The National
Autistic Society

We need to turn the Autism Act into action

Accept difference. Not indifference.

Timeline:
How did we get here?

February 2008:
NAS 'I Exist' campaign launches

New research highlights lack of support for adults with autism, resulting in Government agreement to produce a strategy to address this.

June 2009:
National Audit Office (NAO) reports

An in-depth and influential report published by the NAO, 'Supporting people with autism through adulthood', analyses effective public spending on adults with autism.[1]

November 2009:
Autism Act receives Royal Assent

History is made as a new law puts a duty on the Government to produce a strategy and supporting statutory guidance to improve the lives of adults with autism.

March 2010:
National strategy for adults with autism published

'Fulfilling and Rewarding Lives' strategy document sets out Government commitments, as well as actions for local authorities, the NHS and other statutory bodies.[2]

December 2010:
Statutory guidance published

'Implementing Fulfilling and Rewarding Lives' document sets out new legal duties on local authorities and health bodies to support crucial elements of the strategy.[3]

April 2011:
Self-assessment framework established

A new framework, primarily for commissioners to complete, alongside local partners, is developed as a way to respond to the strategy and statutory guidance.

2013:
Review of adult autism strategy

In the strategy, the Government committed to review the impact it was having, making sure it is being implemented properly and that services are improving for people with autism.

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[1] National Audit Office (2009). *Supporting people with autism through adulthood*. London: The Stationery Office

[2] Department of Health (2010). *Fulfilling and Rewarding Lives: the strategy for adults with autism in England*

[3] Department of Health (2010). *Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*

Contents

Written by Ayla Özmen

Acknowledgements

Thanks to all of the adults with autism, their parents and carers and representatives from local authorities and local health bodies who completed the surveys and took part in the focus groups and interviews that were used to inform this report. Thanks also to Nick Rand for conducting the in-depth interviews and focus groups and to all the National Autistic Society staff who helped to produce this report, including Sarah Lambert, Amanda Batten, Tom Madders, Debbie Moss, Shane Samarasinghe, Kathrine Bancroft, Anna Nicholson, Lydia Hodges, Eleanor Thompson, Tom Purser and Josie O'Donoghue.

Background:
About autism

Autism is a serious, lifelong and disabling condition that affects the way a person communicates with, and relates to, other people.

Autism is a spectrum condition which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. Some people with autism are able to lead independent lives with little support, whilst others need specialist support throughout their lives. Everyone with autism has difficulties in the following three areas.

- **SOCIAL INTERACTION:** **it can be harder for people with autism to recognise and understand other people's feelings and express their own, making it difficult for them to 'fit in' socially. Many adults with autism are socially isolated and their family may be their only form of social contact.**

- **SOCIAL COMMUNICATION:** **people with autism can find it difficult to use and understand language (both verbal and non-verbal) to different degrees. When talking to professionals, adults with autism will benefit from meetings which are set up to take account of their preferred style of communicating. They may like to have an advocate present who can help them express their needs and aspirations.**

- **SOCIAL IMAGINATION:** **people with autism can find it hard to imagine situations outside of their own routine, and, therefore, to plan for the future, to cope with change or to manage in new and unfamiliar settings. They may also find it hard to understand and predict other people's intentions and behaviour.**

In addition, people with autism may experience over- or under-sensitivity to sounds, tastes, smells, lights or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but still have difficulties with understanding and processing language.

Research has shown that more than 1 in 100 people in England have autism. By applying the 1 in 100 figure to the general population, we can estimate that there are 300,000 adults with autism in England.

Throughout this report, unless otherwise specified, where we refer to autism we are referring to the entire autism spectrum, including Kanner autism, Asperger syndrome and high-functioning autism.

Foreword:
Rt Hon Cheryl Gillan MP

The Autism Act 2009 was a landmark in the battle to improve the lives of adults with autism. For adults living with the condition and their families, and for the 15 autism charities and my colleagues in Parliament – from all parties – who supported me in getting the Bill through Parliament, it was a phenomenal achievement.

Back in 1992, through my colleague Angela Browning MP (now Baroness Browning), I became aware that too many adults with autism were being isolated and ignored. Over the years awareness grew of the needs of children with autism, but even by 2009 there still wasn't any recognition of the challenges facing adults. More than 1 in every 100 adults has the condition. Some need help to get washed and dressed, others need specialist support to find sustainable employment, and others just want a way to participate in their local community.

Choosing autism as a subject for my Private Member's Bill was therefore an easy decision to reflect the great need across the country. Today, the Autism Act is unique – it remains the only disability-specific legislation in England. It guaranteed the introduction of the first ever adult autism strategy, setting out how adults with autism should be better supported, underpinned by guidance, placing duties on local authorities and the NHS to take action.

I am immensely proud of what has been achieved so far. Yet, despite much progress, change has still been slow and patchy. Research by The National Autistic Society (NAS) shows that, four years on, many adults with autism are still waiting for the support they need.

So we must urge local authorities to press on, with necessary support from the Government. This year we have an opportunity to bridge the gap between the solid building blocks we have laid and real change on the ground.

Cheryl Gillan

Chapter 1:
The 2013 Review

In 2009, in recognition of the lack of services and support available for adults with autism in England, Parliament passed the Autism Act. This led to the publication of the adult autism strategy for England in March 2010,[4] and statutory guidance, which put legal duties on local authorities and the NHS, in December 2010.[5]

In the strategy, the Government committed to reviewing progress in 2013. Ahead of that review, we at The National Autistic Society (NAS) have undertaken our own research looking at how local authorities and the NHS are implementing the strategy and what the barriers are to progress. We have also spoken to people with autism and their families about their experiences. This report is the result of that research. It shows that the direction of travel set by the Act was the right one, but that greater momentum is needed to ensure that implementation is universal and goes far enough to make a real difference for people with autism and their families.

What support do people with autism need?

Of the more than 1,000 adults with autism we spoke to for this report about their experiences of accessing support, 70% said that they still aren't getting the help they need from social services.[6]

They told us they need help with washing and dressing (36%), preparing a meal (63%), doing housework (73%), shopping (68%), paying a bill or dealing with letters (83%) and managing money (77%), but in the majority of cases they are unable to access this help from their local authority.[7]

The level of support that adults with autism need varies greatly. Just 7% of respondents to our survey said they need no support. 40%, however, need at least 30 hours a week, including 25% who need 24-hour care.[8]

In other recent research carried out by The National Autistic Society, 70% of adults with autism told us that with more support they would be less isolated. 62% said that with more support their general health would improve and 45% said that with additional help they would be able to work.[9]

There are also ongoing and significant gaps between the types of support that adults with autism say that they would like and what they actually receive. The chart opposite demonstrates the clear gaps that exist in services.

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[4] Department of Health (2010). *Fulfilling and Rewarding Lives: the strategy for adults with autism in England*

[5] Department of Health (2010). *Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*

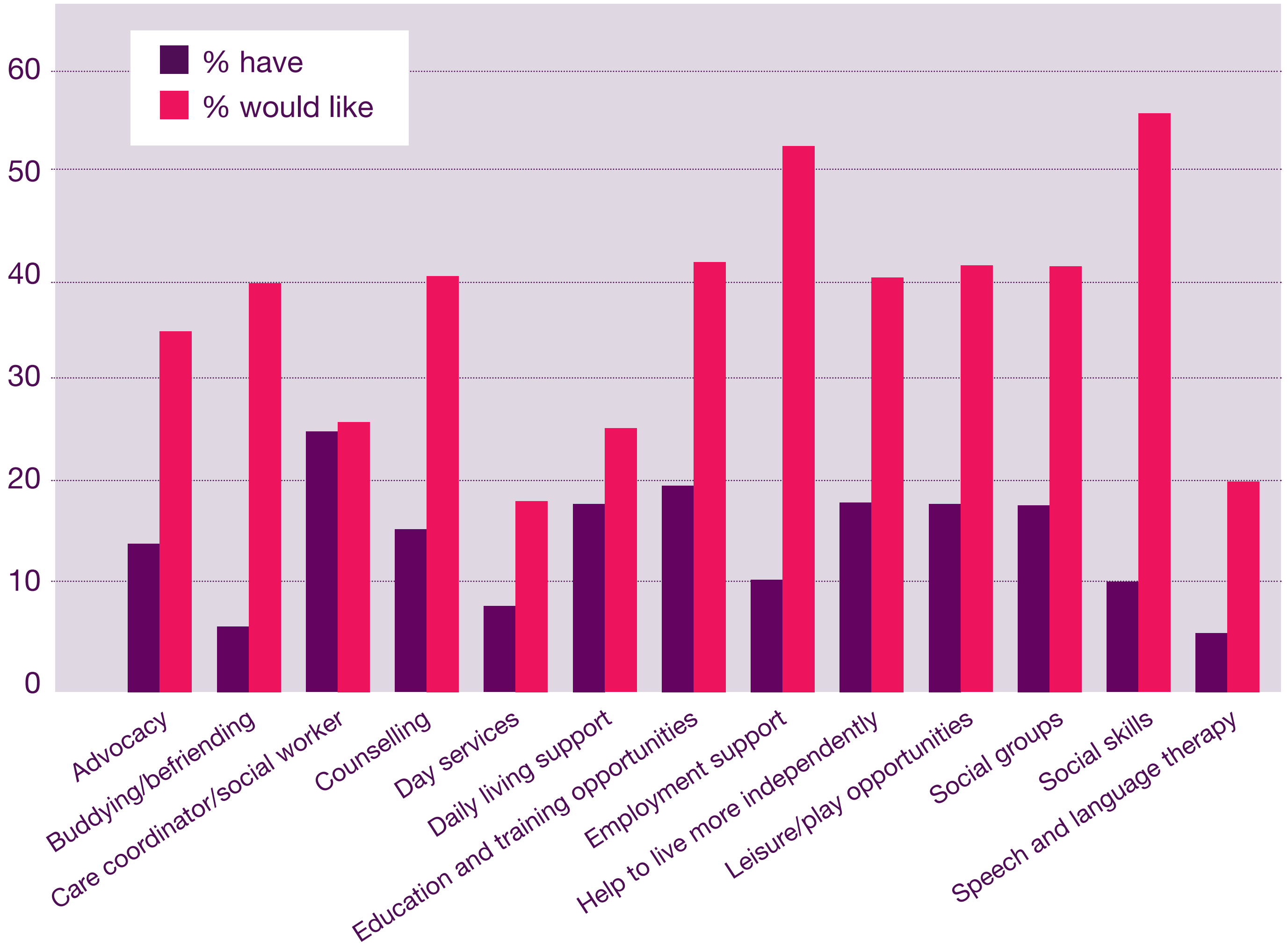
[6] This figure includes both people with autism who responded directly to our survey and parents/carers responding on their behalf. Bancroft et al (2012). *The Way We Are: Autism in 2012*. London: The National Autistic Society

[7] The National Autistic Society (2013). *NAS survey for Push for Action campaign*

[8] Ibid

[9] Bancroft et al (2012). Op cit.

Types of support: access and need



The biggest gaps between what people say they need and what they access are in social skills (only 10% receive this support but 55% would like to receive it), employment support (10% receive this support but 53% would like to receive it) and social groups (17% receive this type of support but 42% would like to receive it).[10]

This demonstrates a clear demand from adults with autism for what could be described as 'preventative services', those services that are low level and less intensive in nature but which help to prevent the development of more complex needs over time.

> "It's great to get help with the little things. Little tweaks to your life – that's what you really need. A bit of individual attention. But there is so little." *(Adult with autism)*

Failure to provide these services can have a significant impact. It can mean that people fall into crisis situations. A third of adults with autism responding to a previous NAS survey said that they had developed serious mental health problems as a result of a lack of support.[11]

> "Low-level support can make all the difference between leading an 'everyday' life and falling into a crisis." *(Parent)*

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[10] Bancroft et al (2012). Op cit.

[11] Rosenblatt, M. (2008). *I Exist: the message from adults with autism* London: The National Autistic Society

In 2009, The National Audit Office (NAO) carried out research looking at the cost-effectiveness of services for adults with autism in England.[12] The NAO highlighted the importance of early identification of and support for the needs of adults with autism, and stressed the costs of failing to provide this type of low level support. The 2009 NAO report explains:

> "Beside the negative impact of such crises on a person's life, acute services are also expensive, with inpatient mental health care costing between £200 and £300 per day."[13]

For those with autism who have higher support needs, however, the situation is not vastly different. Although this group are more likely to be accessing some services, too often these are insufficient and not tailored to meet the needs of adults with autism. Our survey showed that of those who needed 24-hour care, more than two thirds didn't receive this level of support from statutory services.[14]

DEVELOPMENTS ON THE GROUND

Preventative services in Kirklees

In Kirklees, 'prevention' has been supported by the Council on a long-term basis. The viability of this approach has been strengthened by evidence on social return, including a report from the New Economics Foundation that evaluates the cost-effectiveness of establishing community groups.[15] The Council supports over 220 community projects that are part of a more universal offer and are also available to people with a wide range of social care needs. Described as 'Community Partnerships', a network has been created that is in touch with some 9,000 people a week.

This long-term investment means that people who are not automatically eligible for local authority funded care services have access to some community support.

Alongside a strong belief that investment in prevention is stopping issues escalating into more expensive support solutions, there is evidence that referral rates to social care are reducing over time in Kirklees.

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[12] National Audit Office (2009). *Supporting people with autism through adulthood*. London: The Stationery Office

[13] Ibid, p.24

[14] The National Autistic Society (2013). *NAS survey for Push for Action campaign*

[15] Trudi Wright, JIP Project Manager, Kirklees Council and Jonathan Schifferes, nef Consulting (2012). *Growing social capital: A social return on investment analysis of the impact of voluntary and community sector activities funded by grant aid*

Another issue raised, particularly by parents, is the importance of short breaks or respite care. This was also reflected by our 2012 survey, in which nearly half of parents (45%) responding called for more help in this area.[16]

> "The people who hold the purse strings are not aware of what autism means. What is needed is for these people to be educated. For instance, about respite – what it is to be trapped at home. People are not aware of the reality of the situation, and they should be." *(Parent)*

> "I can't get my son into respite services or outreach because he's been let down so much, from them not turning up... He becomes very aggressive, very violent, because he has been let down so much. And he kicked a worker, so now he can't have respite." *(Parent)*

Impact of lack of support on families and carers

Lack of support can have a massive impact on the lives of family members. Of those who are not receiving the level of support they need from social services, 77% said they were relying on parents and 22% on friends to provide that support.[17]

70% of carers responding to our 2012 survey said that they often feel isolated, 61% said that it has put a strain on their marriage or relationship, and 52% said it has negatively affected their mental health.

Furthermore, two thirds of carers say that being a carer has had a negative impact on their work life, with 20% saying they had to reduce their hours and 17% that they had to give up work altogether.[18]

Addressing need

Many of these issues are the same ones that adults were facing prior to the Autism Act 2009. It was the compelling stories of the impact of not accessing the right support that led politicians to legislate. The key actions and duties that have resulted from this set out the importance of better planning and commissioning of services, and the building blocks that need to be put in place in order to achieve that. Although these building blocks are starting to materialise, some areas are yet to make real progress and it is clear that, broadly speaking, these changes are still not being felt by people with autism and their families. We wanted to find out why.

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[16] Bancroft et al (2012). Op cit.

[17] The National Autistic Society (2013). *NAS survey for Push for Action campaign*

[18] Bancroft et al (2012). Op cit.

Chapter 2:
Getting the Act implemented at a local level

A central part of our research involved qualitative interviews with 14 professionals who have a lead responsibility for implementing the strategy and the statutory guidance at a local level. We spoke to them about the impact of the Autism Act. We asked them about progress in implementation in their area and the impact it has had on individuals, before exploring some of the key barriers and enablers that have helped or held back implementation. This is what we found.

Autism Act – a driver for change?

In 2009, when the Act was passed, there were a very limited number of areas demonstrating good practice in autism services. Where good services and support did exist this was usually as a result of committed local professionals driving change and often having to 'battle' at a local level to push forward key actions to improve services and support.

For this group of professionals, the Act, strategy and guidance have been a spur to action and helped to 'strengthen their hand', allowing them to have more productive and constructive discussions with senior colleagues and to push forward change more quickly.

"What it has done is that for the first time ever we have a condition-specific government paper that dictates what people need to be doing. It's really given us some strength to our arm... It's some of the things that we've been trying to do despite everything. It's really been helpful to say to people, 'It's not just us who think this is a good idea. It's actually a Department of Health drive." *(Local authority professional)*

For many local areas, however, the Autism Act put autism on the agenda for the very first time, and the statutory guidance has provided a template for action in areas where previously no action at all was being taken to meet the needs of adults with autism.

"The statutory guidance brought up the agenda of autism explicitly. The fact that it's statutory guidance gives it relevance, for the organisation to pay attention. The guidance started the process of change for people with autism across the borough." *(Local authority professional)*

In other areas, where action since the publication of the strategy has been slow, the prospect of the 2013 Government review and the next round of self-assessment returns that local authorities have to submit to the Department of Health has been the major spur to action.[19] It has demonstrated the need to ensure that there is continued momentum and ongoing monitoring and evaluation of progress, to make sure that the aspirations of the Act can be felt across England.

Why did we need an Autism Act?

Historically, the needs of adults with autism have been 'hidden' from view at both national and local levels, meaning that appropriate services and support have not been developed.

There is very little data on the numbers of adults with autism, let alone their needs, and as a result, commissioners had failed to understand the scale of need and have not prioritised the development of appropriate local services.

There is also a clear structural challenge at the local level and there has been a lack of local leadership on the development of autism services and support. Local services tend to organise delivery of support through specific teams which are categorised into client groups. Consequently, people with autism will usually come into contact with the learning disability team and/or the mental health team. As autism is neither a learning disability nor a mental health problem, however, many people with autism, and particularly those with Asperger syndrome or high-functioning autism (those without a co-occurring learning difficulty), find themselves 'falling through the gap' between teams, not 'fitting' into either category.

It is also important to note that for those individuals who do have a co-occurring learning disability or mental health problem and are receiving services, without proper identification of their autism, learning disability and/or mental health services may not be providing the right support.

The strategy and statutory guidance aimed to address this imbalance by setting out key actions and duties, including establishing local leadership on the development of services and support, and building a framework for the long-term delivery of services, in order to ensure that autism could be built into local structures.

Professionals that we spoke to as part of the research were clear that in order to transform services and support for all adults with autism, autism must be embedded into local structures effectively:

"We needed to plan. We needed to set the journey. These are the building blocks of the journey. Because you can't commission a pathway for autism if you do not know what the local situation is – if you do not talk to your local partners, if you do not talk to local people. You need to create a framework. And that's what we now have: a real framework... which will drive the work forward." *(Local authority professional)*

Professionals concede, however, that because the initial focus in the strategy and statutory guidance is on getting the structures in place, it is unlikely that people with autism and their families will have experienced substantial changes yet.

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[19] See 'What does implementation look like so far?' on p.11 of this report for further details on the self-assessment.

What does implementation look like so far?

In 2011, the Government published a new 'tool' for local authorities and NHS bodies to monitor progress on the implementation of the strategy and statutory guidance. The 'local self-assessment framework' sets out actions that local authorities and NHS bodies should take in order to implement the strategy and statutory guidance, and asks them to rate their own progress against these actions.

The self-assessment returns from local authorities give an insight into what is going on on the ground. There is some degree of variation, however, between how authorities have rated themselves. As the NAO states:

> "In particular, the tool has not set out criteria for its 'red/amber/green' scoring system so it is unclear that local authorities have responded to the questions in a consistent and reliable fashion."[20]

This means that we cannot accurately compare local authorities. In addition, not all local authorities have taken part in the process.

We therefore welcome the Department of Health's intention to change aspects of the form and to repeat the self-assessment exercise in 2013.

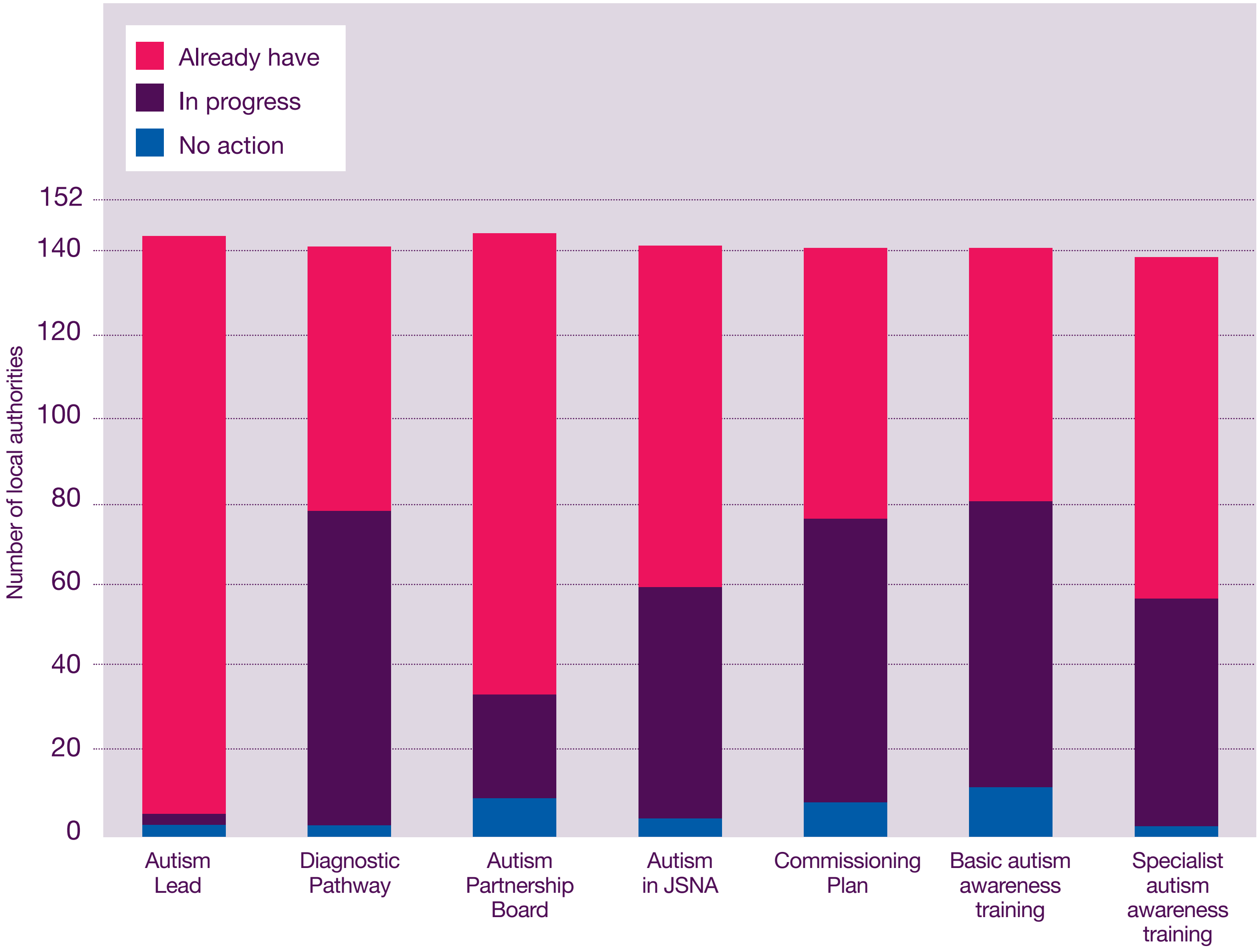
Since 2010, The National Autistic Society has been collecting our own information from local authorities. We asked them about their actions in the following areas:[21]

1. Appointment of an autism lead
2. Development of a working pathway for diagnosis and assessment of adults with suspected autism
3. Establishment of an autism partnership board – a local strategic planning group comprising key commissioners and stakeholders, including people with autism and their families
4. Inclusion of the needs of adults with autism in the Joint Strategic Needs Assessment (JSNA) – a key planning tool for local authorities and the local NHS
5. Development of a local commissioning plan for services for adults with autism
6. Inclusion of autism awareness training as part of standard equality and diversity training
7. Development of specific autism awareness training for community care assessors.

Results

As you can see from the graph opposite, progress has been made against all indicators, though the results are variable. It is to be particularly welcomed that nearly all local authorities have now appointed an autism lead and have a partnership board, or similar, in place. This will make it much clearer who is responsible for the planning of local services. Local authorities, however, are struggling far more to take forward actions on local planning, which is essential to transforming local services. In addition, it is disappointing that although diagnosis was a key issue in the strategy, only around half of all local authorities currently have a working diagnostic pathway. Despite the clear direction from the Department of Health that training is essential for community care assessors to ensure that the needs of adults with autism are fairly assessed, just over half have specialist training available for their staff.

Progress on implementation of the strategy and statutory guidance



What are the barriers to progress?

Securing senior management buy-in and funding

A challenge that some professionals highlighted was ensuring that senior management understood the importance of the programme of work around autism. One respondent noted that senior managers in his local authority still had little understanding of the Act and its implications. Professionals also talked about the importance of senior managers understanding the compulsory nature of the statutory guidance and recognising that the strategy and statutory guidance will not be too burdensome to implement, as well as understanding that implementing it could actually save money in the long run even if some funds had to be found upfront.

The lack of additional central funding attached to the strategy adds to the challenge. Those we spoke to noted that similar strategies had attracted funding, and professionals said that start-up funds had been particularly helpful in the past for getting services started and enabling them to try out new services.

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[20] NAO (2012), p.12

[21] From looking at the strategy and statutory guidance and speaking to The National Autistic Society area development teams, who work with local authorities on a daily basis, these seven areas were identified as the key steps that needed to be taken to ensure the development of services.

The Department of Health has a key role to play here in highlighting the importance of the Act to senior managers. We are also calling for the Department to introduce an innovation fund for local authorities, working in partnership with the voluntary sector, to assist the development, evaluation and dissemination of new service models.

Lack of guidance

For a number of professionals, the lack of a recognised standard setting out how to proceed is a real challenge and is holding them back. This was true in relation to a number of strands of the strategy, but is particularly the case around the development of diagnostic and care pathways.

> "We're waiting for guidance before jumping in to commission bespoke services. We want to make sure that there's some real thinking done about it."
> *(Local authority professional)*

Professionals also told us that competing priorities and change within their organisations meant that less time could be dedicated to scoping out new pathways and services. Clear, tried and tested models for different types of service and support, set out in guidance, or shared in some other way, would enable faster progress, therefore, particularly at this time of change.

Difficulty engaging health

Another common theme with respondents within local authorities was that they had faced challenges in engaging with local health bodies.

The current restructuring of the NHS was reported as posing a particular challenge. Over the past year or so, preparations for replacing primary care trusts (PCTs) with Clinical Commissioning Groups (CCGs) have led to delays. PCTs haven't wanted to commit to anything that the CCGs aren't fully signed up to. New pathways or services have therefore been agreed in theory but are waiting to be signed off by the CCG, adding a further layer of complexity and bureaucracy.

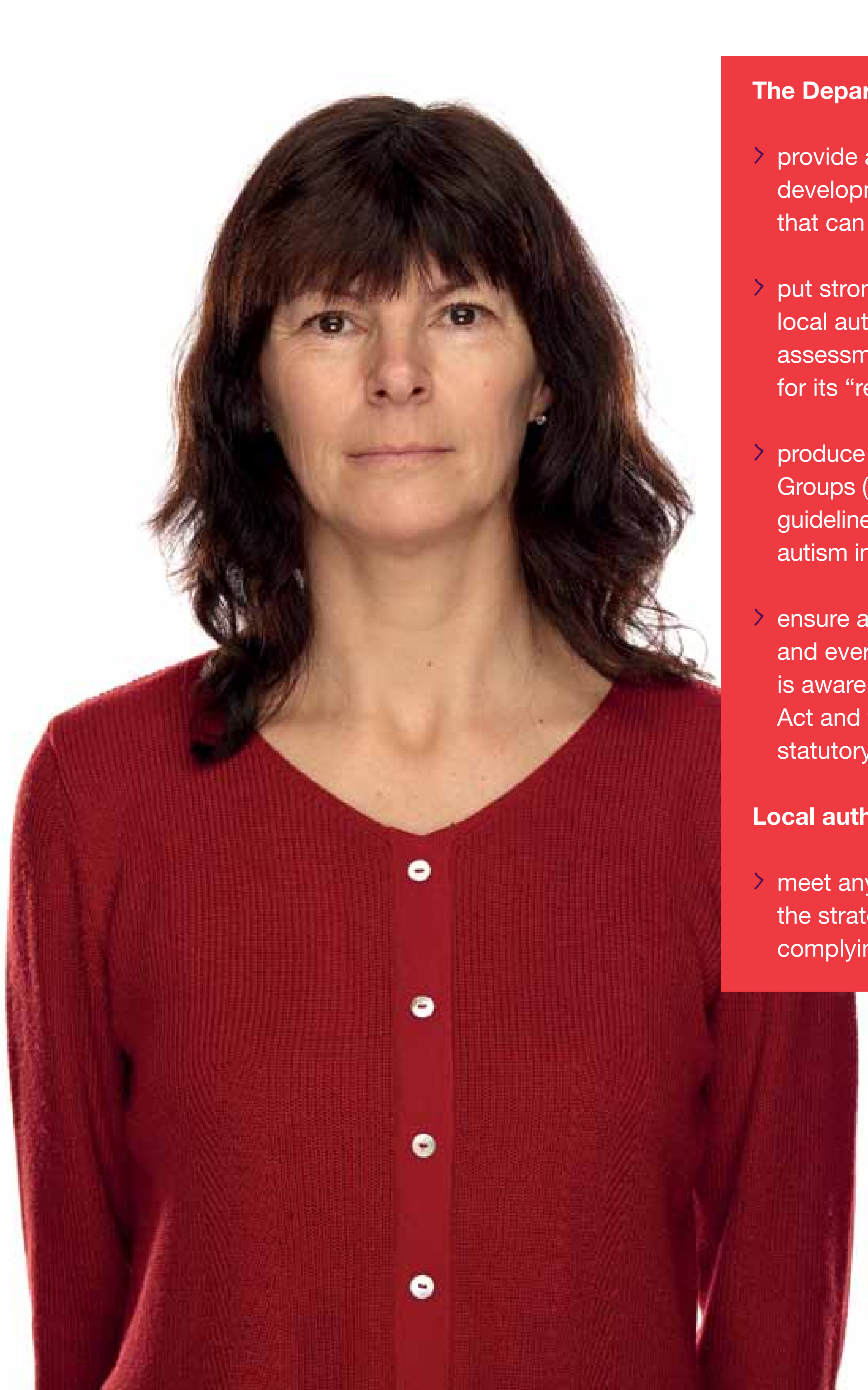
Professionals also spoke about the challenge of identifying where autism should fit into local health and social care structures. Professionals reported a particular issue around access to mental health services from their local NHS. Strict criteria for mental health support often means that adults with autism do not qualify for help, or, where an additional mental health problem was present, health professionals said they could 'treat' the mental health problem but couldn't provide any help in relation to an individual's autism.

Professionals called for a clearer steer from the Department of Health on the need for the NHS to take responsibility for autism.

> "We've struggled to bring Health with us. Autism has no definitive place in Health. It's not clear where it sits... When we talk to professionals at Health, they say that it would help if the Department of Health made a decision."
> *(Local authority professional)*

> "It's the issue of it being recognised that if a person with autism has a mental health issue, then they are entitled to access mental health services but still have their autism recognised. I've had a letter today from a practitioner saying, 'I've been told that I'm allowed to work with someone in relation to his anxiety and depression but not in relation to his potential spectrum condition.' That's the kind of issue that we're coming up against."
> *(Local authority professional)*

Our recommendations



The Department of Health must:

- provide an innovation fund to assist the development of new and innovative projects that can be shared with other areas
- put stronger levers in place to ensure local authorities take part in the next self-assessment exercise and set clear criteria for its "red/amber/green" scorings
- produce guidance for Clinical Commissioning Groups (CCGs) on implementing NICE guidelines on diagnosing and managing autism in adults
- ensure all Directors of Adult Social Services and every Clinical Commissioning Group is aware of the importance of the Autism Act and their obligations under the statutory guidance.

Local authorities and health bodies must:

- meet any outstanding commitments in the strategy and ensure that they are fully complying with the statutory guidance.

PUSH FOR ACTION

Chapter 3:
Planning and leadership

What's the issue?

Adults with autism have been excluded from local service planning and delivery and have, as a result, routinely struggled to access the services they need. Few local authorities or local health bodies collect information on the needs of their local population of adults with autism; the structure of local service provision has meant adults with autism have been systemically excluded from access to services; and very few professionals have had autism as part of their portfolio of responsibilities.

The strategy recognised that effective leadership was key to bridging the gap in local service provision and improving services for adults with autism. It therefore calls for the appointment of a named individual in every area who will lead on developing a commissioning plan around support for adults with autism, in a way that reflects local need. The strategy also recognises the importance of monitoring progress in this area.

AUTISM STRATEGY AND STATUTORY GUIDANCE: key actions and duties on planning and leadership

Local areas to:

- **appoint a named joint commissioner/senior manager** to lead commissioning of community care services for adults with autism in their area[22]
- **establish a local autism partnership board** that brings together local stakeholders and sets a clear direction for improved services[23]
- develop a **commissioning plan for services for adults with autism that reflects the local assessment of need and other relevant prevalence data**[24]
- **gather local information about prevalence, range of need and age profiles of adults with autism in the area.**[25]

The Department of Health to:

- lead the development of an agreed **protocol for what information should be recorded and how it should be shared with other services**[26]
- **identify best practice and promote effective service models** – best practice shows that where outcomes for adults have improved this has been as a result of the **development of local autism teams.**[27]

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[22] Department of Health (2010). *Implementing Fulfilling and Rewarding Lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*, p24

[23] Department of Health (2010). *Fulfilling and Rewarding Lives: the strategy for adults with autism in England*, p61, *Implementing Fulfilling and Rewarding Lives*, p26

[24] *Implementing Fulfilling and Rewarding Lives*, p24

[25] Ibid, p25

[26] *Fulfilling and Rewarding Lives*, p62

[27] *Implementing Fulfilling and Rewarding Lives*, p26

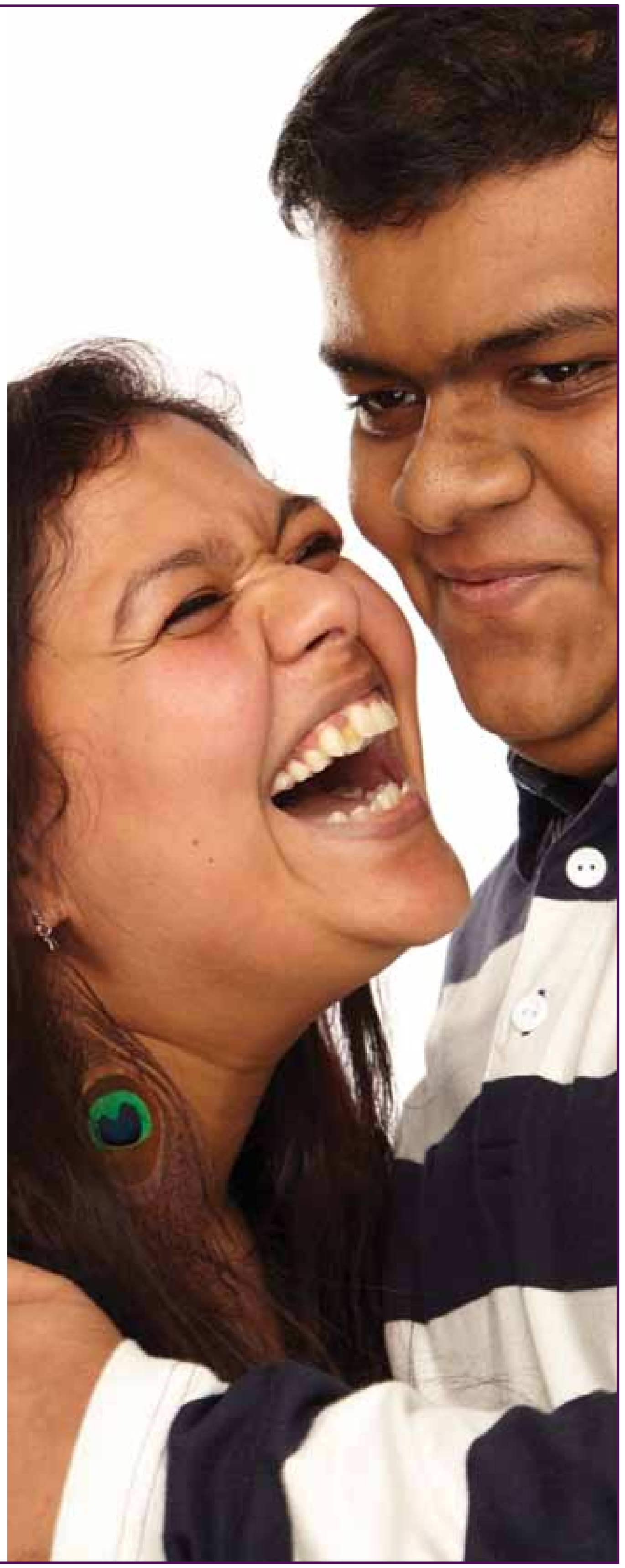
Case study: Samyukta

Samyukta is the older sister of 18-year-old Indranil.

Indranil was diagnosed with autism and severe learning disability at the age of two and has a limited ability to communicate. He can gesture and answer monosyllabically. In spite of his difficulties with using language he enjoys being a part of other people's conversations. There are situations, however, which he finds challenging and he has a history of displaying challenging behaviours in unknown, unquantifiable situations.

He currently attends a specialist school during the week where he has access to one-to-one training and where activities can be tailored to individual needs. Indranil experienced a traumatic transition from children's to adult social services last year and is still suffering from the repercussions of these changes, which led to him almost losing his place at school.

Samyukta worries about the future, once Indranil finishes at school. "Post-19 provisions are highly sought after but also incredibly oversubscribed. My brother has specialist needs which are very hard to find relevant provisions for. This comes from better and effective service planning. Currently, we have no access to short-term breaks or respite services. He needs to have a life outside of his home. If we want our young people to thrive, then the local provisions need to reflect their needs. This will avoid people becoming critical cases where, in the end, the local authority ends up spending more anyway."



PLANNING FOR TRANSITIONS

For young people with autism, who can find dealing with change particularly difficult because of the nature of their condition, the transition from school to adult life can be particularly challenging.

The strategy and statutory guidance recognised this issue and made clear that local authorities and health bodies should ensure they properly plan for transition for children and young people with autism. This is important both on an individual level and on a strategic level. Data and information on the needs of children with autism is better than that available for adults. It is therefore crucial that children's services share information with adult services. In addition, as the strategy is reviewed in 2013, it is vital that the Department for Education ensure that the current reforms to the special educational needs system are reflected in the review.

Transition is not only about the move from children's to adult services, however. Transitions take place throughout a person's life and for people with autism will need to be planned for effectively at each stage. Little is known about the specific needs of older adults with autism. Local authorities need to start effectively planning for adults with autism as they reach older age. The National Autistic Society is currently researching the needs of older adults with autism and the barriers they face in accessing services. As the Department of Health reviews the strategy in 2013, it is important that they look at the impact of the strategy on all adults with autism, no matter what their age.

Progress so far

Many local authorities tell us that they have now taken the key steps to improve planning and leadership locally. It is welcome that 145 out of the 152 local authorities have told us they have appointed an autism lead and 110 say they have established a partnership board, or similar, with responsibility for planning strategy implementation.

Local authorities, however, are much further behind when it comes to the development of their commissioning plans. **Just 64 told us they had a commissioning plan in place**. In part, this can be attributed to the lack of information and data that local authorities have on local need. **Only 79 out of 152 told us that they included autism in their Joint Strategic Needs Assessment** (JSNA), the key local planning tool that brings together information on health and wellbeing needs and the availability of services in an area. Local areas must urgently prioritise the development of needs assessments and commissioning plans.

Despite the progress made, most of the professionals that we spoke to recognise that presently very little improvement to services will have been felt by people with autism. The first three years of strategy implementation has been about putting systems in place to build autism into local structures, ensuring that autism becomes part of the planning and delivery processes in the future.

Moreover, while the appointment of local leads was intended to address, at least in part, the gap between mental health and learning disability,[28] we continue to hear from individuals that they are unable to access services, because they don't 'fit' in the current structures.

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[28] As discussed in 'Why did we need an Autism Act?' on p10 of this report.

> "High functioning doesn't equal no problem. People at the higher end of the spectrum aren't eligible for any services. That's where the biggest gap is." *(Parent)*

What is holding back progress?

National commitments

In July 2012, the National Audit Office (NAO) published a memorandum looking at national progress to date on implementing the strategy.[29] This follows the 2009 report by the NAO that looked at the cost effectiveness of services for adults with autism. A constant theme running through the NAO's 2009 investigation was that very little data is collected nationally on adults with autism, making it very difficult to identify need and to measure the impact of services and support. This also holds back local progress. There are standardised data collections that local authorities are expected to carry out on learning disability, mental health, physical disability, older people and carers. Professionals tell us that standardised collections are needed on autism, to ensure that data collection in this area is prioritised locally and done in the most effective way.

To address this problem, the Department of Health committed in the autism strategy to:

> "lead [on] the development of an agreed protocol for what information should be recorded and how it should be shared with other services."[30]

This data protocol would allow local agencies to securely share data and we need national consistency to develop an empirical baseline from which to measure progress.

DEVELOPMENTS ON THE GROUND

Getting autism on the agenda in Derbyshire

Derbyshire decided that, especially during a time of great change within health and social care, they needed to keep the profile of autism high.

To ensure that autism remains high on the agenda, the local autism lead submits reports on progress to the local Adult Care Board and the Joint Commissioning Board. These boards, along with the Clinical Commissioning Group (CCG) boards, decide on topics to be included on the Health and Wellbeing Board's agenda. Health and Wellbeing Boards are new committees of key leaders from health and care that will exist in every local authority and will be responsible for producing the local JSNA.

The autism lead in Derbyshire recognised that although Health and Wellbeing Boards have a huge remit, it is important to get them thinking about autism. As a result, the Joint Strategic priority to implement the autism strategy has now been endorsed by the Health and Wellbeing Board in this area.

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[29] National Audit Office (2012). *Memorandum: Progress in implementing the 2010 Adult Autism Strategy*. London: National Audit Office

Although the Government has not yet developed such a protocol, this commitment could still be met. The NHS Information Centre, the Department of Health and the Association of Directors of Adult Social Services (ADASS) recently consulted on proposals to make radical changes to the kind of data collected by local authorities in relation to social care in England. Importantly, it proposed to adjust the standard equality classifications to include autism. The Government must urgently take forward these recommendations to meet their commitments on improving data.

Promoting autism through organisational change and national leadership

The passing of the Autism Act and the publication of the adult autism strategy and statutory guidance sent a clear message from the Government that action was needed to improve support for adults with autism.

In addition, the current changes to health and social care provide a unique opportunity to reverse the historic disregard for autism in policy terms. The Government's reference to ensuring that people with autism receive high quality care in their new health mandate, which says what the priorities for the NHS should be, is very welcome.[31] We are pleased too, that the National Institute of Health and Clinical Excellence (NICE) is developing a Quality Standard on autism.[32]

It is disappointing, however, that the needs of people with autism are not being fully reflected in the new national health and social care outcomes frameworks. These new frameworks present the Government with an opportunity to send a clear message to local health and social care commissioners that autism should be seen as a priority when commissioning services and measuring progress.

As the Government takes forward its review of the autism strategy over 2013, it should prioritise looking at ways to incorporate autism into new structures – in particular in the autumn 2013 revision of the Social Care Outcomes Framework, as well as other outcomes frameworks.

Our recommendations

The Department of Health must:

- adjust the standard equality classifications to include new autism classifications, in line with the recent consultation recommendations on data collection
- include autism in relevant health and social care outcomes frameworks, including the Adult Social Care Outcomes Framework
- look at the impact of the strategy on adults with autism of all ages.

Local authorities and health bodies must:

- meet any outstanding commitments in the strategy and ensure that they are fully complying with the statutory guidance in relation to planning and leadership.

PUSH FOR ACTION

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[30] *Fulfilling and Rewarding Lives,* p62

[31] The Mandate says that the NHS will have 'to ensure that clinical commissioning groups work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care'.

[32] NICE Quality Standards are sets of specific statements that act as markers of high-quality, cost-effective patient care, covering the management of different diseases and conditions. Prioritisation for new indicators in outcome frameworks is based on recently published NICE clinical guidelines and NICE Quality Standards.

Chapter 4:
Diagnosis and the care pathway

What's the issue?

Getting a diagnosis can be a critical milestone for people with autism, providing an explanation for years of not fitting in, or helping family and friends to understand the individual better. It can also offer a gateway to identifying appropriate support. For this to happen, a 'pathway' into support has to be available following diagnosis and also when a young person is transitioning into adult services.

> "We had a diagnosis, after about nine months. And it was, 'Here's the diagnosis. I'm giving you a few pointers about what you need to do, but I can't offer you any services.' There is nothing." *(Parent)*

Ensuring a clear pathway to diagnosis is a key aim of the strategy. The strategy clearly states that "by 2013, when this strategy will be reviewed, we expect there to be a clear pathway to diagnosis in every area".[33]

In addition, as a result of the strategy, NICE published guidelines on diagnosing, assessing and managing autism in adults.[34] The strategy also highlights the importance of access to support following a diagnosis and for those who already have a diagnosis.

AUTISM STRATEGY AND STATUTORY GUIDANCE: key actions and duties on diagnosis and provision of post-diagnosis support

Local areas to:

- **appoint a lead professional** to develop diagnostic and assessment services for adults with autism[35]
- **develop a pathway to diagnosis in every local area by 2013**[36]
- ensure a diagnosis of autism **triggers a community care assessment and a carer's assessment**[37]
- **provide information on local autism support groups**, as well as other relevant signposting, to adults with autism when they have been diagnosed[38]
- **review their practice against NICE guidelines on diagnosing**, assessing and managing autism.[39]

Progress so far

Our research has shown that developing a pathway to diagnosis and developing a care pathway post-diagnosis for those already diagnosed is one of the key actions that local areas are struggling most with.

> "Our Achilles heel is diagnosis – how to get from diagnosis to assessment and how to translate that into options." *(Local authority professional)*

Despite clear direction from the Department of Health that action is needed in this area, **just 63 local authorities out of 152 report that they currently have a diagnostic pathway in place**.

Issues including difficulties with joint working between health and social care, a lack of guidance on the best models, and funding constraints, have slowed implementation by local authorities and health bodies. This has resulted in little progress being felt on the ground.

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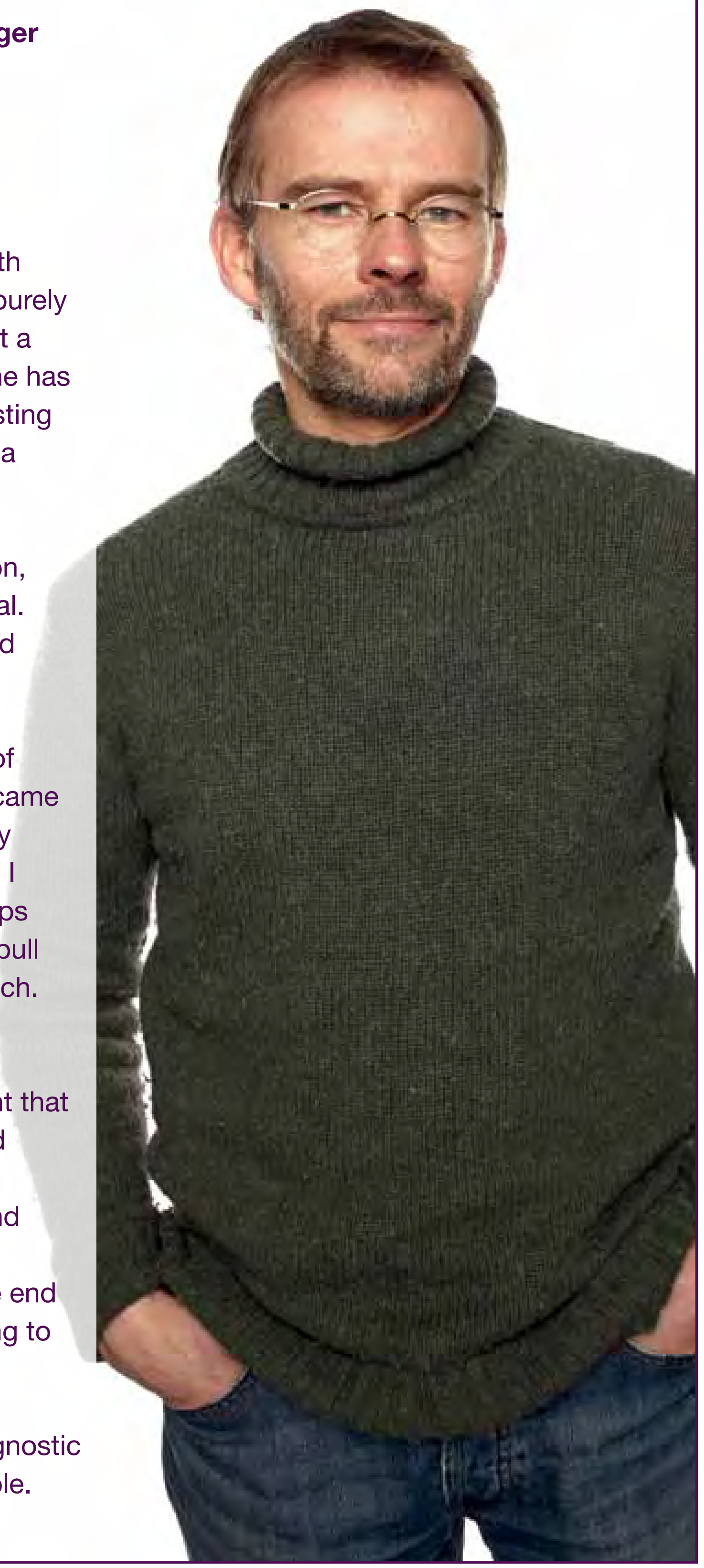
[33] *Fulfilling and Rewarding Lives*, p35
[34] NICE (2012). *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum*
[35] *Fulfilling and Rewarding Lives*, p35
[36] Ibid, p35
[37] *Implementing Fulfilling and Rewarding Lives*, p17
[38] Ibid, p18
[39] Ibid, p16

Case study: Chris



Chris is 47 and was diagnosed with Asperger syndrome in 2007.

"I was hospitalised when I was 15 and given a formal diagnosis of depression, OCD and mild Tourette's. These weren't seen as co-morbid conditions. I had always struggled with depression and was told my problems were purely psychological. It was extremely difficult to get a diagnosis of Aspergers, partly because no one has an understanding of autism. It was an exhausting process and it's not getting any easier to get a diagnosis in mid-life.

Although for many years I was able to function, my needs were never really met. I was suicidal. If I hadn't been able to get a diagnosis I would have taken my own life.

I admit it wasn't an easy diagnosis because of the drive to be normal. My adaptive skills became so highly refined. Because of the nature of my childhood they had to be – if I didn't conform I would be beaten. Work and social relationships were always an enigma to me but if you can pull off looking normal, people will take you as such.

It was only because I went private and met someone who knew the tricks of concealment that I was able to get a diagnosis. I had presented myself to GPs for over 20 years. I was given medication for my mental health problems and told to pull myself together. I had no trust in psychological services. I went privately in the end rather than go through the humiliation of going to my GP.

Since my diagnosis I've tried to get post-diagnostic support but they told me nothing was available. I've had to go private again."

What is holding back progress?

Joint working between health and social care

Our research has identified that a key reason for limited progress in improving access to diagnosis and support is the lack of integrated working between local authorities and local health bodies. Setting up a diagnostic pathway and implementing the NICE guidelines, in particular, calls for effective joined up working between health and social care.

Some authorities highlight delays in waiting for the publication of the NICE guidelines and the major restructuring of the NHS, which has made engagement with health bodies even more difficult, as described in Chapter 2.

In order to incentivise CCGs to implement the strategy and to drive progress in this area in particular, it is important that, as discussed in Chapter 3, autism is included in the new outcomes frameworks, including those which define how GP practices are financially rewarded.[40]

Local authorities and the new Clinical Commissioning Groups (CCGs), responsible for community healthcare commissioning, should urgently look at their working practices to ensure that they are meeting their statutory commitments on getting a diagnostic pathway in place.

Confusion over what is the 'right' model

The strategy states the need to ensure that there is a diagnostic pathway in place, but also emphasises the importance of linking a diagnosis to community care assessments and appropriate support. Local areas are trying to determine the different roles of health and social care in this area and this has caused significant confusion over responsibilities and appropriate models.

Professionals tell us that they would welcome additional guidance from the Department of Health about what a diagnostic and care pathway should look like. Some local authorities have said they would welcome more detailed guidance on the best template for action, so that they feel that they are meeting a national standard.

> "We want to have a local service, but we want to make sure that it's benchmarked as a good standard. And we're still waiting for the Department of Health. I know there are pathways and we've got NICE guidance, but it's still very open to interpretation as to what's the best practice when you're looking at diagnosis. Is it an individual assessing an individual and saying, 'Yes, you've got autism'? Or is it a diagnostic group looking at a multi-elemental assessment framework? What is the best model?" *(Local authority professional)*

The NICE guidelines say that the Care Quality Commission (CQC), who are responsible for health and social care inspections and reviews, "will monitor the extent to which commissioners and providers of health and social care have implemented these guidelines".[41] We believe that a CQC review of the implementation of the NICE guidelines would help to identify good practice as well as look further at what needs to happen to ensure that NICE guidelines are implemented and that there is a clear pathway to diagnosis in every area.

DEVELOPMENTS ON THE GROUND

Swindon's Diagnosis and Care Pathway

In Swindon, the local health body has developed a pathway that embraces both health and social care models. After a clinical diagnosis, a person is offered a community care assessment and support from the autism team which provided the diagnosis.

Alternatively, people can choose to opt out of the community care assessment and go directly to an information and advice centre that has been recently established. Here, they can discuss their needs and the support that might be available to them.

One advantage of this flexibility is that it provides a pathway for those who are not eligible for local authority funded community care services but who might still have presenting care needs. The team discusses the person's needs regardless of whether or not they are eligible for funded care services and the individual is able to consider the support that they might access, including support that they might pay for. They are then signposted to organisations and groups who might be able to provide further support.

Funding

Some local areas are concerned that they won't have the resources to meet the demand for diagnosis. Even if they fulfil the requirement to have a pathway in place, they will still face oversubscribed demand and therefore delays. Others are concerned about the availability of appropriate support for adults diagnosed with autism.

> "We can say that we've got a pathway. But we can't meet the demand. Capacity is so small, and the need is so great. We're only scratching the surface." *(Health professional)*

> "Time and again, the problem is converting the assessment into the support. There's so little available to people. And that's what we come up against time and again." *(Local authority professional)*

The National Autistic Society would like to see further investment in this area. We also know that considerable cost savings can be made once effective pathways to diagnosis and follow up services for adults with autism have been established. As the 2009 National Audit Office report found, if local services identified and supported just 4% of adults with high functioning autism and Asperger syndrome the outlay would become cost neutral over time. If they did the same for just 8% it could save the Government £67 million each year.[42] Further research looking at the cost effectiveness of different models of autism diagnostic services and teams is also important to help assist local authorities and CCGs.

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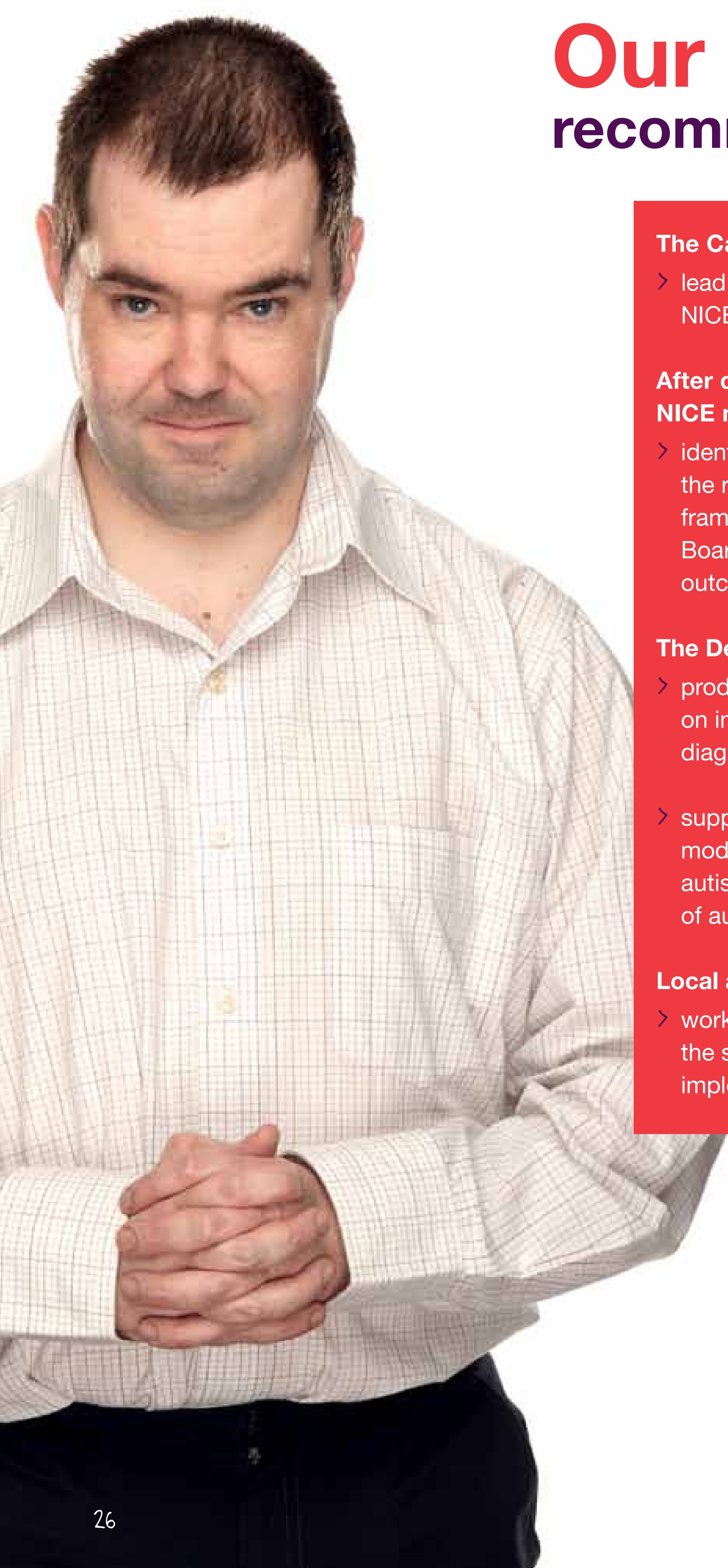
[40] We are referring here to the CCG Outcome Indicator Set and the Quality Outcomes Framework.

[41] NICE (2012). *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum*, p13

[42] National Audit Office (2009). *Supporting people with autism through adulthood*. London: The Stationery Office

Chapter 5:
Training and awareness



Our recommendations

The Care Quality Commission must:

- lead a review of the implementation of the NICE guidelines across England.

After developing Autism Quality Standards, NICE must:

- identify autism indicators to be considered in the relevant health and social care outcomes frameworks and the NHS Commissioning Board must include those indicators in the outcomes frameworks.

The Department of Health must:

- produce guidance for health commissioners on implementing NICE guidelines on diagnosing and managing autism in adults

- support the funding of research into effective models of service delivery for adults with autism, most notably around the development of autism teams.

Local authorities and health bodies must:

- work together to meet their obligations in the strategy and statutory guidance and to implement NICE's autism guidelines.

PUSH FOR ACTION

What's the issue?

Transforming understanding and awareness of autism is central to ensuring that the aspirations of the Autism Act are fulfilled. The Government made this clear in its focus on training in the strategy.

> "Although most people have heard of autism, they do not actually understand the whole spectrum and how it affects people differently. Most will cite 'Rain Man' and assume that all autistic people are the same as the character in the film." *'Fulfilling and rewarding lives'*

The strategy and statutory guidance made it particularly clear that improving understanding of autism among key 'gatekeepers' such as community care assessors, who assess people for eligibility for support from social services, and GPs, who are the first port of call for diagnosis and other support, was a priority.

As GPs' new responsibilities for commissioning local services (through the creation of Clinical Commissioning Groups) mean that they will be making key decisions in developing a diagnostic and care pathway for adults with autism, this further increases the imperative to improve autism awareness amongst the profession.

AUTISM STRATEGY AND STATUTORY GUIDANCE: key actions and duties on training

Local areas to:

- **make autism awareness training available** to all staff working in health and social care[43]

- provide **specialist autism training** for those key roles that have a direct impact on access to services for adults with autism – such as **GPs** or **community care assessors**[44]

The Government to:

- **include autism training in the core training curricula for doctors, nurses and other clinicians**

- include autism awareness in **general equality and diversity training across the public sector**, and lead the way by including it in training for central Government departments

- **work with primary care trusts (PCTs) and local authorities to develop effective training modules** for use by local authorities and PCTs

- work with PCTs and local authorities to **identify priority groups** for training

- work with Skills for Health, Skills for Care, professional bodies and the Royal Colleges to ensure that **effective training is developed for those who wish to specialise** in autism or develop further knowledge

- make autism awareness training available to **all staff working in the criminal justice sector.**[45]

[43] *Implementing Fulfilling and Rewarding Lives*, p12
[44] *Implementing Fulfilling and Rewarding Lives*, p12
[45] All actions in this section taken from *Fulfilling and Rewarding Lives*, pp.28-31

Case study: Chloe

Parent of adult with autism.[46]

“We got to the point where Peter couldn’t live at home, for his own and our safety. After moving around between people he knew and staying in a B&B, eventually he got a flat but he still doesn’t get any support. Social services don’t understand autism and how it affects him.

They’re not asking the right questions. They say ‘How are you?’ and he say’s ‘I’m fine’ so they come back to me and say ‘He’s fine, he doesn’t need any help’. But of course he says he’s fine at that point because he probably is at that point, if the question is taken literally. Also, he doesn’t trust them so if he answers ‘fine’ they will go away! Because they don’t understand him, he doesn’t want to see them.

He had a mental capacity assessment and they asked him about managing his money. He told them that he was saving money for a motorbike but he doesn’t have any money. He can’t manage his money. He gets into all sorts of trouble, he has had two or three phone contracts on the go – I have to take his bank card off him and manage his money for him. He has had contact with the police too, but they don’t get it at all either.

I’ve given up asking for support. Me and my husband now do everything ourselves which is stressful and relentless but we have decided it is easier this way. Now we have no expectations of what ‘services’ should be providing and don’t have the stresses of chasing them up and challenging them about what they should be doing.”

Progress so far

Many of the professionals we spoke to said that training was an area in which they felt confident that progress had been made. They told us that it was relatively clear what was expected of them in relation to training and in some cases they already had experienced staff who could deliver training.

The data we collected from local authorities, however, shows that while some progress is being made in some parts of the country on training, there is still a long way to go in ensuring that training in autism becomes embedded across health and social care.

Just 57 out of 152 local authorities say they have included autism awareness training as part of their standard equality and diversity training. More encouragingly, given the importance of this group, **82 local authorities say that they have autism training in place for community care assessors and 60 say that this is in progress**. Local authorities and the NHS, however, need to put a much greater focus on training to ensure they are meeting their statutory commitments in this area.

In addition, it is clear from talking to people with autism and their families that while they have experiences of professionals with good understanding and awareness, they feel that a systemic change has yet to be made.

“Understanding is really low, really poor. Services are really disjointed. No one talks to each other... The social workers are appalling. They don’t know how to give support. They haven’t got the training. They don’t have the understanding.” *(Adult with autism)*

“My son had a bad experience with a social worker. She told him that he didn’t have Aspergers. And he tried to hang himself that night because he was so confused. That was about the twelfth time.” *(Parent)*

Aside from health and social care, people with autism we spoke to as part of our research cited that, in particular, housing departments, as well as Jobcentre Plus staff and the police, were groups that needed to improve their awareness of autism.

DEVELOPMENTS ON THE GROUND

Upskilling and the ‘Bristol model’

Professionals we spoke to discussed the benefits of employing a trained, specialist autism team and how this team could be used to upskill and support other staff across the health and social care sector.

Several local authorities argued in favour of what people sometimes call the ‘Bristol model’: a small team of specialists who provide a hub of expertise and advocacy.

Crucially, the team are not on hand to organise all the care and support for adults with autism in the authority area. Instead, their role is to support other local services in meeting the needs of people with autism. So there are specialists on hand but the onus is on developing expertise amongst the general staff. As one health professional put it, “*Mainstream services should do it, and specialists should support them.*”

The advocates of this model warn against appointing the team to meet all autism needs in a local area. They dismissed this as a ‘naive’, ‘box-ticking’ approach that fails to recognise the danger of overwhelming a small team who would quickly become swamped by demand. This upskilling of other services is crucial to ensure that this does not happen.

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[46] Names have been changed in this case study to protect identity.

What is holding back progress?

National commitments

The NAO memorandum[47] sets out that the Department of Health has not met a number of commitments around training. Most notably, the Department has not ensured that autism awareness training is included in the core curricula for doctors, nurses and other clinicians. They also have further work to do, with local authorities and local health bodies, to ensure that training structures are in place and to identify priority groups for training.

Other departments, too, are yet to fulfil commitments made in the strategy. The Ministry of Justice, for example, has not made autism awareness training available to all staff in the criminal justice sector, as it committed to. The urgency of ensuring that training in autism becomes a standard part of police training was demonstrated in a recent high profile court case concerning the treatment of a young person with autism by the Metropolitan Police.[48] Ruling on the case, the judge made clear that he felt that there was a very real need for training in autism across the public sector.

In the strategy, all central Government departments also committed to including autism awareness training in equality and diversity training, and in single equality schemes. The NAO is clear that this is yet to be completed. Given the need, the provision of this training across Government would be a good first step. In addition, given the current large scale reform of the welfare system, it is particularly important that the Department for Work and Pensions review their training for frontline staff. With only 15% of adults with autism in full-time employment[49], it is also crucial that the Department for Work and Pensions works with employer organisations to raise awareness of the benefits of employing people with autism, as committed to in the strategy.

Funding

Some local authorities noted funding issues as a barrier to training provision. Local authorities have seen cuts to the training budgets and in many areas, we know that training is only being delivered on an ad hoc case-by-case basis.

Our recommendations

The Department of Health must:

- urgently review how training in autism can be included in the core curricula for doctors, nurses and other clinicians, in line with their outstanding commitment
- embed the requirement for specialist training for community care assessors into the forthcoming social care legislation

The Ministry of Justice must:

- ensure that training in autism is available to all staff in the criminal justice system, in line with the strategy.

The Department for Work and Pensions must:

- review the training in place for frontline Jobcentre staff in autism
- work with employer organisations to raise awareness of the benefits of employing people with autism.

All central Government departments must:

- include autism awareness in equality and diversity training and single equality schemes, in line with the strategy.

Local authorities and health bodies must:

- meet any outstanding strategy and statutory guidance commitments on training.

PUSH FOR ACTION

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[47] National Audit Office (2012). *Memorandum: Progress in implementing the 2010 Adult Autism Strategy* London: National Audit Office

[48] http://www.equalityhumanrights.com/news/2013/february/court-of-appeal-condemns-the-treatment-of-an-autistic-boy-by-the-police/

[49] Redman, S et al (2009). *Don't Write Me Off:* Make the system fair for people with autism. London: The National Autistic Society, p8

Conclusion

This report has shown that while progress has been made, much more needs to happen to make the aspirations of the Act a reality for people living with autism every day.

We've seen how professionals tasked with implementing the Act have been concentrating their efforts on getting the building blocks in place: appointing autism leads and building autism into local planning mechanisms. It is really positive that these crucial steps are being taken.

But for most adults with autism and their families, things just aren't moving fast enough. Those 'building blocks' must lead to improved services and support, ensuring that those adults are no longer isolated and ignored.

Strategy delivery is a local issue, but the Government must do more to help, ensuring that autism is prioritised at a local level and the barriers to faster progress, as set out in this report, are removed. The Government needs to ensure that autism is part of the mainstream, and is fully integrated into new health and social care frameworks as these are developed.

The 2013 review is a unique opportunity to shine a light on what needs to happen to make progress in implementing the Act.

National and local governments, as well as other public services, urgently need to look at the recommendations we have made in this report and take action to ensure that all adults with autism can lead the life they choose.

Methodology

The research for this report was carried out between November 2012 and February 2013. There were three main stages to the report as outlined below.

1. Exploring the experiences of adults with autism and parents/carers

A) Qualitative discussions
We commissioned an external independent researcher to run three focus groups with adults with autism and parents/carers to look at their experiences of accessing care and support, their experiences of the implementation of the Autism Act and the key things that they felt needed to change.

Participants were recruited through NAS networks – both local branches and national supporters we are in contact with. The sample included adults with autism as well as parents/carers of adults from across the autism spectrum. The focus groups were held across the country in Bristol, London and Chester.

B) Quantitative data
In 2012, we commissioned an external researcher to develop and analyse an online survey of the experiences of people with autism and their families across the UK. Over 8,000 people responded to the survey and many of the statistics quoted in this report are sourced from the results of that survey.

In addition, in January 2013, we published a further online survey for adults with autism and parents/carers to respond to about experiences and ease of accessing support. Over 1,000 people in England responded to this survey.

2. Exploring the barriers to implementation of the strategy

A) Qualitative discussions
We commissioned an external researcher to interview 14 professionals working in health and social care, who are tasked with the implementation of the strategy locally. The interviews looked at the key barriers and enablers to implementing the strategy at a local level.

Participants were selected through our area development teams who identified a range of willing professionals, who were at varying stages in terms of local implementation. Most of the professionals were interviewed over the telephone, but in three areas, the researcher went to visit the professionals to get a more in-depth understanding of progress in those areas.

3. Examining progress in delivery

In 2010, The National Autistic Society began collecting data about strategy implementation in every local authority in England. We looked at seven key areas of the strategy and statutory guidance. For the report, we sent out a form to every local authority asking them to check and update the information we held on each area. We received returns back from 141 local authorities, meaning only ten failed to get back to us (autism strategy implementation in Cornwall and the Isles of Scilly is combined). These ten authorities responded to our previous round of data collection, however, and that feedback has been incorporated into our results.

PUSH FOR ACTION

Summary of our recommendations

The Department of Health must:

- provide an innovation fund to assist the development of new and innovative projects that can be shared with other areas
- put stronger levers in place to ensure local authorities take part in the next self-assessment exercise and set clear criteria for its “red/amber/green” scorings
- ensure all directors of Adult Social Services and every Clinical Commissioning Group is aware of the importance of the Autism Act and their obligations under the statutory guidance
- adjust the standard equality classifications to include new autism classifications in line with the recent consultation recommendations on data collection
- include autism in relevant health and social care outcomes frameworks, including the Adult Social Care Outcomes Framework
- look at the impact of the strategy on adults with autism of all ages
- produce guidance for health commissioners on implementing NICE guidelines on diagnosing and managing autism in adults
- support the funding of research into effective models of service delivery for adults with autism, most notably around the development of autism teams
- urgently review how training in autism can be included in the core curricula for doctors, nurses and other clinicians, in line with their outstanding commitment
- embed the requirement for specialist training for community care assessors into the forthcoming social care legislation.

Local authorities and health bodies must:

- meet any outstanding commitments in the strategy and ensure that they are fully complying with the statutory guidance.

The Care Quality Commission must:

- lead a review of the implementation of the NICE guidelines across England.

NICE must:

- identify autism indicators to be considered in the relevant health and social care outcomes frameworks and the NHS Commissioning Board must include those indicators in those outcomes frameworks.

The Ministry of Justice must:

- ensure that training in autism is available to all staff in the criminal justice system, in line with the strategy.

The Department for Work and Pensions must:

- review the training in place for frontline Jobcentre staff in autism
- work with employer organisations to raise awareness of the benefits of employing people with autism.

All central Government departments must:

- include autism awareness in equality and diversity training and single equality schemes, in line with the strategy.

We are the leading UK charity for people with autism (including Asperger syndrome) and their families. With the help of our members, supporters and volunteers we provide information, support and pioneering services, and campaign for a better world for people with autism.

Around 700,000 people in the UK have autism. Together with their families they make up over 2.5 million people whose lives are touched by autism every single day. Despite this, autism is still relatively unknown and misunderstood. This means that many people don't get the level of help, support and understanding they need. Together, we are going to change this.

From good times to challenging times, The National Autistic Society is there at every stage, to help transform the lives of everyone living with autism.

We are proud of the difference we make.

We rely on donations to enable us to fund campaigns, such as this one, to bring about positive change.

Adults with autism are still waiting for the everyday support they need.
It's time to turn the Autism Act into action.

Join our campaign today at autism.org.uk/push

PUSH
FOR
ACTION

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