



HM Government

# Progress Report on *Think Autism*: the updated strategy for adults with autism in England.

January 2016

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# Foreword

Just over 18 months ago you were asked to *Think Autism*. And with over half a million people in England estimated to have autism this was done for a very good reason. Your organisations and services will be coming into contact with people on the autistic spectrum on a daily basis. By engaging with those people effectively you can ensure that they do not miss out on accessing services and support, and by doing so you can have a positive influence on their mental and physical health.

To help with local implementation and planning it was right that many of the actions in *Think Autism* were for government departments and agencies to play their part in policy development and improving operational processes, and so help you in your important work. *Think Autism* followed the review of the 2010 autism strategy *Fulfilling and Rewarding Lives*, and was published in April 2014. It set out an updated programme of action to deliver the aims of the Autism Act. This report summarises progress since then and looks at how this work will go forward over the next 18 months with a number of refreshed actions building on progress made. A list of the original actions is found at **Appendix A**.

*Think Autism* continued to highlight the role that local authorities and NHS bodies should have in planning services for adults with autism. It placed greater emphasis on involvement and awareness within the local community and on ways to look differently at support and engagement. It also moved the original vision of the strategy on, including an increased focus on areas such

as young people, criminal justice and employment. The ethos of prevention, personalisation and opportunity runs through the revised strategy.

Local authorities and the NHS need to work in collaboration with their partners to continue to implement the autism strategy. Crucially, at the core of *Think Autism*, people with autism need to have access to a clear pathway to diagnosis and know that this pathway is aligned with care and support assessments, and that there is post-diagnostic support available even if the person does not meet social care support criteria. Commissioning decisions need to be based on knowledge and awareness of autism, the needs of the local population, and informed by people with autism and their families.

Government policy is assisting people with autism on the journey to reach their potential, to have full lives and to live as independently as possible. It is also right that we link work in autism to the Government's key priorities, as after all the mark of a civilised society is the support that is offered to vulnerable people to provide them with opportunities and improve their lives.

The new actions that are set out include those that:

- underpin successful implementation of the major reforms to the Special Educational Needs and Disability system in improving support for children and young people, including a greater focus on preparing for

adulthood and extending support from 0–25 years old;

- can better focus support to help with employment opportunities, both to the job applicant and the potential employer, at interview and if successful once in work;
- achieve better awareness of autism within the criminal justice system, if the person who has autism is a victim, a witness or an alleged perpetrator of a crime;
- will allow better reporting of progress and the use of information, to help commissioners plan services and for people with autism and their families to see what is happening in their local areas.

Failure to provide adequate services or make reasonable adjustments can have costly consequences for people with autism and for services. At worst it can mean that individuals fall into crisis situations and then require expensive

mental health services or residential care, do not fulfil their potential in employment, or end up losing their liberty if they come into contact with the police and the courts. A number of studies have estimated the costs of autism and the National Autism Project supported by the Shirley Foundation is currently looking at this issue.

The Department of Health is also working with University College London to look at evidence of cost-effective approaches for supporting people with autism. Awareness work by the Autism Alliance UK is also doing much to increase understanding of autism within parts of the public and private sectors. Other autistic charities are also playing their part with similar work. Our aim is to support the better joining up of work in this area.

The refreshing of the actions in *Think Autism* should ensure that momentum is not lost over the next 18 months. As we go forward with national policy and local plans it is important that we continue to *Think Autism*.



*Alistair Burt*

**Alistair Burt**  
Minister for  
Community and  
Social Care



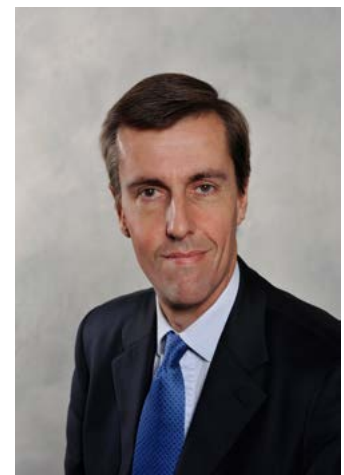
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Minister for Children  
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*Andrew Selous*

**Andrew Selous**  
Minister for Prisons,  
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Sentencing

# Introduction

The focus of the work outlined in *Think Autism*,<sup>1</sup> the update to the 2010 autism strategy,<sup>2</sup> was to improve outcomes for people with autism by developing policies that helped local implementation. It crossed many government departments and agencies: from health and social care to employment, education and criminal justice.

This progress report sets autism and the aims of *Think Autism* in the context of government reform to:

- deliver quality care to those who need it and making a positive impact on people's health in an efficient way;
- be a core part of health and care delivery;
- make sure that people have a good experience of care and services;
- prevent people from having episodes of crisis;
- join up better the NHS and social care, and other local partners.

The report sets out progress against each of the 33 *Think Autism* actions. They are referred to within the text and linked to the list of actions set out in **Appendix A**.

Where appropriate, further actions for the coming 18 months have been agreed to continue momentum and they are set out in each section and at **Appendix E**.

Within each section, progress has also been highlighted from the latest local authority area autism self-assessment exercise. Each section is introduced by what people with autism said when the autism strategy was being reviewed during 2013/14, to remind the Government and local services that the views of the autism community should be at the centre of all that we do. Case studies, including summaries of Autism Innovation Fund projects, are also included to illustrate good practice and innovative approaches.

1. *Think Autism: Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update* (November 2014). Available at: [www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy](http://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy)
2. *Fulfilling and Rewarding Lives: The strategy for adults with autism in England* (March 2010). Available at: [http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)

## About autism

Throughout this progress report, unless otherwise specified, the term ‘autism’ is used to refer to all diagnoses on the autism spectrum, including Asperger syndrome, high-functioning autism, Kanner syndrome<sup>3</sup> or classic autism.

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 or a learning disability. 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 focused or literal in nature.

A person with autism may also have sensory and motor difficulties, including sensitivity to light, sound, touch and balance. These difficulties may result in a range of regulatory behaviours, including rocking, self-injury, and avoidance such as running away. Often these are coping mechanisms. 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-calming mechanism and should not be stopped or discouraged or seen as a deficit.

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.

3. Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child* 2:217–250. Available at: <http://simonsfoundation.s3.amazonaws.com/share/071207-leo-kanner-autistic-affective-contact.pdf>



# 1. Delivering quality care to those who need it and making a positive impact on people's health in an efficient way

1.1 *Think Autism* was about supporting local authorities and the NHS to overcome challenges and barriers to make a difference for people with autism. This section looks at progress made, the role of planning at a local level and the importance of staff being trained about and aware of autism. The extensive reforms to the Special Educational Needs and Disability (SEND) system for 0–25-year-olds<sup>4</sup> show how resources, if used effectively, will make a positive impact on people with autism throughout their lives.

## National Autism Programme Board

1.2 The cross-government National Autism Programme Board has continued to oversee progress on the strategy and will

continue to do so. New self-advocates and family carer members have joined the board and its full membership can be viewed at [**Think Autism Action 2**].<sup>5</sup>

1.3 Going forward the board will be jointly chaired by a person who has autism or is a carer for a person with autism. The board has received regular reports on progress against the actions in *Think Autism* and this report is a summary of progress so far [**Think Autism Action 3**]. It is central to the autism 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.

4. *Special Educational Needs and Disability Code of Practice: 0 to 25 years* (January 2015). Available at: [www.gov.uk/government/publications/send-code-of-practice-0-to-25](http://www.gov.uk/government/publications/send-code-of-practice-0-to-25)

5. Available at: [www.gov.uk/government/groups/aapb#membership](http://www.gov.uk/government/groups/aapb#membership)

## Progress and planning

### What people with autism want (as heard during the review of the 2010 strategy)

*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.*

*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, are available for people with autism.*

### Progress indicated in the 2014 self-assessment exercise

- Joint Strategic Needs Assessment (JSNA) – A majority of local authorities reported including autism in their local JSNA (101; 66%) and commissioning plans (117; 77%), with 92 (61%) reporting that the needs of children and young people with autism were specifically considered. Public Health England's Learning Disabilities Observatory team analyse the content of JSNAs annually to monitor inclusion of people with learning disabilities. This year they will also report on coverage of adults and children with autism.
- Data about people with autism accessing health and social care services – Some 11 (7%) local authorities reported that they routinely collect and share data about all health and social care use by people with autism; while 123 (81%) reported that they were working towards this.
- A total of 125 (82%) local authorities reported that they collect data on the number of people with autism eligible for social care.
- Some 90 (59%) local authorities reported that corresponding clinical commissioning groups (CCGs) were fully involved in planning and implementation of the autism strategy.
- A total of 59 (39%) local authorities gave themselves the highest rating for engaging people with autism and their carers fully in the planning and implementation of the autism strategy.
- Some 12 (8%) local authorities reported having a clear policy and widely implemented policy for making reasonable adjustments to council-provided services to improve access and support for people with autism; while 19 (13%) reported evidence of implementation of reasonable adjustments to other publicly or commercially provided public services.

## Autism statutory guidance

1.4 Updated autism statutory guidance was issued in March 2015<sup>6</sup> following a period of consultation during November and December 2014.<sup>7</sup> It supports *Think Autism* by giving guidance to local authorities and NHS bodies about the exercise, respectively, of their social care and health service functions, for the purpose of securing the implementation of the strategy and its update [**Think Autism Action 1**]. The statutory guidance builds on progress made over the last five years and sets out the expectations for local areas so they can continue to develop services and support in ways that reflect the assessed needs and priorities of their communities.

1.5 Additionally, as well as reflecting the key legislation and health and social care reforms since 2010, the guidance puts greater emphasis on involvement and awareness within local communities.

## Wider legislative changes

1.6 Recent legislative changes will also enable local services to support people with autism and their families better, and they are also outlined in this statutory guidance. The Care Act 2014<sup>8</sup> places a strong emphasis on preventing and delaying needs for care and support by

making sure that there is appropriate information and advice for people, support for carers, and promoting integration between social care and health care services. It also places a duty on local authorities to promote a person's well-being when carrying out any of their care and support functions in respect of that person. This is explored in more detail in **section 4** of this report. The Children and Families Act 2014<sup>9</sup> will help to support young people in preparing for adulthood and this is outlined in more detail later in this section.

## The national autism self-assessment exercise

1.7 There have been two previous self-assessment exercises undertaken by local authorities and their social care, health and other partners. A baseline assessment was carried out in 2011,<sup>10</sup> with a follow-up assessment completed in 2013.<sup>11</sup> The self-assessments enable adults with autism, their families and carers, and autism representative groups to hold services to account and assess whether changes are taking place. The self-assessment exercise enables comparison and benchmarking across local authority areas and supports the identification and planning for areas where further action is required.

6. *Statutory Guidance for Local Authorities and NHS Organisations to Support Implementation of the Adult Autism Strategy* (March 2015). Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/422338/autism-guidance.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf)
7. *The Government Response to the Consultation on Revised Statutory Guidance to Implement the Strategy for Adults with Autism in England* (March 2015). Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/417889/Government\\_Response.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/417889/Government_Response.pdf)
8. *Care Act 2014*. Available at: [www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm](http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm)
9. *Children and Families Act 2014*. Available at: [www.legislation.gov.uk/ukpga/2014/6/contents/enacted/data.htm](http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted/data.htm)
10. Learning Disabilities Observatory (November 2012). *Autism Self-Assessment 2011: Issues from local authorities*. Available at: [www.improvinghealthandlives.org.uk/gsf.php5?f=16323&fv=17474](http://www.improvinghealthandlives.org.uk/gsf.php5?f=16323&fv=17474)
11. Public Health England (August 2014). *Autism Self-Assessment Exercise 2013: Detailed report and thematic analyses*. Available at: [www.improvinghealthandlives.org.uk/gsf.php5?f=312684&fv=20380](http://www.improvinghealthandlives.org.uk/gsf.php5?f=312684&fv=20380)

1.8 The third self-assessment protocol was published in December 2014 for completion by March 2015 [**Think Autism Action 7**].<sup>12</sup> It included 70 substantive questions, including questions about people who care for people with autism [**Think Autism Action 22**]. The principal questions (24 of them) asked local authorities to rate their progress as red, amber or green (RAG) according to a set of specified criteria. More evidence was required to score green or amber this time. A further 15 questions asked for numbers, particularly about adults passing through diagnostic services and the waiting times for this. There was also an opportunity to provide up to five accounts of personal experiences to illustrate the answers. A total of 21 RAG or yes/no questions were either identical (10 questions) or very similar (11 questions) to those in the 2013 self-assessment exercise. All but three local authorities submitted returns.

1.9 The largest number of local authorities rated themselves strong on care and support issues followed by employment. The largest number rated themselves weak on housing and accommodation.

1.10 Public Health England (PHE) has also published:

- a full report providing details of responses to each question, with maps and charts to show the patterns of progress;
- details of the personal experiences submitted;
- an online interactive display of the results;
- a full listing of all responses by all local authorities;
- a spreadsheet version of all the data to facilitate comparisons.

1.11 The results are available on Autism West Midland's Autism Connect website<sup>13</sup> in an easily accessible format allowing independent comments [**Think Autism Action 8**].

Section	Questions	Green	Amber	Red
Planning	9	29%	55%	11%
Training	2	28%	60%	12%
Diagnosis	4	30%	43%	25%
Care/support	4	45%	47%	7%
Housing/accommodation	1	8%	45%	45%
Employment	2	33%	59%	7%
Criminal justice system	2	16%	64%	17%

**Some local authorities did not answer every question.**

12. Available at: [www.improvinghealthandlives.org.uk/projects/autsaf201415](http://www.improvinghealthandlives.org.uk/projects/autsaf201415)

13. See: <https://autism-connect.org.uk/>

### **Autism Connect – autism-connect.org.uk**

This website was originally developed with funding from the Department for Education and was expanded to have a national focus with Autism Innovation project funding. Through Autism Connect it is possible to connect with like-minded people, share experiences, and ask and answer questions within the autism community. Additionally, users can find, rate and review local services as well as autism friendly venues. Also referenced are many free information sheets on aspects of autism. The events and calendar section enables users to find and add details of local events and activities.

1.12 Good approaches and practice locally will also be promoted online, such as that in Lincolnshire.

### **Rob Barber, Commissioning Officer, Specialist Adult Services at Lincolnshire County Council, sets out recent developments:**

In a collaboration between Lincolnshire County Council, the four Lincolnshire CCGs and members of the Lincolnshire Autism Partnership, we launched our All-Age Autism Strategy for Lincolnshire on 2 April 2015, to coincide with World Autism Awareness Day. At the beginning of 2015 we re-launched our Autism Partnership Board in readiness for the release of our strategy. This included the introduction of reasonable adjustments, such as communication cards, to ensure that meetings are more accessible for people with

autism. The partnership is key to helping drive the strategy forward, so we needed to ensure that we had appropriate stakeholders on board covering services for children and young people, as well as adults. A number of new working groups have been established and we have had an influx of people on the spectrum who are now heavily involved in the work we are doing, which is great.

Additionally, in December 2014, we appointed an autism 'expert by experience' to work across health and social care within our Joint Commissioning Team. This has been a crucial step to ensure that somebody with lived experience of autism is at the heart of our commissioning work and can help inform and educate us, as well as be directly involved in service design and development.

**For further information contact:  
autism.partnership@lincolnshire.gov.uk**

## Data

1.13 Good-quality data is integral to the successful development and implementation of autism strategies and commissioning. Local authorities and their health and wellbeing boards, CCGs and other partners need to have access to as comprehensive data as possible on prevalence and need. But gathering data on the number of people with autism and their needs can be challenging. Health and adult social care services are currently likely to be aware of only a proportion of people with autism.

1.14 Local estimates of prevalence can be calculated from national data using PANSI<sup>14</sup> (Projecting Adult Needs and Service Information). This database enables projections on the possible impact of demography and certain conditions on local populations, and allows local authorities to estimate unmet need. Estimates for children of school age were produced by the Learning Disabilities Observatory in 2011.<sup>15</sup>

1.15 Having agreed definitions of autism will improve data capture and analysis. As GPs are often the first point of contact for adults with autism, both before and after diagnosis, the Department of Health (DH) is working with NHS England and with the Royal College of General Practitioners (RCGP) through their autism clinical priority programme to explore the feasibility of introducing a Read Code for Autism [**Think Autism Action 18**].<sup>16</sup> The introduction of a Read Code for Autism may improve the quality of gathered data and lead to more effective local planning and commissioning of services in relation to need. In addition, the RCGP has developed a standard format letter to be sent to GPs by diagnostic services that has also been approved by the Royal College of Psychiatrists (RCP) and uses a limited number of codes.

1.16 From April 2014, local authorities started to collect Short and Long Term (SALT)<sup>17</sup> support data for users and carers that records their primary reason for support. Certain health conditions, including autism, are recorded in parts of the collection. This enhanced data set was published for the first time in October 2015 and will enable DH to commence analysis of the data to inform future data collections.

1.17 DH, in partnership with PHE, established a data and information working group that includes the Department for Work and Pensions (DWP), the Department for Education (DfE), the Ministry of Justice (MoJ), the Health and Social Care Information Centre (HSCIC) and the National Autistic Society (NAS), with a remit to compile a list of available data sources on autism (at **Appendix D**) for local authorities. The group will set out its programme going forward by January 2016 [**Think Autism Action 19**]. As part of this work, the HSCIC will consider the longer-term case for producing a report on autism in its *Focus On* series detailing information and statistics on autism.

14. See: [www.pansi.org.uk/](http://www.pansi.org.uk/)

15. Learning Disabilities Observatory (May 2012). *People with Learning Disabilities in England 2011*. Available at: [www.improvinghealthandlives.org.uk/publications/1063/People\\_with\\_Learning\\_Disabilities\\_in\\_England\\_2011](http://www.improvinghealthandlives.org.uk/publications/1063/People_with_Learning_Disabilities_in_England_2011)

16. NHS Information Centre (February 2010). *Access to Healthcare for People with Learning Disabilities*. Available at: [www.hscic.gov.uk/catalogue/PUB08591/acc-heal-care-peop-lear-disa-rep.pdf](http://www.hscic.gov.uk/catalogue/PUB08591/acc-heal-care-peop-lear-disa-rep.pdf)

17. HSCIC (September 2014). *Short and Long Term (SALT) Return: Guidance*. Available at: [www.hscic.gov.uk/media/12020/Guidance-supporting-SALT-collection/pdf/SALT\\_Guidance\\_v1\\_5.pdf](http://www.hscic.gov.uk/media/12020/Guidance-supporting-SALT-collection/pdf/SALT_Guidance_v1_5.pdf)



### **Good practice on types of data to collect**

To achieve the most accurate local information about the numbers of adults with autism and their needs, good practice suggests including the number of people with autism:

- from Black Asian Minority Ethnic communities;
- by gender (men, women or other), including transgender;
- in employment;
- likely to need employment support to gain or stay in work;
- placed in the area (and funded) by other local authorities;
- placed out of area by local authorities and/or NHS bodies;
- in hospital or living in other NHS-funded accommodation;
- resettled from long-stay beds or NHS residential campuses to community provision;
- living at home on their own, or with family members, or with older family carers and not receiving health or social care services.

Key professionals to engage in this evidence gathering are:

- social care professionals;
- GPs (who could identify numbers of people on their practice list who have an autism diagnosis and could also follow up with diagnostic services to find out whether their patients have been given an autism diagnosis if this information has not come back after referral);
- Jobcentre managers;
- employment support providers;
- local autism groups and branches of national autism third-sector organisations.

## Information-sharing agreement – Leicester, Leicestershire and Rutland

### Jane Forte, Commissioning Manager for Mental Health, Learning Disabilities and Autism at Leicester City Council, outlines arrangements put in place locally:

As three local authorities, three CCGs, two local hospital trusts and specialised commissioning services, we already work closely on Transforming Care and the Learning Disability and Autism self-assessment exercises. We also have joint delivery action plans that link with *Better Care Together*.

The weak link in this work was the sourcing and gathering of accurate data, having conversations when you knew who you were talking about but could not mention the name, or two people with the same initials get mixed up. We therefore looked at what information was required, why and from whom, so we could justify the reasoning behind sharing personal data. These are the questions, which with their answers are the basis for the agreement:

- What is the legal basis – the laws that let you to share this information?
- Is there consent?
- Can Information be shared without consent?
- Are there issues concerning a lack of capacity to give consent?
- Are there issues under the Data Protection Act 1998?
- Do we need to consider the Human Rights Act 1998?
- What information does each signatory need to share?
- Who is the data controller for this information?
- Indemnity required?
- How are we going to keep information accurate?
- How long will the information be kept?
- How will we share and keep information secure?
- What if we want to use the information for something else?
- What do we do if information is lost, disclosed or misused?
- How will we check whether our colleagues are complying with this agreement and if it is still current?
- What happens if there is a major security breach?
- What do we do if we are asked to disclose information that we receive under this information-sharing agreement?
- Who are the responsible people in each organisation?



The practical issues of sharing and destruction methods, and security requirements, were also to be agreed.

We are fortunate in the local authorities having coterminous boundaries with the three CCGs and the two hospital trusts. One of the CCGs takes the lead in collating the Transforming Care data. In the City of Leicester, GP data is on one system that is accessible to the CCG, whereas Leicestershire County and Rutland have different systems, which do not link. Children's services are included in the agreement but, again, have different systems and information streams. These are some of the ongoing issues, currently being worked on. Work is still being undertaken with the police, prisons and probation service, as they are not yet signed up. The agreement is currently under review and will be amended to reflect changes since it was drawn up – e.g. Winterbourne View changing to Transforming Care. There are gaps in information in both the Learning Disabilities and Autism self- assessments where we need more robust data and potentially need to work with partners to ensure that they are collecting data in a way that is useful to all parties involved.

The information-sharing agreement has made a tremendous difference in our ability to gather and cross reference data for the most recent self-assessment exercises and therefore provide evidence to support the development of services.

**For further information contact: [jane.forte@leicester.gov.uk](mailto:jane.forte@leicester.gov.uk)**

## **Actions going forward**

**Progress Report (PR) Action 1.** Public Health England's Learning Disabilities Observatory team to undertake an analysis of Joint Strategic Needs Assessments to identify the information they include about adults and children with autism and issue a report. By end of January 2016.

**Progress Report (PR) Action 2.** The Autism Programme Board to be jointly chaired by a person who has autism or is a carer for a person with autism. By February 2016.

**Progress Report (PR) Action 3.** DH to work with partners so that regional workshops can be held with local authorities, the NHS and other key stakeholders to support the implementation of the new statutory guidance, consider progress made and encourage regular network meetings to promote best practice and share information. From December 2015 to March 2016.

**Progress Report (PR) Action 4.** The next Autism self-assessment exercise to be undertaken by PHE from April 2016.

**Progress Report (PR) Action 5.** The PHE and DH led data and information working group to set out its work programme for going forward by end of January 2016.

## Training

### What people with autism want

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

### Progress indicated in the 2014 self-assessment exercise

- A total of 82 (54%) local authorities reported having a multi-agency autism training plan, with 60 (39%) reporting that CCGs, primary and secondary care practitioners are involved in this.
- A total of 109 (72%) local authorities reported involvement of the police in autism training.
- Some 38 (25%) local authorities reported involvement of local court services, and 69 (45%) reported involvement of the local probation service.
- A total of 44 (29%) local authorities scored themselves as green on whether autism awareness training has been made available to all staff working in health and social care, including staff in children's services. This included having a comprehensive range of local autism training that meets NICE (National Institute for Health and Care Excellence) guidelines and having a published autism training plan.
- Some 38 (25%) local authority areas reported that at least three quarters of their staff who carry out statutory assessments have attended specialist autism training.

## Local authorities and the NHS

1.18 In line with the 2010 and 2015 statutory guidance, local authorities and the NHS should be providing general autism awareness training to all frontline staff in contact with adults with autism, so that staff are able to identify potential signs of autism and understand how to make reasonable adjustments in their behaviour and communication. In addition to this, local authorities are expected to have made good progress on developing and providing specialist training for those in roles that have a direct impact on, and make decisions about, the lives of adults with autism, including those conducting needs assessments.

1.19 The regulations supporting the Care Act 2014 require those undertaking an assessment to have suitable skills, knowledge and competence in the assessment they are undertaking, such as autism. Where assessors do not have relevant experience of the condition, they should contact someone who does.

1.20 Health Education England's (HEE) role is to ensure that the NHS workforce has the right numbers, skills, values and behaviours to meet the NHS's needs of today and tomorrow. As part of its 2014/15 mandate with the Government,<sup>18</sup> HEE has been required to work with the Royal Colleges and other stakeholders to focus on supporting autism awareness training.

1.21 In partnership with Skills for Health (SFH) and Skills for Care (SFC), HEE has scoped, reviewed and collated a suite of

18. Department of Health (May 2014). *Delivering High Quality, Effective, Compassionate Care: Developing the right people with the right skills and the right values – a mandate from the Government to Health Education England: April 2014 to March 2015*. Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/310170/DH\\_HEE\\_Mandate.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/310170/DH_HEE_Mandate.pdf)

existing autism awareness resources.<sup>19</sup> These resources will enable the workforce to understand the needs of adults with autism, to respond appropriately or to make necessary adjustments. The resources were made available via the HEE website in June 2015 and launched at a national learning disability awareness-raising event in July 2015. A programme wide communication strategy has also been completed.

1.22 Funding from DH has been made available for HEE to work in partnership with SFC and SFH to develop positive behavioural support and autism training to health and social care providers. Funding has also been made available to facilitate the discharge from – and help avoid admission into – inappropriate hospital settings of individuals with a learning disability, autism, and behaviour that challenges. This will, for instance, include funding a unique approach to positive behaviour support involving people who work with, or are carers for, an individual with a learning disability, autism, and behaviour that challenges. It will be implemented across Transforming Care fast-track sites early in 2016.

1.23 The mental health and learning disability programme is taking forward parity of practice that focuses on physical health, mental health and intellectual disability. At times, individuals with autism display challenging behaviour. Education and training materials are being developed to ensure that the workforce is able to apply mindfulness approaches safely and

reflectively, and make adjustments in practice where clinically indicated. A revised learning disability skills and competency framework will address the needs of adults with autism. This will be complete by March 2016.

1.24 A long-term piece of work for HEE is to work with the Royal Colleges to develop and incorporate awareness, knowledge and skills for NHS health professionals in recognised areas of health, including autism, mental illness, physical illness and social support needs across all programmes. Work will commence in December 2015 and continue into 2018.

1.25 The Health and Care Professions Council (HCPC, formerly the Health Professions Council) is a statutory regulator of health and care professionals in the UK. It does this by setting and maintaining standards of proficiency and conduct for the professions it regulates. Its key functions include approving education and training programmes that health and care professionals – including chiropodists, podiatrists, dietitians, hearing aid dispensers, occupational therapists, paramedics and physiotherapists – should complete before they can register with the HCPC; and maintaining and publishing a register of health and care providers who meet predetermined professional requirements and standards of practice. DH will discuss with the HCPC to determine the element of autism awareness training that health and care professionals should meet within the education and training programmes.

19. Available at: <https://hee.nhs.uk/work-programmes/mental-health-and-learning-disability/learning-disability/education-and-training-for-the-whole-workforce/autism-awareness-learning-resources/>

## Raising the level of autism awareness across government

1.26 Guidance and e-learning products developed as a result of the original autism strategy were publicised across other government departments by Una O'Brien, the DH's most senior civil servant [**Think Autism Action 12**]. Other government departments shared their autism activity. Some 16 valued the importance of autism awareness, welcomed the work that had been undertaken to raise awareness across government, and shared the guidance and e-learning products with their department's disability network groups. In addition, some made available the links to online training resources via their intranets to raise awareness among staff.

1.27 Departments have put in place support for their staff who are on the autism spectrum along with wider staff awareness training. Some have run staff awareness sessions on the themes of neurodiversity, the autistic spectrum and attention deficit hyperactivity disorder (ADHD); have provided additional training for managers of staff with autism; or have an autism buddy group as part of their disability support network. Other departments have requested support from DH to disseminate and promote autism awareness training and to be made aware of developments with e-learning training products.

### Work experience case study

The Office for National Statistics was approached by a third-sector autism charity who asked if they would consider providing an eight-week work experience placement for a young man with autism who had expressed a specific interest in working for the organisation. This individual had achieved a degree in Mathematics and was keen to gain some experience within the research/statistics field in the hope that it would stand him in good stead for permanent employment. The placement was very successful and paved the way to employment, which was obtained through fair and open competition. The exercise was also an important learning experience for those involved with managing, mentoring and working alongside someone with autism.

## Upgrades of autism e-learning training and awareness tools

1.28 Following a review by John Simpson – then a self-advocate member of the Autism Programme Board – of the e-learning training funded by DH under the original 2010 autism strategy, funding was made available to update the e-learning training [**Think Autism Action 21**] to eight organisations that had developed their training packages in 2010/11.

1.29 These organisations were the British Psychological Society, University of Oxford, Royal College of GPs, Royal College of Nursing, Skills for Health, Skills for Care, Social Care Institute for Excellence, and the National Autistic Society.

1.30 Earlier in 2015, the organisations all submitted plans for updating their e-learning and awareness tools to enable professionals using them for training and awareness purposes to follow the most up-to-date approaches. Each of the organisations set out how it would update its e-learning materials, including sharing work between organisations. The organisations have followed a best value approach to assist GPs, social workers, clinicians and nurses to update their autism learning. This will have a direct impact on the quality and effectiveness of the services they provide. By building staff capabilities on autism awareness, there will be better outcomes for people with autism and their families and a better use of public resources. On completion they will be accessible via <https://www.gov.uk/government/news/autism-training-resources>

1.31 Some of the proposals, for example, will develop e-learning modules on autism that appeal to a range of learners by delivering knowledge and understanding from introductory to specialised levels. This includes developing and updating video clips of people with autism, and carers recounting their experiences. The work by the RCGP, for instance, will be linked to the GP curriculum, and can be used by over 50,000 RCGP members and their local faculties and other relevant networks.

1.32 The e-learning content updates will include clearly defined objectives, educational material and self-assessments to facilitate engagement and reflection. All the organisations are currently in the process of undertaking their updates.

## Department of Health staff autism awareness training

1.33 Work is ongoing so that staff in DH and its arm's-length bodies (organisations that deliver public services but are not government departments) have access to training on autism as part of their equality and diversity training [**Think Autism Action 11**]. DH wants to lead the way and is working towards delivering good-quality autism awareness training to its staff in partnership with people who have autism.

1.34 The interactive sessions will raise awareness on the issues facing people with autism and provide practical help, advice and shared experience on developing policy, communications, hosting meetings involving people with autism, and how these approaches can benefit everyone. The sessions will be made available to all policy-makers and staff who communicate with the public, to those who want to increase their awareness of the issues around autism, and to those who may work with people on the spectrum. Following the sessions, DH will provide links and signpost staff to resources for continued learning. In addition, DH will explore whether autism could be included in a new policy training programme that has been established for staff, and through the Connecting Programme will discuss the possibility of promoting autism-related placements for staff as part of their ongoing learning and development. DH will encourage its arm's-length bodies to follow a similar approach within the equality and diversity training for their staff.

## Social work training

1.35 DH worked with the then College of Social Work to commission the development of a comprehensive continuing



professional development (CPD) framework for social workers. This was issued in October 2015. A guide to improve the knowledge and skills of social workers working with people with autism [**Think Autism Action 20**] has also been published. Both are available at <https://www.gov.uk/government/publications/learning-resources-for-social-work-with-adults-who-have-autism>.

## Transport-related issues

1.36 The Department for Transport (DfT) reviewed the use of a derogation applied under EU Regulation 181/2011<sup>20</sup> exempting bus and coach drivers from undertaking mandatory disability awareness training in 2014, a year after its introduction [**Think Autism Action 14**]. This review was informed by an informal consultation with bus industry representatives, disability stakeholders, and charities with an interest to determine whether drivers are receiving adequate disability awareness training under the current voluntary arrangement. A summary of responses to this review was published on the Gov.uk website in January 2015.<sup>21</sup>

1.37 The findings of the review led to discussions with the Disabled Persons Transport Advisory Committee (DPTAC), the Government's statutory advisers on accessible transport, about undertaking a research project on the quality and impact of disability equality awareness training for bus and coach drivers. The aim being that this will then result in the development of good practice guidance on disability awareness training packages for these drivers and will be made available to operators to assist them in the

development and delivery of training in the run up to it becoming compulsory in 2018. The work will begin this January and will conclude fully in the autumn. DfT is also conducting research into the impact of a person's impairment when accessing transport and the social and economic losses as a result of restricted access. The overall aim of this project is to identify what evidence exists on the impact of a range of impairments on an individual's ability to access transport (the sampling includes autism) and what evidence exists on the social, economic and commercial costs (and benefits) of a fully accessible transport system. The evidence review report was received in October 2015 and is currently being considered by DfT officials and will be published this January on the GOV.UK website.

## National bus concession application forms

1.38 The national bus concession provides almost a million disabled people with free off-peak bus travel throughout England. Eligibility for the disabled person's concession is governed by seven legal criteria, against which local authorities, which administer the concession, are responsible for assessing applicants. DfT provides authorities with guidance to help them understand the criteria and implement them in a fair and consistent manner. Ultimately, however, local authorities remain legally responsible for administering the concession consistent with relevant legislation.

1.39 Sometimes it can be more difficult for people with certain categories of disability to demonstrate their entitlement to

20. Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:055:0001:0012:EN:PDF>

21. See: [www.gov.uk/government/publications/bus-and-coach-drivers-summary-of-disability-awareness-training-review](http://www.gov.uk/government/publications/bus-and-coach-drivers-summary-of-disability-awareness-training-review)

the concession than it is for others. DfT is currently updating a technical guidance document that provides advice on accessible communications and application processes. DfT also expects to review the eligibility guidance soon, and will consider how it can help local authorities to ensure that everyone entitled to use the concession is helped to access it. This might include recommendations regarding the information requested on application forms. Any future

changes to eligibility guidance will also be consulted on with DPTAC.

1.40 At present DfT does not have legal powers to require authorities to use a specific application form. However, by amending its guidance DfT hopes to influence authorities into making changes that will help all potential users, including people with autism, to apply for and use the national bus concession.

## Actions going forward

**Progress Report (PR) Action 6.** HEE to develop a revised learning disability skills and competency framework that will address the needs of adults with autism by March 2016.

**Progress Report (PR) Action 7.** HEE to develop and incorporate awareness, knowledge and skills in recognised areas of health, including autism, mental illness, physical illness and social support needs, across all programmes for NHS health professionals by 2018.

**Progress Report (PR) Action 8.** DH to approach the HCPC to determine the level of autism awareness included in its criteria covering education/training for those on its register, by the end of February 2016. Further action to be considered following the outcome of the discussions.

**Progress Report (PR) Action 9.** DH will look at feedback received from autism awareness sessions to set out further actions and encourage other government departments and arm's-length bodies to review autism awareness for their staff by the end of March 2016.

**Progress Report (PR) Action 10.** The DfT bus and coach driver disability awareness training research to be split into two phases:

- Phase 1 (by the summer 2016) to consist of research seeking to understand the current level of disability awareness training on offer and the impact it has on disabled customers.
- Phase 2 (by the summer 2016) to develop good practice guidance on bus and coach disability awareness training. The guidance will provide a detailed specification on the needs of disabled passengers and the expected conduct of bus and coach drivers at all different stages of the journey. The guidance will also include recommendations on evaluation schemes and provide detailed information on the desired learning outcomes.

## Transition from childhood to adulthood

### What people with autism want

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

### Progress indicated in the 2014 self-assessment exercise

- A total of 68 (45%) local authorities rated themselves as green on consideration of the particular needs of young people with autism in the transition process. This included having training inclusive of young people's services, carrying out analysis of the needs of young people including those without education, health and care plans, having specialist commissioning where necessary, and making appropriate reasonable adjustments.

## The Children and Families Act 2014

1.41 The Children and Families Act 2014 introduced the most significant reforms to the framework for children and young people with special educational needs or disabilities (SEND) for 30 years. Effective implementation of the reforms set out in Part 3 of the Act is improving the way needs are identified and support is provided. The aim is to secure better

outcomes for children and young people with special educational needs or disabilities from 0 to 25 years of age, including those with autism, and their families.

1.42 The Children and Families Act took effect in September 2014, and the reforms are currently being embedded. DfE is monitoring national implementation, working with the sector and gathering feedback on how the transition is going, and providing support to local authorities. As the reforms bed in, it is expected that children, parents and young people will have better information about the support available, and be more involved in decisions about their support and in the development of local services, while those with more complex needs will have greater control over their support through personal budgets.

1.43 In March 2015, DfE published a framework for SEND<sup>22</sup> accountability that provides the structure for improving outcomes and experiences for children, young people and their families. The new framework will show how the system is performing, hold partners to account and support self-improvement. This includes the Office for Standards in Education, Children's Services and Skills (Ofsted) and the Care Quality Commission (CQC) independent inspections of local areas' effectiveness in fulfilling their new duties.

1.44 An update on work in this area was presented to the Autism Programme Board at its March 2015 meeting [**Think Autism Action 23**].

22. Department for Education (March 2015). *Special Educational Needs and Disability: Supporting local and national accountability*. Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/416347/Accountability\\_Publication.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/416347/Accountability_Publication.pdf)



## The views of children and young people

1.45 The Act places much greater emphasis on local authorities taking account of the views, wishes and feelings of children and young people, including those with autism, and parents when carrying out their SEND duties.

## Better information and advice

1.46 Local authorities have to provide information for parents and young people through a local offer on the education, health, care and other services that are available locally. Children, young people and parents must be consulted by local authorities when developing the local offer and this is an opportunity to highlight the need for development in local services, including local autism services.

1.47 Young people with autism and their parents will be better informed about the options available to them. The local offer must include advice and information to help young people make the transition from school and from post-16 provision to adult life, about independent living, and the arrangements for supporting young people moving from child to adult social care services.

1.48 Under grant funding from DfE, National Autistic Society has worked with young people and local authorities to ensure that the voice of young people with autism is heard in the development of local offers and it has published *Local Voices, Local Choices*, which gives local authorities guidance on involving young people with autism in developing their local offers<sup>23</sup>

### **[Think Autism Action 6].**

1.49 Every local authority has a duty to provide impartial information, advice and support for children, young people and their parents. The Government is also investing £30m (2014–2016) to provide independent supporters who can support parents and young people with education, health and care (EHC) plans, needs assessments and plans, including the transition from learning difficulty assessments (LDAs) and statements. Independent supporters explain how the process works, including the legal requirements, and how families are able to engage with it, and then help them to engage.

1.50 There is an independent supporters service in every local authority area. An ongoing survey commissioned by the Council for Disabled Children, based on the first 900 responses from parents and young people, found that 90% felt the work with independent supporters was very or extremely useful 87% saying the support they received had a positive impact. In 2015/16, independent supporters services anticipated providing support to more than 35,000 families.

## Education, health and care plans

1.51 A key change within the Act is that it replaces SEND statements and Learning Difficulty Assessments (LDAs) with more coordinated EHC plans for children and young people aged 0–25 with the most complex needs. EHC plans are drawn up following a more participative and coordinated assessment than the assessments for SEND statements and LDAs. They are more person-centred, reflecting the wishes and aspirations of the children and young people themselves.

23. National Autistic Society (2014). *Local Voices, Local Choices: A guide to consulting young people with autism on your local offer*. Available at: [www.autism.org.uk/~/-/media/NAS/eCommerce/G-M/Local Voices Local Choices.ashx](http://www.autism.org.uk/~/-/media/NAS/eCommerce/G-M/Local%20Voices%20Local%20Choices.ashx)

1.52 At January 2015, 60% of children identified by schools and local authorities whose primary need was an autistic spectrum disorder had SEND statements or EHC plans, with extra support being arranged by the local authority. This is a higher percentage than for most other types of need. DfE expects that no children and young people with statements of SEND will lose their statement and not have it replaced by an EHC plan just because the system is changing. It is expected that those who would have continued to have a statement under the old system will be transferred to EHC plans following a transfer review. In future it is expected that many children and young people with autism will benefit from the extra and more coordinated support that comes with EHC plans.

### Children and young people with autism without SEND statements/ EHC plans

1.53 Support for those with autism but without EHC plans will also be improving under the new arrangements. The *Special Educational Needs and Disability Code of Practice: 0 to 25 years*, the statutory guidance that accompanies the new legislation<sup>24</sup> sets out clearer guidance on identifying children and young people's needs.

1.54 The guidance makes it clear that children with autism can have difficulties across all four main areas of need:

- communication and interaction;
- cognition and learning;

- social, emotional and mental health difficulties;
- sensory and/or physical needs.

1.55 The autism statutory guidance highlights that local authorities, NHS bodies and NHS Foundation Trusts need to recognise that not all young people with autism will have EHC plans. Receiving support in making the transition to adulthood, and accessing appropriate services as an adult, should not be dependent on having an EHC plan.

1.56 Under the care and support statutory guidance, issued under the Care Act,<sup>25</sup> local authorities should consider how they can identify young people who are not receiving children's services and are likely to have care and support needs as adults. The guidance identifies young people with autism whose needs have been largely met by their educational institution as an example.

### Joint commissioning and working

1.57 Local authorities are required to jointly commission, with health bodies, services for children and young people with SEND and to integrate services to improve outcomes. Joint commissioning arrangements will build on local JSNAs and be a key part of local health and wellbeing strategies. The NHS England Mandate has a specific objective on children and young people with SEND, and health bodies must have regard to the *Special Educational Needs and Disability Code of Practice*. A separate guide on the SEND reforms has been produced for health and wellbeing boards. Children with

24. *Special Educational Needs and Disability Code of Practice: 0 to 25 years* (January 2015). Available at: [www.gov.uk/government/publications/send-code-of-practice-0-to-25](http://www.gov.uk/government/publications/send-code-of-practice-0-to-25)

25. *Care and Support Statutory Guidance: Issued under the Care Act 2014* (October 2014). Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/366104/43380\\_23902777\\_Care\\_Act\\_Book.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/366104/43380_23902777_Care_Act_Book.pdf)

autism often require multi-agency assessment and intervention, and the reforms strengthen this. Already there is evidence of some local authorities having developed new integrated assessment

pathways for children with autism, for instance in Doncaster, St Helens, Manchester and Leicestershire ([http://www.leics.gov.uk/autism\\_spectrum\\_disorder\\_pathway.pdf](http://www.leics.gov.uk/autism_spectrum_disorder_pathway.pdf))

### **Case study: an effective multi-agency assessment pathway in Doncaster**

In 2011 Doncaster CCG identified some real concerns about the autism pathway in their area, with over 400 children and young people waiting up to two years for an assessment. To tackle this problem, the CCG appointed a lead commissioner, while partner agencies agreed to set up a steering group with high-level representation, including consultants, psychologists, parents and education and early years professionals who brought a wealth of experience to the group.

The steering group worked together to look at solutions based around NICE guidance and input from stakeholders, in particular parents and carers. It explored family experiences in detail and identified what support families wanted. From these discussions the themes that emerged were the importance of early identification, services talking to each other and post-diagnosis support. Families explained that support from professionals who could offer real coping mechanisms to help build their resilience was often the most helpful intervention.

As a result of this work with families and between professionals, from August 2014 a new NICE compliant autism pathway has been in place which significantly increases capacity and expertise from a range of partners, including consultants, speech and language therapists, clinical psychologists, educational psychologists and early years professionals. This core team works together to carry out a comprehensive assessment of each child or young person.

The post-diagnosis landscape is also much improved. Families are able to access support directly from highly skilled family practitioners, an outreach education team, coordinated parent programmes, increased specialist nursery provision, a short breaks service and an integrated Children with Disabilities Team. Most importantly, there is a commitment to embed these services so they are sustainable in the longer term.

The steering group has now evolved into Doncaster's Autism Strategy Group and will continue to oversee these services. Parents and carers are fundamental to this group and it has been a real driver in getting to where Doncaster is now with the autism pathway, which means there are no longer any children younger than 5 waiting for an autism assessment and the waiting list for those aged over 5 has been cut by two-thirds. Doncaster CCG is confident that, from May 2016, all children and young people will have a diagnosis within 18 weeks of referral – a remarkable achievement considering the starting point in 2011.

Feedback from parents and carers who have been through the new pathway is extremely positive across all services, and is the result of the commitment and dedication of many stakeholders.

## Addressing the adversarial nature of the system

1.58 One of the difficulties with the former SEND framework was that parents felt they had to fight for the right support for their children, too often having to register appeals at the First-tier Tribunal (SEND). Of the 3,147 SEND appeals registered at the Tribunal in 2014/15, 1,094 (nearly 35%) were in relation to children with autism. This was the largest number for any one type of need.

1.59 In order to address the adversarial nature of the former system, the 2014 Children and Families Act and the Code of Practice encourage closer working between parents, young people and local authorities. Together with the information, advice and guidance services for parents and young people, these provisions should help to avoid and reduce disputes between young people, parents and local authorities.

1.60 The legislation also maintains the duty on local authorities to have disagreement resolution services available and introduces a mediation stage in the Tribunal appeal process. Parents and young people who are intending to appeal to the Tribunal now have to contact an independent mediation adviser and say whether they want to go to mediation before appealing to the Tribunal. The local authority has to attend the mediation and this provides the opportunity for disputes to be resolved earlier.

1.61 A joint review of arrangements for disagreement resolution under the new SEND system is under way by DfE and MoJ. This includes the operation of disagreement resolution and mediation services, the impact of EHC plans in

promoting early agreement, and health and social care avenues for complaints. There is also a SEND Tribunal pilot, which extends Tribunal powers to make recommendations on health and social care issues as well as educational ones. Ministers are required to report back to Parliament following the review, by 31 March 2017.

## School and further education legislation joined up

1.62 The Children and Families Act has ended the divide between the legislation which applied to children with SEND in schools and those with learning difficulties and disabilities in further education (FE), which too often led to young people ‘falling off a cliff edge’ at 16. Under the Act there is now a coherent 0–25 years system, bringing parity of rights for those at school and at college. There will also be continuity of support beyond 18 and up to 25 for a young person if they need it to achieve their desired education and training outcomes and to help them prepare for adulthood. EHC plans will provide a much greater focus on these long-term outcomes, which will be identified through discussion between the young people and the other parties involved.

1.63 The Act places FE colleges under new duties, including the duty to ‘use [their] best endeavours’ to secure the special educational provision that all young people need, not just those with EHC plans. This is a significant area of the reforms for those approaching the transition to adulthood. FE colleges must have regard to the Code of Practice and cooperate with local authorities.

1.64 Chapter 7 of the Code of Practice is devoted to the FE sector, and sets out what



FE providers should be delivering for young people with SEND, including the expectation that they will be providing tailored and stretching study programmes designed to help prepare young people for adulthood. Funding for learners aged 16–18 in FE with special educational needs or disabilities (and those up to age 25 if they have an LDA/EHC plan) is provided by DfE through the Education Funding Agency.

1.65 DfE is working closely with the sector to provide support on implementing the reforms, producing a guide to the Code to help the sector prepare for implementation, running ongoing workshops for colleges and local authorities on EHC plans and how good study programmes can help young people achieve the outcomes in their EHC plans, and running a SEN FE Implementation Group to address issues.

1.66 FE colleges and other training providers across England have the freedom to respond to the needs of learners in their local communities. Many have developed innovative ways of responding to the needs of learners with SEND and are working with a wide range of partners.

### Provision for the 19 years+ age group without plans

1.67 Education providers are required under the Equality Act 2010<sup>26</sup> to provide reasonable adjustments for learners with learning difficulties and/or disabilities, and

the Equality Act Further and Higher Education providers' guidance<sup>27</sup> includes a wide range of examples of what might constitute reasonable adjustments in FE. The Department for Business, Innovation and Skills (BIS) provides learning support funding to colleges and training providers through the Skills Funding Agency. This is to help them meet the additional needs of learners with learning difficulties and/or disabilities who are aged 19 or over and who do not have an LDA or EHC plan. This includes those on a traineeship or apprenticeship, so that they can participate fully in education and training. This funding also helps providers to meet the cost of reasonable adjustments as set out in the Equality Act 2010. BIS have also funded Disability Rights UK<sup>28</sup> to work with key organisations to produce a new best practice toolkit, bringing together and augmenting good practice resources for colleges on support for disabled learners, including those with autism.

1.68 The Office of Qualifications and Examinations Regulation (Ofqual) places General Conditions of Recognition on the awarding organisations they regulate in relation to reasonable adjustments so as to enable a disabled learner to demonstrate his or her knowledge, skills and understanding to the levels of attainment required; these are published. NAS is involved with ongoing work with Ofqual to consider how exam papers can be designed to be more accessible to autistic students.

26. See: [www.legislation.gov.uk/ukpga/2010/15/contents/enacted/data.htm](http://www.legislation.gov.uk/ukpga/2010/15/contents/enacted/data.htm)

27. See: [www.equalityhumanrights.com/advice-and-guidance/further-and-higher-education-providers-guidance](http://www.equalityhumanrights.com/advice-and-guidance/further-and-higher-education-providers-guidance)

28. See: [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)

### **Case study: Askham Bryan College's autism champions**

Askham Bryan College has experienced a significant increase in the number of students with autism. Over a five-year period, the number of young people with autism attending the college trebled, from 31 in 2008/09 to approximately 90 in 2013/14. The college already had a dedicated autism coordinator in place, but she was struggling to meet the demand posed by these increasing numbers. In response, the college decided to create an 'autism champion' for each department. The aim was to increase learners' access to staff trained in working with young people with autism.

Achievement and progression data suggested that, while many young people with autism were able to move from entry level to level one, and in some cases from level one to level two, progression from level two to level three was less effective. As a result, the college prioritised training for staff working at levels two and three.

By training an autism champion in each department, the college ensured that young people with autism could access specialist support from a member of staff with an understanding of their autism and the subject matter, expectations, delivery style and examination requirements of their course. The autism champion was well placed to provide support and guidance to individual learners and their tutors about appropriate adjustments, including adaptations and strategies for support. The autism champion is the first point of contact for a learner with autism; the person they can go to if they are having any problems. The autism champion will liaise with departmental staff and, where additional support is required, refer the young person to the autism coordinator.

There are currently 20 autism champions across the college, all of whom have undertaken a specialist level two accredited qualification. In rolling out the training, the college prioritised the departments which had the highest numbers of young people with autism. It also trained the level two course manager and a senior manager as autism champions. The level two course manager has an overview of all level two provision. As such, she is well placed to understand the implications of level two course entry requirements, methods of assessment and accreditation. Being trained as an autism champion has enabled her both to identify potential barriers for young people with autism and work with department staff to develop and implement solutions to support progression for individual learners and across subject disciplines.

Training a senior manager as an autism champion has also proved very effective. Learning about autism has enabled her to better understand the reasons for any challenging behaviours shown by young people with autism, and to make an appropriate judgement about the best ways to address them. In making these judgements, the college can also draw on the relevant autism champion, someone who knows the individual concerned and has an understanding of autism and the way it affects them. This approach has not only led to a significant reduction in the number of young people with autism being subject to the college's disciplinary process, but it has also enabled the college to put in place more appropriate

strategies to effectively manage behaviours which challenge – and, in some cases, to eliminate them altogether.

The autism champions have proved so effective that the college aims to train another 20 staff, and to extend the role to others such as receptionists, librarians and catering staff. Moreover, the adaptations made to the college curriculum and environment as a result of the autism champions have significantly reduced the levels of anxiety and stress experienced by some of the young people with autism, enabling them to access learning more effectively.

### **Case study: learner with autism**

#### **Miss E. Burgess, Head of Learning Support at Heathfield Community College, talks about the college's facility for students with high functioning autism.**

'When Steve joined us in year 9, we were almost six months into our first year as a specialist autistic spectrum condition facility. While we had staffing, enthusiasm and many plans in place, we were still often working on a "batten down the hatches and get through the day" basis. Our strategy was born out of a recognition of our success with challenging students and a highly inclusive ethos, and we had the clear vision and strategy to ensure that our facility would provide expertise, awareness and a flexible environment so that students who might otherwise be catered for in specialist provision could attend and be ultimately successful in a mainstream environment.

'Steve was the epitome of this. Having been unsuccessful in his previous secondary setting, he had spent the best part of a year out of education and was described as academically able but lazy and aggressive. However, what we were in fact presented with was a boy who was so highly anxious that he could not bear coming into the school building if he was in sight of others and who winced every time the bell rang. We started with a flexible timetable, which built up over the course of six weeks from one hour a day to the full week in school, each day holding our breath in case it all went terribly wrong and he refused to come in, but he never did. It was not all plain sailing, of course. There were a number of incidents where the stress and anxiety of a busy school took their toll – several mock exam papers ripped into pieces and an unmovable garden table which did not live up to its description when he managed to upend it. When these incidents occurred we were fortunate that the leadership at the college shared our flexible approach and that procedures could be established to accommodate someone whose behaviour was clearly a result of anxiety, sensory issues and very real difficulties with social understanding.

'Steve is no longer at our college – having achieved GCSEs and A Levels he is now living and working abroad with a long-term partner. Since he left we've had many other "Steves" in our facility, each just as unique but all with a range of complex needs. In 2010 we were proud to be awarded accreditation by NAS. Our college

provision has developed through these experiences and, while we still have days when it feels like we are firefighting, in reality we have well-established provision that starts with every member of the college staff being aware of autistic needs and ends with individual packages for students, wherever possible. We continue to promote an inclusive philosophy and many of those who ask to visit the facility are met with the reply that there is really nothing physical to see here. There is no separate unit with students being taught outside the classroom. Instead we have the opportunity for withdrawal, if needed, and teaching staff who are equipped to meet the needs of the most anxious or exceptional. We feel that this is the greatest illustration of what we are aiming to achieve – a parity of school experience for all students, autistic or otherwise, where the curriculum and school environment are accessible to all and where reasonable adjustments are made on an individual basis rather than a “one adjustment fits all” model.

‘For our part we will continue to welcome the “Steves” of this world to our college. We are pretty sure there are a few in this year’s cohort, with whom we look forward to working. And so we recommence the necessary cycle of staff awareness training, communication, preparation and winning the hearts and minds of students and parents, who are understandably wary of the mainstream system.’

### **Case study: Brain in Hand**

Brain in Hand is one form of an assistive technology for people on the autism spectrum. NAS ran a small trial of Brain in Hand as part of its support for higher education (HE) students in London, funded by DH as an Autism Innovation Fund project. Thirty organisations in the UK have now introduced the system into their services, including eight local authority social services teams, autism service providers and schools and colleges.

More and more people on the autism spectrum are entering HE. The Higher Education Statistical Agency recorded over 2,400 students with autism spectrum conditions in UK universities in 2013/14, a 300% rise in three years. These students require appropriate support and adjustments to really thrive. For young adults, moving from further education to university can be overwhelming and worrying.

The results were encouraging: overall, 53% of students rated the impact of Brain in Hand as positive or extremely positive, while the same number felt more able to implement strategies and half reported feeling more confident.

Brain in Hand is a web-based mobile assistive technology. It uses a secure, cloud-based service that synchronises with a smartphone or tablet, giving students access to their coping strategies when they need them, and allowing them to report their mood and feelings.



The key features are:

- A diary feature creates a structured routine and 'recipes' for difficult-to-remember tasks.
- Users can build pre-planned coping strategies into the system to help them deal with difficult situations. These strategies are instantly accessible in a simple format on their smartphone.
- A traffic light system alerts a facilitator when a user reports high anxiety, enabling a timely intervention.
- Data is recorded in real time and displayed on a timeline, allowing users and support team members to track and understand situations or issues.

Brain in Hand is now available to students on the autism spectrum at universities across the UK through Disabled Students' Allowances, supported by NAS who provide facilitation in response to the traffic light alerts.

You can get more information and case studies from Matt Daniel: email [info@braininhand.co.uk](mailto:info@braininhand.co.uk) or visit [www.braininhand.co.uk](http://www.braininhand.co.uk)

## Provision for students in higher education

1.69 As previously indicated, HE providers have specific legal duties under the Equality Act 2010 to provide reasonable adjustments for disabled students. In addition to the support available through HE providers, the Government also provides individual support for disabled students in the form of Disabled Students' Allowances. Disabled Students' Allowances are non-repayable grants that are not means tested and are available for a range of support, including non-medical help (i.e. human support such as note-taking), funding for items of specialist equipment and assistive technology, and accommodation. Students wishing to apply for Disabled Students' Allowances will undergo a study needs assessment, during which their particular needs will be discussed within the context of their course of study. Students with an EHC plan may ask the local authority to provide a copy of the EHC plan to the Disabled

Students' Allowances study assessor to help inform discussions, if they wish.

1.70 For undergraduate students studying full time the maximum allowances are £20,725 annually for non-medical help and up to £5,212 for specialist equipment. Funding is also available for disabled students studying part time and at postgraduate level. BIS has been working with experts in the sector on how to make applying for Disabled Students' Allowances easier for students with autism, and some changes to guidance documents are under way.

1.71 The Government has recently consulted on how Disabled Students' Allowances will be provided in the future, and a response will be published in due course. The consultation considered how institutions might work towards a more consistent, more inclusive learning environment for all students, including disabled students.

## Guidance on the transition to adulthood and employment

1.72 A new chapter in the SEND Code of Practice is devoted to preparing for adulthood, giving advice on planning for the transition to adulthood from an early age and focusing on aspirations and outcomes to ensure that there are pathways into employment, independent living, participation in society and good health. The National Development Team for Inclusion is being funded by DfE to support local areas in developing their approach to preparation for adulthood.

## Support for work-based learning into employment

1.73 We know that too many adults with autism are not in employment, and that 79% of those with autism on out of work benefits want to work. This means that the increasing emphasis on pathways to employment for young people with SEND should be particularly beneficial for those with autism. Work-based learning is available through personalised study programmes for all young people aged 16–19, or up to age 25 if the young person has an EHC plan.

1.74 Traineeships and supported internships are two study programmes which are specifically designed to prepare young people for employment. Traineeships are a mainstream study programme for those who are almost ready to start paid employment or an apprenticeship. Supported internships enable young people aged 16–24 with a statement of SEND, an LDA or an EHC plan to achieve sustainable paid employment by equipping them with the skills they need for work, through learning

in the workplace. They are based primarily at an employer's premises and, wherever possible, they support the young person to move into paid employment [**Think Autism Action 24**]. In addition to these study programmes, apprenticeships allow young people or adult learners to earn while they learn in a real job, while also gaining a qualification. Thousands of disabled people have already benefited from apprenticeships. In 2013/14, the most recent year for data, over 38,000 of those starting an apprenticeship declared a disability of learning difficulty.

1.75 The Government is supporting local authorities to improve pathways to employment for young people with SEND through the national delivery support contract, *Delivering Better Outcomes Together*. Delivery partners support local areas and promote best practice. In March 2015 an additional £5m was made available for local authorities to fund preparation for employment for young people with SEND. Local authorities are targeting funding to:

- significantly increase the numbers of supported internships offered by FE colleges and schools, leading to more young people with SEND entering paid employment and improving the low current employment rate of just 7% for those with moderate and severe learning difficulties;
- build strong relationships with employers of all sizes and strategically coordinate activity at a local and regional level on behalf of schools and colleges. Employer engagement can be a barrier for schools and colleges and this should increase work experience for young people with SEND, including supported internship work placements;

- enable schools and colleges to improve the preparation for employment activities they offer through personalised study programmes for all young people with SEND, not just those with EHC plans, resulting in more young people finding paid employment.

### **Supported internship case study: Taurai at National Grid**

Taurai is 19 years old. He is autistic and had a statement of SEND at his special school. He had been bullied throughout his life for his 'label', which made him hate himself and his condition. When Taurai was 17, he had very few options for his future. Then his school told him about Employability, Let's Work Together, a supported internship programme they were setting up with National Grid.

Through this programme, Taurai worked in three placements throughout the year while continuing to study English and Maths. At the end of the year he could apply for any available roles, just like any other prospective employee.

Taurai's first placement was in the Safety, Sustainability and Resilience department. He was asked to create a presentation linking sustainability performance with financial performance. He had never done anything like that before, and it required a lot of research, planning and coordination. At first, Taurai thought there was no way he could do it. But he carried on reading and analysed the text, and realised he could. For the first time, he did something that was beyond what he thought were his abilities. Both he and his mentor were proud and deeply impressed by this achievement. Over the course of the year, Taurai worked hard and did extremely well in his other placements.

At the end of his supported internship, Taurai was offered a permanent paid job. He was delighted that National Grid had noticed how much hard work he had put in to succeed. He accepted the job and began getting ready for the rest of his career.

Taurai says: 'Being in Employability, Let's Work Together made me realise that anything is possible and that I can do things I never thought I could. If there were more companies using models like this, then a lot of us would be so much better off. Employability has shown me that it doesn't matter if you have autism or disabilities – you can still do it. Now, I dare to have an ambition, the sky's the limit and I will keep on working hard until I can say I've reached my goal!'

## Supporting the transition to adult health services

1.76 Under the Children and Families Act 2014, CCGs must cooperate with local authorities to jointly commission services that will help meet the outcomes in EHC plans. This should include supporting the transition between paediatric and adult services.

## Supporting ongoing social care needs

1.77 Under the Care Act 2014, from April 2015 local authorities must carry out a transition assessment if it appears to them that a young person under 18 years of age, whether or not they have an EHC plan, is likely to have care and support needs after turning 18 and the local authority is satisfied that it would be of significant benefit to that young person to do so. Care and support statutory guidance highlights young people with autism as a group who may not have received support as children but who might have care needs as adults.

1.78 The SEND Code of Practice makes it clear that, under statutory guidance accompanying the autism strategy, SEND coordinators in schools should inform young people with autism of their right to a community care assessment and their parents of the right to a carer's assessment. This should be built into the preparing for adulthood review meetings of EHC plans.

## Support for voluntary sector projects

1.79 DfE is funding a programme of support in 2015/16 to voluntary organisations to encourage better provision and ensure successful implementation of the reforms through:

- the Autism Education Trust, which provides three-tiered training in autism to early years providers, schools and FE colleges. Since the spring of 2012 almost 80,000 education staff have received training;
- Ambitious about Autism's Succeeding at College project,<sup>29</sup> which identified good practice to help students settle well after making the transition from school to college. This builds on their Finished at School programme,<sup>30</sup> which looked at innovative ways of supporting young people with autism, particularly those towards the more severe end of the spectrum, to make the transition from school to FE;
- NAS, which improves understanding of, and provides families with information and advice on, exclusions, disability discrimination claims and alternative provision; advises professionals on early intervention; maps alternative provision, identifying gaps and good practice; and trains teachers in the use of autism-friendly online teaching as a form of alternative provision. This builds on earlier work to improve understanding of and participation in the reforms of the SEND system and to provide advice on exclusions.

29. Ambitious about Autism. 'Funding Awarded for New Succeeding at College Project' (press release, 26 June 2015). Available at: [www.ambitiousaboutautism.org.uk/understanding-autism/funding-awarded-for-new-succeeding-at-college-project](http://www.ambitiousaboutautism.org.uk/understanding-autism/funding-awarded-for-new-succeeding-at-college-project)

30. Ambitious about Autism. *Finished at School: Supporting young people with autism to move from school to college*. Available at: [www.ambitiousaboutautism.org.uk/sites/default/files/Finished\\_at\\_School\\_guide.pdf](http://www.ambitiousaboutautism.org.uk/sites/default/files/Finished_at_School_guide.pdf)

### Case study: the Autism Education Trust's post-16 training programme

The DfE-funded Autism Education Trust's (AET) training hubs programme 2013–15 represents a widening and deepening of the AET (school age) programme 2011–13. The 2013–15 programme involved the development of new early years (EY) and post-16 (P-16) training materials for workforces and settings supporting EY and P-16 children and young people with autism, and this has been extended in the current DfE-funded 2015/16 programme. The P-16 strand of the programme consists of three stages of training, which are delivered via seven P-16 training hubs linked to two improvement frameworks: the AET National Standards and the AET Competency Framework.

An independent evaluation of the AET programme by Warwick University highlights initial examples of the successful use of the P-16 programme to train a range of FE college staff, in order to provide better autism support for college students.

A head of transitions at one college said: 'The training has enabled staff to have a better awareness and understanding of the challenges students with autism may face, along with the practical strategies that they are able to apply when supporting students with autism.'

A CPD trainer from another college trained the entire student services staff in Tier 1 (basic training) and briefed them about the role they had in supporting young people with autism to access the curriculum. The evaluation found that target numbers for Tier 1 had been exceeded, with significant levels of interest from delegates in a range of P-16 settings. However, the evaluation highlighted some challenges with take up of the more in-depth Tier 2 and Tier 3 training.

Steve Huggett, Director of the AET, reports that the organisation is currently reviewing options to increase the take-up of its Tier 2 and 3 training for colleges. A number of approaches are being considered, but an important one is looking at how to engage with senior management teams in P-16 settings. The size and complexity of FE colleges and the differences in funding compared with schools will need to be addressed if this challenge is to be met.

### New school provision for children with autism

1.80 School provision for children with autism over the years has developed across the local authority maintained, academy and independent sectors. Under DfE's free schools programme, there are now 19 special free schools open across the country, six of which specialise in provision for children with autism. These include the

NAS Church Lawton School in Cheshire and Thames Valley School in Reading.

1.81 There are a further 11 special free schools due to open in the future, five of which will specialise in provision for children with autism. These include the Heartlands free school in Haringey and a second NAS free school, the Vanguard free school in Lambeth. The other six schools will offer some places to children with autism.



## Actions going forward

**Progress Report (PR) Action 11.** DfE to monitor the effective implementation of the SEND reform programme. In March 2015 DfE published a framework for SEND which will show how the system is performing, hold partners to account and support self-improvement. This includes inspections by Ofsted and the CQC of local areas' effectiveness in fulfilling their duties in relation to children and young people with SEND. Ofsted and the CQC launched a public consultation on the proposed inspection framework in October 2015, with the first inspections planned for May 2016.

**Progress Report (PR) Action 12.** DfE to review arrangements for disagreement resolution in 2015–17, including a Tribunal pilot. The pilot will investigate the case for a single point of access to the Tribunal on education, health and social care issues. DfE and MoJ ministers must report back to Parliament on the outcome of the review by the end of March 2017.

**Progress Report (PR) Action 13.** DfE has funded Autism Education Trust, Ambitious about Autism and NAS projects in 2015/16 to support children and young people with autism through training education staff, exploring good practice in the transition to FE colleges, and offering support related to exclusion and alternative provision. Resources from these projects will be made available by the end of March 2016.

## 2. A core part of health and care delivery

2.1 The NHS, working with local authorities, has a responsibility to provide autism diagnostic services.

### Diagnosis

#### What people with autism want

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

#### Progress indicated in the 2014 self-assessment exercise

- In total, 83 local authorities (55%) rated their performance as green for the establishment of a local diagnostic pathway. This required a pathway to be in place and accessible, GPs to be involved in the process, and the wait for referral to the diagnostic service to be less than three months.
- A total of 95 (63%) reported that they offered a specialist autism-specific service.
- A total of 82 (54%) reported that diagnosis triggered an automatic offer of a community care assessment.
- Some 45 local authority areas (30%) rated themselves as green on whether people with autism can access post-diagnostic autism-specific or reasonably adjusted psychology assessments, with 26

(17%) rating themselves as green for accessing speech and language therapy assessments.

- A total of 27 local authority areas (18%) rated themselves as green on whether post-diagnostic autism-specific or reasonably adjusted occupational therapy assessments can be accessed.
- There was a large improvement nationally in the number of diagnostic pathways established since the 2013 self-assessment. Some 23 partnership boards reported that they had established a pathway since that year, while three partnership boards reported that no local diagnostic service had been planned or established. A total of 63 (41%) reported that implementation of a pathway was currently in progress. Local authority areas commonly reported that there were different pathways in place for adults with and without learning disabilities.
- The reported average wait between referral and assessment was similar to that in the previous year's framework, ranging from 27.9 weeks to 29.6 weeks. The NICE recommendation is 30 weeks. This question had been slightly modified from the previous self-assessment exercise, and this had the effect of producing wider variation in the waiting times reported.

2.2 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, and of not understanding the way they respond to situations or why they find social settings difficult. They may also have been users of 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.

2.3 In every local area, health services should have a pathway to diagnosis, just as the local authority should have a clear framework for assessing the care and support needs of children and adults with autism. Local areas will continue to be asked to assess their progress on this through the local area self-assessment exercise. It is recommended that the NICE guidelines are followed.

2.4 While local authorities lead commissioning for care and support services for people with autism, CCGs take the lead responsibility for commissioning diagnostic services and work with local authorities to provide post-diagnostic support, regardless of whether the person has an accompanying learning disability, other hidden impairments or a co-occurring mental health problem. Some people with suspected autism may not need further support. However, this does not mean that they should not have access to a diagnosis. For some people, simply having a diagnosis of autism confirmed can be incredibly important, and can help them avoid needing more intensive support at a later stage, for example if they have a crisis.

2.5 The autism statutory guidance states that NHS England local audit teams will assess the quality of autism diagnostic pathways and people's experiences of using them [**Think Autism Action 17**], and this work will continue over the coming months (see 'Actions going forward').

2.6 DH has supported the work of the Joint Commissioning Panel (JCP) for Mental Health, a collaboration between 17 leading organisations co-chaired by the RCP and the RCGP. They have been developing a guide to encourage commissioners to use a values-based commissioning model when planning diagnostic services [**Think Autism Action 16**]. The JCP will now issue the practical guide on autism by April 2016, in order to include learning from work by NHS England (see action below).

### Action going forward

#### **Progress Report (PR) Action 14.**

NHS England, working with the Association of Directors of Adult Social Services and advice from PHE and DH, will use data from the autism self-assessment exercise to work with a sample of local authority areas to identify the barriers that are stopping them having fully established diagnostic pathways, and share the learning from this exercise with all local authorities and CCGs. Initial work to take place in January and February 2016.



## 3. Making sure that people have a good experience of care and services

3.1 Innovation, awareness and a better use of technology can all improve support for people with autism.

### Innovation, awareness and technology

#### What people with autism want

*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.*

*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.*

### The Autism Innovation Fund

3.2 *Think Autism* wanted people with autism to really be included as part of the community. This meant looking beyond statutory services at how communities can be more aware of and accessible to the needs of people with autism. The successful approach taken on dementia in response to the Prime Minister's Dementia Challenge provided an innovative model from which to learn. *Think Autism* also

wanted to promote innovative local ideas, services or projects which could 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 included models which would support early intervention or crisis prevention or which would support people to gain and grow their independence, or to find employment. It was hoped that this would also improve understanding of the cost-effectiveness involved and help local authorities get more for their local populations.

3.3 A £1m Autism Innovation Fund was launched to help drive creative and cost-effective solutions, and identify new models of good practice that could be replicated in other areas [**Think Autism Action 4**]. A total of 360 bids were received and ultimately 42 were successful; these are listed at **Appendix B**. Examples are given as case studies in this report.

3.4 As the projects end and are evaluated, reports will be placed on the Autism Connect website by the end of January 2016 and can be accessed at: [www.autism-connect.org.uk](http://www.autism-connect.org.uk).

## Living with Autism project

**Manar Matusiak summarises the Living with Autism project, which was a partnership project assisting people with autism and their families in order to improve their quality of life.**

The aim was to develop practical early intervention strategies to prevent crises and enhance wellbeing. The partnership comprised one private company and three charities in North Yorkshire, Cheshire and Warwickshire. The partnership organisations were Living Autism, a national online and offline hub for those seeking support, advice, information and connections to specialist autism services; Independent Advocacy, a Warwickshire charity working with young people; Space4Autism, a Cheshire charity providing an autism support network for families; and Time Together, a support group for adults with autism.

The project has taken innovative ideas from various sources to develop a range of practical autism strategies for use nationally – a helpline for all, practical workshops for families, coaching for young people, and enabling adults to access leisure activities. Through partnership, the project has provided preventative strategies and techniques to adolescents and adults of all ages. Project partners were in daily contact with people with autism and their families in a variety of situations and have addressed different issues.

Projects undertaken were:

- expanding the Living Autism national helpline service;
- developing the ‘Coach in My Pocket’ software application for daily use by people with autism;
- supporting the needs of young adults with autism in transition from secondary education in Warwickshire, and working with North Warwickshire College and local schools to raise awareness of issues facing these young people;
- practical workshops for families in Cheshire, covering issues they face every day and developing materials to enable lessons learned to be used nationally;
- facilitating a group of adults with autism to organise and access leisure activities in North Yorkshire.

The underlying message is that there is much knowledge already in the public domain of benefit to people with autism in their daily lives. Collaborative projects involving independent, charitable and user-led organisations can collate guidance of value nationally using structured projects such as this.

Some themes that emerged have been:

- There is a strong appetite for workshops providing sensible, practical strategies, delivered in an expert and accessible manner.
- Appropriate, unobtrusive support can help people with autism improve their confidence, social interaction and independence skills as part of a group.
- Initial pilot studies show that a software tool to help people with autism organise their lives can be of benefit to some.
- Raising awareness within education of issues surrounding autism can improve young adults' success in accessing further education or work.
- Effective use of online publicity attracts more people needing help with issues surrounding autism.

Evidence of projects working:

- repeat uptake of practical workshops and sourcing of new funding to continue workshops;
- positive initial user reaction to the pilot app;
- a 20% increase in requests to the helpline during the project;
- high enthusiasm of those taking part in organising their own activities;
- greater understanding of young people in transition to adult life by education staff following awareness-raising.

**For further information contact: [www.livingautism.co.uk](http://www.livingautism.co.uk)**

3.5 Capital funding of £3m was also made available and £18,500 was allocated to every local authority as the Autism Capital Fund. The use of innovative technology was encouraged to help increase and maintain independence. Equipment could also be purchased 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. Details of how funding was used were asked for in the autism self-assessment exercise.

3.6 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 people they support to help develop their confidence, sense of achievement and independence.

**Karen Kime, Change Manager at Stockport Council, outlines how the £18,500 was used there.**

In Stockport, we were keen to invest the grant in projects that would:

- add value or extend existing and planned projects;
- encourage local groups to work collaboratively;
- focus on building social and communication skills in ways that would help people with autism find and retain employment.

Following a period of consultation, it was agreed that some of the funding would be used to enable Pure Innovations to build additional soundproof radio studio space so they could extend their National Open College Network-accredited Media Work Skills course to people with high-functioning autism. The course started in April 2015 and runs for two days a week for 48 weeks. It is designed to help students gain transferable communication skills and to improve the employment rate for people with autism. The course is supported by staff and volunteers from the in-house radio station Pure 107.8FM (see: [www.pure-radio.org/home/4587844803](http://www.pure-radio.org/home/4587844803)).

Most of the funding has contributed to the creation of an autism-friendly space in the new premises that Stockport Advocacy ([www.stockportadvocacy.org.uk/](http://www.stockportadvocacy.org.uk/)) have recently acquired. Careful consideration has been given to soundproofing, decor and lighting. Stockport Advocacy already host a group of young adults with autism (Group 48) and they are involved in designing the space, which includes a small quiet room as well as a larger ground floor meeting and activity space.

The purchase of 3DNovations software and laptops from Hao2 ([www.hao2.eu/](http://www.hao2.eu/)) has enabled software designed by people with autism to be used for people with autism. It enables people with autism to gain valuable 3D technology skills, and to use avatars to begin to develop confidence to deal with a range of social and workplace situations. People have been trained and supported to use the software and laptops.

Building on the individual projects that the Innovation Fund has funded, Pure Innovations and Stockport Advocacy have worked together to enable people with autism to develop skills and confidence in ways that suit them best. People can start to use the Hao2 software at home, then meet up and use it alongside other people; perhaps they can graduate to a media course, and maybe attend a town centre social group where they can start to develop a support network of friends, as well as professionals and other people who are active in their communities. The aim is for people to move between organisations and projects at their own pace, and to build sustainable relationships along the way. By working together, and in partnership with adults with autism, the two organisations can facilitate and develop a much wider range of experiences and options by pooling resources and expertise.

Both Pure Innovations and Stockport Advocacy are also applying for further funding to extend the work that has already begun. The Autism Capital Fund has provided seed funding to demonstrate what is possible and how future funding can add further value in terms of developing services.

**For further information contact: [karen.kime@stockport.gov.uk](mailto:karen.kime@stockport.gov.uk)**

### **Autism Innovation Project at Dorset HealthCare**

Dorset HealthCare wished to increase its ability to recognise and treat all service users with sensory processing disorder and autism through the development of an integrated care pathway, sensory therapy room and increased provision of Ayres Sensory Integration Therapy.

#### **Kate Hardy, Improvement and Experience Manager at Dorset HealthCare University NHS Foundation Trust, sets out what they did.**

The funding allocated from the Autism Innovation Fund has enabled a sensory therapy suite to be installed at Dorset HealthCare University NHS Foundation Trust. The existing physiotherapy gym has been converted at one of our community hospital locations, Alderney Hospital, Poole, to provide a versatile room for Sensory Integration Therapy. This room was identified as being suitable and will enable additional use to be gained for physiotherapy as well as sensory therapy due to the installation of the weight-bearing beam for hoists and swings. A usage plan was developed to ensure that the room is utilised for the maximum time, allowing additional sensory therapy to be provided across Dorset. Care pathways were reviewed to develop awareness of the availability of Sensory Integration Therapy and to support speedy assessment and intervention for new referrals.

#### **Case study**

E is a female in her 40s, married with a family and a full-time job. She was recently diagnosed with Asperger syndrome. She was referred to the occupational therapy team for management of sensory overload and development of strategies for organisation. E had applied for a care package to manage some of her domestic tasks due to disorganisation. She also feared losing her job due to her inability to perform certain tasks.

The occupational therapy team intervention consisted of the formulation of a sensory diet and some education to support her, as well as four sessions in the sensory therapy room for direct therapy. The occupational therapist looked at dyspraxia and retrained E's brain to be more organised, to perform simple planning tasks and to be more coordinated.

The outcomes of the intervention were:

- E cancelled the care package for domestic tasks as she was able to plan, organise and complete tasks independently and without struggle.
- Provision of in-work support and intervention resulted in E keeping her job and having appropriate support in place to sustain employment.
- Sensory diet and organisational strategies helped her in not feeling overwhelmed and feeling able to cope with daily sensory input.

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## Autism awareness and champions project

3.7 National charities and organisations like Ambitious about Autism, the Autism Alliance UK, Autism Plus, NAS and the many smaller local and national organisations and groups work to raise awareness day in and day out. This makes a real difference. The awareness and champions project was an opportunity to test out ways of working, and the Autism Alliance UK were successful with their bid [**Think Autism Action 5**].

3.8 The Autism Alliance UK Connect to Autism project has:

- worked across eight geographical areas with national and local services, venues and activities to provide people who work in retail, leisure and public services with information about how they can make their buildings and services autism friendly through reasonable adjustments and providing a supportive approach;
- focused on developing partnerships in some local areas to join up local authorities, other partners, local services, businesses, retailers and people with autism;

- worked with people with autism to design an Autism Charter which employers, retailers and service providers can sign up to;
- set up a Champions Network of people who are committed to promoting awareness both publicly and in activities in their spheres of interest and influence.

3.9 Progress achieved in Phase 1 of the project can be found at [www.autism-connect.org.uk](http://www.autism-connect.org.uk). Phase 2 is subject to approval but includes the development of plans to support the autism third sector to work on specific issues in partnership. Details can also be found at the above link.

### Action going forward

#### **Progress Report (PR) Action 15.**

Subject to approval, the Autism Alliance UK to complete Phase 2 of the autism awareness project, including the development of plans to support the autism third sector to work on specific issues in partnership, by March 2016.



## Transforming care for people who have autism

### What people with autism want

*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.*

3.10 From April 2015, the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014<sup>31</sup> state that service users must be treated with dignity and respect, and in particular that a registered person must have due regard to any relevant protected characteristic (such as disability) of the service user. These regulations also state that care or treatment for a service user must not be provided in a way that includes discrimination against them on grounds of any protected characteristic, such as the disability of that service user.

3.11 People with autism or learning disabilities who also have mental health conditions or behaviours that challenge are entitled to get safe, good quality care, whether at home, in the community or in hospital. However, studies and investigations have found that too many people with autism – including those who may have behaviours that challenge, or complex needs – continue to be placed in hospital settings, including specialist hospitals, for assessment and treatment. In

some cases they can be in hospital for many years, often far from their home community, and may receive poor quality care.

3.12 Often a hospital environment is not conducive to the needs of someone on the autistic spectrum, where the environment is a critical factor in meeting their needs. Wherever possible, individuals should receive the appropriate assessment, treatment and support in a community setting, and certainly in the least restrictive setting possible. Having autism and/or complex needs does not mean that long-term inpatient residential care or assessment and treatment centres should be used inappropriately or indefinitely.

### No Voice Unheard, No Right Ignored

3.13 The previous government launched this consultation in March 2015. It concerned people with learning disabilities, autism and mental health conditions, and sought views on a range of proposals for potential new primary legislation, changes to existing primary and secondary legislation, statutory guidance and other non-legislative proposals. It was a wide-ranging consultation covering rights and responsibilities across health, social care and justice. The Government has responded to the consultation by setting out an ambitious programme that includes some immediate actions, as well as a commitment to tackling some of the more complex issues over a longer timeframe. The response<sup>32</sup> is a statement of future ambition and is part of an ongoing

31. See: [www.cqc.org.uk/content/regulation-10-dignity-and-respect](http://www.cqc.org.uk/content/regulation-10-dignity-and-respect)

32. *Government Response to No Voice Unheard, No Right Ignored – A consultation for people with learning disabilities, autism and mental health conditions* (November 2015). Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/475155/Gvt\\_Resp\\_Acc.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/475155/Gvt_Resp_Acc.pdf)

programme. The Government will keep the impact of guidance/proposals under review, with a view to making further, more binding, changes if the planned impact is not being achieved.

### Transforming Care

3.14 NHS England has set out a clear programme of work with other national partners, outlined in *Transforming Care – Next Steps*,<sup>33</sup> to improve services for people with learning disabilities and/or autism, and drive system-wide change. This will enable more people to live in the community, with the right support, ideally close to home. The *Transforming Care* programme is jointly led by NHS England, the Association of Directors of Adult Social Services (ADASS), the CQC, the Local Government Association (LGA), HEE and DH, and focuses on the five key areas of empowering individuals; right care, right place; workforce; regulation; and data.

3.15 A progress report was published in July 2015 outlining what has already been delivered and setting out important milestones for 2015/16. The report acknowledges that, while progress has been made, there is still much more to do to ensure that, where appropriate, people are cared for in the community and close to home.

3.16 Progress in recent months includes:

- developing and undertaking care reviews for people with learning disabilities to support them moving out of inpatient hospital settings and prevent unnecessary hospital admissions and lengthy hospital stays;
- launching the Fast-Track programme in five areas to test and accelerate service redesign;
- testing a new competency framework for staff, to ensure that staff with the right skills are in the right place;
- ensuring more robust collection and sharing of data to track progress.

3.17 A national transformation plan was published by NHS England, the LGA and ADASS in October 2015 called *Building the Right Support: A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition*.<sup>34</sup> A service model setting out the key expectations and requirements for local services was also published. All local areas have been asked to reflect this service model in their business plans for 2016/17.

33. *Transforming Care for People with Learning Disabilities – Next Steps* (January 2015). Available at: [www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf](http://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf)

34. *Building the Right Support: A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition* (October 2015). Available at: [www.england.nhs.uk/wp-content/uploads/2015/10/ld-net-plan-er.pdf](http://www.england.nhs.uk/wp-content/uploads/2015/10/ld-net-plan-er.pdf)

## Mental Health Act Code of Practice

3.18 A revised Mental Health Act Code of Practice<sup>35</sup> came into force in April 2015. It was prepared in accordance with section 118 of the Mental Health Act 1983. Chapter 20 of the Code addresses the key issues from the Act and the Mental Capacity Act 2005;<sup>36</sup> these are relevant to people with autistic spectrum conditions in that they require professionals to ensure the independence and dignity of those they treat and assess, and to show them respect.

3.19 Many people with autism who have been detained under specific sections of the Mental Health Act 1983 will require, and be entitled to, aftercare. Discharge planning for people with autism should begin when the person is admitted, and should involve health and local authorities working together in the interests of the individual to ensure appropriate community-based support is in place before discharge. This will require assessment by a practitioner with expertise in autism.

### Action going forward

#### **Progress Report (PR) Action 16.**

The Government will keep the impact of guidance/proposals in response to *No Voice Unheard, No Right Ignored* under review to ensure significant progress is made between now and March 2020.

35. *Mental Health Act 1983: Code of Practice* (January 2015). Available at: [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/435512/MHA\\_Code\\_of\\_Practice.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/435512/MHA_Code_of_Practice.pdf)

36. See: [www.legislation.gov.uk/ukpga/2005/9/contents/enacted/data.htm](http://www.legislation.gov.uk/ukpga/2005/9/contents/enacted/data.htm)

## 4. Preventing people from having episodes of crisis

4.1 Preventative support can do much to give people with autism confidence and reduce their levels of anxiety, allow them independence and avoid crisis situations linked to events in their lives. Such support can be more cost-effective in relation to more expensive interventions should a crisis develop.

### Supporting people with autism

#### **What people with autism want**

*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.*

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

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

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.

### Care and support

4.2 Many people with autism do not meet the criteria for social care support. However, from April 2015 section 2 of the Care Act placed a duty on local authorities to provide or arrange preventative services for people within their communities. In discharging their duties on prevention, local authorities should, in particular, ensure that they are considering the needs of their local adult population who have autism, including those who do not meet the eligibility threshold for care and support.

4.3 Preventative support can be provided in many different ways. 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 also support independent living and being part of the community. Such provision should form part of a comprehensive range of preventative support and should be accessible and provide choice – for example, by ensuring there are a number of support options across a geographical area. Preventative support and advocacy are also important themes in the Care Act statutory guidance.

### Progress indicated in the 2014 self-assessment exercise

- In total, 34 local authorities (22%) reported having a single identifiable point of contact where people with autism could find autism-friendly entry points to a wide range of local services.
- A total of 132 (87%) reported having a recognised pathway for people with autism but without a learning disability to access a community care assessment.
- A total of 54 (36%) reported that there was a programme in place which ensured that all advocates working with people with autism have training in the specific requirements of their role.
- Some 73 local authorities (48%) reported that adults with autism have access to appropriately trained advocates who can participate in needs assessments, care and support planning, appeals, reviews and safeguarding processes.
- A total of 141 local authorities (93%) reported that people with autism who are not eligible under Fair Access criteria or not eligible for statutory services for other reasons can access support.

In total, 102 (67%) rated themselves as green on offering assessments to carers of people with autism who are eligible for social care support. This requires carers to be routinely identified and offered an assessment themselves following the assessment of anyone needing support for autism who they care for. They should also have the option of requesting a carer's assessment, and information about obtaining a carer's assessment should be clearly available.

4.4 If a person with autism 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 Act adults 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.

4.5 DH has funded a three-year NAS brokerage/personalisation project from April 2013 to March 2016 under the Innovation, Excellence and Strategic Development Fund to help support people with autism to get more personalised support and develop a self-sustaining model for the future. DH has engaged with NAS throughout the project to ensure that there is learning from the emerging findings. [**Think Autism Action 31**]



### **Lesley Waugh NAS National Brokerage Coordinator, tells us about the National Brokerage Project.**

The project is based in Plymouth, Northants, Leicestershire, Newcastle, Greater Manchester and their surrounding areas.

Support brokerage is about making sure that people with autism and their families get support to plan and make choices. It enables people to get the life they choose and get good support to meet their assessed needs. Support brokers develop plans with the person, help in negotiations with local authorities and assist in the implementation of the plan. Support brokers can also support the reviewing process.

The key aims of brokerage are:

- to empower people who have autism and their families to understand social care and health systems;
- to share best practice;
- to identify internal and external researchers and implement measures to quantify satisfaction with brokerage support;
- to test and develop a sustainable model for the delivery of brokerage support.

Outcomes include:

- people with autism having increased self-esteem;
- through community solutions, people get a life and not just a service;
- people with autism having reduced social isolation and having choice and control over support planning and processes;
- long-term cost savings for health and social care.

#### **Case study**

T has high support needs and this would normally have meant her moving into a residential setting. After using the brokerage service, T chose to stay at home and be supported by her mother and specialist support workers rather than move into a residential setting. Her budget was £30,000 per year. T's choice of support has saved the health and social care system £42,000 a year.

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4.6 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. The establishment and maintenance of a

service for providing people in their area with information relating to care and support for adults is a duty which was placed on local authorities from April 2015 (under section 4 of the Care Act 2014).



### **Mandy Shrimpton of Rainbow Autism Company of Community Interest (CIC) provides details of the Spectrum Hub.**

Rainbow Autism CIC is a social enterprise and a professionally independent supporters led specialist support service. We currently provide support in the Worcestershire area but have begun to develop our service in Herefordshire. Over our five years of business we have identified the need for a menu of support and services, collaboration between different disciplines and multi-agency working. As a result we have developed a 'spectrum hub' model that provides the basis for a variety of support and services and gives us the flexibility to meet the fluctuating and complex needs of those with autism.

The Autism Innovation Fund has enabled introduction of the hub model to allow our highly experienced specialist professionals (including social workers, a counsellor/ psychotherapist and diagnostic assessment practitioners) and experienced support staff to deliver early intervention and crisis management support and introduce group projects to improve, promote or maintain greater independence and wellbeing. We have worked with many people in crisis, some feeling suicidal, self-harming and/or at imminent risk of homelessness or unemployment or at risk of harm from others and feeling socially isolated.

Our hub has provided the following outcomes in six months:

- received referrals from 106 individuals in total, supporting 76 (the others merely required information or appropriate signposting) on a one-to-one basis to meet a variety of needs, including crisis management (many of our members are at significant risk of harm to themselves or others);
- assessments of individual needs; advocacy and support to individuals on the spectrum (and other professionals requiring information/support to maximise their ability to help the individuals they were working with) to introduce or enhance access to support and services required; providing or enabling access to diagnostic assessments where required; supporting individuals to access benefits they are entitled to; enabling access to vital services required (such as mental health services, housing, employment support, etc.); providing specialist counselling/psychotherapy to those with an identified need; delivering autism awareness presentations (for example as part of our female group to enable greater understanding of 'self');
- introduced a weekly workshop, 'Skills for Meaningful Occupation', and as a result have so far successfully supported four people into voluntary placements and one into paid employment);
- introduced a weekly social group. Some of the group are working with us to develop an 'Autism Service User Reviewing Team' to champion, review and offer suggestions for 'reasonable adjustments' to local services;
- introduced a female group that meets regularly to socialise;

- introduced a craft group in response to some service users' interests and skills in this area;
- promoted collaboration with other professionals/agencies to enable a sharing of resources, experience and expertise for a more holistic approach to support. This has resulted in access to a cooking group with one of our associates;
- attended local panels/a meeting with MPs, commissioners and housing providers with the intention of raising awareness and advocating for the general needs of those with autism, in order to gain more appropriate services;
- begun to develop Rainbow Autism CIC support and services in Herefordshire.

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4.7 It is critical to the vision in the Care Act that the care and support system works to actively promote wellbeing and independence, and does not just wait to respond when people reach a crisis point. It is vital that the care and support system intervenes early to support individuals, helps people retain or regain their skills and confidence, and prevents care and support

needs developing (or delays deterioration in such needs) wherever possible.

4.8 DH has commissioned University College London to carry out research on low level support for people with autism [**Think Autism Action 9**]. The first phase of this work will report by March 2016.

### **Melanie Howard from Autism East Midlands provides an overview of its Autism Innovation Fund project Enterprise for Autism.**

#### *Project aims and design*

The Enterprise for Autism six-month pilot project was designed by Autism East Midlands to support seven adults with autism in Nottinghamshire who do not meet the eligibility criteria for statutory support. The project operated out of Autism East Midlands' Enterprise Hub in Worksop. The project's aims were:

- to help participants develop vocational and independence skills in order to enable them to progress to work experience placements during the life of the project;
- to equip participants with the skills and experience to secure employment in the future.

The project was designed to guide participants through three phases of development:

- a baseline assessment of an individual's skills, knowledge, experience, needs and aspirations, followed by vocational skills development at the Enterprise Hub;
- a volunteer placement in a not-for-profit organisation to achieve a specific goal, supported by staff from Autism East Midlands;

- a work placement with a buddy provided by the employer and trained by Autism East Midlands.

### *Outcomes and achievements*

During the course of the project, participants demonstrated increased self-confidence and growing levels of independence. For example, one participant began his work experience placement requiring staff to plan his journey to Sheffield, purchase his train tickets and accompany him on the journey. By the end of his work placement, he was happily making the journey independently.

By the end of the project, the following outcomes had been achieved by the eight participants:

- all undertook voluntary placements in not-for-profit organisations;
- all undertook work experience placements, five of whom secured positive references to support their applications for future employment;
- three had their work experience placements extended;
- two secured paid employment.

Maxine Rawling, a Health and Safety Training Manager for DHL who was involved in the project, said: 'Our experience has been truly positive. J is a hard-working young man and working with him has helped to dispel the stereotype of autism. Like many young people, J just needed a chance.'

The Enterprise for Autism pilot project faced a number of challenges, including:

- unmet mental health issues and a number of participants (and their families) struggling to come to terms with a relatively recent diagnosis of autism. The original project design did not include clinical input from the Autism East Midlands Psychology Team, which at the start of the project had only recently been set up. Although clinical input was identified as a need for several people as the project progressed, participants struggled to engage with the additional support offered. With hindsight, the project design should have factored in the involvement of the Psychology Team in the very early stages of the project so that participants could get to know team members and recognise them as an integral part of the project support team;
- the need to be less prescriptive in the design of the three project phases, which in practice became very bespoke for each individual;
- flexibility in the location of the base for the project. Part-way through the project, a second base (Nottingham) was introduced as an alternative venue to accommodate participants' preferences and needs.

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## Autism Passports

4.9 One of the things many people with autism 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 an important role in enabling a person to share with services what adjustments they need. DH has worked with Baroness Angela Browning and NAS, and an evaluation of Autism Passports is currently taking place [**Think Autism Action 10**]. From July 2014 to April 2015, the Autism Passport was downloaded a total of 6,424 times by 4,959 users.<sup>37</sup>

## Diversity

4.10 More work will be taking place to 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, people who are lesbian, gay, bisexual or transgender, and members of Black, Asian and Minority Ethnic (BAME) groups who have autism [**Think Autism Action 15**]. Issues discussed to date include GP understanding, community awareness, the use of inappropriate mental health services, and sexuality across the spectrum; these will be explored further in three workshops to be held by March 2016.

### Carol Povey from NAS outlines the Autism in Pink project.

The Autism in Pink project was an innovative project which aimed to understand and improve the wellbeing of women on the autism spectrum across Europe. Funded through the European Union Lifelong Learning Programme, the project focused on the lived experiences of women from Portugal, Spain, Lithuania and the UK.

The women involved participated in structured workshops led by NAS, using the Personal Wellbeing Index – a standardised subjective quality of life framework with the following domains:

- general satisfaction with life;
- standard of living;
- personal health;
- achievements in life;
- personal relationships;
- personal safety;
- community connectedness;
- future security;
- spirituality or religion.

37. Ford, S. "Passport" aims to help autistic patients communicate with nurses', *Nursing Times* (17 July 2014). Available at: <http://prod.nursingtimes.net/roles/learning-disability-nurses/passport-aims-to-help-autistic-patients-communicate-with-nurses/5073087.fullarticle>

The workshops also afforded the women the opportunity to develop a greater understanding of themselves and their diagnosis in a supportive atmosphere. The research indicated that these participants, when compared with their neurotypical peers, scored lower across all domains; the overarching impact of anxiety and stress was particularly highlighted. These results were used to develop an e-book, learning materials and a documentary film.

The e-book and learning materials raise awareness of the challenges women with autism face and offer potential strategies and solutions. They can be used and contributed to by women with autism and anyone else who wishes to gain greater understanding or provide support. This will be of interest to women and their families and to educational, vocational, social and health care professionals.

Additionally, a study of prevalence in the four partner countries was undertaken, showing the starkly contrasting rates of autism in those countries and highlighting the importance of awareness and identification. In 2014, the women met with legislators in each partner country and with members of the European Parliament in Brussels to present findings on the ways in which the rights of women with autism are often breached under current legislation and to propose solutions in terms of further work and legislation. The project culminated in an international conference in Lisbon, which attracted policy-makers, educators, family members and other autistic women in an atmosphere of empowerment and celebration.

Since then, some of the women involved have presented the project findings across the UK, including at the NAS's women and girls' conference. A number of them have gone on to contribute to other initiatives, including research. The products produced by the project are available in English, Lithuanian, Spanish and Portuguese on the Autism in Pink website ([www.autisminpink.net](http://www.autisminpink.net)).

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## Older people

4.11 Older adults with autism are a neglected group and have received less attention through policy, research and service provision. In part, this is because autism was only identified in the 1940s and the first generation of adults to be diagnosed is only now moving into older age. It is clear that approaches to older people with autism will need to change and develop. Older adults with autism frequently rely solely on their families and

friends for support. Preventative services will be particularly important for older adults with autism who are not eligible for social care support. Furthermore, special consideration is needed when planning for the transition into older age and the increased likelihood of other health issues, particularly when family may not be around to support adults with autism.

4.12 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 Act has put 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.

4.13 The House of Lords Autism and Ageing Commission looked specifically at the issues facing older people with autism and, following this, in July 2013 NAS published a policy report entitled *Getting On? Growing Older With Autism*.<sup>38</sup> Older people's issues were highlighted in the autism statutory guidance [**Think Autism Action 25**], with the key message for local

authorities and NHS bodies being that they need to plan appropriate services for older people with autism who live in the area, and ensure that mainstream services used by older people can be appropriately accessed.

### Black, Asian and Minority Ethnic communities

4.14 People with autism from BAME communities report the same issues with accessing diagnoses and support, but these issues can be compounded if their local authorities find these communities harder to reach. In July 2014 NAS issued

#### **Lesley Waugh outlines work with the BAME community that is taking place as part of the Calderdale Autism Development project.**

We have attempted to engage the local mosques and community leaders. We have held a number of drop-in sessions at mosques and GP surgeries and have also worked with imams to raise awareness about autism through their Friday sermons.

Through the project lead we:

- continue to meet regularly with BAME professionals at the working group;
- liaise and work in partnership with Calderdale Council for Mosques;
- liaise with all Calderdale mosques to raise awareness about autism after the Friday sermon, including during World Autism Week;
- explore other social support groups that are currently running;
- liaise with mosques and health centres to arrange drop-in sessions;
- set up a women's social support group;
- liaise with the local NAS branch, Ravenscliffe School, Calderdale College and parents and carers.

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38. National Autistic Society. *Getting On? Growing Older with Autism: A policy report* (July 2013). Available at: [www.autism.org.uk/~media/NAS/Documents/Campaigns/Getting-on-Growing-older-with-autism/Getting-on-full-policy-report.ashx](http://www.autism.org.uk/~media/NAS/Documents/Campaigns/Getting-on-Growing-older-with-autism/Getting-on-full-policy-report.ashx)



its report *Diverse Perspectives*,<sup>39</sup> which suggested ways that government and local authorities can better meet the needs of BAME families affected by autism.

4.15 In accordance with the autism statutory guidance, local authorities, NHS bodies and NHS Foundation Trusts should be reaching out to BAME communities to raise awareness of autism, for example through champions in faith and other community networks. The provision of accessible information and consultation with families are key. Local authorities, NHS bodies and Foundation Trusts should therefore ensure that information on autism and support services is provided in a range of languages, as appropriate, and that translation and advocacy services are available. Services should also be available in appropriate locations and at appropriate times.

## Housing

### Progress indicated in the 2014 self-assessment exercise

- In total, 12 local authorities (8%) reported that their local housing strategies specifically referenced people with autism and had estimates of the numbers of placements required in each category.
- A total of 25 local authorities (16%) reported that they had at least one staff member with training in autism to help people make applications and fill in necessary forms.

4.16 Housing can play a vital role in supporting people with autism to maintain good health and independence and improve quality of life. From April 2015, section 2 of the Care Act placed a duty on local authorities to provide or arrange services, facilities or resources (or take other steps) to contribute towards preventing, delaying and reducing the need for care and support of adults in their areas. Sections 6 and 7 of the Care Act require local authorities to ensure the cooperation of their officers who exercise care and support functions with their officers who exercise housing functions, both generally and in specific cases, and provide for local authorities to cooperate with other relevant partners or persons, such as private registered providers of social housing.

4.17 Further, local authorities will be required to exercise their functions, under section 3 of the Care Act, with a view to ensuring integration between the provision of care and support, health services, and health-related services such as the provision of housing, where they consider that doing so would promote the wellbeing of adults in their area with care and support needs, contribute to the prevention or delay of the development of such needs or improve the quality of care and support for adults.

39. National Autistic Society. *Diverse Perspectives: The challenges for families affected by autism from Black, Asian and Minority Ethnic communities* (July 2014). Available at: [www.autism.org.uk/~media/NAS/Documents/Publications/NAS-Diverse-perspectives-report.ashx](http://www.autism.org.uk/~media/NAS/Documents/Publications/NAS-Diverse-perspectives-report.ashx)

## **Actions going forward**

***Progress Report (PR) Action 17.*** DH to take forward with University College London phase 1 of research into low level support for people with autism, by April 2016.

***Progress Report (PR) Action 18.*** DH and NAS to explore diversity issues further and develop actions for going forward through three workshops to be held by March 2016.

***Progress Report (PR) Action 19.*** NAS to issue the results of the Autism Passport evaluation and next steps by June 2016.

***Progress Report (PR) Action 20.*** DH and NAS to agree further action in relation to the earlier NAS work on older people, involving other government departments and public bodies as appropriate. By February 2016.

***Progress Report (PR) Action 21.*** DH to agree with ADASS, the LGA and the Department for Communities and Local Government (DCLG) how best to promote the housing needs of people with autism, and best practice. By March 2016.

## 5. Joining up better the NHS, social care and other local partners

5.1 It is crucial that, in meeting the needs of people with autism, services and agencies at a local level work together in the best interests of such people. Examples of this are in finding employment and within the criminal justice system, where a successful outcome is dependent on autism being recognised and the appropriate support given.

### Employment for adults with autism

#### What people with autism want

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

5.2 The 2010 autism strategy and *Think Autism* 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 sought ways to improve access to its services and has responded positively to the commitments outlined in *Think Autism*, undertaking a significant amount of work to improve service provision for people with autism, such as those with Asperger syndrome and/or associated hidden impairment conditions including ADHD, dyslexia, dyspraxia, dyscalculia and speech and language difficulties. DWP recognises that many people with autism have the skills, talent

and intellectual ability to gain and maintain employment if the necessary reasonable adjustments are made in the workplace.

#### Progress indicated in the 2014 self-assessment exercise

- In total, 40 local authorities (26%) rated their performance on promoting employment for people with autism as green. These bodies had included autism within their local employment strategy or in a disability employment strategy, offering focused autism-trained employment support, proactive engagement with local employers on the employment of people with autism, and the engagement of the local job centre in supporting reasonable adjustments in the workplace via Access to Work.
- A further 92 local authorities (61%) gave themselves the amber rating, indicating that autism awareness is delivered to employers on an individual basis, local employment support services include autism and there is some contact with local job centres in most areas.
- Some 58 local authorities (38%) made detailed reference to employment in their guidance on the transition to adult services.

## DWP action plan

5.3 In March 2014, DWP hosted an event prior to the publication of *Think Autism* in partnership with DH and NAS which involved disabled people, disability-specific organisations and other interested stakeholders. Discussions took place on ways to improve DWP services for people with autism and recommendations were made which helped to develop an Autism Strategy Action Plan, which became part of *Think Autism* [**Think Autism Action 33**].

5.4 That plan focused on three strategic areas:

- autism awareness training for DWP staff/managers;
- promotion of the autism agenda to the employment support provider community to ensure that reasonable adjustment solutions are identified/implemented at the earliest possible stage;
- promotion of the autism agenda to the business community, seeking to increase work opportunities for people with autism and associated hidden impairment conditions.

5.5 DWP regularly reviews the action plan, working with key stakeholders to identify ways to make further progress and build on achievements to date. DWP has undertaken an internal survey to help Jobcentre Plus managers assess their local capacity to fully support people with autism and associated hidden impairment conditions. The survey, which was completed by staff in varying job roles across the UK, enabled DWP to capture robust evaluation information that can be used to better support the development of improved services for claimants. Utilising the findings from the survey, DWP is

working in collaboration with key stakeholders to:

- build an Autism Network across all Jobcentre Plus offices, to be completed during 2015/16 and 2016/17;
- upskill the autism knowledge and awareness of staff involved in the Personalisation Pathfinder pilots, to be completed during 2015/16;
- develop an autism e-learning tool for staff/managers, to be completed in 2016/17.

5.6 The training specification developed by DWP has taken into account the learning from the autism awareness pilot initiatives delivered by NAS and Autism Plus [**Think Autism Action 32**].

## Other DWP work

5.7 DWP is working to ensure that Work Choice providers receive timely, relevant and pertinent information at the point of referral, so that they may more accurately identify individuals with autism. This will enable them to recognise, prepare for and provide the most effective support for job seekers, putting in place reasonable adjustment solutions as appropriate. The referral process is based on voluntary self-declaration of disability. The improved Work Choice referral process for people with autism will be in place from October 2015.

5.8 DWP is also keen to develop opportunities for job shadowing and internships. On the 2014 International Day of Disabled Persons (3 December), DWP announced the introduction of a job shadowing work placement initiative for young disabled people, specifically encouraging the involvement of young

people with autism and learning disabilities. In total, 100 work placement opportunities were made available across the country, in a variety of sectors and in workplaces ranging in size from small firms to large corporate organisations. The pilot will be evaluated by DWP and decisions will be made about future activity.

5.9 DWP is looking at ways to develop an autism internship programme for people with autism by December 2015, which will encourage DWP staff to get more involved in its work programme for people with autism. A DWP official has been seconded to Adviser Plus, based in North West England. This arrangement, which supports the upskilling of human resource professionals, has enabled DWP to promote the Disability Confident agenda to the wider business community (including small and medium-sized enterprises), focusing on the positive promotion of recruiting and retaining people with autism and associated hidden impairment conditions. DWP is also working in partnership with Carillion plc, supporting them to improve the retention rates of

young apprentices with autism and associated hidden impairment conditions.

5.10 In June 2015, DWP and DH co-hosted a meeting of eight of the Autism Innovation Fund projects that have an employment focus, in order to share their outcomes and experiences with officials from DfE and BIS. Practical suggestions were made about initiatives such as supported internships, applications for Access to Work, and educational qualification criteria being used to access apprenticeships locally.

### DH/DWP Joint Unit

5.11 In the summer of 2015, DWP and DH established a new, innovative unit to improve employment outcomes for people with health conditions and who are disabled, in order to contribute towards halving the disability employment gap. This Work and Health Joint Unit will explore how best to support people with autism to find and stay in work, while also improving their health.

#### **Dr Beatriz Lopez from the University of Portsmouth summarises the Autism Centre for Employment project.**

The grant awarded from the Autism Innovation Fund to the Department of Psychology at the University of Portsmouth has been used to create an innovative service to help people with autism into employment at the Autism Centre for Employment (ACE). The team and I are working in partnership with Portsmouth, Hampshire, Southampton and Isle of Wight Councils.

#### *What is ACE?*

ACE takes a unique approach to employment for people with autism. The service has been designed to:

- meet the latest NICE guidelines;
- address the needs identified by carers, adults with autism and practitioners in a wide-ranging consultation exercise carried out by our team in 2014;

- apply our own research findings, which highlight the large heterogeneity of cognitive profiles, and therefore individual needs, in this particular population.

#### *Development of employment-specific assessment tools*

We developed and piloted a set of quantitative and qualitative tools specifically designed for work settings. The tools evaluate the individual employment profile (career preferences and employability skills) and individual cognitive profile (social and communication skills, sensory issues and flexibility) of each client. Both clients and employers receive a summary report detailing the strengths of the client and recommendations for minor adjustments.

#### *Person-centred employer training*

We piloted an innovative training protocol for employers. Employers offering work placements have received person-centred training about their particular employee on the basis of that employee's individual employment profile.

#### *Supported work placements*

We have provided 18 eight-week placements, which are supported by mentors. Each placement has been sought to match the preferences and strengths of the client with autism. The originality of ACE is that, in the work programme, the employers are trained to eventually become mentors of the employees.

#### *Evaluation of the service*

This innovative approach has demonstrated a cost-effective means of delivering work placements. By week 3, the employees only needed, on average, one hour of support a week from the mentors. This reduced support did not result in less satisfaction: 100% of employers and over 80% of employees were very satisfied with the scheme. More importantly, there was a significant increase in self-esteem, confidence and wellbeing.

#### *What next?*

An online assessment service is to be rolled out nationwide. We have secured further funding from Research Autism to pilot an online version of the service so we can deliver our services nationwide. This service will be offered to employers, employees with autism, young adults with autism about to leave the education system, and local authorities. We are currently discussing a collaboration with the City Deals programme (Portsmouth and Southampton) to extend the service to people with learning disabilities.

#### *Research database*

The website will include a searchable database of all research articles on employment and autism from 1990 to date.

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## The Hidden Impairment National Group

5.12 DWP developed the Hidden Impairment National Group (HING) in response to issues about DWP service provision for people with autism and associated hidden impairment conditions. The group comprises disabled people with autism and associated hidden impairment conditions, medical professionals/ academics, and disability-specific organisations such as Autism Plus, NAS, the Discovery Centre, the Dyslexia Foundation and Complex Minds.

5.13 HING originally focused on improving DWP service provision for people with autism, offering practical advice and guidance. It has been reformed, and going forward is being facilitated and chaired by Philip Bartey (CEO of Autism Plus), having a cross-government remit that will support the development of inclusive government policy. DWP will remain closely involved with the group and will continue to explore ways to improve services and increase job opportunities for people with autism.

5.14 In support of this agenda, HING has undertaken a range of practical activities, including:

- development and implementation of a comprehensive Hidden Impairment Toolkit, available to all DWP staff to help them better understand how they can support people with autism and associated hidden impairment conditions. This learning and development resource has been shared with Autism Programme Board members and has been promoted as part of the Accessible Britain campaign. It has also been shared with

### Actions going forward

DWP will work co-productively with the Autism Alliance UK and other partner organisations to:

#### **Progress Report (PR) Action 22.**

Develop an Autism Network across all Jobcentre Plus offices, providing autism and associated hidden impairment training to nominated staff who will lead on this agenda. By April 2017.

#### **Progress Report (PR) Action 23.**

Deliver autism training to all staff involved in the Personalisation Pathfinder pilots in Greater Wessex, South West Wales and Surrey and Sussex. By October 2016.

#### **Progress Report (PR) Action 24.**

Develop an autism e-learning training package for staff and managers that will support a better understanding of autism and how best to support people with autism into work. By December 2016.

#### **Progress Report (PR) Action 25.**

Continue to support the work of HING and together explore ways to encourage employers to recruit and retain people with autism and associated hidden impairment conditions. Review at the end of 2016.

#### **Progress Report (PR) Action 26.**

Review the autism action plan by the end of 2016 against the key priorities in *Think Autism*, take action on outstanding issues and provide support to other government departments.

Work Choice providers and employers at Disability Confidence employer events, and is available to other organisations via the HING website;

- delivery of a number of employer-focused events aimed at promoting the skills and talents of disabled people and in particular individuals with autism and associated hidden impairment conditions;
- development and implementation of the HING website (<http://hing.org.uk>), managed by Autism Plus, which offers information to employers and other organisations.

## Contact with the criminal justice system

5.15 A Cross-Criminal Justice System Government Group, chaired by the MoJ, was set up in spring 2014 and now meets quarterly to discuss work across the criminal justice system to improve services for people with autism, including progress with commitments under the autism strategy. Membership includes MoJ, the Home Office, the Crown Prosecution Service (CPS), the Youth Justice Board, the National Offender Management Service (NOMS), the National Police Chiefs' Council (NPCC) which was formerly the Association of Chief Police Officers or ACPO, DH and NHS England, as well as a number of special interest bodies (including NAS) and self-advocates. Meetings cover issues such as training and awareness, screening, reasonable adjustments, and the use of IT systems to better support people with autism [**Think Autism Action 26**].

### What adults with autism want

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

*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.*

### Progress indicated in the 2014 self-assessment exercise

- In total, 17 local authorities (11%) gave themselves a green rating for work with the criminal justice system. This was based on people with autism being included in the development of local criminal justice diversion schemes: representatives from criminal justice system agencies regularly attend meetings of the local autism partnership board and there is evidence of joint working.
- A further 85 local authorities (56%) gave themselves amber ratings, indicating that discussions were under way to improve criminal justice system involvement in planning for adults with autism.
- A total of 32 local authorities (21%) rated themselves as green on whether access to an appropriate adult service is available for people on the autistic spectrum in custody suites and nominated 'places of safety', with staff who have had autism awareness training. Some 107 local authority areas classed themselves as amber, meaning that appropriate adults have not necessarily had autism awareness training.

## The Crown Prosecution Service

5.16 The CPS launched an autism guide for prosecutors in April 2015. This provides basic information and signposting in relation to issues arising from a victim's, witness's or defendant's perspective. To produce the guide, the CPS set up training sessions and sought feedback from prosecutors and further specialists, including NAS [**Think Autism Action 13**].

## The College of Policing

5.17 The College of Policing is working with the Home Office to deliver recommendations for improvements to the police curriculum, including developing a new module of Authorised Professional Practice for the Police Service [**Think Autism Action 27**]. This product will be the primary electronic resource for information regarding the legal and appropriate response to all incidents involving people with mental health and learning disabilities (including autism). This will fully replace and supersede the 2010 ACPO guidance on mental health and learning disabilities. It will include some additional guidance on vulnerability assessment and strategies for interacting with individuals who may have difficulties with communication and/or processing information, and who require reasonable adjustments. The guidance will be issued by February 2016.

5.18 In addition, a new package of training is being developed which includes modules for all staff, first response officers, specialists and leaders. This work has highlighted the requirement to understand the extent to which police training will need to include condition-specific awareness, and autism is part of this. Training products will be ready for implementation nationally by the end of June 2016.

## The Police National Computer

5.19 The NPCC has agreed to use an existing flag on the Police National Computer (PNC) to identify people with autism. Consideration is now being given to what information should usefully be put onto the PNC under the flag (given that there is limited space and a finite number of characters); this may include, for example, risk assessment criteria and a simple paragraph alerting the user to the fact that the individual has autism and may need additional support/adjustments. Once this has been resolved, the NPCC aims to circulate national guidance. There is also a longer term plan to accommodate similar details in relation to victims in a more appropriate format in a new generation PNC to be developed over the next few years.

## The police

5.20 MoJ has been working with the Home Office and the CPS to develop a new Police Service guide to help officers identify, at the first opportunity, people who may need support or special measures to give evidence. The aim is to issue this guide by February 2016.

5.21 Support services are now commissioned locally by police and crime commissioners, rather than central government. This means that they can join with local commissioners of health and social care to ensure a shared approach to support provision for victims and witnesses; the statutory guidance that supports *Think Autism* outlines the importance of this. There is guidance available through the Bar Council and the Law Society about how to question a witness. Specifically, the Advocacy Training Council has produced toolkits covering autism.

5.22 The NPCC lead for disability has set up three new communities of practice to spread learning across the police. One of these covers autism, and Hampshire Constabulary is leading on this work on behalf of the national lead, Chief Constable Simon Cole. Best practice approaches being trialled include an autism alert card and a mobile phone app that can hold information about a person with autism, including ways of helping them to deal with difficult situations. The NPCC will consider whether and how this best practice will be rolled out nationally through the College of Policing. Alongside this, Hampshire Constabulary is looking to expand the use of widget sheets, which are a set of Easy Read forms designed to provide an explanation of the legal paperwork used in custody; see: <https://widgit.com/>.

## Offender management

5.23 As a result of the probation reforms undertaken in the last Parliament, 21 Community Rehabilitation Companies (CRCs) were established to deliver rehabilitation services in England and Wales for low and medium risk offenders. A new National Probation Service (NPS) was also created to manage those offenders assessed as being at high risk of serious harm to the public, or those released from custody who have committed the most serious offences. The introduction of payment by results and a clear focus on the achievement of outcomes, coupled with greater competition for offender services, is intended to offer real solutions to some long-standing problems. We expect to see innovative responses from the new providers to help address some of the causes of crime, with targeted support for offenders to help with specific needs. Probation providers are supported in this by the work of the Probation Institute.

5.24 Staff from the Bristol, Gloucestershire, Somerset and Wiltshire CRC and their local colleagues in the NPS have been working in conjunction with the social enterprise group SEQOL and autism experts to improve their services for people with autism. The group won a national autism award in May 2015 for this project.

5.25 Children under the age of 18 are managed by youth offending teams based within the local authority, and local authorities can play an important role in raising awareness of how to work with autistic young people among these teams.

## The Probation Institute

5.26 One of the Probation Institute's earliest priorities was creating a broad professional network for mental health workers in the criminal justice system, which included a commitment to providing training and awareness-raising on lifelong developmental conditions such as autism. The Institute is now looking to extend training days to Probation Institute members, and several regional events have taken place, delivered in partnership with Key-Ring. In addition, the Institute held an equality and diversity conference in Bristol in March 2015, which featured a workshop on addressing the needs of service users with autism [**Think Autism Action 30**].

5.27 The Probation Institute will continue to promote best practice relating to addressing the needs of those with lifelong developmental conditions, and will explore funding opportunities to help it deliver autism training and research to its members. The Institute has also launched the Probation Institute Register and the professional networks functionality, which are part of a new professional development project. One of these networks is to focus



on health partnerships. Joining the Probation Institute Register allows members to demonstrate their professionalism and provide evidence of their qualifications and experience.

5.28 A number of publications and links concerning autism were placed in the Institute's Data Room to inform CRCs (private sector providers of probation services) bidding for new contracts prior to the submission of bids in 2014 [**Think Autism Action 30**].

### Liaison and diversion

5.29 Liaison and diversion services have been developed to provide early interventions for all people identified as having a range of vulnerabilities, including autism, as they come to the attention of the criminal justice system, with the aim of referring them to appropriate treatment or support. Liaison and diversion services provide a prompt response to concerns raised by the police, youth offending teams and court staff, and provide critical real-time information to decision-makers in the criminal justice system when it comes to charging and sentencing these vulnerable people. This may result in a diversion away from the criminal justice system, or from a prison sentence to a community order with a treatment requirement.

5.30 NHS England is working with DH, MoJ and the Home Office to trial a centrally commissioned model and is submitting a full business case to HM Treasury. In total, 10 trial sites were launched in April 2014 and another 15 went live in April 2015, bringing coverage to over 50% of England. The aim, subject to agreement of the full business case, is for NHS England to roll out the services to the whole population of

England. A revised liaison and diversion specification, which includes autism, will be issued by the end of January 2016.

### Prison and other forms of custody

5.31 MoJ has continued to support the spreading of best practice across both private and public prisons. As an example of examining and sharing good practice [**Think Autism Action 28**], NAS has been working with Feltham Young Offenders Institute to develop Autism Accreditation standards for prisons. This includes standards for the education provider, the primary care and mental health providers and the prison itself. Feltham is aiming to achieve accreditation in the first quarter of 2016. In addition, NAS extended the pilot to take into account the adult prison estate and started work with three other prisons – Parc, Wakefield and Dovegate – in June 2015. All four parts of the prison (as detailed above) are required to work collectively to improve support for people with autism and, if successful, will result in the whole prison receiving accreditation.

5.32 The standards cover a number of areas, including training on autism given to staff and how it affects their practice; looking at the admissions process to see if it takes account of autism screening; and the environment of the prison – for example, whether there can be flexibility in the activities of an autistic prisoner, if appropriate. It also looks at release. Three National Probation Service/Community Rehabilitation Companies and three police forces are now working with NAS to develop accreditation schemes based on the prison scheme. The prison pilot is still ongoing and lessons are being learned and acted upon as work progresses.

5.33 The Minister for Prisons, Probation, Rehabilitation and Sentencing, Andrew Selous, visited Feltham in March 2015 and subsequently wrote to all prison governors and directors to encourage them to consider working towards Autism Accreditation status. By October 2015 NAS had received over 20 enquiries from other prisons interested in working towards accreditation.

5.34 Autism and learning difficulties are covered under the refreshed Young Offender Institution training on working with young people in custody. This includes content on autism within the Youth Justice Board's e-learning platform, Youth Justice Interactive Learning Space. An assessment of functional skills for all adult prisoners has been mandatory since August 2014 [***Think Autism Action 29***].

5.35 NOMS-funded work in 2013/14 to improve outcomes for offenders with learning disabilities has resulted in the production of autism awareness pocket guides for staff and a web-based toolkit. Further work was commissioned in 2014/15, which has led to the development and testing of a tool to help offender managers identify specific communication-related needs and plan how to meet them. This includes considering the communication needs of offenders with autism.

5.36 Further work is planned in 2015/16 to support the wider ambition of making communication accessible. This includes testing peer-led models to identify, adapt and quality-assure written communications in Easy Read format.

5.37 NOMS has designed a range of accredited programmes for offenders which aim to reduce reoffending. A specially designed suite of programmes has been developed for intellectually disabled sexual offenders which are also applicable to some people who have autism. These programmes are available for commissioning in both prisons and the community. NOMS is extending its provision of programmes for this group. A new intervention which aims to reduce reoffending by helping participants to develop skills in the areas of problem solving, self-control, positive relationships and goal setting has recently been piloted for general offenders. The programme was piloted in three men's prisons (HMP Whatton, HMP Wymott and HMP Wakefield) and the intention is to deliver further pilots and seek accreditation from the Correctional Services Accreditation Panel. The needs of high-functioning autistic individuals would be determined on a case by case basis. Adjustments would be made to ensure that treatment provision was responsive to individual needs.



## Actions going forward

**Progress Report (PR) Action 27.** Development of a comprehensive package of training by the College of Policing, to be implemented by the end of June 2016.

**Progress Report (PR) Action 28.** The NPCC is exploring the opportunities to create a new 'vulnerability' marker to be added to the Police National Computer to replace the previous 'mental' and 'ailment' markers, which were created in the 1960s and were subsequently outdated and inappropriate. The new marker will be used to record many different vulnerabilities including an autism spectrum diagnosis and will be developed within the upgrade to the PNC system due by June 2016.

**Progress Report (PR) Action 29.** MoJ has been working with the Home Office and the CPS to develop a new Police Service guide to help officers identify people who may need support or special measures to give evidence. The aim is to issue this guide by February 2016.

**Progress Report (PR) Action 30.** A forum took place in November 2015 involving the Disability communities of practice and the NPCC lead to discuss both the progress of the (now widely available) autism phone app and widget sheets. It was shared that Hertfordshire Police have developed their own version of easy-to-read custody sheets. The projects will be presented to the NPCC custody lead with a view to encouraging all police forces have easy-to-read sheets within their custody suites by June 2016.

**Progress Report (PR) Action 31.** NHS England to issue a revised liaison and diversion specification, to include autism, by end of January 2016.

## Appendix A

### Actions from *Think Autism* (2014)

Number	Action	Lead	Timescale
1	Issue statutory guidance to support the updated strategy. [page 9]	DH	December 2014
2	Advertise for new members to join the Autism Programme Board. [page 7]	DH	By end of Summer 2014
3	Publish a summary of progress. [page 7]	DH	August 2015
4	Provide further information on the Autism Innovation Fund. [page 39]	DH	By end of June 2014
5	Provide further information on the Autism Awareness and Champions programme. [page 44]	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. [page 23]	NAS (funded by DfE)	Summer 2014
7	Issue the 3rd Autism self-assessment exercise for local areas. [page 10]	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. [page 10]	Public Health England, with support from DH, NHS England and NAS	By end of March 2015

Number	Action	Lead	Timescale
9	Explore the feasibility of research to review the effectiveness of low- level interventions aimed at adults with autism who do not meet Fair Access to Care Services (FACS) social criteria. [page 52]	DH	By end of March 2015
10	Assist with the promotion of Autism Passports being developed by Baroness Browning and NAS. [page 54]	DH	By end of March 2015
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. [page 19]	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. [page 18]	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. [page 65]	CPS	Autumn 2014
14	Report on their review of bus driver disability awareness training to the Autism Programme Board. [page 20]	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. [page 54]	DH	March 2015
16	Issue guide summarising recent guidelines on autism diagnostic commissioning. [page 38]	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 it is 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. [page 38]	NHS England and Care Quality Commission	By end 2014

Number	Action	Lead	Timescale
18	Through the RCGP autism clinical priority programme look at the feasibility of introducing a Read Code for Autism. [page 12]	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. [page 12]	DH and Public Health England	November 2014
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. [page 20]	DH	December 2014
21	Provide support to update the e- learning training developed under the 2010 strategy. [page 18]	DH	March 2015
22	Ensure that the LA autism self-evaluation includes carers. [page 10]	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. [page 22]	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. [page 32]	DH/ 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. [page 56]	DH	March 2015

Number	Action	Lead	Timescale
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. [page 64]	Ministry of Justice	By the end of 2014/15
27	Work with the College of Policing to update and add to its 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. [page 65]	Home Office	By end of October 2014
28	Examine and share good practice in prisons towards prisoners with autism. [page 67]	National Offender Management Service	During 2014/15
29	Report back to the Autism Programme Board on the impact that the mandatory assessment of functional skills for all prisoners from August 2014 has had on identifying prisoners with autism. [page 68]	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. [pages 66 and 67]	Ministry of Justice	End of March 2015 and end of April 2014
31	Evaluate the NAS brokerage and personalisation project with other stakeholders in order to embed learning in developing further models. [page 49]	DH and NAS	December 2016
32	Respond to the results of NAS pilot on new training in autism for disability employment advisers. [page 60]	DWP	May 2014

Number	Action	Lead	Timescale
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. [page 60]	DWP	November 2014



## Appendix B

### Autism Innovation Fund projects

Project name	Organisation and location	Funding (£k)	Description
<b>Autism Innovation Fund – Projects (Third Sector)</b>			
<b>Advice and information</b>			
Red2Green	In the Spectrum Cambridge	12.9	30 young people will participate in creating the content for 10 short information films about autism and Asperger syndrome to improve awareness and help people get support.
Leeds Autism AIM	Leeds Advocacy	20	A new service providing advocacy, information and mentoring for autistic adults to enable them to better access mainstream services.
Enabling Autism	Taunton & District Citizens Advice Bureau	34	A facilitation service to improve access to advice and information services for people with autism and their families, and bridging the gap between specialist and mainstream services.
ALAG Peer Support Planning and Brokerage Project	Asperger London Area Group (ALAG)	17	To train six peer support brokers with Asperger syndrome to help others plan the support they need and to provide advice and information.
Fulfilling Futures, life after school	Telford and Wrekin Council for Voluntary Service	19.7	Develop a transition outreach service with local partners, offering targeted preventive social welfare support around life after school to young people with autism.
Living with Autism	Living Autism UK wide	36.5	To produce practical information and strategies to address daily difficulties by people with autism, working through a consortium of local and national charity groups.

Project name	Organisation and location	Funding (£k)	Description
Connecting with Autism Community	Autism West Midlands	50	Updating and upgrading the existing social network for Autism Connect so it can provide more information and advice across England. This website will act as a digital platform for the national self-assessment data.
<b>Gaining and growing skills for independence</b>			
College Without Walls	New Ideas Advocacy Project Warwickshire	14.7	Courses on helping people with autism to be life resilient and manage their own money.
NAS HelpTech for students with autism	NAS UK-wide	66	To use cloud-based services to allow real-time users and mentors to track and understand situations, issues and anxiety levels for each day using smartphones and tablets.
Luv2MeetU Inclusion for People with Autism	Luv2MeetU Bradford	13	A review of up to 40 social and active-based events that take place each month so that a good practice model is established to best help people with autism develop confidence in social situations.
Enterprise for Autism	Autism East Midlands	40	Pilot to support adults with autism who do not meet the eligibility criteria for statutory support and help with vocational and independence skills.
Good Food for the Soul	Asperger Syndrome Access to Provision Harrow	3	Two 3-hour sessions per month for 10 clients per session over six months teaching basic nutrition, budgeting, menu planning and the effects of poor diet on health.
Independence Support	Black & Minority Ethnic Carers Support Service London	25	Delivering culturally appropriate, ethnically sensitive and flexible support to meet the needs of people with autism towards increasing life skills and being independent.
Understanding Autism	Bury College	50	Accredited training for staff, more tailored classes for people with autism and awareness work.

Project name	Organisation and location	Funding (£k)	Description
Autism Angels	Learning to Listen and Autism Angels Wetherby	15	Increasing the reach of a service using horses as therapy.
Create and Sell, Autism Manchester Initiative	Alice Darlington Funding to be held by Trafford Housing	10.8	User-led by a person who has autism, with professional support, to offer creative sessions and business start-up advice at easily accessible community centres in Greater Manchester on a rotating basis.
Connect Up	Balance Stockport and Kingston	33.2	Creating a hub whereby individuals with autism will be supported via a 3D virtual world with the aim of reducing isolation and promoting emotional wellbeing.
Post-diagnostic psycho-educational courses and therapeutic support for people with autism	Care & Support Partnership Community Interest Company trading as SEQOL in Swindon	12	Widening post-diagnostic support, developing supportive tools and providing clear outcomes to local commissioners.
<b>Early intervention and crisis prevention</b>			
Autism Peer Advocacy	Autism Plus Sheffield	25.5	Supporting people with autism through a programme of peer advocacy to give them skills to support their peers.
Early Intervention – addressing sexually harmful behaviour in young people and adults with autism	Circles South East Didcot	27	Providing training to professionals/families of individuals with autism in Hampshire, Berkshire and Oxfordshire who display sexually harmful behaviour.
Somerset Adult Autism Respite Service	NAS	85	Provides an alternative respite service for adults with autism in Somerset, based around two yurts.

Project name	Organisation and location	Funding (£k)	Description
The Spectrum Hub	Rainbow Autism CIC Worcestershire	40	Social work-led support for crisis prevention.
<b>Employment</b>			
Employment and Autism – Unlocking Untapped Potential	Derbyshire Autism Services Group	23	A focus on employers adapting their recruiting process/procedures in order to make them more autism friendly.
Autism Centre for Employment	University of Portsmouth	65	Providing up to 40 adults with the confidence and employment skills to access the job market and take part in a work placement scheme, changing employer attitudes and designing a tool to identify individual employment skills.
Increasing positive employment outcomes for young people with autism	Daisy Chain Project Teesside	48.2	Providing a wide range of employment opportunities and work experience and volunteering for up to 30 people with autism in the charity's superstore.
Employment opportunities	Caretrade Charitable Trust London	53	To help 16 young people with autism gain paid employment or an apprenticeship.
Specialisterne work and wellbeing project	Specialisterne Foundation UK	45	Providing work opportunities, assessment and work experience to lead to employment for up to 20 people.
Linkage STAR employability project	Linkage Community Trust Lincoln	15	Deliver an employability support service to help 12 adults with autism into work opportunities.
<b>Autism Innovation Fund – Projects (Local Authorities)</b>			
<b>Advice and information</b>			
Reaching Communities	South Gloucestershire Council	8.3	Extending the reach of an existing advice and information service by taking it into the semi-rural community, including through the use of mobile libraries.

Project name	Organisation and location	Funding (£k)	Description
<b>Gaining and growing skills for independence</b>			
Slough Autism Connect	Slough Borough Council	11	Fund the travel training for travel trainers element of the proposal.
Autism Training Works	Nottinghamshire County Council	22.1	Creating a social enterprise to enable people with autism to gain skills around training and presenting, creating employment opportunities and enabling autism awareness training to reach a wider audience.
Developing arts skills and related work experience opportunities for young people with autism	Croydon Council	16.5	Building on pilot work to have a more focused programme for young people with autism between the years of 16–19 and providing programmes such as work experience.
Spectrum: personal development courses	East Sussex County Council	12.5	A series of 12 six-week skill-building programmes that enable young people with autism to explore, discuss, prepare for and practice life skills.
<b>Early intervention and crisis prevention</b>			
Autism Peer and Mentor Support Network	Lancashire County Council	30	Development of a peer and mentor support network within central Lancashire and to be part of the wider Connect 4 Life Agenda.
Focus on Autism – York	City of York Council	25	Establishing an Autism Friends programme.
Knowsley Autism Innovation Programme	Knowsley Metropolitan Borough Council	16	Gaining and growing skills for independence, along with an intensive music programme for six people with the Liverpool Philharmonic Orchestra, with the opportunity to gain an arts award qualification.

Project name	Organisation and location	Funding (£k)	Description
<b>Employment</b>			
Employment Works for Autism	Surrey County Council	36.8	Focus on social skills and work experience for 12 people in a real workplace along with job coaching and support.
Autism Employment Challenge	Royal Borough of Windsor and Maidenhead	37.6	Securing 10 employers as Autism Employment Champions and 10 young people with autism securing apprenticeships.
Building an interactive online learning and peer support community to support access to employment	London Borough of Richmond upon Thames	23.7	To enable people with autism to gain skills and confidence to access employment opportunities.
The improvement of the local authority-supported employment service in St Helens	St Helens Council	7	Providing supported employment to assist people with autism to secure work placements through job coaching.
<b>Autism Innovation Fund – Projects (NHS)</b>			
<b>Advice and information</b>			
People with autism spectrum conditions in the criminal justice and mental health systems in south London	South London and Maudsley NHS Foundation Trust	36	Aims to improve recognition of autism in the criminal justice system, including developing guidelines.



Project name	Organisation and location	Funding (£k)	Description
<b>Gaining and growing skills for independence</b>			
Pan Dorset Sensory Integration Therapy	Dorset Healthcare University NHS Foundation Trust	56	Increase the Trust's ability to recognise and treat all service users with sensory processing disorder and autism, through the development of an integrated care pathway, sensory therapy room and increased provision of sensory integration therapy.

## Appendix C

### Abbreviations

<b>ACE</b>	Autism Centre for Employment (University of Portsmouth)
<b>ACPO</b>	Association of Chief Police Officers (replaced by NPCC)
<b>ADASS</b>	Association of Directors of Adult Social Services
<b>ADHD</b>	attention deficit hyperactivity disorder
<b>AET</b>	Autism Education Trust
<b>BAME</b>	Black, Asian and Minority Ethnic
<b>BIS</b>	Department for Business, Innovation and Skills
<b>CCG</b>	clinical commissioning group
<b>CJS</b>	Criminal Justice System
<b>CPS</b>	Crown Prosecution Service
<b>CQC</b>	Care Quality Commission
<b>CRC</b>	Community Rehabilitation Company
<b>DfE</b>	Department for Education
<b>DH</b>	Department of Health
<b>DPTAC</b>	Disabled Persons Transport Advisory Committee
<b>DWP</b>	Department for Work and Pensions
<b>EHC plans</b>	education, health and care plans
<b>EY</b>	early years
<b>FE</b>	further education
<b>HCPC</b>	Health and Care Professions Council
<b>HEE</b>	Health Education England
<b>HING</b>	Hidden Impairment National Group
<b>HSCIC</b>	Health and Social Care Information Centre
<b>IS</b>	independent supporter
<b>JCP</b>	Joint Commissioning Panel for Mental Health
<b>JSNA</b>	Joint Strategic Needs Assessment
<b>LDA</b>	learning difficulty assessment
<b>LGA</b>	Local Government Association

<b>MoJ</b>	Ministry of Justice
<b>NAS</b>	National Autistic Society
<b>NICE</b>	National Institute for Health and Care Excellence
<b>NOMS</b>	National Offender Management Service
<b>NPCC</b>	National Police Chiefs' Council
<b>NPS</b>	National Probation Service
<b>Ofsted</b>	Office for Standards in Education, Children's Services and Skills
<b>Ofqual</b>	Office of Qualifications and Examinations Regulation
<b>P-16</b>	post-16
<b>PANSI</b>	Projecting Adult Needs and Service Information
<b>PNC</b>	Police National Computer
<b>PHE</b>	Public Health England
<b>RCGP</b>	Royal College of General Practitioners
<b>RCP</b>	Royal College of Psychiatrists
<b>SALT</b>	Short and Long Term support data
<b>SEND</b>	Speciality Educational Needs and Disability
<b>SFC</b>	Skills for Care
<b>SFH</b>	Skills for Health

## Appendix D

### Autism information collected or planned

Department/ Agency	Description of current and anticipated data collection and publications	Status: Current publication/ Forthcoming new publication/ Possible area currently being explored
Health and Social Care Information Centre (HSCIC)	<p>Numbers of people with autism in the population are studied as part of the adult psychiatric morbidity survey. A major report on this topic, based on the 2007 morbidity survey, was published in 2012.  <a href="http://www.hscic.gov.uk/pubs/autism11">http://www.hscic.gov.uk/pubs/autism11</a></p> <p>The survey was repeated in 2014.</p> <p>The prevalence of autism in children and young people is studied in the child psychiatric morbidity survey, most recently in August 2005.  <a href="http://www.hscic.gov.uk/catalogue/PUB06116">http://www.hscic.gov.uk/catalogue/PUB06116</a></p> <p>A new child survey has been awarded.</p> <p>Numbers of people receiving psychiatric inpatient care who have autism have been studied and reported as part of the learning disabilities inpatient census in 2013 and 2014. This survey will be repeated in 2015. It is anticipated that it will be subsumed into the Mental Health and Learning Disabilities minimum dataset.</p> <p>2014:  <a href="http://www.hscic.gov.uk/catalogue/PUB16760">http://www.hscic.gov.uk/catalogue/PUB16760</a>  and  <a href="http://www.hscic.gov.uk/catalogue/PUB17469">http://www.hscic.gov.uk/catalogue/PUB17469</a></p>	<p>January 2012</p> <p>Findings are expected in 2016.</p> <p>Being collected at present. First reported data (2015/16 year) anticipated mid-2016.</p>

Department/ Agency	Description of current and anticipated data collection and publications	Status: Current publication/ Forthcoming new publication/ Possible area currently being explored
	<p>2013:  <a href="http://www.hscic.gov.uk/catalogue/PUB13149">http://www.hscic.gov.uk/catalogue/PUB13149</a>            and  <a href="http://www.hscic.gov.uk/catalogue/PUB14046">http://www.hscic.gov.uk/catalogue/PUB14046</a></p> <p>In addition to data about inpatient psychiatric care collected from providers, clinical commissioning groups and NHS England specialist commissioners report quarterly to the HSCIC about numbers of psychiatric inpatients with autism for whom they are financially responsible. These figures are published regularly as the Assuring Transformation dataset.  <a href="http://www.hscic.gov.uk/article/6328/Reports-from-Assuring-Transformation-Collection">http://www.hscic.gov.uk/article/6328/Reports-from-Assuring-Transformation-Collection</a></p> <p>The HSCIC collects data at individual case level about clinical events (admissions, outpatient attendances, accident and emergency attendances, and mental health care) in Hospital Episode Statistics and, in relation to mental health care, in the Mental Health and Learning Disabilities minimum dataset. Where individuals are identified by diagnosis records as having autism, activity relating to them in these areas can be reported in fully flexible ways.</p> <p>Where individuals have records in other clinical settings, these can be linked by their NHS number and other fields. This allows reporting about people who have been identified as having autism in at least one setting. If successful, the work (described above) with the Royal College of GPs to improve the consistency of recording autism in general practice notes should substantially improve the potential completeness of this. The Data and Information Working Group is exploring the potential value of this approach.</p>	

Department/ Agency	Description of current and anticipated data collection and publications	Status: Current publication/ Forthcoming new publication/ Possible area currently being explored
	<p>The HSCIC also collects data from local authorities about local authority social care services. To date, statistics collected have not identified autism as a distinct reason for using services. A new social care return (introduced in April 2015) asks about the numbers receiving a range of long-term support options at the year-end by reported health condition. Categories include autism, Asperger syndrome and learning disabilities.</p>	
Department for Education	<p>Special Educational Needs in England (January 2014) – School census data showing numbers of pupils with specific types of SEN, including autism (Tables 10A and 10B).  <a href="https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2014">https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2014</a></p> <p>Children with Special Educational Needs: An analysis (2014). Prevalence and attainment data.  <a href="https://www.gov.uk/government/statistics/children-with-special-educational-needs-an-analysis-2014">https://www.gov.uk/government/statistics/children-with-special-educational-needs-an-analysis-2014</a></p>	<p>Published annually in January</p> <p>Published annually in September</p>



Department/ Agency	Description of current and anticipated data collection and publications	Status: Current publication/ Forthcoming new publication/ Possible area currently being explored
Ministry of Justice (MoJ)	<p>Currently there is no published data on the numbers of people within the criminal justice system who are on the autistic spectrum.</p> <p>MoJ is working with its partners in a number of areas to develop understanding of the levels of health needs of offenders, including those with autism.</p> <p>The Government's Liaison and Diversion Programme, currently being trialled in 12 sites in England, assesses people coming into contact with the justice system for a range of health and care needs, including autism. This assessment is carried out by staff commissioned by NHS England.</p>	An evaluation of the trial sites is due in late 2015.
	MoJ is also working with the Department for Education to develop a new data share. This should enable better understanding of the Special Educational Needs status and educational outcomes of a cohort of offenders, to help the MoJ to develop programmes to reduce reoffending.	

Department/ Agency	Description of current and anticipated data collection and publications	Status: Current publication/ Forthcoming new publication/ Possible area currently being explored
Department for Work and Pensions (DWP)	<p>The Access to Work programme provides financial assistance for people who require equipment, adaptations, support workers or a communication assistant at interview. Regular statistics from this programme include details of breakdowns by type of disability of the person receiving assistance.</p> <p>Work Choice is the programme through which DWP helps disabled people whose needs in obtaining jobs cannot be met through simple workplace adjustments. Referral information of people to the Work Choice programme and their passage through it to jobs is collected for the Work Choice official statistics. These record the nature of clients' disabilities and the geographical area in which they are based. DWP is adapting the referral process to ensure that people with autism receive the support they need as quickly as possible. Geographically the programme is organised in 28 Contract Package Areas comprising groups of local authorities.</p> <p>DWP is working to enhance both statistical data sources to identify people with autism as a distinct category.</p>	Statistics currently published as described. There are plans for enhancements to data to identify people with autism.
Public Health England	<p>The Learning Disabilities team in Public Health England collects and publishes data about services for people with autism in the annual local authority autism self-assessment.</p> <p>Publications from the 2013 survey are at: <a href="http://www.ihal.org.uk/projects/autism2013">http://www.ihal.org.uk/projects/autism2013</a></p> <p>Reports from the 2014 survey are due to be published by January 2016.</p>	<p>Published 2014</p> <p>Published 2016</p>

# Appendix E

## Progress Report (PR) on *Think Autism*: Actions going forward

Number	Action	Lead	Timescale
<b>Progress and planning</b>			
PR1	Public Health England's Learning Disabilities Observatory team to undertake an analysis of Joint Strategic Needs Assessments to identify the information they include about adults and children with autism and issue a report.	PHE	By end of January 2016
PR2	The Autism Programme Board to be jointly chaired by a person who has autism or is a carer for a person with autism.	DH	By February 2016
PR3	DH to work with partners so that regional workshops can be held with local authorities (LAs), the NHS and other key stakeholders to support the implementation of the new statutory guidance, consider progress made and encourage regular network meetings to promote best practice and share information.	DH, NHS, LAs, key stakeholders	From December 2015 to March 2016
PR4	The next Autism self- assessment exercise to be undertaken by PHE.	PHE	From April 2016
PR5	The PHE and DH led data and information working group to set out its work programme for 2016.	PHE and DH	By end of January 2016
<b>Training</b>			
PR6	HEE to develop a revised learning disability skills and competency framework that will address the needs of adults with autism.	HEE	By March 2016
PR7	HEE to develop and incorporate awareness, knowledge and skills in recognised areas of health including autism, mental illness, physical illness and social support needs across all programmes for NHS health professionals.	HEE	By 2018

Number	Action	Lead	Timescale
PR8	DH to approach the HCPC to determine the level of autism awareness included in its criteria covering education/training for those on its register. Further action to be considered following the outcome of the discussions.	DH and HCPC	By the end of February 2016
PR9	DH will look at feedback received from autism awareness sessions to set out further actions and encourage other government departments and arm's-length bodies to review autism awareness for their staff.	DH	By the end of March 2016
PR10	<p>The DfT bus and coach driver disability awareness training research to be split into two phases:</p> <ul style="list-style-type: none"> <li>Phase 1 – to consist of research seeking to understand the current level of disability awareness training on offer and the impact it has on disabled customers.</li> <li>Phase 2 – to develop good practice guidance on bus and coach disability awareness training. The guidance will provide a detailed specification on the needs of disabled passengers and the expected conduct of bus and coach drivers at all different stages of the journey. The guidance will also include recommendations on evaluation schemes and provide detailed information on the desired learning outcomes.</li> </ul>	DfT	<p>By the summer 2016</p> <p>By the summer 2016</p>
PR11	DfE to monitor the effective implementation of the SEND reform programme. In March 2015 DfE published a framework for SEND which will show how the system is performing, hold partners to account and support self-improvement. This includes inspections by Ofsted and the CQC of local areas' effectiveness in fulfilling their duties in relation to children and young people with SEND. Ofsted and the CQC launched a public consultation on the proposed inspection framework in October 2015, with first inspections planned for May 2016.	DfE	May 2016

Number	Action	Lead	Timescale
PR12	DfE to review arrangements for disagreement resolution 2015–17, including a Tribunal pilot. The pilot will investigate the case for a single point of access to the Tribunal on education, health and social care issues. DfE and MoJ ministers must report back to Parliament on the outcome of the review by the end of March 2017.	DfE and MoJ	End of March 2017
PR13	DfE has funded Autism Education Trust, Ambitious about Autism and NAS projects in 2015/16 to support children and young people with autism through training education staff, exploring good practice in transition to FE colleges, and support related to exclusion and alternative provision. Resources from these projects will be made available by the end of March 2016.	DfE, Autism Education Trust, Ambitious about Autism and NAS	End of March 2016
<b>Diagnosis</b>			
PR14	NHS England, working with the Association of Directors of Adult Social Services and advice from PHE and DH, will use data from the autism self-assessment exercise to work with a sample of local authority areas to identify the barriers that are stopping them having fully established diagnostic pathways, and share the learning from this exercise with all local authorities and CCGs.	NHS England, ADASS, PHE and DH	Initial work to be undertaken by the end of February 2016
<b>Awareness</b>			
PR15	Subject to approval, the Autism Alliance UK to complete Phase 2 of the autism awareness project, including the development of plans to support the autism third sector to work on specific issues in partnership.	Autism Alliance UK	March 2016
<b>Transforming care for people who have autism</b>			
PR16	The Government will keep the impact of guidance/proposals in response to <i>No Voice Unheard, No Right Ignored</i> under review to ensure significant progress is made between now and March 2020.	HMG	March 2020

Number	Action	Lead	Timescale
<b>Care and support</b>			
PR17	DH to take forward with University College London phase 1 of research into low level support for people with autism.	DH and University College London	By April 2016
PR18	DH and NAS to explore diversity issues further and develop actions for going forward through three workshops.	DH and NAS	By March 2016
PR19	NAS to issue the results of the Autism Passport evaluation and next steps.	NAS	By June 2016
PR20	DH and NAS to agree further action in relation to the earlier NAS work on older people, involving other government departments and public bodies as appropriate.	DH and NAS	By February 2016
PR21	DH to agree with ADASS, LGA and the Department for Communities and Local Government (DCLG) how to best promote the housing needs of people with autism and best practice.	DH, ADASS, LGA and DCLG	By March 2016
<b>Employment for adults with autism</b>			
PR22	Develop an Autism Network across all Jobcentre Plus offices, providing autism and associated hidden impairment training to nominated staff who will lead on this agenda.	DWP	By April 2017
PR23	Deliver autism training to all staff involved in the Personalisation Pathfinder pilots in Greater Wessex, South West Wales and Surrey and Sussex.	DWP	By October 2016
PR24	Develop an autism e- learning training package for staff and managers that will support a better understanding of autism and how best to support people with autism into work.	DWP	By December 2016
PR25	Continue to support the work of HING and together explore ways to encourage employers to recruit and retain people with autism and associated hidden impairment conditions.	DWP	Review at the end of 2016



Number	Action	Lead	Timescale
PR26	Review the autism action plan against the key priorities in <i>Think Autism</i> , take action on outstanding issues and provide support to other government departments.	DWP	By end of 2016
<b>Contact with the criminal justice system</b>			
PR27	Development of a comprehensive package of training by the College of Policing.	MoJ and College of Policing	To be implemented by the end of June 2016
PR28	The NPCC is exploring the opportunities to create a new 'vulnerability' marker to be added to the Police National Computer to replace the previous 'mental' and 'ailment' markers, which were created in the 1960s and were subsequently outdated and inappropriate. The new marker will be used to record many different vulnerabilities including an autism spectrum diagnosis and will be developed within the upgrade to the PNC system due by June 2016.	NPCC	By end of June 2016
PR29	MoJ has been working with the Home Office and the CPS to develop a new Police Service guide to help officers identify people who may need support or special measures to give evidence. The aim is to issue this guide by the end of January 2016.	MoJ, Home Office and CPS	By February 2016
PR30	A forum took place in November 2015 involving the Disability communities of practice and the NPCC lead to discuss both the progress of the (now widely available) autism phone app and widget sheets. It was shared that Hertfordshire Police have developed their own version of easy-to-read custody sheets. The projects will be presented to the NPCC custody lead with a view to encouraging all police forces have easy-to-read sheets within their custody suites by June 2016.	Hampshire communities of practice, NPCC	June 2016
PR31	NHS England to issue a revised liaison and diversion specification to include autism.	NHS England	By end of January 2016

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