

A report on the listening phase of the review of the 2010 Adult Autism Strategy to assist in developing recommendations for the re-fresh of the strategy

Presented at 3rd February 2014 Autism Programme Board

Contents

This report and next steps	3
1. Public Awareness	5
2. Planning and Commissioning	6
3. Autism Partnership Boards	8
4. Data collection	9
5. Training	10
6. Access to services	12
7. Diagnosis and post diagnostic support	15
8. Support	17
Transition	17
Employment	19
Housing support	21
Criminal Justice System	22
Hate crime	23
Use of Technological resources	24
Appendix A: The Listening Phase	25
Appendix B: The 2010 Adult Autism Strategy	30
Appendix C: Autism	31

This report and next steps

This report sets out what the Department of Health (DH) has been told during the listening stage of the Review of the Adult Autism Strategy which took place from April to November 2013.

It is presented to the Autism Programme Board, chaired by the Minister for Care and Support, Norman Lamb MP and which is overseeing the Review, along with other information set out in the account of the listening exercise in **Appendix A**. Some of the issues in this report are set out in more detail in the initial report by Public Health England on the Local Authority (LA) area self assessment exercise and the report of the on-line survey led by Autism Plus which are also being sent to the Autism Programme Board. All the material submitted can be found at www.gov.uk.

Amongst the things we have been told is that that local areas are at different stages in implementing the strategy and taking measures to support adults with autism and their families. Work has been done by LAs and their partners to put in place the infrastructure that the strategy set out, but the expected benefits may not necessarily have reached individuals with autism yet. There was widespread acknowledgment that some LAs have begun to make progress but in other areas people with autism saw a slower pace of change.

People with autism wanted to have more information about local services they could access and many people with Asperger syndrome felt frustrated in that they did not meet Fair Access to Care Services (FACS) social care needs criteria. While some people did not meet the criteria, others struggled to receive an assessment and when they are assessed, they felt that the person assessing them may not have the training needed to identify their needs effectively or communicate with them in a way that is appropriate to them. Many people with autism also wanted support to help them get into employment.

This report will be used as a discussion document to consider how the issues it outlines could be addressed in the refresh of the strategy. The strategy will be refreshed by the end of March 2014 and will reflect progress made and changes in health and social care, including the increased focus on devolved delivery and local accountability.

We have been helped in this work by a very large number of people and organisations, including the National Autistic Society (NAS), Autism Alliance UK, Autism Plus, Public Health England, LAs and their partners, The Association of Directors of Adult Social Services (ADASS) and members of the Autism Programme Board. We want to thank everyone for their contributions and, in

- 4 A report on the listening phase of the review of the 2010 Adult Autism Strategy to assist in developing recommendations for the re-fresh of the strategy

particular, the family carers and people with autism for their willingness to engage with us in this work and for their insight.

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1. Public Awareness

1.1 This issue was mainly explored in focus groups. Public awareness was seen by people with autism to be better but this differed across the country.

1.2 Key issues to emerge were:

- Some people with autism felt the public still associated autism only with Rain Man and autistic savants and that there was a need for a public awareness campaign;
- Across many focus groups people said that the lack of awareness of autism and of the strategy meant that many adults are still socially isolated, have low self-esteem, and can suffer from mental health issues and depression;
- In some focus groups there was a view that the strategy had had no meaningful impact on the lives of people with autism and for some the invitation to take part in a group was the first time that they had heard of an initiative to improve support for people with autism;
- Many people with autism said that not only was there generally poor awareness of autism, the greater problem lay in the fact that GPs and hospital staff, staff in Job Centres, social workers and other staff in front line roles had a very low awareness of autism in many cases. It was also felt that those commissioning

services needed more awareness of autism;

- Focus group discussion also identified that people with autism have a great deal to offer. Adults on the autism spectrum may have unique skills and abilities that can be particularly useful in a work setting and may demonstrate particular strengths such as conscientiousness and attention to detail. More needed to be done to raise the issue of employability among employers.

2. Planning and Commissioning

2.1 Effective local services and support are crucial in improving outcomes for people with autism. We mainly gathered evidence on this issue through the LA self assessment exercise. In this almost all areas (97%) reported that they have a joint commissioner/senior manager responsible for services for adults with autism. Some 54% of areas reported using data about people with autism in their Joint Strategic Needs Assessment (JSNA) and most (84%) in their commissioning plans. Data on the numbers of people with autism eligible for social care was collected in 61% of areas. We also explored both the personal experiences of people with autism and their families and carers and the views of local commissioners or autism leads and professionals through face to face discussions and focus groups.

2.2 Key issues to emerge were:

- Many parents, carers and adults with autism generally stated that they felt the foundations of the strategy were in place, but that services and provision at ground level had not changed much, although some had seen new services and better awareness;
- People with autism had concerns that cuts to LA and NHS budgets despite the government protecting health spending, were already or would result in a reduction in support for service users, in particular speech and language therapy,

occupational therapy, physiotherapy and support such as advice and information provision;

- Many people highlighted budget reductions as a reason for services not being developed. Participants in focus groups also talked about restructuring and a high turnover of social care staff and the impact this had on service stability and continuity. Some felt the level of awareness and understanding is inconsistent and people have to tell their story time and time again. Many people with autism said that their GP did not always know where to sign post to or who the relevant autism lead was in their area;
- For many LAs and their partners the strategy had been a useful spur to take action and most regarded the guidance as a useful template for local action. They reported that they felt that the strategy had been useful in pushing autism up the agenda, alongside other evidence and guidance;
- Professionals implementing the strategy said that some areas have further to travel than others in terms of making progress, ie some still have diagnosis taking place out of area, while others already have an in area capacity. In some areas, there were historically strong links between the LA and health services, which had helped with a co-ordinated approach to implementation;

- In some areas the experience of people with autism was that diagnostic pathways were clearly defined and resourced, while in other areas, people reported experiencing long waiting lists and confusion over the points of access to the system;
- Both people with autism and professionals said a major factor in implementation can be the drive and commitment of individual professionals within LA and health bodies;
- Several local areas reported that strong joint commissioning arrangements, which have eased the way in terms of implementing measures for autism, have helped to avoid disagreements between organisations and teams about responsibilities for autism. In particular, strong relationships have helped in the development of diagnostic and care pathways and in narrowing the potential gap that can occur between learning disability and mental health;
- Where there are examples of collaboration and joint working service users could see that resources were being used effectively, where there wasn't there were fears over future commissioning of services;
- Professionals in some areas stated that autism does not actually require huge budgets to achieve improvements and plenty can be achieved with a degree of creativity and determination. They argued that lack of funds is an unavoidable reality in the current economic climate, but it does not need to be an absolute barrier to progress. Many people with autism believed that adopting less ambitious low cost measures would in the long term save high costs if a person went into crisis;
- The NAS has proposed that an innovation fund is set up to support LAs and charities in the delivery of projects that address areas of the strategy making less progress, with the fund being used to encourage creative and cost effective solutions and helping to identify new models of good practice that could be transferred to other areas;
- Autism is seen by some professionals as competing with other priorities within LAs and health bodies, such as learning disabilities, dementia, mental health, and alcohol and drug treatment. Individual commissioners and professionals are often dealing with a wide variety of competing work and resource pressures;
- The self assessment exercise showed that autism was now getting written into planning documents, but in some areas still at a fairly superficial level and it was not a separate and easy-to-find topic on many LA websites. Some areas had concerns about capacity and a fear that they won't be able to meet overall demand for services as children and young people come through the system and the increased demand for services as a consequence of improved diagnosis.

3. Autism Partnership Boards

3.1 The strategy saw Autism Partnership Boards (APBs) playing a key local engagement role. The on-line survey captured data on APBs and how well they engaged with individuals with autism locally. The vast majority of respondents, 83%, did not know or are not sure if their LA has an APB. Experiences of people who participate in local APBs were also explored in discussions organised by NAS.

3.2 Key learning from the NAS work on this issue included:

- APBs or local equivalents are called different things in different parts of the country. Examples include autism planning groups, autism steering groups and autism services development groups. However, the remit and role of these groups are the same;
- There are many excellent examples of effective and inclusive APBs, which enable participation by people with autism and their families and which have been instrumental in shaping local strategies. These include the creation of sub-groups and the inclusion of other relevant stakeholder groups in the work of the Board. There is much variation across the country, including in relation to membership, effectiveness and accountability;
- In some areas, APB members with autism describe feeling side lined and/or not listened to. Other people with autism voiced concerns that the momentum of their local Board is slowing;
- A key challenge identified by participants was that three years on from the publication of the strategy, some partnership boards have started to lose momentum and focus. In some cases, this has led to decreased engagement from some of the key stakeholders who need to be involved in order to deliver local change;
- People reported that they did not feel that their access needs were always understood and the meetings were run in a way that was most beneficial to the LA, rather than adjustments being made to suit those with autism. LAs needed more guidance on how to do this properly and resource it;
- There was a consistent message that ensuring the voices of a wide range of individuals are heard is absolutely crucial for local areas in their service planning and delivery. For example, in one area, themed focus groups are used in order to reach those groups less likely to be heard and to understand differences in need.

4. Data collection

4.1 The strategy was clear that without accurate and comprehensive data on adults with autism it is impossible to commission local services efficiently and effectively.

4.2 One of the key challenges identified in a NAS organised roundtable discussion on this issue was the lack of a comprehensive local database of numbers of people with autism. Both LA and health representatives identified that GPs potentially hold the answer. The majority of people are registered with a GP and they are often the first point of contact for adults with autism, for both pre and post diagnosis.

4.3 Other key issues to emerge in the roundtable discussion were:

- GPs currently routinely record patient conditions using what are known as read codes. There is, however, no single read code used consistently for autism;
- Not all people with autism will come into contact with social care services and so they were unlikely to have information on them or their needs. In order to plan effectively, however, LA professionals emphasised the importance of having access to as comprehensive data on numbers and needs as is possible. One problem discussed was that LAs sometimes struggle to access this data from other agencies;
- The difficulty of cross-referencing LA data with data collected by other agencies. Where LAs are able to access other agency data it is not possible to cross-reference it with their own;
- In the absence of comprehensive local data on adults with autism, many LAs rely on local estimates calculated from national data to feed into their JSNAs. National data can also be useful in the absence of comprehensive local data as it allows LAs to estimate unmet need;
- Autism affects about 1% of the population, but it isn't known in any detail how that 1% divides between people who need no support; low but occasional support; low but continuing support; medium support; high support and so on;
- The 'dementia calculator' was discussed as a potentially useful model that could be used to inform the development of an equivalent system for autism. The dementia calculator proportions national statistics to local statistics and informs JSNAs, in terms of age range and employment status for people with dementia.

5. Training

5.1 The strategy stressed the importance that health and social care professionals as well as other frontline staff have a good understanding of autism to enable them to recognise the condition and respond effectively when they are working with people with autism.

5.2 We explored this issue through the LA self assessment, discussions with professionals and through discussions with people with autism and their families and carers about their own experiences. The self assessment exercise reported that just over half of areas (56%) had a multi-agency training plan, with 59% stating that Clinical Commissioning Groups (CCGs) and primary care practitioners were involved in training. There was at least a good range of autism awareness training available in most areas (90%); but specialist training for staff who carry out statutory assessments had not been offered in 19% of areas.

5.3 Autism Programme Board member and self advocate John Simpson has undertaken work to look at the e-learning training that DH commissioned from organisations such as NAS and the Royal Colleges. His report which looks at how this material has been developed and used, and how it can be updated for the future is also being shared with the Autism Programme Board.

5.4 Key issues to emerge in discussions were:

- Many people with autism felt that awareness and understanding of autism amongst front-line practitioners remained inconsistent and too often led to negative experiences and/or restricted access to services for people with autism;
- There were repeated comments that GPs lack expertise in recognising signs for referral and knowing how to access the diagnostic pathway. This is not surprising as without training a standard GP list is unlikely to contain enough people with autism for this capability to be developed;
- Adult mental health professionals were also mentioned by many people with autism as having a weaker understanding of autism.
- Many people with autism felt that generally more awareness training was needed across a range of mainstream health and care services, including Out of Hours GP services, paramedics, A&E staff and social workers.
- Job Centre staff were also frequently mentioned as having a poor understanding of autism, including Disability Employment Advisers and those making decisions on capability for work;

- Many people with autism felt that mandatory training for those working in the Criminal Justice System (CJS), such as probation staff, was needed as well as at schools improved training for Special Educational Needs Coordinators (SENCOs). Teacher training could include a broader training in special educational needs, and some participants thought that teachers only had half a day's Special Education Needs training which was not autism specific;
- Many people with autism also thought that psychiatrists, counsellors and psychiatric nurses should be trained about Asperger syndrome and counselling should be adapted as appropriate;
- Other people with autism felt that awareness by professionals had distinctly improved and local initiatives such as training Autism Champions, who then train other staff, was having an impact on raising the general awareness of autism;
- There were also some accounts of positive experiences of the knowledge and awareness of social care and health professionals, including social workers, psychiatrists and psychologists. However, participants who had autism stated that they felt that all too often a positive experience is dependent on the particular professional having a personal interest in autism rather than it being a requirement of their role.

6. Access to services

6.1 The strategy didn't guarantee that everybody with a diagnosis of autism would receive support or services from LAs. If a person does not meet the eligibility criteria set out by the LA, that person may not receive social care services. However the person should be given information about what other support from charities or other community groups are available in local areas, and there may be some general support available. We explored this in a number of ways including drawing on the NAS Push for Action research as well as the self assessment exercise and the on-line survey and focus groups to explore the experiences of people with autism and family carers. The NAS Push for Action research highlighted that people's expectations can be higher than the care and support they are actually receiving based on their assessed care needs. However, while some people had been assessed and did not meet the criteria, others struggled to receive an assessment or when they were assessed, felt that the person assessing them may not have the training needed to identify their needs effectively or communicate with them in a way that is appropriate to them.

6.2 Mainstream public services can be inaccessible for adults with autism and the strategy includes a number of commitments aimed at ensuring that adults with autism can fully benefit from public services to live independently. It includes commitments

to improve the transition between child and adult services; make reasonable adjustments to services; and enable access to personalised social care.

6.3 Key issues to emerge under this area were:

- A majority of areas (67%) reported in the self assessment having had a single identifiable contact point where people with autism could get information. This included a designated person or service, an information advice service/switch board directing the caller to an appropriate service or a website;
- The LA self assessment exercise showed that services based around low level interpersonal support, such as buddying schemes have also enabled adults with autism to participate in different social and leisure activities, and promoted social inclusion;
- However, during focus groups many parents of people with autism commented on a lack of services and support for carers;
- Many people responding to the on-line survey said that they had not been involved in meetings with statutory services where their own support was being planned;

- There was still a general view from people with autism, parents and the voluntary sector that people with learning disabilities will be assessed by learning disability services and people with mental health issues will be assessed by mental health services, and people with autism can fall through a gap between those services;
- Many of the most effective advocacy and buddy schemes are delivered through the third sector and by volunteer groups, who can have a real insight into the challenges faced by adults with autism. However, during focus group discussion it was clear that funding was a significant issue for such groups and makes it hard for them to increase their capacity;
- People reported that direct payments and personal budgets can be very useful for people with Asperger syndrome to 'buy-in' support but many said they needed support to manage this and to access the help they need;
- The data from the on-line survey suggests that most universal and mainstream services were making some reasonable adjustments. However, the view expressed in focus groups was that local services were not always making enough adjustments to enable individuals with autism to access them effectively and austerity measures were seen by people with autism as having a negative impact on accessibility of support services;
- Only 12% of areas in the self assessment had both a clear council policy of applying reasonable adjustments for people with autism in everyday services and evidence that this had been widely implemented, although another 62% said they were making good progress toward this.

Issues not highlighted in the 2010 strategy

6.4 There were a number of issues not specifically highlighted in the strategy but which have been raised since and explored as part of this exercise. These included complex needs and older people where NAS have done some research. More discussion is also needed on the issues women and members of the Black and Minority Ethnic community (BME) may experience. For example, people have highlighted that the coping mechanisms employed by women are often referred to as masking (learnt behaviours from observation and mimicking their peers), and can be a barrier to a diagnosis and accessing services. NAS is currently doing research to look at the experiences of people with autism and family members from BME communities. From previous work with BME communities the feeling has been that they experience many of the same difficulties as everyone else. Additional barriers include language issues and stigma in some communities.

6.5 NAS organised a small group for people with more complex needs. This reported that:

- reasonable adjustments were important when they visited the GP for example;
- more help was wanted in finding employment, developing independent living skills and travel training;
- the people taking part had concerns about how their neighbours reacted to them and how they were treated in their local communities.

- LAs and CCGs need to ensure that they are including the needs of older adults with autism in their local plans.

6.6 Work by NAS looking at the specific needs of older people with autism across the spectrum found:

- A need for good practice to be more widely shared on supporting older adults, particularly around transitions;
- A need for more research on how the needs of people with autism change as they age and how autism effects the aging process;
- A need for clarity on how to use diagnostic tools to diagnose those older adults who require or need a diagnosis;
- Older adults with autism should be eligible for annual health checks. This would help to compensate for a lack of knowledge on co-morbid conditions in older age and the difficulties people with autism have in identifying ill health, particularly in older age;

7. Diagnosis and post diagnostic support

7.1 The strategy includes a number of commitments aimed at improving: guidance on diagnostic pathways; access to social care assessments; and the quality of diagnostic services in LAs. By 2013, it was expected there would be a clear pathway to diagnosis in every area. While it is recognised that specialist diagnostic services have proved a highly effective way of making diagnosis more accessible in many areas, it is not expected that a diagnostic team or service will be located in all areas. Instead, the most important step for now is that a diagnostic service should be easily accessible for all areas.

7.2 A formal clinical diagnosis can help adults with autism to access services and support. Diagnosis is particularly important for adults who have not previously had their condition recognised: their life to date may have been greatly affected by a sense of not fitting in, of not understanding the way they respond to situations or why social settings, for example, are difficult. The statutory guidance linked to the strategy set out that when adults receive a diagnosis of autism, they should expect to be offered a social care assessment. The guidance made existing legislation even clearer that people with autism must not be refused an assessment or access to support because their IQ is too high and they do not have a learning disability. We explored the issues

around diagnosis in a number of ways including the LA self assessment, the on-line survey and discussions with professionals, people with autism and carers. The LA area self assessment exercise has shown that specific training on autism has not always been provided to staff that carry out statutory assessments and that a diagnosis of autism does not always automatically trigger an offer of a community care assessment.

7.3 Key issues to emerge were:

- In the self assessment about half of areas (48%) rated themselves as having an appropriate local diagnostic pathway in place, accessible, and with a waiting list less than 6 months. Some 51% reported a diagnostic service that was specifically an autism assessment service, in others it was part of a more mainstream service;
- In 70% of LA areas the diagnostic service was reported as CCG led, and in 58% a diagnosis of autism by the local diagnostic service was reported to trigger an automatic offer of a Community Care Assessment;
- Of the 575 respondents to the on-line survey questions on diagnosis, 27% received their diagnosis after the launch of the strategy in 2010. A total of 60% of respondents had received their diagnosis

pre strategy and a further 13% did not specify when they were diagnosed;

- Out of 679 respondents, 89% noted that they were not offered a community care assessment on receiving their diagnosis, with 22% of those not being offered an assessment having received their diagnosis post 2010. Some reported that an assessment was not available locally unless their needs were thought to likely be critical, others reporting they had to request an assessment as it was not automatically offered. Others also reported that they didn't receive anything post diagnosis and didn't know where to go to ask for support and an assessment;
- When looking at post diagnosis support only 29% said they received any information after receiving their diagnosis. Those who had received further information were asked to explain in what format this information had been received, and the majority of respondents said post diagnosis information was provided verbally. Many people with autism found it difficult to remember information provided verbally where this was not followed up with written instructions;
- Some people with autism said that in some instances the quality of privately obtained diagnosis can be questioned or not recognised by statutory bodies, that advocacy support was vital to enable individuals to navigate the diagnostic process and effectively communicate their difficulties, and support needed to be in place before diagnosis to ensure individuals knew what would happen;
- Many comments from focus groups suggested that LAs and NHS bodies had more services available than were generally known to the public and publicising these can significantly improve the public's perception of services available;
- The need for flexibility and for people with autism to be able to get the right support at the right time, treating them as an individual and adapting support mechanisms to suit the person was emphasised;
- The need to look at the family's needs as a whole during assessment processes was also raised and enabling parents to advocate for their older children was thought by families to have a significant improvement on how individuals with autism experience services and access opportunities. Individuals with autism also said they wanted better access to good local advocacy services so they can be supported in what they want to say and get more independence;
- People with autism felt that peer support for parents and individuals from people who have had the same experiences could provide a helpful source of advice;
- Some people with autism said there was still limited availability of local specialist services with individuals still being concerned about having to travel out of area for support.

8. Support

Transition

8.1 The needs of adults may have been significantly influenced by their experiences within children's services. It is thought that early intervention, and interventions throughout childhood can have a significant bearing on the individual skills and abilities of adults with autism. The strategy saw transition as a key period in an individual's life and the majority of respondents to the on-line survey who are currently experiencing transition support said this could improve. As well as the on-line survey, we explored people's experiences through discussions and transition was also covered in the LA self assessment. Early intervention, and well supported transition is seen as a key driver in improving outcomes and also delivering less costly solutions as crisis situations can be less frequent.

8.2 When the strategy was launched DH and the Department for Education funded the University of York to carry out research on transition and young people with autism. The research was published this year and helps to inform the review.

8.3 Key findings include:

- Some local areas have developed systems to support transition of all young people with autism, but there are specific

challenges for those with Asperger syndrome or high functioning autism, who are not always deemed eligible for support;

- College careers were sometimes foreshortened because mainstream colleges struggled to support young people with autism;
- Young people and their families said they lacked autism-specific advice and support as they anticipated leaving further education;
- The absence of any meaningful daytime occupation, and the increased vulnerabilities associated with greater independence, were enormous worries for parents;
- A lack of appropriate employment opportunities and insufficient support to gain and maintain employment, were key barriers to paid work;
- Young adults endorsed the benefits of autism-specific, preventive or 'low intensity' support;
- Peer support opportunities were highly valued;
- Parents found themselves, often reluctantly, assuming a key-worker role. They felt unskilled and uninformed in this role.

8.4 In the focus groups there was criticism from people with autism that transition can be badly managed, with inadequate preparation and also starting late, and with young people suddenly deprived of support with resulting crisis. The new legislation proposed in the current Children and Families Bill that will cover multi agency assessment and support up to 25 years where it is needed was however generally welcomed.

8.5 People with autism also said that:

- They were concerned that children who have been supported to age 18 can be unsupported once they reach that age. Although there are examples of good transition between children's and adult services these were not thought to be universal;
- They were concerned that adult services departments within the LA were not able to adequately plan financially because of poor transitional arrangement. Several parents described good levels of support received from children's services, and how moving to adult services was difficult;
- Support during degree courses can be quite good at some universities, but post graduation help is limited;
- They felt there was a lack of co-ordination between the Disabled Students Allowance and direct payments, which led to confusion and anxiety for individuals with autism;
- Transition from children's to adult mental health services could be particularly difficult, with adult mental health services perceived as having much less understanding of autism than children's mental health services, despite statutory guidance on ensuring local protocols are in place;
- The data that LAs collect on the numbers of children approaching transitional age and data on establishing what happens to young people once they leave school, needed to be better used in local planning;
- They felt that an increase in independence training on leaving education needed to be available to individuals with disabilities in mainstream schools and not restricted to special schools;
- They thought there was less provision for pupils within a secondary school setting to access any specialist support;
- Once someone turned 18 professionals would not always include parents/carers in decisions even if the person asked for this to happen.

8.6 A small number of general school issues were also reported by people with autism:

- There should be more and increased flexibility in adaptations, ie 25% extra time in exams does not suit everyone;
- A lack of support to suit high ability individuals with autism with low

independence skills, ie special schools teach life skills within a limited range of subjects while mainstream schools teach a variety of subjects but don't offer life skills;

- Schools need to look at adjustments to break and lunch times to suit the needs of individuals with autism as well as classroom time. There should be places in schools for children to go to at times of heightened anxiety;
- Some parents thought that children with autism were more at risk of having to work in isolation, being excluded from school or being moved to other schools;
- People with autism and parents suggested that a module on autism should be included in all teacher training. More advanced training should be available to SENCOs, as they will often be involved in identifying children on the spectrum who may not have been spotted by any other professional group.

Employment

8.7 Adults with autism are currently significantly under represented in the labour market, which has a detrimental impact on their financial circumstances and social inclusion. The strategy includes 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. The Department for Work and Pensions (DWP) had introduced the Work Programme which provides personalised back to work support for unemployed people including disabled people; and Access to Work and Work Choice help people who face the most complex barriers to employment find and stay in work. We explored the issues around employment through the LA self assessment, the on-line survey and focus group discussions.

8.8 Key issues were:

- From the self assessment exercise a majority of LAs (64%) reported that autism awareness was delivered to some employers on an individual basis, that local employment support services include autism and that there had been contact with local Jobs Centres. Some 24% were able to report more extensive work in these areas. Just fewer than half of areas (49%) reported detailed reference to employment in the transition processes to adult services;
- A total of 657 people answered the questions on benefits in the on-line survey and the results showed a high proportion of respondents claiming Disability Living Allowance (490) and Employment Support Allowance (190), while 113 people did not receive any benefits at all. A few commented on difficulties with applying for benefits, while others expressed concerns over the new Personal Independence Payment and the impact the assessment criteria may

have. Many also said they are fearful of receiving letters asking for forms to be completed and what they perceive as ambiguous questions;

- Fewer individuals overall responded to the employment section of the survey with many saying it was not relevant to them at the current time. Out of a total of 529 people who did respond a high proportion of those are unemployed, although 72 were in full time and 74 in part-time work, with 12 on work placements and 69 doing voluntary work. In the context of all respondents to the survey it might be assumed that a significant proportion of the 573 who didn't answer this part of the survey are also unemployed. Data showed that only 16% of respondents who answered the employment questions were aware of Access to Work and how to access it, with only 4% receiving support from this service, and 9% referred to the Work Programme.

8.9 Other issues and suggestions reported by people with autism in focus groups and meetings were:

- Incentives and training for employers were needed, and further guidance for employers on employing people with autism;
- Face to face interviews disadvantaged people with autism, and employers should be encouraged to consider work

trials so they could then see the benefit of employing someone with autism;

- Business people who have the appropriate awareness could be recruited as ambassadors for employing people with autism;
- More work experience for people with autism was needed while in Higher/ Further education;
- Support to retain employment is as important as support needed to get a job;
- More publicity is needed about the help and support available. Access to Work needs to be more widely publicised;
- Include an indicator on DWP systems to denote an individual has autism so they can more easily get the right help and support, and that the individual will need help in communicating with DWP;
- The IT system used by Job Centres requires service users to complete quite complicated forms. The focus groups commented on how difficult the computer systems are and how if forms are not completed within a given timescale, the applicant is timed out. More simplified access was welcomed;
- Trade Unions could play a role in autism awareness;
- Support self employment opportunities, business start up and development of social enterprises for people with autism;

- There was a lack of support for highly skilled individuals with Aspergers syndrome to find suitable vacancies;
- Many people with autism reported that having a 'relaxed' pace of work, a low reliance on interpersonal skills and clear instruction, regular guidance and good supervision was helpful, and routine is very important;
- People expressed fears in accessing the Job Centre which included intimidating buildings, sensory issues related to open plan layouts, apprehension of speaking to the security staff and not knowing what to expect. There was a need for clearer guidance to be given to people with autism who go to the Job Centre on what to expect, who to ask for etc;
- Concerns around asking for reasonable adjustments through worry of how work colleagues will perceive them;
- Barriers to accessing Disability Employment Advisor support, having to be able to advocate for themselves to get this and then often long waiting lists for an appointment;
- Support in work placements and voluntary work should be more readily available to enable individuals to have a positive work experience and help develop work related skills;
- Some people in focus groups felt there was too much emphasis on employment as an outcome for all; and felt that independent living should be addressed first, as if adults are equipped with essential life skills they are more likely to succeed in work;
- Many people were not clear about the law on disability discrimination and what obligations this placed on employers;
- People with autism felt they lost out because the support they require from the Work Programme is too difficult/expensive to be provided;
- People with autism need help in interview techniques that address specific social interaction issues, for example, not to talk for too long on their hobby if asked about it, how to dress appropriately and to look at the person doing the interviewing;
- Participants talked of their personal experiences and perceptions of being financially disadvantaged as a consequence of the recent welfare reforms and that better autism awareness training was needed by Atos and other assessment staff.

Housing support

8.10 In the self assessment, most LAs reported that their housing strategies (81%) included no specific consideration of the needs of people with autism, and although the needs of people with disabilities might receive general mention, there were only limited data on individual needs or housing service usage.

8.11 Respondents were asked in the on-line survey if anyone had spoken to them about the housing options available to them, with only 6% stating yes they had been made aware of options, and a large number of respondents (66%) having received no information. However, 79% of respondents to the survey were either living with parents, family or their partner, so it would not necessarily be expected that a high proportion of respondents would have been spoken to by the LA about housing options.

8.12 People with autism also reported in focus groups that:

- There were concerns that some adults with autism would not be able to maintain their own home without a reasonable level of support, and cuts to LA budgets and changes to housing benefit placed some of that support at risk;
- There was a need for greater autism awareness among those providing housing;
- Many had limited awareness of housing options ie supported living;
- Waiting lists for housing support can be long;
- Planning for housing support needs to start much earlier, not when someone is in a crisis or elderly parents have passed away;
- The under occupancy penalty was felt to be causing difficulties for individuals with autism who needed extra space due to

sensory issues and who struggle to live with others;

- LAs could be more flexible when commissioning housing options and listen more to what service users want and design services around their needs, and sensory needs should be taken into account when looking at housing assessments and placements;
- Greater support for individuals to understand personal budgets was needed and how these can be used for housing support;
- More support and advice was needed for things like paying bills and managing a domestic budget.

Criminal Justice System

8.13 A majority of LAs (60%) reported in their self assessment that they had discussions underway to improve CJS involvement in planning for adults with autism. Many people with autism thought that training on autism for those who work in the CJS should be mandatory, with custody sergeants mentioned a number of times in this regard. There is very little literature relating to the number of people with autism in the prison population or in the CJS overall. The widespread assumption that people with autism are over represented in the offender population is not supported by consistent evidence. Derbyshire County Council held a conference on autism and the CJS during the listening phase and the British Psychological

Society have also been undertaking their own research and they also have held a conference. We drew on these sources.

8.14 Issues we heard from professionals on this included:

- A lack of liaison and diversion services and autism specific treatment programmes to reduce the risk of offending. Where these do exist, frequently their criteria excludes people with Asperger syndrome or high functioning autism;
- The difficulty of using screening tools in the police and prison context;
- The lack of intermediaries and trained autism advocacy and the challenges faced by defendants following cuts in the legal system;
- People with autism who have been diagnosed in prison being released to areas where the local police, health and social care services are unaware of their diagnosis and how this may impact on re-offending and vulnerability. More trained staff within the prison service were needed to advise and link into multi-agency interventions;
- A lack of taught social skills. For some individuals with autism who offend, often the potential signs were there at an early age. If issues aren't addressed, the person can progress to offending behaviour;

- The potential for collaboration to define a nationally recognised care pathway;
- People with autism may not understand the police caution;
- People with autism can be particularly vulnerable to bullying in prison;
- Adults with autism in the CJS can be seen as more risky or dangerous than they are, as they may appear to lack empathy for their victims.

Hate crime

8.15 This had not been covered specifically in the strategy. However, we explored this through a focus group of people with autism and they reported that:

- There was a general lack of awareness of this issue involving people with autism, but some improved access to support, including telephone support lines;
- There can be an inability by people with autism to articulate their own needs at a time of heightened anxiety. Some people talked of "meltdowns" as a consequence of highly stressed environments and situations which with training can be avoided. Many people with autism become non verbal in times of stress. A meltdown can be seen as threatening behaviour and the situation if not handled correctly can escalate;

- Improved training and awareness was needed for front line police officers and custody officers;
- People may result in self-isolating to avoid confrontations; some can self-injure or at worse attempt/threaten suicide;
- Some adaptations were being made to the housing selection process in some areas to allow individuals with autism to not be placed in locations where they are likely to be more at risk;
- There was an increased presence of public “safe places” but a need to ensure signs are visible and easy for people to spot when they are anxious;
- They felt there was a lack of post incident support, some people felt that their confidence and independence was drastically affected after being a victim of hate crime but they were not offered any on going support;
- There should be more availability of personal alarms to vulnerable adults who express a fear of leaving the house on their own;
- Increased awareness of autism amongst housing officers and council workers was needed when issues arise around tenancy or neighbour disputes.

Use of Technological resources

8.16 Many people with autism felt they could benefit enormously from the use of new technologies to help increase and maintain their independence, for example, through using interactive smart phone apps. Using assistive technology to the maximum effect will require specialist understanding of the individual with autism, and of their preferences and communication styles. Specialist providers working with commissioners in planning how to use assistive technology could help in bringing down costs. The Carlisle focus group brought together people from the most rural areas, and they said they needed better broadband connections and more information online, including Skype groups, to aid their independence.

Appendix A: The Listening Phase

1. The listening phase of the Review has seen DH working with partners across Government, with LAs and the NHS, stakeholders from the voluntary sector and with people who have autism, their families and carers. Many people with autism and their families took part in an on-line survey and follow up focus groups and events, and LAs and their partners also gave their views by undertaking a self assessment of progress achieved.

2. We used 7 main ways to gather information:

- a. LA area self-assessment exercise;
- b. On-line survey;
- c. Focus groups;
- d. National and other conferences;
- e. Regional network meetings;
- f. NAS Push for Action and other research; and
- g. An assessment of the e-learning training.

The LA area self-assessment exercise

3. This was led by Public Health England with support from ADASS, NAS and DH. **All 152 LAs, working with their partners and people with autism, took part.** It ran for two

months from early August. This work built on the first self assessment exercise which looked at what progress had been made by February 2012. The results of the self assessment exercise have given a national overview of local area implementation of the strategy and identified examples of how people with autism have been helped and supported.

4. In their responses, LAs were asked to come to a multi-agency perspective, including liaison with CCGs, to reflect the requirements of the implementation of the strategy, agree their response with the local APB or equivalent group, and have their answers validated by people who have autism. The individual returns will also be discussed by Health and Well Being Boards by early 2014 as evidence for local planning and health needs assessment strategy development and supporting local implementation work.

5. The returns are being analysed by the Public Health England learning disabilities observatory. An initial summary of the data submitted, and a compilation of over 200 stories where work has assisted people with autism can be found at www.improvinghealthandlives.org.uk/projects/autism2013 to facilitate local discussions. Each of the individual 152 LA area returns will be published in early 2014.

On-line survey

6. Autism Plus in partnership with the DWP led Hidden Impairment National Group conducted an online survey for adults with autism and their parents and carers to identify the impact the strategy has had on individuals. **1,102 people with autism or their carers or family members took part.** The survey captured information on all aspects of the strategy including, education and transition, housing, employment, awareness raising and training. Of the 1,102 individuals who took part 363 (33%) were on the autism spectrum and 67% either parents, family members or carers representing the views of people with autism. Of these, 54% of respondents were themselves or representing individuals between the ages of 18 and 34 and 36% of respondents were themselves or representing individuals between the ages of 35 and 54. Those taking part came from 125 LAs areas, and the survey was followed by focus group discussions. The survey ran from June until September. A short report on the online survey is available at www.autismplus.co.uk/s/autismstrategyreview

Focus groups

7. Following the on-line survey Autism Plus then organised and ran focus groups mainly for people with autism and their families:

- in Sheffield on hate crime (12 September), education (12 September) and housing (27 September);
- in Hull on housing (13 September), employment (17 September) and education (17 September);
- in Leeds on housing (18 September), employment (18 September) and diagnosis (4 October);
- in Manchester on diagnosis (19 September), employment (2 October) and education (2 October).

8. General/broader issues were also discussed at these focus groups and **over 150 people** took part in total. A large number of other focus and discussion groups also took place around the country:

- The NAS London and South East Area Development Team ran a number of focus groups to see what impact the strategy had had on the lives of people living within two London Boroughs (LB) and two Berkshire Unitary Authorities. Four groups were held during September and October 2013 in the LB of Barnet, LB of Harrow, Bracknell Forest and Wokingham. Some **59 people took part**, including people with autism and parents and carers;
- NAS also ran a focus group in the West Cheshire area, brought together a meeting of professionals involved in data collection and consulted with people with

more complex needs and people who participate on local APBs;

- NORSCA held three focus groups on 12 August in Worksop, Nottinghamshire, on support into Employment; on 19 August, in Bestwood, Nottinghamshire, on housing and moving towards an independent life style; and on 20 August, in Nottingham, on Transition and moving into adult services. All three events had a speaker with direct experience of services in each of these focus areas, as well as a facilitator/trainer who had Asperger Syndrome, and **20 people** took part;
- Autism Wessex held a focus group in Wimborne in Dorset on 12 September and the North East Autism Society held one in Newcastle on 25 September, and also held a small focus group in Carlisle. Over **60 people attended** in total.

9. People with autism and family members/carers played a full part in the facilitated group discussions. Many were also attended by policy officials who gave updates on their areas and directed people to practical support where appropriate.

Conferences

10. The Autism Alliance UK organised a good practice, challenges & solutions conference which took place in London on 9 October. **Around 120 people attended**

to hear presentations and take part in focus group discussions.

11. DH officials and Autism Programme Board Members also spoke and ran workshops at a wide range of other conferences and events that included:

- A presentation about the review at the Celtic Nations Autism Partnership event in Belfast on 1/2 May. The Northern Irish, Scottish and Welsh Autism Strategies also presented. **150 people attended;**
- With DWP and London Autism, meeting with **25 people with autism** in Kentish Town to discuss employment support on 14 May;
- With the Ministry of Justice, attended a workshop held in London on 15 May which was led by the British Psychological Society and focused on autism and the CJS. Ideas that emerged were discussed at a conference in Manchester on 19 September. Derbyshire County Council also led an event on behalf of the East Midlands on Autism and the CJS on 15 October **involving 100 people;**
- A presentation and workshops on the transition from childhood to adult services at the Autism Plus organised Autism and Transitions conference in Doncaster on 31 May. **200 people attended;**
- A presentation on the review and a workshop on accessing GPs at the Effective support for people with autism

event organised by SEQOL (a health and social care social enterprise) in Swindon on 11 June. **125 people attended;**

- A workshop on Autism training and awareness at the Autism Show in London on 14 June, which involved **over 100 people;**
- A presentation with the Autism lead for Leeds LA on the review and a workshop taking views from attendees at the Autism Show in Manchester on 28 June, which **over 300 people** took part in;
- A Question and Answer session at the Living Autism conference in York on 1 November which was attended by **80 people.**

Regional Network Meetings

12. Autism leads, other professionals and people with autism and carers, came together on a regional basis in Preston, York, Taunton, London and in Guildford, in NAS organised events which **involved over 400 people.** The North East Autism Consortia also held a network meeting in Sunderland which involved **25 people.**

The NAS and Push for Action

13. The NAS Push for Action campaign has been run in parallel with the Review and has an important focus on local implementation. During the listening phase NAS organised a number of focus groups

looking at issues including taking the views of people who had complex needs, who came from BME communities or who were older.

14. NAS also looked at the key barriers and enablers to progressing recommendations on data collection and on including autism in JSNAs as set out in the strategy and statutory guidance. JSNAs provides an assessment of the health and social care needs of a local population to inform the commissioning of health and social care services within LA areas. As part of this work, NAS undertook desk based research on current practices and existing databases as well as using findings from the research for Push for Action. NAS also hosted a roundtable discussion to allow good practice LAs, as well as representatives from the ADASS, the NHS, and a self advocate, to discuss and share their experiences of improving data collection on adults with autism in order to improve service planning and delivery.

15. Finally NAS carried out a piece of focused work in seven LAs areas on supporting the involvement of people with autism and their families in the delivery of the strategy. The project had two parts. The first involved interviewing people with autism or parents who had been involved in APBs. The second involved working intensively in three different areas across the country to look at the wider mechanisms for the engagement of people with autism and their families in strategy delivery. NAS are using the learning from the project to create a best tips guide on

involving people with autism and their families for LAs and health bodies.

E-learning Training

16. The strategy's statutory guidance made clear to LAs, NHS bodies and NHS Foundation Trusts that they should seek ways to make autism awareness training available to all staff working in health and social care. To support this DH commissioned on-line resources and information about autism for those working in the health and social care sector, and funding of £500,000 was awarded to the Royal Colleges of Nursing, GPs and Psychiatrists, the Social Care Institute for Excellence, the British Psychological Society, Skills for Health and Skills for Care and NAS to produce these materials. John Simpson, a self advocate member of the Autism Programme Board has written a short report on how these materials have been developed and used, and what the plans are for the future. It is available at www.gov.uk/government/organisations/departments-of-health

Ministerial and Parliamentary engagement

17. People on the autism spectrum have been able to talk to Norman Lamb MP, the Minister for Care and Support, about their experiences and hopes for the future. The Minister spoke at the conference organised by the Autism Alliance UK, at a NAS Push

for Action event in Parliament, visited a NAS service in Ladbroke Grove and met people with autism and local autism strategy implementers from Essex and surrounding areas on 24 October.

Other means of getting views and comments

18. Officials issued a small number of blogs, and articles were written for NHS News and the Local Government Bulletin amongst others. On 2 October officials took part in webchat organised by Ambitious about Autism. A total of **52 e-mails** were sent to a Review e-mail mailbox.

Appendix B: The 2010 Adult Autism Strategy

1. The Autism Act 2009 was followed in 2010 by the Adult Autism Strategy and strategic guidance for LAs and the NHS which set out five areas for action aimed at improving the lives of adults with autism:

- increasing awareness and understanding of autism;
- developing a clear, consistent pathway for diagnosis of autism;
- improving access for adults with autism to services and support;
- helping adults with autism into work;
- enabling local partners to develop relevant services.

2. The overall aim was that:

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

3. The strategy is built on a fundamental recognition that too many people with autism are missing out on the chance of the quality of life that others enjoy. This is a denial of their potential, their personal aspirations,

their hopes for the future and places a heavy burden on their families. Change is though a long-term process and the strategy offered a practical approach to that including identifying how to make existing policies work better for adults with autism. This did not depend on new investment and focused on ensuring mainstream services actively identify and respond to the needs of adults with autism.

4. The strategy aimed to put in place central structures and statutory guidance to support implementation of specialist services and joint working by local commissioners – LAs and the NHS, responsible for planning and funding services for people with autism – and public, private and third sector delivery organisations, responsible for providing services for people with autism. DH is the lead policy department for the strategy, but with delivery shared across a range of government departments and agencies and reflecting the move to local accountability, health and social care service providers.

Appendix C: Autism

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