' Code to assess victims at an early stage. Every victim is entitled to have their details passed on to victims' services who offer emotional and practical support to help victims to cope with and, as far as is possible, recover from the impacts of the crime. These services can also be accessed by victims who do not report the crime to the police.

5.4 From 1 October 2014 the majority of emotional and practical support services for victims of crime will be locally commissioned by Police and Crime Commissioners (PCCs), rather than central Government. They will be able to join with

commissioners for health and social care locally to ensure a shared approach to support provision for victims and witnesses. In particular, it will be important for them to engage with local APBs or their equivalent.

### **Special measures for victims and witnesses**

5.5 Provision of special measures to victims and witnesses, including the Intermediary special measure, are currently being reviewed with a view to increase the uptake and consequently the support to vulnerable and intimidated witnesses when giving evidence to the police and in court. The Crown Prosecution Service's (CPS) web site includes information, and interactive programmes developed to help and support vulnerable victims and witnesses. For example, one scenario involves a character called Joe, a victim with autism. In undertaking the modules and exercise, participants explore matters that may arise and the support that is available throughout the life of a case. Particular attention is given to special measures and questioning techniques that barristers may use during a trial. The information highlights good practice which aims to achieve greater access to justice for a section of society that is exposed to higher levels of victimisation. The CPS is currently working to develop further material. It is intended that this will take the form of an aide-memoire and support material for prosecutors, highlighting key issues, implications for the prosecution process and sources of support.

### **[Action 13]**

## Preventing disability related harassment on public transport

5.6 In February 2014, the Minister of State for Transport, Baroness Kramer, wrote to bus industry representatives to re-iterate the Government's support for disability awareness training and to encourage bus and coach drivers to undertake such training courses at the earliest opportunity. The Department for Transport also committed to review the uptake of disability awareness training amongst bus and coach drivers by March 2014. To inform the review, the Minister sought input from industry on the number of drivers who have undertaken the training, as well as on the structure and effectiveness of disability awareness training courses used by various organisations. Each train operator is required to have a Disabled Persons' Protection policy as part of their licence to operate which commits them to providing disability awareness training to all passenger facing staff and managers.

5.7 In 2013 the Department for Transport endorsed an industry led initiative making bus travel more accessible for people with hidden disabilities by encouraging operators to sign up to the Journey Assistance Card scheme developed by the Confederation of Passenger Transport<sup>10</sup>. The Cards are not a ticket to travel, but when presented to the driver they indicate that the passenger requires specific assistance.

5.8 The Autism Programme Board will ask the Department for Transport to provide a report on their review of disability awareness training, including autism and work to prevent disability related harassment, and their planned next steps, by the end of 2014/15. **[Action 14]**

5.9 The Government recognises that educating young people about online safety is key to tackling cyberbullying. So from September 2014 pupils in all four key stages will be taught about e-safety as part of the new curriculum. The Government has also pressed for progress through the UK Council for Child Internet Safety and works to bring together key organisations such as Facebook and Microsoft and is chaired by Government Ministers. Internet providers, schools and parents all have a role to play in keeping children and young people safe online.

10. The Confederation of Passenger Transport UK (CPT), <http://www.cpt-uk.org/>

## ***6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.***

6.1 Feedback from focus groups during the Review of the Autism Strategy suggested that a wide range of professionals and individuals encountered by people on the autistic spectrum do not look beyond the individual's autism.

6.2 People have many stereotypes and preconceptions about what someone with autism is like: “male”, “white”, “good at maths” are often things people have in their mind. Some of these pre-conceptions may prevent people accessing support that they need, for example, in relation to their sexuality or which is right for their cultural or religious background. It may also be leading to significant under-diagnosis amongst certain groups, for example, people from a BME background.

6.3 Although this was raised during the Review by people with autism as a really important area, we don't yet know enough about these issues. So to learn more and gather case studies, during 2014/15 DH will bring together groups and networks that work on equality issues, including race, gender and sexuality, with third sector and other experts on autism to look at the issues experienced by women and people who are lesbian, gay, bi-sexual or transgender, and members of BME groups, who have autism. **[Action 15]** We will seek to build partnerships between equality and autism third sectors groups to explore what their networks can do together to support people with autism as part of the *Think Autism* champions programme.

## The right support at the right time during my lifetime

### ***7. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.***

7.1 In 2013, the majority of people newly diagnosed with autism were children. The Department for Education (DfE) and DH have worked closely over a number of years to encourage early identification of potential autism and to link this with relevant support in schools. However, there is a very significant group of adults, including many older adults, who were not diagnosed as children, mainly because autism wasn't very well recognised in the past.

7.2 Diagnosis can be particularly important for adults who did not have their condition recognised as children. Their life to date may have been affected by a sense of not fitting in, of not understanding the way they respond to situations or why they find social settings difficult. They may also have been in learning disability or mental health services, where their autism was not recognised or supported. A diagnosis can be an important step in ensuring that support takes account of how a person's autism affects them and their whole family.

7.3 GPs are usually the gatekeepers to diagnostic services and need to have a good understanding of the whole autistic spectrum and the diagnostic pathway that has been developed in their area. This will enable adults with autism to be supported more effectively from the start of their assessment process.

7.4 We have taken a number of steps since 2010 to support local areas to develop a clear pathway to diagnosis and post-diagnosis. In every local area, health services should have a pathway to diagnosis, just as the local authority will have a clear framework for assessing the care and support needs of children and adults with autism. We will continue to ask local areas to assess their progress on this through the local area self-evaluation exercise.

#### **NICE guides**

7.5 To help standardise and improve the care and management of autism, and to enable health and social care services to support people with autism more effectively, the National Institute for Health and Care Excellence (NICE)<sup>11</sup> has published three clinical guidelines on autism and a quality standard.

7.6 NICE has also produced (details of which are found in **Appendix C**):

- an Implementation Pack: developing a multi-agency local autism team, to support local areas;
- a series of costing tools; and
- *Support for Commissioning*, which outlines the key actions that commissioners should take to deliver the quality improvement outlined in the NICE quality standard.

11. National Institute for Health and Care Excellence (NICE), <http://www.nice.org.uk/>

7.7 DH has also supported the work of the Joint Commissioning Panel (JCP) for Mental Health, a collaboration between seventeen leading organisations, co-chaired by the Royal College of Psychiatrists and the Royal College of General Practitioners. They have looked at how to encourage commissioners to use a values-based commissioning model. The JCP will issue a practical guide on autism by September 2014. **[Action 16]**

7.8 The comprehensive suite of tools available will enable local areas to ensure there is a clear pathway to diagnosis in every area. It is not expected that a specialist diagnostic team or service will be located in all areas. However, there is a

duty for each area to have an easily accessible autism diagnostic service and for people such as GPs to be aware of the pathway.

7.9 DH will ensure that NHS England are fully aware of this evidence and guidance on diagnosis so they can determine how to take account of it, along with the Care Quality Commission (CQC) in its wider statutory role in primary and secondary care in driving up quality. **[Action 17]** The Autism Programme Board will seek updates from CQC and NHS England on how they are doing this. DH will also reflect the guidance on diagnosis in the updated statutory guidance for the Autism Strategy later this year.

## Diagnosis in Bristol

The Bristol Autism Spectrum Service (BASS) is a multi-agency, specialist autism team providing a range of services to adults with autism and the professionals working with them. In terms of direct work with people with autism, the team provides a diagnostic clinic accessible from primary care, and a programme of post-diagnostic support delivered through a weekly autism Advice Service. The Advice Service is available to anyone with autism in the local area, but is targeted at people who are not eligible for social care services. Its aim is to offer timely, easy-to-access support designed to increase peoples' wellbeing and levels of social inclusion, and to prevent them from experiencing avoidable crises. Interventions offered include 1:1 sessions with BASS staff and volunteers around problem-solving, signposting, employment support, housing, and benefits advice, and a range of groups, including: post-diagnostic support, mindfulness, and anxiety management.

Given that people with autism should also be able to access support from mainstream services, BASS work closely with providers in the statutory and voluntary sector to enable them to develop their skills around working with people on the spectrum, through the provision of specialist training and liaison. Crucially, the team do not take on care management responsibility – this remains with the referring agency – but instead offer intensive ongoing support and supervision to health and social care professionals to enable them to provide the best and most autism-friendly service possible to their clients.

For further information contact: [ian.ensum@nhs.net](mailto:ian.ensum@nhs.net)



## **8. I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism.**

8.1 In order to plan and commission services effectively, local authorities and their Health and Wellbeing Boards, CCGs and other partners, need to have access to as comprehensive data on local numbers and needs as is possible. But gathering data on the numbers and needs of people with autism at a local level can be challenging. Health and adult social care services are currently likely to know only a small number of all local people with autism. There are many reasons for this, including:

- many people with autism are likely to be undiagnosed;
- not all people with autism will come into contact with social care services and so local authorities are unlikely to have information on them or their needs;
- many people, especially older adults or people from certain communities, have got by with the support of family and friends and are unknown to statutory services. This may be because they are not eligible for statutory services or because they do not know what help is available;
- the way local services are organised (e.g. learning disability and mental health teams which may miss those with autism who don't also have these needs).

8.2 Historically, services have also not collected comprehensive data about this population. Local authorities are not required to “register” people with autism and many people with autism would find

such an approach stigmatising. However, from April 2014, local authorities have to now record information about a person's primary reason for support and whether the person has reported certain other health conditions, such as autism. This will initially include autism generally and Asperger syndrome/high functioning autism if that information is known. It is important that local authorities are ready to record this information to ensure that over time there is a better understanding of the local population of adults with autism.

### **Local action**

8.3 There is a lot of other Action that local areas can take to gather effective data at a local level to plan and deliver the right services for local needs, including on those people with low level needs who are not eligible for care and support.

### **Local estimates of prevalence**

8.4 Firstly, local estimates of prevalence can be calculated from national data. This can be useful as it allows local authorities to estimate unmet need. To do this, local authorities can use PANSI (Projecting Adult Needs and Service Information),<sup>12</sup> a database that uses national data to make projections on the possible impact of demography and certain conditions on local populations. The DH will also consult with the Institute of Public Care (IPC) about the feasibility of including prevalence on older adults with autism in the Projecting Older People Population Information System (POPPI)<sup>13</sup>.

12. Projecting Adult Needs and Service Information (PANSI), <http://www.pansi.org.uk/>

13. Projecting Older People Population Information (POPPI), <http://www.poppi.org.uk/>

## GPs

8.5 Secondly, the majority of people are registered with a GP and they are often the first point of contact for adults with autism, both pre and post diagnosis. GPs currently routinely record patient conditions using Read Codes'. There is, however, no single Read Code used consistently for autism. A data gathering project carried out in Leicestershire revealed that GPs commonly either write in the notes that someone has autism, do not make a note at all, add codes incorrectly, or add them inconsistently within practices and within local areas.

8.6 DH will work with NHS England and with the Royal College of General Practitioners (RCGP) through their autism clinical priority programme which runs from April 2014 to 2017 to look at the feasibility of introducing a Read Code for Autism.

**[Action 18]** The aims of the RCGP's work include:

- raising the profile and awareness of autism;
- improving quality of patient care of individuals with autism;
- improving the support offered to family and carers;
- offering support to CCGs to help implement and deliver the NICE quality standard for autism;
- liaison with clinical curriculum guardians; and
- the development of a clinical network of general practitioners.

## Advocacy and other local services

8.7 Thirdly, local authorities can work with local groups such as those that provide advocacy services and befriending services to gather information about the number of people they help.

### A data and information working group

8.8 With Public Health England data experts, we will establish a data and information working group to include DWP, DfE and others to report to the national Autism Programme Board to compile a list of available data sources for local authorities on people with autism and to consider the development of a data modelling tool like the dementia calculator.

**[Action 19]** A draft guide on the use of data which has been prepared by NAS will be agreed by the data and information working group and then issued. Commissioners will be able to use this to inform their processes for commissioning person centred services.

## **9. I want staff in health and social care services to understand that I have autism and how this affects me.**

9.1 It is important that health and care professionals have a good understanding of autism. Where professionals do understand autism, the positive impact on the lives of adults with autism can be immense. Health and social care professionals must be able to communicate effectively with people with autism if they are to be able to manage their own care and exercise genuine choice and control. The 2010 statutory guidance for local authorities and the NHS made it clear that basic autism training should be available to all staff working in health and social care. We do not intend to change this in the forthcoming statutory guidance.

The regulations to support the Care Bill, subject to Parliament, will require those undertaking an assessment to have suitable skills knowledge and competence in the assessment they are undertaking, such as autism, and where the assessor does not have experience in the condition, that he or she contact someone with the relevant experience.

9.2 In addition to general autism awareness training for staff, local areas should develop or provide specialist training for those in roles that have a direct impact on access to services for adults with autism.

### **Autism awareness training for staff in Harrow**

Harrow Adult Social Care has worked with a local voluntary organisation to set up Autism Awareness training for staff. The training model involves adults with autism and parents or carers as part of the local Empowering Ourselves to be Heard Project. Using local speakers brings a unique insight into autism and personal experiences of services. Attendees then have the opportunity to participate in group sessions with speakers, ask questions and discuss how to improve their practice. As well as social care, training places have been extended to housing, customer services and voluntary sector advocacy staff. The inclusion of customer services has proved particularly effective. The courses have been popular and will continue to run regularly. This work has also led to links being made between the Empowering Project and other parts of the Council, providing adults with autism opportunities to participate in improving the delivery of a range of services.

For further information contact: [Elena.Murray@harrow.gov.uk](mailto:Elena.Murray@harrow.gov.uk)

9.3 As part of DH's response to the reviews of social work education by Professor Croisdale-Appleby and Sir Martin Narey, we will be commissioning the scoping and development of a comprehensive Continuing Professional Development (CPD) framework for social workers. One of the early priorities will be the development of CPD materials to improve the knowledge and skills of social workers working with vulnerable people with autism. **[Action 20]**

### **E-learning training**

9.4 Following *Fulfilling and Rewarding Lives*, DH commissioned a comprehensive package of e-learning products for professionals (listed in **Appendix C**). Following a report carried out for the Review by John Simpson, one of the self-advocate members of the Autism Programme Board, DH will provide support to update this e-learning training. **[Action 21]**

9.5 Since the 2010 strategy, Health Education England (HEE) has been established to ensure that the NHS workforce has the right numbers, skills and values and behaviours to meet the NHS needs today and tomorrow. As part of the Government's 2014/15 Mandate to HEE they will be required to work with the Royal Colleges and other stakeholders to focus on supporting autism awareness training.

9.6 The RCGP's clinical priority work is also likely to focus on training and awareness-raising. People with autism can be serial presenters at primary care because they may not be able to access other support and it is essential that GPs are autism aware. We are exploring the potential for the inclusion of autism in a proposed additional year of GP training.

## 10. *I want to know that my family can get help and support when they need it.*

10.1 We know that caring for someone with autism can be extremely rewarding but can also be hugely challenging, both emotionally and financially, and we are determined to improve the support available to carers. The Care Bill will simplify the assessment processes for adult carers so that more of them are able to access an assessment, based on the appearance of a need for support. This should ensure more carers can get more support than currently. The Children and Families Act ensures that young carers' assessments are simplified – for the first

time, all young carers will have the right to an assessment of their needs for support as part of a whole family approach to assessment. Local commissioners will also be expected to consider specific support for carers, such as respite care. The Act also consolidates existing legislation and brings parent carers' rights to an assessment to the same level as those of other carers. It requires local authorities to also have regard to the well being of parent carers in undertaking an assessment of their needs.

### Working together in Swindon

SEQOL diagnostic service in Swindon has run events, which aim to strengthen the adult autism economy in the town. These events have encouraged both specialist and universal services to come together and share resources and expertise that will ultimately benefit people with autism and their families. Organisations were invited to run stalls and encouraged to provide information and resources to each other as well as people with autism and their families. This information was then captured for an on line and paper directory of services for adults with autism in Swindon.

Types of services identified from *Fulfilling and Rewarding lives* were invited. The aim was then to provide awareness training and ensure that people with autism and their families have a clearer idea of what is available to them in the local community and were able to highlight any gaps directly. The events have included voluntary sector organisations, local colleges, emergency services, primary care, employment, supported living, housing, diagnostic and therapeutic services. After inviting the local fire service, they became aware of some of the different needs for many adults with autism, and were keen to offer advice and support on fire safety that recognized different sensory needs.

These events have demonstrated how vital it is to nurture enthusiastic individuals within voluntary and statutory services and ensure that pockets of good practice are joined up and well understood. This is particularly important for people with autism who are not eligible for specific support and need to be effectively supported by universal services.

For further information contact: [Sue.smith@seqol.org](mailto:Sue.smith@seqol.org)

## Local Carers Strategies

10.2 Local authorities should ensure that their local Autism Strategies are linked to local Carers Strategies (or equivalent). Involvement of self-advocates and family carers directly is essential to support a joined up approach across the strategies. NAS, other parent support groups and helplines can play an important support and signposting role. For many people with autism the main carer may be a spouse, or other family member who is not a person's parent. It is also important to recognise the impact of the ageing population and that people with autism may have carers who are older than them. Carers may be very anxious about what will happen to the person they support when they can no longer care for them or when they die.

10.3 As set out in the current statutory guidance, a diagnosis of autism should act as a trigger for a carers assessment for any carers of the individual diagnosed. We do not intend to change this in the updated statutory guidance. We will ensure that any statutory guidance that follows the carers' provisions in the Care Bill or the Children and Families Act is consistent in taking account of the needs of people with autism. DH will also ensure that the Local area self-evaluation includes carers.

### **[Action 22]**

10.4 Financial support for carers is also available in the form of Carer's Allowance which is a social security benefit administered by DWP. Carer's Allowance is available to people aged 16 or over who spend at least 35 hours a week caring for someone who is in receipt of certain disability benefits. The carer can earn up to £100 per week after allowable expenses. This will increase to £102 per week from May 2014. The carer cannot be studying more than 21 hours per week.



**11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.**

### Think Young Adults

11.1 The needs of adults with autism may have been significantly influenced by their experiences within education and children's services. It is thought that early intervention, and interventions throughout childhood can have a significant bearing on the individual skills and abilities of adults with autism.

11.2 Transition from school to college and beyond into adult life from children's services into adult services is an important time for many young people with autism and their families. Good transition planning in schools brings together education, health and social care staff when a young person has complex needs. Better transition planning for the move to further education and universities is being developed and will help to support people with autism to lead independent lives and fulfil their potential.

11.3 The Care Bill provides duties for local authorities to assess young people and child carers before they (or the person they care for) turn 18 in order to help them plan for transition to adult care and support. The duty applies irrespective of whether the child is currently receiving a service – provided that they are likely to have needs on becoming 18 and that assessment would be of significant benefit.

11.4 The Children and Families Act will bring significant improvements to the transition of young people with autism from school, through college and into adult life. Importantly for young adults with autism, it

provides comparable rights and protections for 16 – 25 year olds in further education and training to those of children in schools.

### Education, Health and Care Plans

11.5 The Act introduces a single Education, Health and Care (EHC) plan for 0-25 year olds, in place of the current statements of SEN and Learning Difficulty Assessments. EHC plans will be more person-centred and put greater emphasis on long term outcomes for young people. Annual Reviews of support will have to consider progress made against agreed outcomes within the plan, and from Year 9 onwards must include a focus on preparing for adulthood. At the point a young person with an EHC plan is expected to leave education, the local authority must agree the support they need to engage with adult services and provision. The Act also includes duties on local authorities to maintain support for young people with EHC plans who become NEET (not in education, employment or training), and re-engage them in education. The DfE will report back to the Autism Programme Board by the end of 2014/15 on the wider changes linked to the SEN reforms and related issues for people with autism.

#### [Action 23]

11.6 Further Education (FE) colleges and providers can also arrange an assessment for those people aged 19 and over who do not have an EHC plan but who self-declare a learning difficulty and/or disability. The Department for Business Innovation and Skills (BIS) provides Learning Support

funding to colleges and providers to help them meet the additional needs of learners with learning difficulties and/or disabilities so that they can participate fully in education and training.

11.7 The National Careers Service in England provides access to professional, independent careers advice through an on-line and telephone offer. The offer is available to everyone aged 13 and above with a face to face offer for adults aged 19 and above (or 18 and above if out of work and on benefits). Details of their website and the information available is found in **Appendix C**.

## Apprenticeships

11.8 The Government sees apprenticeships as an important tool for social mobility. Apprenticeships provide a great opportunity for people of all ages and backgrounds to secure a job with excellent training and real career prospects.

11.9 The National Apprenticeship Service website <http://www.apprenticeships.org.uk/> contains research and materials to support equality and diversity within apprenticeships. The site includes a link to *Engaging individuals with learning difficulties and disabilities in workplace learning* developed on behalf of the Skills Funding Agency. The report by Peter Little OBE; *Creating an Inclusive Apprenticeship Offer*<sup>14</sup> showed that apprentices who have autism are likely to successfully complete their apprenticeship: 66.7% (16-18 year olds) and 87.5% (19-24). The Skills Funding Statement sets out additional funding that can be used to support disabled learners. Apprentices may also be entitled to Access to Work payments to help with adjustments

to the workplace, for more details go to the Access to Work website: <https://www.gov.uk/access-to-work/overview>

11.10 DH will seek feedback on the type of apprenticeships being offered to people with autism, and discuss this further with BIS [**Action 24**] following the event that the TUC is hosting with BIS and the National Apprenticeship Service on 29 April 2014 called *A call for Action on equality in apprenticeships*.

11.11 Supported internships are study programmes for young people aged 16 to 24 with a statement of SEN, a Learning Difficulty Assessment, or an EHC plan for those who want to move into employment and need extra support to do so. They enable young people with complex learning difficulties to achieve sustainable paid employment by equipping them with the skills they need for work, through learning in the workplace. Wherever possible, they support the young person to move into paid employment at the end of the programme. DfE's supported internship trial in 2012/13 allowed young people with the most complex needs to show employers what they can do. It resulted in an employment rate of 36%, against a national average employment rate of 7% for people with complex learning difficulties. Since September 2013, supported internships can be delivered by all qualified education providers in England.

11.12 *Implementing Fulfilling and Rewarding Lives* was clear that professionals working with a young person with autism approaching transition should make them and their parents or carers aware of the right to a community care assessment. We do not intend to change

14. Creating an Inclusive Apprenticeship Offer (January 2012)  
<http://www.apprenticeships.org.uk/news-media/latest-news/article140.aspx>

these duties in the updated statutory guidance and will ensure there is consistency between this guidance and guidance following the new Children and Families legislation.

11.13 DfE is funding Ambitious about Autism, with £660,000 over two years from 2013 – 2015, to work with the Association of Colleges and four general FE colleges on transitions into further education for young people with autism. DfE is also funding the Autism Education Trust, £1.5m over two years from 2013 – 2015, to provide tiered training across early years, schools and further education. The three levels of the training are:

- Level 1 where staff have been given basic autism awareness training;
- Level 2 which provides training in practical knowledge and techniques; and
- Level 3 training for people like lead practitioners for autism, Special Educational Needs Coordinators and inclusion managers.

11.14 Greater awareness and better skills amongst school and FE staff should lead to better transitions for young people with autism.

11.15 Many children and young people will now be identified as having autism earlier on in life but identification/diagnosis may still be an issue for those with Asperger syndrome. The number of children identified with autism while at school has increased over the years, the majority of whom have SEN statements. EHC plans can be given to children across the spectrum and other children can have their needs met through school support without the need of a statement or plan.

## **A personal story – Supporting my apprenticeship**

I live in Coventry and I started an apprenticeship with Coventry City Council in August 2012. I have a real passion for IT so I was really pleased when I was told about the opportunity.

Within a short space of time both me and my manager felt I was experiencing some challenges in work which I am told is due to my autism. My work mentor explained that there were no problems around teaching me the job, however he said there were some personal and social behaviours that impacted on my work and made it difficult for me to integrate into the team. My Manager asked for some help from the Council's apprenticeship scheme and they made contact with The Employment Support Service. This is a supported employment service within the Council's Employment Team. I felt that this was a good idea as I knew that things needed to change for me to be able to continue doing the apprenticeship. Soon afterwards I met Hannah a specialist Autism Employment Advisor from The Employment Support Service. Hannah spent some time getting to know me on a one to one basis so that I felt comfortable in discussing the behaviours that I needed to change and arranged a weekly review meeting with me to discuss my workload and to talk through any specific areas for improvement. We both agreed that I respond well to a direct approach so that I knew clearly what was expected of me in the workplace. This I felt was important as when I first started I had great difficulty in working out what was taboo and what wasn't. There are so many unwritten rules that I just don't pick up on.

At the weekly review my Autism Employment Adviser would go through what had worked well from the previous week and encourage me to maintain that level of performance. With regard to the areas that I struggled with, they would suggest ways that I could improve my behaviour. She quickly realised that I work well when things are in bullets so she produced the reviews in a format that worked well for me. My supervisor has said that they have seen a real change in me and where once I would have struggled in certain social situations I am now a lot more comfortable.

A large part of my role is dealing with customers on the telephone. Since working with Hannah from The Employment Support Service, I have had no end of compliments about my telephone manner and customer service skills which I am now told is my strongest quality. I enjoy working with my Autism Employment Adviser because I feel that she really gets me. Since working together I have completed my apprentice and with support from the Employment Support Service I have gained a regular job in the Council. I really feel now that I'm part of the workforce.

## Think Older People

11.16 The Autism Strategy is not just about young adults with autism. It is critical that local services and communities think autism in relation to older people too.

11.17 A key challenge for many older adults with autism is that they will have had significant support from their families, but as families age, this becomes less possible. The Care Bill currently before Parliament puts a duty on local authorities to provide independent advocacy where a person has substantial difficulty in navigating the care system and has nobody around to support them. This will include some people with autism. We are also clear that in planning local services, local authorities should ensure that they are including the specific needs of older people with autism.

11.18 The House of Lords Autism and Ageing Commission looked specifically at the issues of older people with autism and, following this, in July 2013, the NAS published a policy report *Getting on? Growing Older With Autism*<sup>15</sup> which contains important insights. This update to the Autism Strategy provides an important opportunity to work with NAS on their findings and ensure that supporting older people with autism is embedded in future work [**Action 25**], including:

- Autism aware communities, including volunteer led models to support older people with autism;
- The update to the statutory guidance which will follow this update to the strategy;
- Relevant guidance which will follow the Care Bill; and

- Working with NICE to clarify how their guideline applies to older people.

## Think about other significant changes in a person's life

11.19 Changes such as bereavement, moving home, getting married and divorced, having children or becoming unemployed can have a significant effect on someone with autism. Amongst those who support people at these critical points in life, such as psychiatrists, counsellors and psychiatric nurses, staff who are trained about autism should be available and counselling should be adapted as appropriate. When services such as these do not meet people with autism's needs, the result can be that they can spiral into mental health crises with parents/carers left to pick up the pieces or if they are not available, expensive and inappropriate inpatient admissions or to contact with the criminal justice system. The Care Bill puts a duty on local authorities to develop preventative services for people within their communities. In discharging their duties on prevention, local authorities should ensure they are looking at the needs of their local autism population and developing such services appropriately.

15. *Getting on? Growing Older with Autism* A policy report (July 2013), <http://www.autism.org.uk/gettingon>



## **12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.**

12.1 Some people with autism will have additional, more complex needs. Mental health problems are more common among people with autism and it is estimated that around half of people with autism also have a learning disability. However, poor mental health is not an inevitable consequence of having autism and when someone with autism has a mental health problem, such as anxiety or depression, it is essential that they can access appropriate help and support.

12.2 Some people with additional needs such as these may communicate through behaviours that others may perceive as challenging, particularly if they are in an environment or context which they find unsettling or distressing. Some people with autism will also have additional long term physical health needs such as epilepsy and may require much higher levels of care, support and healthcare. Services and care planning for people with these needs should reflect their needs related specifically to their autism as well as those relating to learning disability or mental or physical health issues.

12.3 The terrible events exposed at Winterbourne View hospital threw a spotlight on the needs of some people with autism who have more complex needs, particularly behaviour others may find challenging or more severe mental health problems and/or learning disability. A third

of people within Winterbourne View had autism. *Transforming care*<sup>16</sup>, the DH's report following its review of the abuses exposed at Winterbourne View hospital and the accompanying Concordat<sup>17</sup> set out a programme of Action agreed to by over 50 organisations. Many of these actions will specifically target the needs of people with autism and/or learning disabilities who also have mental health problems or sometimes behave in a way that is challenging to others.

12.4 Most importantly is the aim for there to be a substantial reduction on reliance on inpatient care for this group of people. This requires personalised care planning, the provision of alternative community based settings and crisis intervention and support. NHS England is taking a lead on delivering this with health commissioners, working in partnership with local government and the LGA to secure transfers into the community. A joint LGA and NHS England improvement programme is providing leadership and support to local areas to transform services.

12.5 DH is also reviewing the Code of Practice for the Mental Health Act during 2014, including the chapter on autism. DH will also launch a new programme designed to reduce the use of restrictive practice and promote safe, positive and therapeutic environments. DH will ensure

16. *Transforming care: A national response to Winterbourne View Hospital Department of Health Review: Final Report* (December 2012) [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213215/final-report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf)
17. *DH Winterbourne View Review Concordat: Programme of Action* (December 2012) [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213217/Concordat.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213217/Concordat.pdf)



the specific needs of people with autism are factored into this programme.

12.6 It is possible for people with complex needs and autism to be supported appropriately to live in the community. They have equal rights to a fulfilling and rewarding life as anyone else.

### **13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.**

13.1 People with autism need access to support whether they are a victim, or witness, as set out earlier in priority challenge five, or are suspected of committing a crime. Criminal justice agencies (in particular the police, the CPS, probation and courts) should ensure that they have access to expertise to support adults with autism and consider the most effective way of ensuring that autism awareness guidance/training is available to staff. When people with autism come into contact with the criminal justice system it is often up to them, or their carer, to explain what having autism means. In some cases, it can change the way that police or courts view a situation. Police, probation services, courts and prisons at the very least need to be aware of the communication challenges experienced by people with autism in their interactions with other people.

13.2 A Cross Government Group led by the Ministry of Justice (MoJ) will consider issues to do with autism and the criminal justice system and report on progress to the Autism Programme Board by the end of 2014/15. This will cover issues such as training and awareness, screening, and reasonable adjustments and the use of IT systems to better support people with autism within the criminal justice system. This will take account of the awaited good practice work from the British Psychological Society's current Autism and the criminal justice system project.

#### **[Action 26]**

#### **Police**

13.3 The Home Office (HO) will work with the College of Policing to update and add to their mental health e-learning materials which include information on autism for new police officers in autism awareness. There is an absence of evidence-based advice for managing autism within justice settings. The HO will consider the scope for this with relevant professions, to go alongside training, and whether the markers on local police force systems to indicate an individual with mental health or learning difficulties can be extended to autism. It is proposed that the Metropolitan Police's local intelligence database could have such a flag for autism and have a simple flow chart for staff guidance and the impact of this will be considered.

#### **[Action 27]**

#### **Courts**

13.4 An aide memoire is also being developed by the CPS to assist prosecutors in cases where any party has autism. Cases involving offenders with autism often involve an application for special measures. The Judicial College has delivered training on the use of special measures and there is also access to materials via a private judicial training website. This includes the NAS publication *Autism: a guide for criminal justice professionals*<sup>18</sup>. The Judicial College also publishes the Equal Treatment Bench Book<sup>19</sup> which includes a section on Mental

18. *Autism: a guide for criminal justice professionals (2005)*, <http://www.autism.org.uk/cjs>

19. *Equal Treatment Bench Book (2013)*, <https://www.judiciary.gov.uk/Resources/JCO/Documents/judicial-college/equal-treatment-bb-2013.pdf>

Disability, including mental illness and specific learning difficulties. This assists judges to deal confidently, sensitively and fairly with all those who appear before them in whatever capacity.

### Liaison and Diversion

13.5 There is also a need for the criminal justice system to refer people with autism for appropriate health and care support to divert them, where appropriate; and prevent re-offending. If pilots are successful, Liaison and Diversion services will be available in every police custody suite and criminal court in England by 2017/18. The new liaison and diversion standard service specification requires providers to identify a validated screening tool for autism acceptable to NHS England Area Team Health & Justice Commissioners. Information gained from assessments will (with the informed consent of the individual) be shared with relevant key decision makers within youth and criminal justice agencies, to enable them to make more informed decisions about, charging, case management and sentencing. These information flows will also assist criminal justice agencies to consider whether reasonable adjustments are required to enable individuals to effectively engage in the youth and criminal justice systems. The ability of some people with autism to make decisions and predict consequences may need to be considered when looking at informed consent.

### Prison

13.6 Prison Officer training aims to ensure that staff are aware that someone may have hidden disabilities or difficulties and that learning will continue at prisons. The National Offender Management Service (NOMS) has supported this with funding during 2013 –14 to improve outcomes for offenders with learning disabilities and this resulted in the production of autism awareness pocket guides and a web based toolkit. NOMS will share good practice in prisons, such as at HMP Dovegate. **[Action 28]** In prisons mandatory assessment of function skills will take place for all prisoners from August 2014. NOMS will report back to the Autism Programme Board on what effect this has had on identifying prisoners with autism. **[Action 29]** Alongside this MoJ will hold discussions with the new Independent Institute of Probation to look at whether autism awareness training can be built into their work, and where appropriate will look to place relevant information into the Transforming Rehabilitation data room (an information repository for potential bidders for new probation contracts). **[Action 30]**

### **A personal story – Providing training and giving my own experience**

I was encouraged to provide an autism in the criminal justice system talk to the Governor of HM Prison Bedford, the local Police training leads and commissioners for offender health. I gave real life examples of my difficulties coping with interaction with the justice system as a suspect, as a witness and as a victim. They were amazed how I managed to highlight so clearly why having autism put you at a clear disadvantage in the justice system, and they wanted to help change this.

The Prison governor at Bedford was very enthusiastic about identifying prisoners with autism and I agreed to visit the prison with a view to giving more information on autism and what helps. One of my special interests is the NICE guidelines so I gave them loads of information about them, and they agreed to undertake research in screening people suspected of having autism to check if an assessment was needed. I was allocated a prison liaison Mental health in-reach worker and I worked with him to develop a training day for a select group of prison officers. The staff all recognised the characteristic difficulties with social interaction and rigid stereotyped behaviours/ interests which they had seen in people in prison and learnt from my real life examples of misunderstandings over lack of eye contact and thinking that a person is lying. How taking someone literally can be mistaken for sarcasm and being aggressive. For example when I was asked ‘what are you doing?’, and I replied ‘you can see what I’m doing, I’m walking down the street eating a bag of cashew nuts’; this can be misunderstood but with training many such misunderstandings can be avoided.

## Developing my skills and independence and working to the best of my ability.

### *14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.*

14.1 If a person is eligible for adult care and support, personalised approaches should be used to help them identify their support needs, give them greater choice and control and increase their independence. Under the Care Bill, adults will have statutory rights to direct payments and personal budgets as part of their care and support plan, which can be very useful for people with autism across the spectrum to engage support (although they may need help to manage this and to access what they need).

14.2 DH has funded a three year NAS brokerage/personalisation project from April 2013 to March 2016 to help support up to 2,000 people with autism to get more personalised support and develop a self-sustaining model for the future. DH will engage with NAS throughout the project to ensure there is learning from the emergent findings and, at the conclusion of this project, DH will look with NAS and other partners at their evaluation in order to embed learning in developing further models. **[Action 31]**

14.3 A person's access to and experience of education and training also has a direct impact on their skills and ability to live independently, to enter into and remain in employment and to lead a socially inclusive life. Some colleges and universities have worked hard to understand autism and provide appropriate services.

14.4 FE and training is also very important in enabling adults with autism to improve their life skills so they can be as independent as possible.

## **15. I want support to get a job and support from my employer to help me keep it.**

15.1 Most people with autism want to work and have skills and talents that would be useful in the workplace. With support, people with autism can both get and keep a job. Adults with autism are currently significantly under represented in the labour market, which has a detrimental impact on their financial circumstances and social inclusion, as well as being a waste of skills and abilities. The 2010 strategy included commitments aimed at increasing the number of adults with autism in work through the provision of guidance and training to employers and employment support services and ensuring adults with autism benefit from employment initiatives. DWP has since introduced the Work Programme which provides personalised back to work support for unemployed people, including disabled people. It has also established Work Choice and Access to Work, both of which help disabled people, including people with autism, find employment and stay in work.

### **Training for DWP staff**

15.2 DWP employs Disability Employment Advisers (DEAs) who are specialists who work with claimants facing complex employment situations because of their disability or health condition. This includes people with autism. All new DEAs receive training in awareness of autism. DWP will continue to work with key stakeholders to ensure the Department's training remains up-to-date and relevant. DWP is currently working with NAS to pilot

new training in autism for Disability Employment Advisers (DEAs) with the intention to explore the potential to roll out autism training to all DEAs. **[Action 32]**

15.3 In 2013, DWP recognised the need for Customer Care Officers (security staff) to become more aware of hidden impairments. The Department worked with the company providing the staff for the Customer Care Officer function which resulted in the Hidden Impairment Toolkit<sup>20</sup> being included in their training programme. The Toolkit was originally created by The Hidden Impairment National Group (HING) which was established in February 2010 and made up of disabled people, medical practitioners, academics and disability specific organisations. The toolkit was designed to offer practical guidance, hints and tips on how best to support individuals with hidden impairments including reasonable adjustment solutions.

### **The Disability and Health Employment strategy**

15.4 *The Disability and Health Employment strategy: the discussion so far*<sup>21</sup>, outlines a vision for a more personalised and tailored approach to employment support for disabled people in the future, including people with autism. This new approach will include a national network of specialist advisers who will act as a matchmaker between individuals and employers. The specialist adviser will be responsible for pre-employment support,

20. Hidden Impairment Toolkit, <http://www.hing.org.uk/>

21. The disability and health employment strategy: the discussion so far (December 2013) <https://www.gov.uk/government/publications/the-disability-and-health-employment-strategy-the-discussion-so-far>



job matching, work entry and sustained in work support, ensuring that disabled people including people with autism make a smoother transition into work and receive adequate in-work support.

### **The Disability Confident campaign**

15.5 As individual needs can vary, employers also need information about how to support a person with autism in the workplace. The Disability Confident campaign<sup>22</sup> launched at a conference in July 2013 by the Prime Minister is designed to help employers who are unsure about the benefits of employing disabled people as well as challenging negative behaviours and attitudes. It is being followed by a series of regional events during 2014. DWP will also be designing a ‘One Stop Shop’ service to support employers in employing disabled people. DWP has produced ‘Untapped Talent’, a guide for employers to help them to practice autism-friendly recruitment and to better support the people with autism in their workforce.

15.6 The new *Think Autism* community awareness programme will also aim to encourage employers to become more autism friendly in working towards a voluntary award or pledge. DWP will work with DH and its partners to identify new ways to reach out to employers and promote autism-friendly practice through the *Think Autism* awareness programme.

### **Taking forward work to improve support**

15.7 DWP, DH and NAS held a joint workshop on 3 March 2014 with a range of stakeholders and people with autism to hear about their experiences in the labour

market and consider steps to improve future support both in the short and long-term. The event included discussion about what employers can do, how experience of using Jobcentre Plus can be improved and about experiences of Work Choice and Work Programme. DWP will produce an Action plan based on the outcomes from the event and will report back to the Autism Strategy Programme Board in November 2014 on progress made in taking forward operational changes and reasonable adjustments to enable people with autism to have better access to job opportunities. This will include ensuring Access to Work advisors receive training in awareness of autism and increased promotion of how the scheme can support people with autism. DWP will also provide dedicated autism awareness training to a wider range of staff involved in helping people into employment and to providers engaged in delivering Work Choice and Work Programme.

### **[Action 33]**

### **Action for local authorities**

15.8 Local authorities can also play a key role in supporting adults with autism in their area to gain employment. The Autism Innovation Fund could be useful in supporting development here. In developing local plans, it is good practice that the employment support needs of the local population of adults with autism are considered by local authorities and that representatives from Jobcentre Plus as well as employers are invited to join the local Autism Partnership Board. Developing employment support services will help a local authority meet its prevention duties under the Care Act.

22. The Disability Confident campaign (July 2013)  
<https://www.gov.uk/government/publications/the-disability-confident-campaign>

15.9 Other key actions for local authorities to support increased employment include:

- ensuring that transition plans for young people with autism include employment as a key outcome, as appropriate employment is part of the new SEN local offer requirement;
- ensuring that the work of the local authority itself in relation to promoting employment effectively addresses the issues and needs of people with autism;
- promoting apprenticeship schemes;
- ensuring that the care planning process for adult social care needs considers employment as a key outcome, as appropriate, and looks particularly at whether personal budgets can be used to support adults with autism to become work ready;
- ensuring that the assessment process for adult social care includes signposting, as appropriate to Access to Work for interview support, other appropriate benefits and agencies that can help people with autism to find and keep a job;
- setting the example locally and becoming an autism friendly place to work.

### **A personal story – Developing skills and being healthier**

I have two jobs. My main job is at Adwick Community Enterprise, where I am employed as a Horticultural Assistant on a part time relief basis. My second job is a voluntary placement at Hayfield Wheelers where I work one day a week as a General Assistant. I started both my jobs in January 2008 and I am supported at work by the Doncaster Vocational Training Unit. I enjoy both of my jobs because they get me out of the house. I am paid for my work and I meet lots of people and have made new friends.

I think it is good to work as it is good for my health. I cycle to work at Wheelers when the weather is decent. I think I have learnt new skills at both of my jobs and I have become more confident, but I am still wary of new situations and people. At Wheelers I can now tune gears in and this is a skill I can use at home on my own bike. Skills I have learnt at Adwick mean that I can now do my own garden at home. I now represent people at the Choice for all Doncaster meetings and I have attended the Forum where dozens of people attended, which is something I am not keen on but I have learned to deal with it.

## 5. Next Steps

5.1 This update to the Adult Autism Strategy sets out work programmes and actions that will help local authorities, the NHS and their local partners with their local implementation work. Some will also directly help people with autism.

5.2 Autism should not be seen as an add on to services or work programmes, and with over 500,000 people on the autism spectrum in England, everyday services will already be seeing or in contact with many people who have autism. By thinking about and engaging with people who have autism more effectively, by making reasonable adjustments or adaptations and by involving them and building their capabilities, there will be better outcomes for them and a better use of public resources.

5.3 New statutory guidance will follow later in 2014, following a public consultation exercise.

# Appendix A

## About Autism – Key facts

1. Throughout the updated strategy, unless otherwise specified, the term 'autism' is used to refer to all diagnoses on the autism spectrum, including Asperger syndrome, high functioning autism, Kanner or classic autism.
2. Autism occurs early in a person's development. Someone with autism can show marked difficulties with social communication, social interaction and social imagination. They may be preoccupied with a particular subject or interest. Autism is developmental in nature and is not a mental illness in itself. However, people with autism may have additional or related problems, which frequently include anxiety. These may be related to social factors associated with frustration or communication problems or to patterns of thought and behaviour that are focussed or literal in nature.
3. A person with autism may also have sensory and motor difficulties that make them behave in an unusual manner, which is likely to be a coping mechanism. These include sensitivity to light, sound, touch and balance and may result in a range of regulatory behaviours, including rocking, self-injury and avoidance such as running away. There can also be a repetitive or compulsive element to much of the behaviour of people with autism. The person may appear to be choosing to act in a particular way, but their behaviour may be distressing even to themselves. However, these behaviours can also be an important self-claiming mechanism and should not be stopped or discouraged or seen as a deficit.
4. Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people. For example, Asperger syndrome is a form of autism. People with Asperger syndrome typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.
5. Recent estimates by the Health and Social Care Information Centre suggest that around one in one hundred people in England (over 500,000 people in total) have autism. Autism affects people in different ways – some can live relatively independently, in some cases without any additional support, while others require a lifetime of specialist care.
6. Adults with autism will have had very different experiences, depending on factors such as their position on the autistic spectrum, the professionals they have come into contact with and even how and when they got their diagnosis.

# Appendix B

## The 2010 Autism Strategy – Key themes

### From *Fulfilling and Rewarding Lives* to *Think Autism*

1. Published in 2010:

*Fulfilling and rewarding lives: the strategy for adults with autism in England* and *Implementing “Fulfilling and rewarding lives”* and

*Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy.*

2. These two documents started the process of ensuring the needs of adults with autism were met in England and between them contained a series of fundamental building blocks for national Government, local government and the NHS. Four years on from the publication of these two documents, these building blocks remain as important as ever. The recent self assessment exercise identified that most local areas either had these in place or had making significant progress towards implementing them. Whilst this update recognises the progress made, it remains crucial that these building blocks form the foundations of a fundamental improvement to the way in which adults with autism are supported. We continue to expect the following to be in place in every local area in England:

### Training

3. Autism awareness training should be available to all staff working in health and social care. Additionally, local areas should develop or provide specialist training for those in key roles such as GPs, community care assessors, personal assistants, occupational therapists or residential care workers. Organisations should seek to involve adults with autism, their families and carers and autism representative groups when planning or commissioning training.

### Identification, diagnosis and assessment of need

4. We expect there to be a clear pathway to diagnosis in every area and local areas should appoint a lead professional to develop diagnostic and assessment services. The pathway should be from initial referral through to assessment of needs. Diagnosis should lead to a person-centred assessment of need and should be recognised as a catalyst for a carer’s assessment. Assessment of eligibility for care services cannot be denied on the grounds of the person’s IQ. Any assessment of needs should be carried out by a professional who has a good understanding of autism and reasonable adjustments made to the process to enable the adult with autism to take part fully. All NHS practitioners should be able to identify signs of autism and refer for assessment and diagnosis if necessary. They should also then be able to understand how to adapt their behaviour and communication for a patient with autism.

## Transition

5. Local areas must follow statutory duties around transition for children with SEN, which will include most young people with autism. Protocols should be in place in every area for the transition of clinical mental health care for children with autism in receipt of CAMHS.

## Local planning and leadership in the provision of services

6. Local areas should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of community care services for adults with autism in the area. Local authorities, NHS bodies and NHS Foundation Trusts should develop local commissioning plans for services for adults with autism, and review them annually. To develop such plans, it will typically be necessary to gather information locally about:

- The number of adults known to have autism in the area;
- The range of need for support to live independently;
- The age profile of people with autism in the area – including those approaching;
- 65 or above working age and the number of children approaching adulthood, to enable local partners to predict how need and numbers will change over time.

7. Local commissioning plans should set out how local authorities will ensure that adults with autism are able to access personal budgets and benefit from the personalisation of social care. The strategy suggests that “local partners may also want to consider establishing a local autism partnership board that brings together different organisations, services and stakeholders locally and sets a clear direction for improved services.



# Appendix C

## Resources produced since 2010 to support Strategy implementation and related materials

Links to all the Autism Training and Awareness On-line Training:

### **Royal College of Nursing**

These links are available as free downloads for all healthcare professionals that may come into contact with people who have autism, highlighting key issues to consider.

<http://rcnpublishing.com/userimages/ContentEditor/1373363796507/Autism-poster.Pdf>

<http://mentalhealthpractice.rcnpublishing.co.uk/>

[www.rcn.org.uk](http://www.rcn.org.uk) – this link provides a general link to RCN resources, which include links to professional forums for members and publications.

<http://rcnpublishing.com/page/ns/resources/autism-online-resource-centre>

– RCN autism resource centre.

### **Royal College of General Practitioners**

The Autism in General Practice course enables GPs to improve the care they and their practice provide for patients with autism. Using video clips of real patients and carers recounting their experiences, this course helps to understand the challenges that people with autism face on a daily basis.

[www.elearning.rcgp.org.uk](http://www.elearning.rcgp.org.uk)

<http://elearning.rcgp.org.uk/course/view.php?id=78>

### **Royal College of Psychiatrists**

The Royal College of Psychiatrists aims to engage in expanding knowledge about the psychiatry of learning disability and autism. If you encounter any difficulties opening these links, please contact the Royal College of Psychiatrists on

Tel: 020 7235 2351.

<http://www.rcpsych.ac.uk/>

## Skills for Health & Skills for Care

Skills for Health and Skills for Care have developed a framework to guide the delivery of autism training for the mainstream health and social care workforces.

### Skills for Health

[www.skillsforhealth.org.uk/service-area/autism/](http://www.skillsforhealth.org.uk/service-area/autism/)

### Skills for Care

<http://www.skillsforcare.org.uk/Skills/Autism/Autism.aspx>

## Social Care Institute for Excellence

This training package looks at the techniques and skills that care workers and social workers need to support people with autism and help them achieve their goals. The link will take users directly to the page with two Autism films on it.

<http://www.scie.org.uk/socialcaretv/topic.asp?t=workingwithpeoplewithautism>

SCIE have also produced a guide titled *SCIE's Guide 43: Improving Access to Social Care for Adults with Autism*. The link below provides access to the full guide, an at-a-glance summary of it, an easy-read of the summary, and the underpinning research from the University of Sussex:

<http://www.scie.org.uk/topic/careneeds/autism>

## British Psychological Society

The Society has developed three e-learning modules on autism, which appeal to a range of learners by delivering knowledge and understanding from introductory to specialised levels. The e-learning modules are delivered via the BPS Learning Centre. The BPS has worked in partnership with psychologists with expertise in autism and an e-learning provider to produce and deliver these modules. Two modules are freely available to both members and non-members of the BPS and the third is aimed principally at psychologists and all professionals working in this field.

<http://www.bps.org.uk/events/e-learning/e-learning>

## University of Oxford

The Health talk online website lets you share in other people's experiences of health and illness. This information is based on qualitative research into patient experiences led by experts at the University of Oxford.

[www.healthtalkonline.org/Autism/](http://www.healthtalkonline.org/Autism/)

### **National Autistic Society**

The National Autistic Society website provides increased awareness and understanding of autism. It also details some of the examples of autism awareness training that currently exist.

<http://www.autism.org.uk/>

### **National Careers Service**

The website offers access to online tools and a wide range of information including, a skills health check which tests a range of skills, aptitudes and preferences, a CV builder, information on learning opportunities, funding for learning and Lifelong Learning Accounts (LLA) where people can save resources they have generated such as CVs and course information.

<https://nationalcareersservice.direct.gov.uk/Pages/Home.aspx>

### **National Institute for Health and Care Excellence (NICE)**

NICE has published 3 clinical guidelines and a quality standard on autism.

Quality Statement on Autism QS51 – NICE (January 2014)

<http://publications.nice.org.uk/autism-qs51>

Autism in children and young people (CG128) – NICE clinical guideline 128 (2011)

<http://guidance.nice.org.uk/CG128>

Autism – management of autism in children and young people (CG170) – NICE clinical guideline 170 (2013)

<http://guidance.nice.org.uk/CG170>

Autism in adults (CG142) – NICE clinical guideline 142 (2012)

<http://guidance.nice.org.uk/CG142>

### **The Green Light Toolkit 2013**

Green Light Toolkit 2013: A guide to auditing and improving your mental health service so that it is effective in supporting people with autism and people with learning disabilities, produced by the National Development Team for inclusion (NDTi).

[http://www.ndti.org.uk/uploads/files/Green\\_Light\\_Toolkit\\_22\\_Nov\\_2013\\_final.pdf](http://www.ndti.org.uk/uploads/files/Green_Light_Toolkit_22_Nov_2013_final.pdf)

## **Autism and the criminal justice system**

The website of the Autism and the CJS public engagement project funded by the British Psychological Society can be found at (<http://www.autismandcjs.org.uk/>). It is still in the development process, and has links and lay summary literature aimed at CJS professionals. The aim is to have it completed by October 2014.

The guidance for CJS professionals on autism (published by NAS and endorsed by the Association of Chief Police Officers) is available to download at <http://www.autism.org.uk/working-with/criminal-justice/autism-a-guide-for-criminal-justice-professionals.aspx> . There is also a lot of information on the NAS website on autism and the CJS <http://www.autism.org.uk/working-with/criminal-justice/criminal-justice-system-and-asds.aspx>

There is legal training on autism at: <https://www.legaltraining.co.uk/login/index.php?course=172> and the Advocate's Gateway has developed a series of toolkits with advice for advocates when examining vulnerable witnesses and defendants, including one on autism (<http://www.theadvocatesgateway.org/images/toolkits/3AUTISM211013.pdf>)

## Appendix D

### Actions summarised with timescales and leads

Number	Action	Lead	Timescale
1	Issue statutory guidance to support the updated strategy.	DH	December 2014
2	Advertise for new members to join the Autism Programme Board.	DH	By end of Summer 2014
3	Publish a summary of progress	DH	August 2015
4	Provide further information on the Autism Innovation Fund	DH	By end of June 2014
5	Provide further information on the Autism Awareness and Champions programme.	DH	By end of June 2014
6	Issue a guide on how to include young people with autism in the development of the local offer.	NAS (funded by DfE)	Summer 2014
7	Issue the 3rd Autism self-assessment exercise for local areas.	Public Health England, supported by DH, NHS England, Association of Directors of Adult Social Services and the Local Government Association.	November 2014
8	Bring together information on progress locally in a single place digitally so that it is easily accessible, and people with autism can rate services and to allow comparison.	Public Health England, with support from DH, NHS England and NAS	By end of March 2015
9	Explore the feasibility of research to review the effectiveness of low level interventions aimed at adults with autism who do not meet FACS social criteria.	DH	By end of March 2015
10	Assist with the promotion of Autism Passports being developed by Baroness Browning and NAS.	DH	By end of March 2015

Number	Action	Lead	Timescale
11	Staff in DH to have access to training on autism and work with DH's arm's length bodies on including autism in their equality and diversity training.	DH	By end of December 2014
12	Guidance and e-learning products developed as a result of the strategy to be publicised across Government Departments.	DH	June 2014
13	Develop an aide-memoire and support material for prosecutors, highlighting key issues, implications for the prosecution process and sources of support for people with autism.	CPS	Autumn 2014
14	Report on their review of bus driver disability awareness training to the Autism programme Board.	Department for Transport	March 2015
15	Bring together other equality groups and networks with autism groups to (i) build partnerships and (ii) gather case studies.	DH	March 2015
16	Issue guide summarising recent guidelines on autism diagnostic commissioning.	Joint Commissioning Panel of the Royal Colleges of Psychiatrists and GPs	September 2014
17	The Autism Programme Board to be updated by NHS England on how they are driving up quality in autism diagnostic services, and by the CQC in its wider statutory role in primary and secondary care in driving up quality.	NHS England and Care Quality Commission	By end 2014
18	Through the RCGP autism clinical priority programme look at the feasibility of introducing a Read Code for Autism.	DH, NHS England and the Royal College of GPs	March 2017
19	Establish a data and information working group to include DWP, DfE and others to report to the Autism Programme Board on available data sources for LAs on people with autism.	DH and Public Health England	November 2014



Number	Action	Lead	Timescale
20	Commission the scoping and development of a comprehensive Continuing Professional Development (CPD) framework for social workers, with an early priority being the development of CPD materials to improve the knowledge and skills of social workers working with people with autism.	DH	December 2014
21	Provide support to update the e-learning training developed under the 2010 strategy.	DH	March 2015
22	Ensure that the LA autism self-evaluation includes carers.	DH	To be issued in November 2014
23	Report to the Autism Programme Board on the wider changes to the SEND reforms and related issues for people with autism.	DfE	To agree issues to be reported back on by end of June 2014, and to report back by March 2015
24	Seek feedback on the type of apprenticeships being offered to people with autism, and discuss the findings and issues further with BIS.	DH/The Department for Business Innovation and Skills	By September 2014
25	Work with NAS so the findings from their report <i>Getting on? Growing Older With Autism</i> are embedded across future work.	DH	March 2015
26	Establish a Cross Government Group to consider and take forward issues to do with autism and the criminal justice system and report on progress to the Autism Programme Board, including issues such as training and awareness, screening, reasonable adjustments, and the use of IT systems to better support people with autism.	The Ministry of Justice	By the end of 2014/15

Number	Action	Lead	Timescale
27	Work with the College of Policing to update and add to their mental health e-learning training which includes autism for new police officers, look at evidence based advice for managing autism within justice settings, and whether the markers on local police force systems used for offenders with mental health or learning difficulties can be extended for those with autism.	Home Office	By end of October 2014
28	Examine and share good practice in prisons towards prisoners with autism.	National Offender Management Service	During 2014/15
29	Report back to the Autism Programme Board on the impact that the mandatory assessment of function skills for all prisoners from August 2014 has had on identifying prisoners with autism.	National Offender Management Service	During 2015/16
30	Consider whether autism awareness training can be built into the work of the new Institute of Probation, and, where appropriate look to place relevant information in to the Transforming Rehabilitation data room.	The Ministry of Justice	The end of March 2015 and the end of April 2014.
31	Evaluate the NAS brokerage and personalisation project with other stakeholders in order to embed learning in developing further models.	DH and NAS	December 2016
32	Respond to the results of NAS pilot on new training in autism for Disability Employment Advisors.	DWP	May 2014
33	Produce an Action plan based on the outcomes from the DWP/DH/NAS autism and employment event in March 2014 and report back to the Autism Programme Board on progress made in taking forward operational changes and reasonable adjustments to enable people with autism to have better access to job opportunities.	DWP	November 2014