

Autism also affects adults
Most are isolated and ignored

Think. Act. Transform lives.

think
differently
about
autism

I Exist

The message from adults with autism in England.

The National Autistic Society is the UK's leading charity for people affected by autism.

Over 500,000 people in the UK have autism. Together with their families they make up over two million people whose lives are touched by autism every single day.

Despite this, autism is still relatively unknown and misunderstood. Which means that many of these two million people get nothing like the level of help, support and understanding they need.

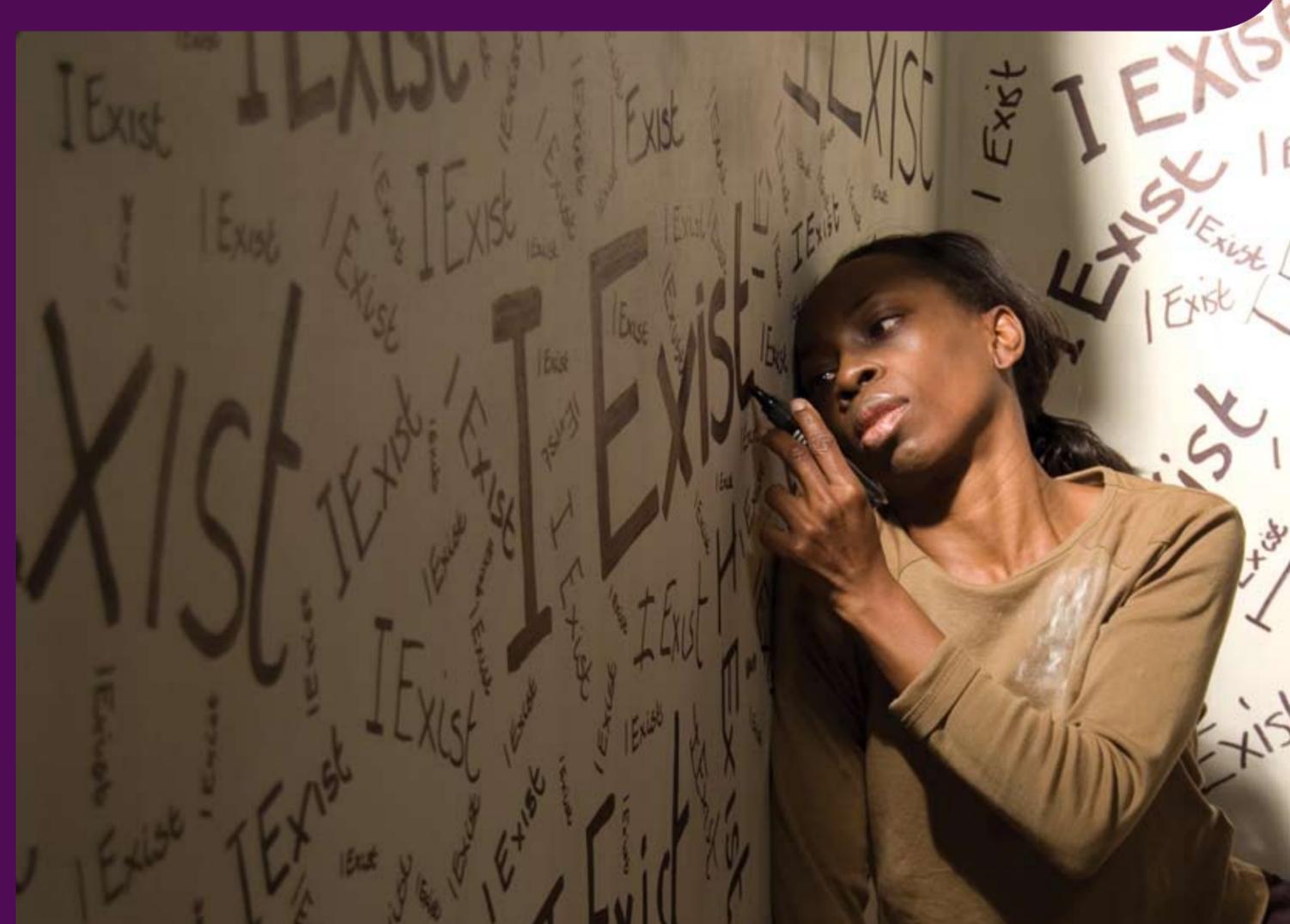
Together, we are going to change this.



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Your autism charity

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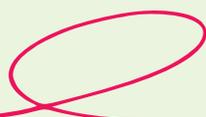
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Executive summary

For too long adults with autism have found themselves isolated and ignored. They struggle to access support and are dependent on their families. This report considers the experiences of adults with autism and their families in England and examines the changes that are needed to transform their lives.

Count me in

The Government, local authorities and primary care trusts do not know how many adults with autism there are in England. This makes it extremely difficult to plan and deliver the services that people with autism need.

The Government should:

- › fund a prevalence study into the number of adults with autism in the UK.

Local authorities and primary care trusts should:

- › have systems in place to accurately record the number of adults with autism in their area
- › include the needs of adults with autism in commissioning strategies and Joint Strategic Needs Assessments.

Understand my needs

There is a range of barriers that prevents adults with autism from accessing the services and support they need. Many of these stem from a lack of understanding of autism; local authorities and health services have services for people with a learning disability or mental health problem, but people with autism do not necessarily fall into either of these groups.

Local authorities should:

- › ensure that staff who carry out care needs assessments are fully trained in autism
- › establish a clear route to enable adults with Asperger syndrome or high-functioning autism to access assessment and services
- › implement the Director of Adult Social Services' guidance and appoint a named individual or a team with responsibility for autism spectrum disorders.

Primary care trusts should:

- › ensure that staff who carry out NHS continuing healthcare assessments are trained in autism.

Meet my needs

Adults with autism say they need a range of support, yet many actually receive little or no help. The biggest gap between the types of support people want and what they actually receive is in the area of social support. To truly meet the needs of an individual with autism, a person-centred approach is required, and those providing the support should be trained in autism.

Local authorities should:

- › fund social support services, including befriending, social programmes, social skills and life skills training for adults with autism
- › ensure that social care support workers who come into regular contact with adults with autism are trained in autism.

Lead the way

Current Government policies do not adequately meet the needs of adults with autism. If this is to change, national leadership is required from the Government.

The Government should:

- › expand capacity, expertise and leadership on autism in the Department of Health
- › ensure that there is regional support to help local authorities and primary care trusts implement good practice
- › issue statutory guidance to local authorities that addresses the barriers that prevent adults with autism from accessing services and produce good practice commissioning guidance for local authorities.

The Health Select Committee should:

- › hold an enquiry into autism.

I Exist is the message from adults with autism.

Most are isolated and ignored. Think. Act. Transform lives.

What is autism?

Imagine waking up in another country where nobody speaks your language, and people live by a set of social rules that are completely unfamiliar to you.

How would you cope if you didn't understand the rules?

To varying degrees this is how people with autism experience their surroundings every day.

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a serious and disabling condition. Without the right support, it can have a profound – sometimes devastating – effect on individuals and families.

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. The three main areas of difficulty are:

- **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 say that they are socially isolated and that their family is 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 also like to have an advocate present, who can help them to 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, cope with change or manage in new and unfamiliar settings. They may also find it hard to understand and predict other people's intentions and behaviour.

People with autism may also experience sensory sensitivity – being over- or under-sensitive to sound, touch or light, or certain tastes, smells or colours.

Some people with autism also have an accompanying learning disability.

Research has shown that 1 in 100 children has autism. Very little is known about how many adults have autism, but by applying the 1 in 100 figure to the adult population, we can estimate that the number of adults with autism in England is more than 300,000.¹ Together with their families they make up over one million people whose lives are touched by autism every single day.

In this report we use the term autism to describe all diagnoses on the autism spectrum, including Kanner autism, Asperger syndrome and high-functioning autism.^{2,3}

¹ The limitations of this prevalence figure are explored in Chapter one.

² While high-functioning autism is not officially recognised clinically as a diagnostic term, some people have this as their diagnosis or identify with this term, and for this reason we use it in this report.

³ Other terms, such as autism spectrum disorder (ASD), are used in the report when they are direct quotes from people or publications.

Introduction

"Our daughter's a very bright, healthy, lovable individual – if only the world would notice."

Parent

"She has quite calmly said that when we die, she plans to kill herself because she knows she will be completely alone and unable to care for herself. She weeps on a daily basis because she is so scared of the future. There is nobody to help her manage her daily life, and more importantly, who will love her when we're gone?"

Parent

Isolated. Unable to access support. Dependent on their families. This is the daily reality for adults with autism.

- 63% of adults with autism do not have enough support to meet their needs.
- 92% of parents are either very worried or quite worried about their son or daughter's future when they are no longer able to support them.

I Exist is the second phase of our think differently about autism campaign. Through it, we want to share the experiences of the many adults with autism who struggle to get the understanding and support that they need.

Over 1,400 people responded to our survey about the experiences of adults with autism. Never before, in England, have so many adults with autism and their families put forward their views. Our campaign has also been informed by the most extensive and comprehensive surveys on adults with autism ever undertaken with local authorities and primary care trusts.

The results not only reveal the impact on adults with autism and their families of not receiving the support they need, but also what they believe it would take to bring real improvement to their lives.



The experiences of adults with autism

Autism affects no two people in quite the same way – it is a complex disability and the individual experiences of people with autism are equally complex. Yet, what unites adults with autism is the ongoing struggle to get the support they need. Without appropriate help, many become socially excluded: 61% of adults with autism rely on their families for financial support, over 40% live at home with their parents and only 15% are in full-time employment. Three quarters of adults with autism either do not have any friends or find it hard or very hard to make friends and 56% have been bullied or harassed as adults.

63% of adults with autism do not have enough support to meet their needs. Of those:

- 82% say that with more support they would be less isolated
- 79% say that with more support they would be able to do the things they want to do
- 70% say that with more support they would be more independent.

"Without support, she is too scared to leave home and become independent. We are terrified about her future when we die – we have no living relatives and she has no friends, so she is utterly alone and vulnerable."

Parent

"She has been doing the same things at her day centre for 22 years."

Parent

"With more support my home would be in a more habitable state, and my anxiety greatly reduced."

Adult with autism

This lack of support has serious consequences:

- two thirds of adults (67%) say they have experienced anxiety because of a lack of support
- one third of adults (33%) say they have experienced serious mental health problems because of a lack of support.

"I only received help when I became suicidal and seriously depressed. At this point the help was too late."

Adult with autism

"She needs constant support for her social needs, her domestic chaos (which is now a health hazard), her lack of self-worth and self-confidence. She feels a complete failure and an oddity. She feels totally misunderstood and socially unaccepted, unwanted and a complete failure. She constantly feels 'she would be better dead' and is currently suicidal."

Parent

Failure to provide help at the right time has led to many adults with autism needing a greater level of support in subsequent years: 60% of parents say that a lack of timely support has resulted in their son or daughter having higher support needs in the long term.

"We have become more isolated and my daughter has gone downhill as she has no quality of life. The outside world becomes more frightening to her. She'd like to be independent and would respond well to support."

Parent

"Lack of knowledge and resources has led to my daughter possibly having greater needs now than she would have had otherwise – they just haven't done enough."

Parent

If the current failure to meet the needs of adults with autism is not addressed, a crisis situation is likely, both for individuals and for local services. When adults receive inappropriate provision it can lead to service placements breaking down and more complex needs emerging. Likewise, too many adults with autism depend on their parents for support and will eventually face a time when this lifeline is no longer there. If there has not been appropriate planning to help them make a smooth transition to other sources of support, there is potential for more complex needs to emerge, requiring higher levels of assistance than would otherwise have been the case.

92% of parents are either very worried or quite worried about their son's or daughter's future when they are no longer able to support them.

"Every waking hour you worry about the future of your child... Who will put up with their temper tantrums? Who will shower and wash them? Especially who will love them as you do? I just don't know what lies ahead for my son."

Parent

"Our son's disability is kept under control by careful family support, but our family is very small and if this support was no longer there, his condition could deteriorate. He would be very unhappy if he was taken away from what he is familiar with. He is aware that one day he may not have us and is very fearful about it. He often says he doesn't want to live to old age and cannot bear the thought of a long lifespan."

Parent

"It gives me great concern and stress to think of what will happen to my son when my husband and I are no longer here. As awful as it is, I seriously hope I outlive him – this gives me great sadness and depression. I have no faith that authorities will support him to live a functioning life."

Parent



The impact on families

The reality for many adults with autism is that they rely on their families to provide support. Over 40% of adults with autism live at home with their parents, and of those people who live in their own flat or house, 44% say that their family provides most of their support.

"My son doesn't eat unless prompted to do so. He won't wash or attend to his own personal hygiene without a fight. He is verbally and physically aggressive, as well as being noise and light sensitive. Having a normal conversation with him is impossible. He has been totally agoraphobic since 2005 and is mentally and physically exhausting to care for. He sleeps badly or not at all. I often feel suicidal due to sleep deprivation."

Parent

"Keeping [her] clean, cooking food for her, doing all her paperwork, opening her letters, doing her washing and ironing, keeping her company because she's very lonely, trying to cheer her up, trying to motivate her. Somewhere in between is ME, hanging on by my fingertips."

Parent

Parents and carers of adults with autism who live at home are rarely given any support to help them in their role as carers – 76% of them are not currently receiving any support from their local authority and 68% have not even received a carer's assessment.

Improving the lives of adults with autism

Our research has revealed that if people with autism receive the support they need at the right time, they can lead more independent⁴ and fulfilling lives:

"The most important thing that happened to make my son go from suicidal to happy was having his needs met."

Parent

"My son now has a structured day plan. He knows what he is doing on a day-to-day basis and he has a social life we were unable to provide when he was living at home. He comes home on alternate weekends and holidays, which we all enjoy. We have been given the opportunity to experience normal family life."

Parent

Action is required to improve the lives of people with autism. But until we have more knowledge about the number of adults with autism in England, it is impossible to ensure that the right support is reaching those who need it. The following chapter highlights what must be done in order to gather this information and how it can be used to plan and commission the services that people with autism and their families actually want. Our report goes on to explore other barriers within local services that prevent people accessing support and proposes solutions for how these can be overcome, before considering in detail the support adults with autism and their families would like to receive. Finally, it examines what more could be done at a national level to improve the experiences of adults with autism.

⁴ Independent living is defined by the Disability Rights Commission as "all disabled people having the same choice, control and freedom as any other citizen – at home, at work and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations." Disability Rights Commission. (2002). *Policy statement on social care and independent living*, paragraph 1.2. London: DRC

Richard



Richard is 20 years old with autism and a learning disability. He is currently living in a residential service but the support he receives is far from sufficient to meet his very complex needs.

When Richard first moved into his current service, three years ago, his behaviour was very difficult to manage and he spent most of his time with a support worker in the attic space of the large Victorian house in which he lives. In the last year, he has been able to spend more time in the small ground floor lounge instead, but still spends a lot of this time alone, lying on the sofa staring at daytime television.

When Richard goes out he has two staff to support him. His diary of activities reflects an ad hoc pattern of experience, with no structure, goals, review or evaluation. A weekly timetable has been devised but it is not kept to. When he wants to go out, he will lead staff to the door or bring his shoes. He spends about two hours a day on the swing in the garden and once or twice each week staff try to take him out in the evening for a walk or to the local pub.

Richard goes on outdoor visits to a local farm, but only two or three times a year. He also sees a music therapist once a week and enjoys his visits to see his family, to whom he is closely attached.

Richard is not allowed to go into the kitchen because he can have issues with food. As a result he has been unable to develop self-help skills in this area. He also has no choice about what he eats, as there is only one available option at every meal. Mealtimes tend not to be a communal activity.

Despite his age, Richard is normally in his pyjamas and ready for bed between 7pm and 9pm. He usually watches television until he decides his own bedtime.

He has not yet been able to develop any form of functional communication, although he is motivated to communicate with others. He also seems able to read other people's reactions. He has an advocate who he is clearly very attached to and who works hard to ensure his needs are met.

Richard loves to sing and to listen to music, especially the 'classic' tunes. However, his hearing is highly sensitive and he becomes very distressed by certain pitches of sound – particularly the sound of crying or shrieking. The other residents he shares his home with often scream and shout which really upsets him and can provoke very challenging behaviour. He is also sensitive to light.

Ian

Ian is 25 and lives with his parents and younger sister. He has autism and a learning disability, as well as epilepsy and hemiplegia. He uses no language and communicates by gesture.



Ian depends greatly on his parents' understanding of his non-verbal communication and is clearly very attached to them. His sleep pattern has always been erratic and limited to a few hours at most, so his parents alternate being awake all night to attend to him.

Ian has particular sensory sensitivities. He dislikes wearing clothing or anything close to his skin. Whenever he is at home, he will only wear a pair of loosely fitting shorts. He particularly dislikes noise and often seems to experience sensory overload. He reacts strongly against anyone who he feels is invading his space. Anyone who stands behind him, or tries to sit near to him, is forcibly removed.

There are very few activities which engage Ian's interest and he gets very bored at home at night. He is more relaxed when travelling in a vehicle and until recently his Dad would take him for a two hour drive every night. His main interest and pleasure is food.

Ian's experience of services has been disappointing and erratic – mainly because they are unable to meet his complex needs. He had not had a care manager for over a year when we met him and since he left school, he has not been able to use any services consistently.

Ian uses a social services day centre three days a week and has individual support workers on Mondays and Fridays. The latter arrangement has worked much better because Ian has come to know and work well with his two support staff. Although Ian's parents would much prefer this service to be extended, this has not been possible because of a shortage of skilled staff able to work with him. He shows many more negative reactions on the days he uses the social services centre, mainly because there are continual staff changes there.

Ian's daily diary

On Mondays and Fridays, Ian leaves home at 10am with his two support staff. He then goes to a cafe for breakfast and goes swimming. On Mondays, he goes to the park or a sensory room after lunch, returning home at 4pm. Ian tolerates swimming more than other forms of physical activity, and probably experiences discomfort when walking, due to the effects of hemiplegia. He can only walk a short distance. On Friday, he goes to a quiet local pub after lunch, with staff support. On mid-week days, Ian goes to a day centre between 10am and 4.30pm.

When Ian returns home, he will either want to have a snack or have a rest for half an hour, followed by a snack. His parents then face the challenge of filling his next 16 hours.

Chapter one: Count me in

The Government, local authorities and primary care trusts do not know how many adults with autism there are in England. This makes it extremely difficult to plan and deliver the services that people with autism need.

- 67% of local authorities and 77% of primary care trusts do not keep a record of how many adults with autism there are in their area.
- 86% of local authorities say that if they had more information about adults with autism in their area it would help with long-term planning.

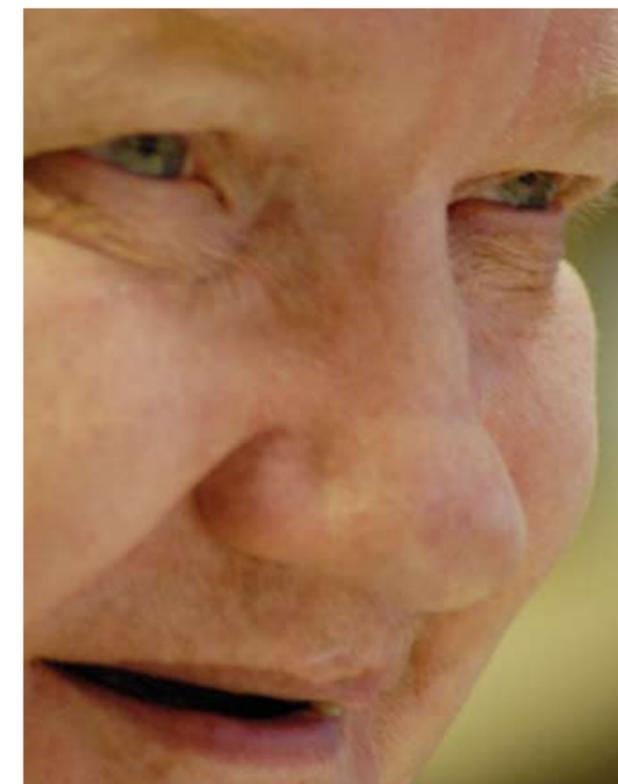
The Government should:

- > fund a prevalence study into the number of adults with autism in the UK.

Local authorities and primary care trusts should:

- > have systems in place to accurately record the number of adults with autism in their area
- > include the needs of adults with autism in commissioning strategies and Joint Strategic Needs Assessments.

Why don't we know how many adults with autism there are in England, and what impact does this have on people with the condition? As yet there have been no prevalence studies to ascertain the true number of adults affected by the disability. In addition, only a limited amount of local data on the number of adults with autism is currently collected by local authorities and primary care trusts. This lack of information leads to the exclusion of people with autism from the processes of planning and commissioning services. In this chapter, we examine this serious shortage of information in more detail and identify how data on the number of adults with autism should inform planning and commissioning processes.



Why is so little known about the number of adults with autism?

i) Awareness of autism is still relatively recent

Many adults with autism, particularly those with Asperger syndrome or high-functioning autism, are only now seeking or receiving a diagnosis, as there was little awareness of the condition when they were growing up. Consequently, although autism is a lifelong disability, older adults are more likely to have received their diagnosis later in life, compared to younger adults.

Another result of this lack of awareness is that many older adults have, in the past, been misdiagnosed with other conditions.

"I was refused treatment for my schizophrenia for 15 years. Then I discovered I had Asperger syndrome."

Adult with autism

ii) There is a lack of research into the number of adults with autism

There has never been a study into how many adults have autism in England. Estimates based on the number of children with autism currently provide the best available indication of the size of the adult population. However, this is far from ideal as, without accurate information, debate will persist over whether the increase in the number of people recognised as having autism is a consequence of improved understanding and diagnosis or an actual increase in the number of people who have the disability.

A recent report undertaken for the Government's Social Exclusion Task Force highlighted the lack of information about the number of adults with autism and emphasised the impact this has upon policy and service design: "We have insufficient epidemiological information reliably to estimate the prevalence of adult neuro-developmental disorders in the UK

population.... This is a major gap in the evidence needed to estimate the prevalence of chronic exclusion and the most effective responses to the needs of the people affected."⁵ Despite this clear acknowledgment of the need for more information, no research has yet been undertaken.

This lack of comprehensive data means that autism is neglected in the development of policy. Nationally, there is very little consideration of the specific needs of adults with autism. Locally, a lack of data means that insufficient attention is given to adults with autism when planning and commissioning services.

The Government should fund a prevalence study into the number of adults with autism in the UK.

iii) Little information is collected or known locally

Insufficient information is collected at a local level about the number of adults with autism: 67% of local authorities do not keep a record of how many adults with autism there are in their area. Those that do frequently fail to include people from across

the autism spectrum – only 19% of local authorities say that they have a record that includes people with Asperger syndrome or high-functioning autism.

"We struggle to identify adults with ASD [autism spectrum disorder] from our recording system. Therefore it makes it difficult to track actual spend."

Local authority

Where local authorities do keep a record of people with autism there is huge variation from local authority to local authority in the number of people identified, both in the total figure and as a proportion of the population. For example, one local authority we surveyed had a record of only one person while another had a record of 900. These figures also suggest significant differences in the way records have been compiled and who qualifies for inclusion. This is not just an issue for people with Asperger syndrome or high-functioning autism – if people with autism who have an accompanying learning disability are included in a learning disability register but their autism is not recorded, then appropriate planning and commissioning for them cannot occur. For practically all local authorities, a true picture of the number of adults with autism in their area does not exist.

Primary care trusts are even less likely than local authorities to have a record of the number of adults with autism in their area. 77% of primary care trusts do not keep a record of adults who have autism and only 9% say they have a record that includes people with Asperger syndrome or high-functioning autism.

"We are currently not fully aware of local need or demographics. We need to undertake [this count] to enable uniform service provision."

Primary care trust

In addition to not knowing how many adults with autism are living in their area, 65% of local authorities do not know how many adults with autism they actually support.

Surrey County Council

Surrey County Council, funded by central government with Learning Disability Development Fund money, has formulated a strategy for the changes needed if adults with autism are to be properly accounted for by services. A wide-ranging action plan was produced as part of this work. To inform the strategy, a mapping exercise into the number of young people with autism in Surrey was undertaken.

Information about children came from the Children with Disability register, specialist schools and children's social work teams. Information about adults came from care management teams and Surrey Oaklands Trust. This mapping exercise significantly increased the number of people with autism recognised within Surrey, but the report acknowledged that a large number of people with autism living in the area would not have been identified through the work. In future, it is hoped that the Surrey Adults Linked Disability Registers will provide clearer centrally-available information about adults with autism, including those who do not receive services.



⁵ Schneider, J. (2007). *Better outcomes for the most excluded*, page 69. Nottingham: The Institute of Mental Health, The University of Nottingham and Nottinghamshire Healthcare NHS Trust

Nottinghamshire's Asperger Commissioning Strategy

Nottinghamshire County Council, working with Nottinghamshire primary care trust, has produced an Adult Social Care & Health Commissioning Strategy for 2007-09.

This incorporates the County's first discreet strategy for meeting the needs of people with Asperger syndrome. It examines the policy context, analyses the number of adults with Asperger syndrome in the county, considers current provision and discusses future commissioning intentions.

In total, 13 actions have been suggested, and for the vast majority of these the funding has been agreed. These include:

- establishing a multi-disciplinary, multi-agency team to provide specialist assessment, care management and short-term interventions
- undertaking a comprehensive needs assessment to determine the level of demand
- developing a range of housing and support solutions
- providing community care services to an extra 20 people per year for the next three years
- establishing protocols to identify and provide guidance for staff about potential service overlaps and interfaces.

The multi-agency team is in the process of being established. It reflects the impact that including people with autism in commissioning strategies can have.

Yet, information from the Department of Health makes it clear that local authorities should already be taking action to record their contact with adults with autism: "Councils should monitor the number of people being referred with a diagnosis of ASD and which services they receive."⁶

Local authorities and primary care trusts should have systems in place to accurately record the number of adults with autism in their area.

More information would lead to better services

86% of local authorities say that if they had more information on adults with autism in their area it would help with long-term planning. This indicates that the current shortage of information is having a negative impact on the development of services and results in a degree of exclusion of adults with autism from the planning and commissioning processes that determine the provision of services.⁷

The need to ensure that people with autism are included in planning processes is particularly pressing in light of recent changes in Government policy, which may increase dependence on existing data sources to inform the development of services. Local authorities and primary care trusts now have to produce a Joint Strategic Needs Assessment (JSNA). JSNAs will use existing data sources, along with other information, to identify the current and future health and wellbeing needs of a local population, thereby informing the priorities and targets set by Local Area Agreements and leading

⁶ Department of Health. (2006). *Better services for people with an autistic spectrum disorder*, page 15. London: DH

⁷ Local authorities should be tracking the number of children with autism that pass through children's services. This information should be used to ensure an appropriate transition to adult services but at present there is often a lack of communication between children and adult services.

to agreed commissioning priorities. If JSNAs are produced with a heavy reliance on existing data, it could lead to further exclusion from vital services for adults with autism.

Including the needs of people with autism in the JSNA would be consistent with Department of Health guidance to the Directors of Adult Social Services (DASS) which states that "Local authorities shall make the DASS responsible for undertaking a strategic needs assessment for adults and families with actual or potential social care needs across the local authority area. The process will involve responsibility and authority for assessing the needs of all client groups."⁸ Autism spectrum disorder is one of the client groups listed. Local authorities should therefore ensure that people with autism are included in this assessment.

This message is reinforced further by the Department of Health: "Policy requires public bodies to identify, assess and meet the needs of the local adult population and this should include people with an ASD. This overall responsibility falls to the Director of Adult Social Services and/or the Director of Public Health. They should ensure there is local data about local people, know what services are available to them and what the gaps are."⁹

Local authorities and primary care trusts should include the needs of adults with autism in commissioning strategies and Joint Strategic Needs Assessments.

⁸ Department of Health. (2006). *Guidance on the statutory chief officer post of the director of adult social services*, page 5. London: DH

⁹ Department of Health. (2006). *Better Services for people with an autistic spectrum disorder*, page 8. London: DH

Cumbria County Council

In October 2006, Cumbria County Council undertook a mapping exercise into the prevalence of autism in the area, in order to continue to improve services. This looked at both children and adults and followed a similar exercise undertaken in 2003.

Since the work was last conducted in 2003 there has been a 60% increase in the number of adults with autism counted or recorded in Cumbria. It is also thought that although people with Asperger syndrome and high-functioning autism were not fully captured in this work, they will be in future in order to ensure continuous improvements.

As a result of this work, a number of recommendations were made, including:

- that the capacity of existing data systems to record a diagnosis of ASD should be evaluated
- that the mapping exercise should be repeated every two to three years until such time as a comprehensive data system is available in order to plan service developments
- that the possibility of developing a diagnostic service for adults either regionally or locally should be explored.

Christopher

Christopher is 50 years old and was diagnosed late in life with Asperger syndrome. He worked in the same office for over 25 years before retiring due to long-term depression and ill health.



Christopher lives in a rented flat which is almost completely filled, from floor to ceiling, with paperwork and objects he has collected. He has become overwhelmed by the volume of its contents and recognises that he needs help to make his home more habitable. He is now trying to gain support for his needs and establish some routine and structure in his life.

"I've been very depressed for quite some years... The main thing is I need the support, whether it's here or somewhere else. Since about a month ago I have a psychiatrist and a mental health nurse. The mental health nurse has been here about an hour a week and she has found a support assistant who she wants to start tomorrow and that person will also have one hour a week, and the task that we have identified for the care assistant is to sort out the paperwork.

"I need [support] for my needs, which I'm not getting. It's practical support and also advocacy support ... I have to wear too many hats. I have to be a disabled person and I have to be a self carer, ... my own parent, ... my own resource investigator, ... my own researcher, ... my own advocate. People think that because I'm advocating for myself, day and night, non-stop, that I'm some sort of clever person and that my needs are fulfilled. I'm worn out with self-advocating. I need to vegetate, I need to be quiet like I was when I was a youngster.

"I need a very wide range of support on a very wide range of everyday practical issues. I need speaking up for with doctors; I need speaking up for with social services. It's nearly two years ago that I rung them and I haven't had what I consider a proper assessment yet... A person with an autism spectrum condition often comes over with an uneven range of... skills. If a person is seemingly clever with words, as I seem to be, it's assumed they can do stuff for themselves."

Christopher lives in the South Midlands. Members of Christopher's family live at least 100 miles away and he does not see much of them. He has limited regular social contact with other people.

"In a good week I manage to get to church and a church-related group. That would be probably about three hours in total. I sometimes spend a few minutes at the door of a neighbour, chatting about the weather or something... And then there's any conversation I get into with people in shops or whatever, which isn't very meaningful ... And then there's what happens over the phone with various friends or acquaintances."

Chapter two: Understand my needs

There is a range of barriers that prevents adults with autism from accessing the services and support they need. Many of these stem from a lack of understanding of autism; local authorities and health services have services for people with a learning disability or mental health problem, but people with autism do not necessarily fall into either of these groups.

- Only 42% of adults with autism have had an assessment of their needs from their local authority since reaching adulthood.
- 45% of local authorities say that they do not have a process in place to manage how people with autism who do not fulfil the criteria of the learning disability team or mental health team receive support.
- Of those local authorities with a Director of Adult Social Services (DASS), only 39% say that the DASS has appointed a lead team or individual with responsibility for assessing and meeting the needs of adults with an autism spectrum disorder.

Local authorities should:

- > ensure that staff who carry out community care assessments are fully trained in autism
- > establish a clear route to enable adults with Asperger syndrome or high-functioning autism to access assessment and services
- > implement the Director of Adult Social Services' guidance and appoint a named individual or a team with responsibility for autism spectrum disorders.

Primary care trusts should:

- > ensure that staff who carry out NHS continuing healthcare assessments are trained in autism.

Adults with autism frequently struggle to access support from local authorities and health services. This chapter identifies the barriers that prevent adults with autism from getting that support. The obstacles are wide-ranging. There is: a lack of understanding of autism, a major shortage of diagnostic services (which can impact on access to other sources of support), difficulty in accessing assessments undertaken by people trained in

autism, and no clear leadership in relation to autism. There is also a structural disadvantage that arises as a result of adults falling into the gap between learning disability and mental health teams and a failure on the part of local authorities and health services to work together to provide support.

Confusion about the nature of autism

Many of the difficulties that adults with autism experience stem from a poor understanding of autism within local services: there is frequently confusion over what autism is, its complexity, the different ways it affects people and the various types of support that people with autism require.

"The health services tried to dismiss Lorna Wing's very clear diagnosis of AS [Asperger syndrome] and put my son into a mental health residential placement."

Parent

"To most services, anyone without a visible disability is not deserving. They have more urgent clients in need. The fact that a normal life cannot be led is not seen as an issue."

Adult with autism

Autism is a developmental disorder; it is not a learning disability or a mental health problem. However, some people with autism will have an accompanying learning disability and/or a mental health problem. Autism is also a spectrum condition; people with autism will experience difficulties in different ways and to varying degrees. A common misunderstanding is that people with autism who have an average or above average IQ do not experience considerable difficulties because of their autism. This is not the case: even if an adult with autism does not have an accompanying learning disability, they may still have very complex needs and can require intensive support. For example, an individual might be academically very able but may struggle to manage straightforward everyday tasks. It is crucial that this is understood if adults with Asperger syndrome or high-functioning autism are to access the support to which they are entitled.

It should also not be assumed that adults with autism who also have a learning disability can access services that meet their needs. Some adults with autism and an accompanying learning disability are entirely reliant on their parents for support, and for those who are able to access services, these often do not take account of their autism. Almost half (47%) of parents and carers of adults with autism who have an accompanying learning disability say that a lack of understanding of autism has been a barrier to their son or daughter receiving support.

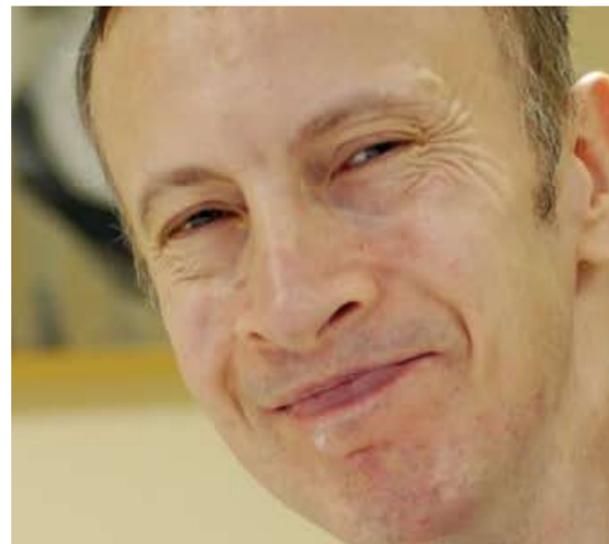
"My son has been placed twice now in accommodation unsuitable for his needs, with disastrous results. We are now picking up the pieces and we have him at home. We have been told by social services that they have nothing for him."

Parent

Without understanding of autism as a starting point, the support and services required by people with this disability cannot even begin to be fully anticipated or developed according to individual need.

"The biggest obstacle is a lack of understanding of ASD and its particular needs."

Local authority



The impact of getting an autism diagnosis

A diagnosis can sometimes make it easier for people to access services. Although support should be based on need and not diagnosis, over half of local authorities (54%) believe that adults with autism who have a diagnosis are more likely to receive support than those without one.

For those adults who grew up when little was known about Asperger syndrome or high-functioning autism, accessing a diagnostic service in adulthood can often seem impossible.

"It has been horrendous. I tried everyone - education, psychology, social services, adult services, doctor. No diagnosis - no help. How do I get a diagnosis? What support do I get if there is no diagnosis? Will it take attempted suicide before anyone acts?"

Adult with autism

"A young man who suspected he had Asperger's came to our service about a month ago. My colleague who assessed him felt that he had a number of symptoms which were conclusive with this diagnosis and recommended a proper assessment by a psychologist. The doctor refused, saying he had no mental health problems. I objected, saying there were services that may help. Doctor snubbed me."

Professional

Nearly three quarters (74%) of primary care trusts believe that there are constraints to providing access to diagnosis for adults with autism.

Just under half (48%) of primary care trusts do not have an autism specialist diagnostic service for adults or an identified person who can undertake assessment within their boundary. For those trusts that say they can undertake assessments within their boundary, this often seems to be limited and not

always of a specialist nature. Barely any know how many adults with autism living in their area received a diagnosis during the financial year 2005-2006.

The National Autistic Society supports the Royal College of Psychiatrists' recommendation that "commissioners should ensure that there is access to local, basic diagnostic expertise that would allow for the firm diagnosis of autistic spectrum disorders in clear cut cases. They should also ensure access to a second level of diagnostic expertise for those individuals where there is diagnostic uncertainty."¹⁰

The National Institute for Health and Clinical Excellence (NICE) is producing clinical guidance in relation to autism spectrum disorders in children and adolescents. This will look primarily at the initial recognition, referral and diagnosis of autism, as well as the management of autism. This guidance is a very welcome development; however, its remit does not go far enough. By excluding adults with autism from this guidance, the difficulties they experience will only continue. We call for NICE to extend the scope of this guidance to cover adults.

Difficulties in having health needs assessed

The NHS provides continuing healthcare for those people whose primary need is health-related.¹¹ In October 2007 the Government implemented a new National Framework to assess eligibility for NHS continuing healthcare and NHS-funded nursing care in England. It is too early to assess the impact of this, but prior to its implementation some parents of adults with autism with an accompanying learning disability were very concerned that their son or

¹⁰ Royal College of Psychiatrists. (2006). *Psychiatric services for adolescents and adults with asperger syndrome and other autistic-spectrum disorders*, page 7. London: RC PSYCH

¹¹ NHS continuing healthcare is the name given to a package of services which is arranged and funded by the NHS for people outside hospital with ongoing health needs. Individuals can receive continuing healthcare in any setting, including their own home or a care home.

daughter faced having their continuing care funding withdrawn following reassessment by a number of primary care trusts:

"I am devastated that he has been assessed as not meeting the criteria to be funded by the PCT. His disability has not changed and he is happy where he is. In my opinion, they have moved the goal posts to save money."

Parent

The assessment for continuing healthcare should be undertaken by people who have an understanding of autism to ensure a fair eligibility decision is made.

Primary care trusts should ensure that staff who carry out NHS continuing healthcare assessments are trained in autism.

Difficulties in having community care needs assessed

All adults have the right to a community care assessment from their local authority, yet, despite this, the majority of adults with autism have not had one. Only 42% of adults with autism say that they have had an assessment of their needs from their local authority since reaching adulthood and this figure drops to 35% among those people aged between 40-64. Just 33% of adults say that they have received such an assessment in the last two years. This falls to just a quarter (25%) among adults who have Asperger syndrome or high-functioning autism.

For those who do have an assessment, their eligibility for services is decided by a system called Fair Access

to Care Services (FACS). FACS guidance provides local authorities with a national framework for determining eligibility for adult social care. Needs are prioritised into four bands: critical, substantial, moderate and low, and local authorities can decide which of these bands they provide services to.¹² Whether an individual qualifies for support will depend on whether, following their assessment, they are judged to fall into one of the bands that their local authority is providing services to. It is becoming increasingly hard to qualify for services from local authorities, as most now only provide them to those people who fall into the critical or substantial bands.

It is essential that whoever is conducting a FACS assessment has an understanding of the nature of the

disability and that they know how to communicate with someone with autism in order to assess their needs properly and fairly. This will include consideration being given to an individual's preferred method of communication, setting up meetings at times that suit them, providing access to an advocate and involving people who know the individual. It is important to understand the difficulty some people with autism have in defining what their needs and aspirations are; for example, some people with autism might not recognise or be able to explain their needs, or might answer a question in a way that they think the assessor wants them to.

¹² In constructing and using their eligibility criteria, and in determining eligibility for individuals, authorities should prioritise needs that are critical ahead of needs that are substantial, needs that are substantial ahead of needs that are moderate and needs that are moderate before needs that are low.

Reasons for lack of support from local authorities and health services

We asked those adults with autism who have had problems receiving support to tell us what explanation they had been given by their local authority and/or health services for this. The information in figure 1 below reveals what those reasons were:

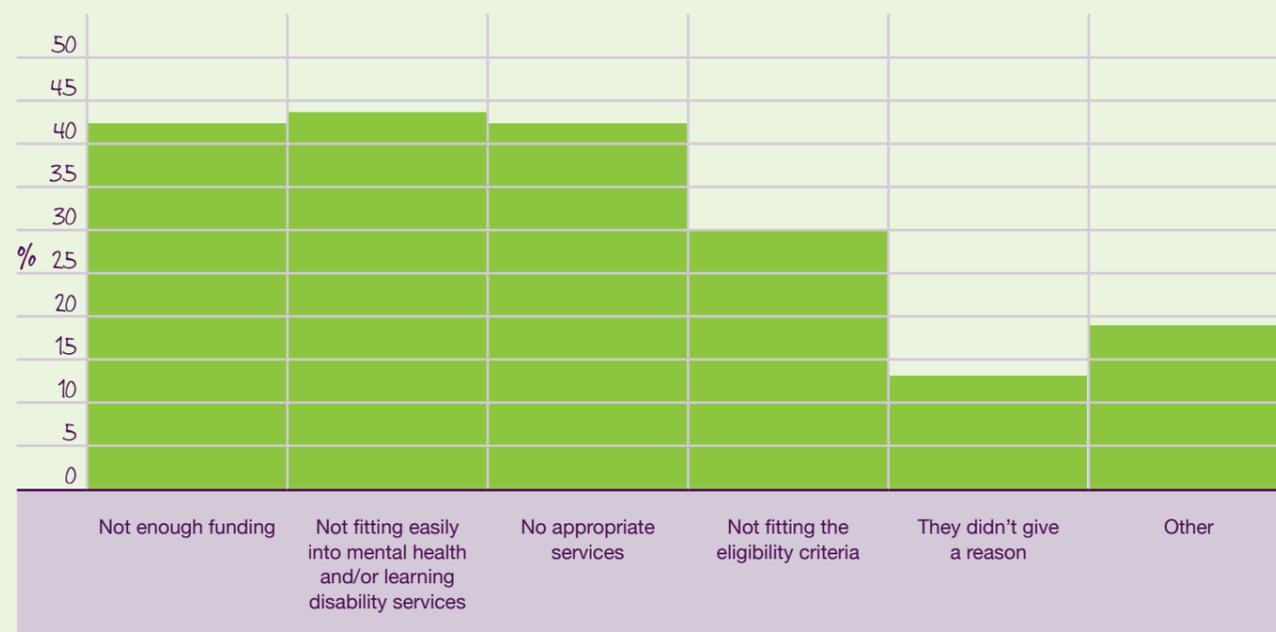


Figure 1 : Reasons given by local authorities/and or health services for not providing support

We also asked parents and carers what they thought the barriers were to the person they care for receiving support. Figure 2 shows their responses:

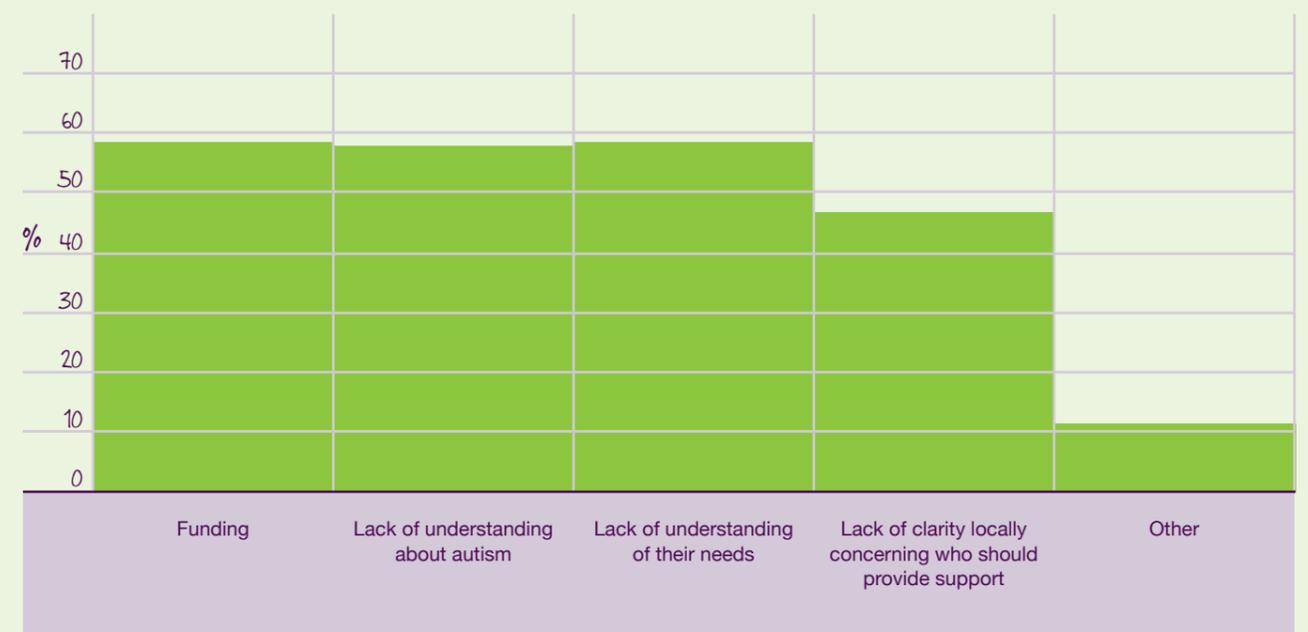


Figure 2 : Barriers identified by parents/carers to their son/daughter receiving support

It is therefore of concern that local authorities do not think that care managers receive sufficient training in autism in their initial professional training (71%) and in their ongoing professional training (67%). Over three quarters (76%) of local authorities do not have an autism training strategy at all.

"The care coordinator is a social worker with the Community Mental Health Team who 'feels out of her depth' and 'not trained to deal with this!'"

Parent

"My obvious verbal intelligence masks the level of my support needs. My mental health history biases 'professionals' against taking me seriously. The last support worker I had knew nothing about autism at all and could not understand the help I required."

Adult with autism

The Department of Health has stated that "proper individual assessments, based on eligibility criteria, as set down in 'Fair Access to Care' are the starting point for people getting the services they need."¹³

The guidance goes on to say that "strong protocols ensure assessors are trained in ASD and they prevent people being delayed or denied access to services as a consequence of secondary testing (eg IQ testing)." As obtaining services from the local authority is so difficult, it is essential that individuals are given an assessment by someone who understands autism.

The Department of Health has also stated that services should be provided based on individual need, rather than assumptions about a condition or disability.¹⁴ This is difficult to ensure, though, without appropriate training for those undertaking the assessments.

Local authorities should ensure that staff who carry out community care assessments are fully trained in autism.

The problem of falling between learning disability and mental health services

Over 60% of adults with Asperger syndrome or high-functioning autism say that they have experienced problems in trying to receive support from their local authority and/or health services. Of these, 52% were told that they do not fit easily into mental health or learning disability services.

"ASDs cut across traditional service boundaries, so it is difficult to develop services in a way that allows for the sharing of expertise as well as funding."

Local authority

"Because of high IQ, I am not eligible and do not fit into any category for support. They do not recognise my disability and send me away. Even if I was eligible, there is no ASD support [here] for people like me."

Adult with autism



¹³ Department of Health. (2006). *Better services for people with an autistic spectrum disorder*, page 9. London: DH

¹⁴ Department of Health. (2006). *Best practice guidance on the role of the Director of Adult Social Services*. London: DH

Dudley Metropolitan Borough Council

Dudley Metropolitan Borough Council, in the West Midlands, has produced a strategy for people aged 16 and over with Asperger syndrome and high-functioning autism. The strategy identifies existing services in Dudley and the gaps in those services, with the intention of setting out clearly which services people with Asperger syndrome and high-functioning autism can access and how these services can be improved.

Some of the main action points covered in the document relate to referral and assessment and the establishment of a specialist service. Under referral and assessment the following is proposed:

- to establish proper protocols that identify a clear referral pathway
- to ask the member champion for learning disability or mental health to also champion services for people with Asperger syndrome and high-functioning autism
- to explore innovative ways of meeting needs and identifying appropriate funding
- to commission specific services and resources from independent sector providers to create services that meet individual needs.

The document makes the case for establishing a specialist team, with a wide range of professional input, that could deliver:

- an online referral service and a helpline
- person-centred holistic assessments
- individual programmes of support including a counseling service, therapy treatments and sensory room
- signposting to other services that would meet individual needs
- training in independent living skills in preparation for moving into supported living accommodation
- work preparation and partnership with local employers to provide work opportunities that utilize people's talents
- support, information and resource material for parents and carers
- a daily drop-in service offering activities and a place for people to meet
- sessional input from private providers to develop schemes or programmes that meet specific needs.

The council is currently seeking funding for this strategy.

"Our county council heavily focuses its support towards learning and physical disability. The authority's social services refuse to support or even acknowledge Asperger syndrome as a unique disability requiring specialist intervention."

Adult with autism

Local authorities tend to provide services via specific teams, with the teams categorised into client groups. As a result, people with autism usually come into contact with either the learning disability team and/or the mental health team. Yet because autism is a developmental disorder, not a learning disability or a mental health problem, many adults with autism – particularly those with Asperger syndrome or high-functioning autism – are passed between the two teams, receiving no proper help from either. Typically, the learning disability team refuses to become involved because the person's IQ is 'too high' and the mental health team turns the person away because they do not have a mental health problem. This is often referred to as people with autism 'falling through the gap' between learning disability and mental health services and is a situation which places many adults with autism at a disadvantage. It is also a source of intense frustration for adults with autism, frequently resulting in their exclusion from services and an increase in their isolation. Many adults in this situation end up developing mental health problems that they might not otherwise have had.

The Department of Health, has, in recognition of this problem, clearly stated that adults with autism should not fall into the gap between services: "the current position whereby some people with an ASD 'fall through' local services – in particular between mental health and learning disability services – is unacceptable and contrary to the intention of government policy."¹⁵

Despite this, 45% of local authorities say they do not have a process in place to manage how people with autism who do not fulfill the criteria of the learning disability team or mental health team receive support. For those that do have a process, the extent to which it adequately addresses the needs of adults with autism varies considerably.

"Obstacles are still around. Where do they fit – learning disability or mental health? It would help to have an Asperger syndrome or ASD-specific service or team."

Local authority

"Bureaucracies can only cope with pigeon holes... ASD is not 'core business' for learning disability or mental health so will not be prioritised within their own 'must dos'."

Local authority

"Service silos mean ASD doesn't fit. ASD falls between service areas."

Local authority

The issue of structural disadvantage does not only exist within local authorities – a clear support structure is absent among health services as well. When we asked primary care trusts whether they have a process to support adults with autism who are not eligible for either learning disability or mental health services, 55% who responded said they do not. This explains in part why many people with autism are unable to access health services.

In 2002, the The National Autistic Society published *Taking responsibility: good practice guidelines for services – adults with Asperger syndrome*¹⁶ to help authorities to address this gap. The publication noted that "guidelines are necessary because Asperger

¹⁵ Department of Health. (2006). *Better services for people with an autistic spectrum disorder*, page 7. London: DH

¹⁶ Powell, A. (2002). *Taking responsibility: good practice guidelines for services – adults with Asperger syndrome*, page 7. London: The National Autistic Society

Liverpool Asperger Team

The Liverpool Asperger Team is one of the best known examples of autism good practice in England. It was established in 2003, following recommendations from a steering group regarding the need for an Asperger syndrome-specific multi-disciplinary team. Funded by the Central Liverpool Primary Care Trust and the local authority, it currently consists of a team manager (who is also a head speech and language therapist), two community nurses, two clinical psychologists, an assistant psychologist, a social worker, two support workers, an assistant clinician and an administrator.

The team has a person-centred approach and uses the concept of a managed care pathway to provide direct support, make referrals and support other service providers. The wider network includes specialist services for people involved in the criminal justice system and those receiving support from mental health and alcohol and substance misuse services. When dealing with employment support, education, and other statutory and non-statutory services, the care management role is normally undertaken by a member of the Asperger Team itself.

Since the formation of the Liverpool Asperger Team, over 400 individuals have been referred for assessment and intervention (although not all have qualified for support). People referred must be over 18 and be a resident of Liverpool or have a Liverpool GP, but the team will also assist young people aged between 16-18 and liaise with children's services if the person is in significant need and is unable to access other services. Service users do not need to have a formal diagnosis of Asperger syndrome, as the team also carries out diagnostic work.

The team has made a real difference to adults with Asperger syndrome in the Liverpool area and they are keen to share the good practice they have developed.



syndrome is generally not recognised by local authorities and other public services as a condition requiring an assessment of need, and people with the diagnosis still find themselves ignored or ineligible.”

Yet, people with autism continue to be failed by local services that refuse to acknowledge their needs.

Local authorities should establish a clear route to enable adults with Asperger syndrome or high-functioning autism to access assessment and support.

A lack of clear leadership

The structural disadvantage faced by adults with autism is exacerbated by a lack of clear responsibility for ensuring that their needs are met. Leadership at a local level is needed in order for this to change.

The Government has recognised this leadership gap and in Statutory Guidance to the Directors of Adult Social Services (DASS) has stated: “Local authorities shall ensure that the DASS draws up clear lines



of responsibility, within his or her staff team, for managing the needs of all adult client groups.”¹⁷

People with an autism spectrum disorder were identified as one of the client groups to which this guidance referred. Yet, local authorities have been slow to implement this requirement. Our evidence has shown that of the 89% of local authorities that say they have appointed a DASS,¹⁸ only 39% say that the DASS has appointed a lead team or individual with responsibility for assessing and meeting the needs of adults with an autism spectrum disorder.

Local authorities should implement the Director of Adult Social Services guidance and appoint a named individual or team with responsibility for autism spectrum disorder.

Local services are not working together to provide support

“Neither health, education, nor social services felt that my needs fell within their remit, and so consequently I didn't receive much in the way of services. Furthermore, they didn't work together and so my support was very disjointed and fragmented.”

Adult with autism

Adults with autism are also falling through the gap between health services and local authorities. While local authorities and primary care trusts often work together to provide services, particularly in areas such as mental health, there is a need for more multi-disciplinary planning in their approach to autism.

¹⁷ Department of Health. (2006). *Guidance on the statutory chief officer post of the director of adult services*, page 4. London: DH

¹⁸ At the time of our survey.

Autism Consortia in Northern England

Greater Manchester

The Greater Manchester Autism Consortium comprises the ten local authorities in Greater Manchester (Bolton, Bury, Manchester, Oldham, Rochdale, Salford, Stockport, Tameside, Trafford and Wigan). It was set up in 1998 and is facilitated by The National Autistic Society. The purpose of the consortium is to allow local authorities to strategically share their knowledge and work together to improve local services for children and adults with autism.

In order to achieve its aims, every local authority has set up a multi-agency Autism Services Development Group (ASDG), comprised of representatives from all statutory agencies, parents and carers, and, in some cases, adults with autism. The chair of each group is on the consortium steering group. The groups look at what can be achieved in the local area by improving current provision within resources, and by better informing the commissioning process. Some of the ASDGs are developing workshops and low-level preventative services for people with autism, such as befriending and social skills training.

The consortium also funds and steers The National Autistic Society's Family Services Development Project, which provides information, advice and support to families across Greater Manchester. Data from this project is then fed back to inform the commissioning process.

The North East

The North East Autism Consortium was established in 2006 with the aim of developing a regional approach to addressing the planning and service needs of people with autism. In particular, it works towards the development of a regional commissioning strategy and addresses the lack of integration with service provision across health and social care.

The consortium is funded for two years by the North East Centre of Excellence and its members are the 12 local authorities in the North East, the primary care trusts in the region, mental health services, the North East Strategic Health Authority, the Learning and Skills Council, the National Offender Management Service and The National Autistic Society.

Four autism services development groups have been established in the region, offering the opportunity to share good practice and development. The key aim of these groups will be to inform the development, planning and commissioning of local services and to feed this information back to the consortium board. Membership of these groups includes people with autism, parents and carers and other voluntary and independent sector representatives.

Kelly

Kelly loves colour and movement. She prefers to wear saris when she goes out and she has a dozen colourful wigs.



Kelly is 30 and has autism and a learning disability. She communicates using spoken language, but will only speak directly to a handful of people, whom she knows very well: her parents, co-tenant and the staff who work with her. She cannot tolerate being with other people for any sustained period and has a strong dislike of groups, noise and children. She also loses concentration on any activity after more than a few minutes.

Kelly lives with Karen, whom she has known since their school days. They are very attached to each other and live together in a new and comfortable semi-detached home. Their tenancies have been arranged under a trust set up by Kelly's parents to support her in taking advantage of direct payments during the last four years.

Kelly's day-to-day support needs are intensive. She has 24-hour staff support from a team of four and her activities are individually tailored to her needs. She easily becomes anxious and then self-harms, so any change has to be introduced very carefully. Kelly attends to her own personal care, with minimal support, chooses her own meals and prepares them herself, in partnership with Karen.

On an average day Kelly gets up and has a long bath before breakfast. She completes her household tasks then goes for a drive, stopping to have sandwiches (which she makes in advance) and a walk. On the way home she buys food and a newspaper from the local shops.

When she gets home Kelly reads the paper. She collects and stores cuttings, photos and objects. This helps her to relax. She then prepares and eats her evening meal, which takes up to one and a half hours. Before she goes to bed at about 11pm she plays pool with Karen in their garage and watches TV.

Kelly took a course at her local further education college but left three years ago when the only option was to repeat the course she had already completed. Now she does not attend any courses.

Kelly's life has only recently got onto an even keel after a disastrous experience at school, where she was excluded for lengthy periods. She was the first person in her local authority area to receive direct payments and then an individual budget but the current quality of her life is threatened by a possible reduction in the resources available to her.

Chapter three: Meet my needs

Adults with autism say they need a range of support, yet many actually receive little or no help. The biggest gap between the types of support people need and what they actually receive is in the area of social support. To truly meet the needs of an individual with autism, a person-centred approach is required, and those providing the support should be trained in autism.

- 82% of parents and carers say that their son or daughter needs some level of daily support to live independently.
- The top three supports that parents and carers believe that their son or daughter would benefit from are social skills training (60%), social groups (56%) and befriending (49%).

Local authorities should:

- > fund social support services, including befriending, social programmes, social skills and life skills training for adults with autism
- > ensure that social care support workers who come into regular contact with adults with autism are trained in autism.

"Few, if any, services have been developed to respond to the distinctive needs of adults with neuro-developmental problems."¹⁹

Many adults with autism are not able to access the services that they feel would make a difference to their lives and give them greater independence. This chapter explores what these services are and also considers the importance of person-centred planning and ensuring that those who provide support have a clear understanding of autism.



¹⁹ Schneider, J. (2007). *Better outcomes for the most excluded*, page 10. Nottingham: The Institute of Mental Health, The University of Nottingham and Nottinghamshire Healthcare NHS Trust

What support do adults with autism want?

82% of parents and carers say that their son or daughter needs some level of daily support to live independently, while only 2% of parents and carers say that their son or daughter would need no support to do so.

"He requires care and support 24 hours a day, seven days a week, with all the activities of daily living. He's a vulnerable adult and at risk... He needs a great deal of support in communication. He needs help managing self-injurious behaviour."

Parent

"She can never be left alone - cannot cross the road alone. She has no understanding of money. She needs help with personal care. She has limited understanding of time."

Parent

Figure 3 highlights the fact that many people with autism require intensive support and that, for most people, some level of assistance is needed. As autism affects different people in different ways, this spectrum of needs must be met by a full spectrum of provision. It is also clear from figure 4 that many adults with autism would like assistance with daily tasks. Yet, from figure 5 it is apparent that there is a significant gap between the type of support adults with autism and their families would like and what it is that they actually receive.

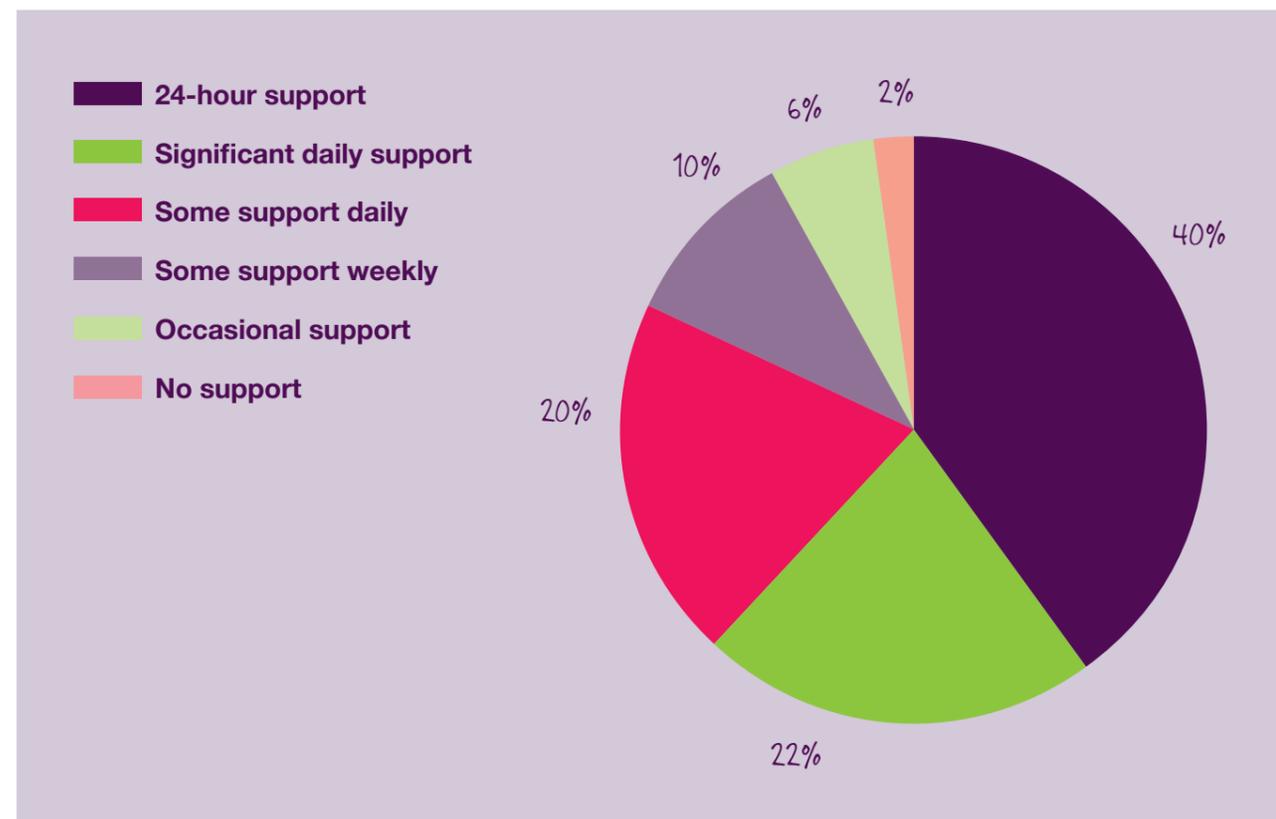


Figure 3 : What support would your son or daughter need to live independently?



Figure 4 : The support adults with autism say they need

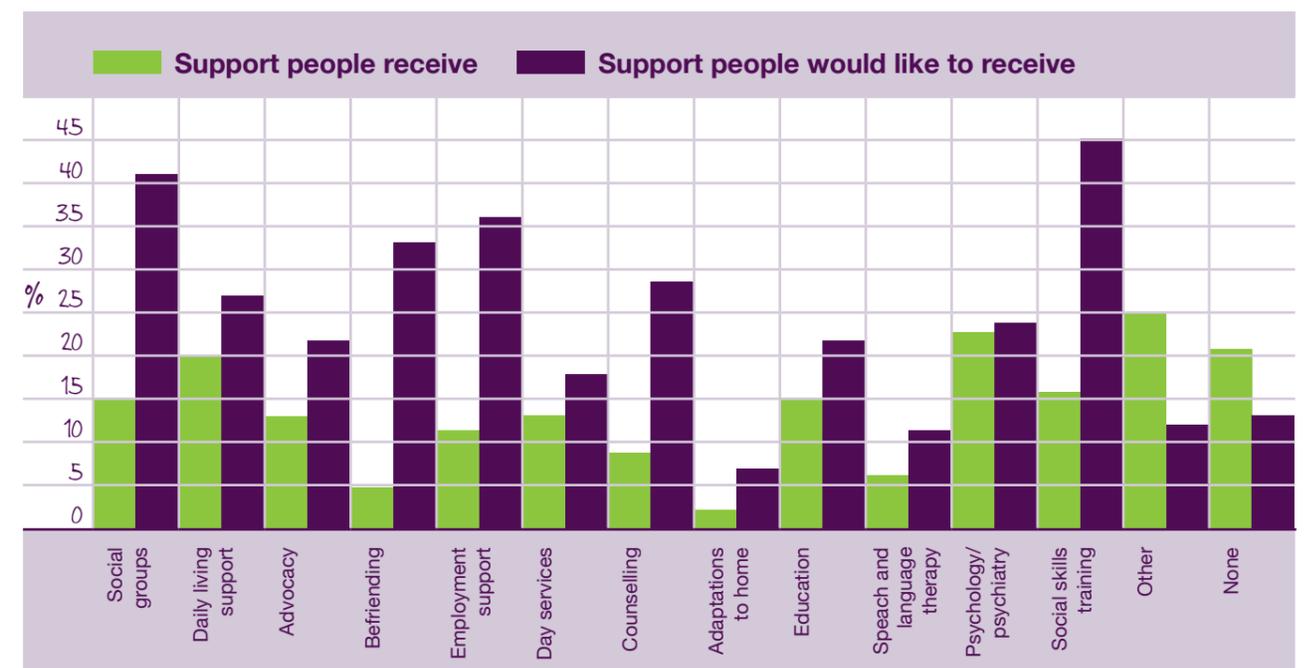


Figure 5 : Actual support provided for adults with autism in comparison to what they would like to receive

From figures 5 and 6 we can see that there is a real need for preventative services; in other words, those services which are often less intensive in nature but which can prevent needs from increasing over the long term. The difference between what people need and what they are actually able to access is most apparent in the area of social support. There is a gap of 29% between those who have access to social skills training and those who need it, a gap of 28% between those who have a befriender and those who would like one, and a gap of 26% between those people who are able to access a social group, compared with those who actually do. This message is reinforced by parents and carers; the top three supports that they believe that their son or daughter would benefit from are social skills training (60%), social groups (56%) and befriending (49%).

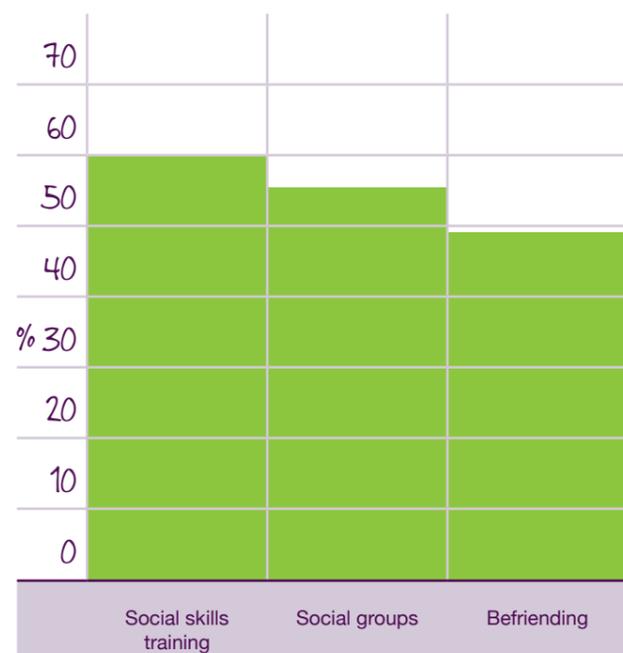


Figure 6 : Top three supports that parents/carers believe would benefit their son or daughter

This need for social supports applies to people from across the spectrum, including those with an accompanying learning disability. Parents and carers of this particular group say that the top four supports that their son or daughter would benefit from are: social skills (61%), social groups (58%), daily living support (52%) and befriending (47%).

Social support might be viewed by some people as being low-level in nature. While this may be true in relation to the relative cost and time spent in providing it, it is not low-level in terms of the impact it has on the lives of adults with autism – it is a lifeline.

"He stays in the house 24/7 unless [my husband] or myself take him out or get one of his Uncles to take him out. He needs someone to go out with to talk to. He needs a befriender to help him. He enjoys going to groups once a month. I hope you can help my son."

Parent

"This [monthly social group meeting] is excellent and gives him something to look forward to – enjoyment, encouragement and the freedom to be himself."

Parent

"Having a befriender for one afternoon a week has had a remarkable effect on his attitudes and behaviours and, I believe, on his quality of life."

Parent

For people with autism there is evidently a shortage in the provision of preventative support that would stop their needs from escalating. Yet the Government has clearly recognised the importance of preventative support in statements such as: "We must reorientate our health and social care services to focus together on prevention and health

promotion."²⁰ The Government has called upon the Directors of Adult Social Services to ensure that there is an appropriate balance between low-level and preventative services and services designed to meet the needs of people at the higher-needs end of the care spectrum.²¹

In addition, the Department of Health has said that "for those people who are not eligible for services but require preventative input there are a wide range of supports that could be made available such as continuing education, social, discussion and special interest groups."²²

The Department of Health is currently considering the long-term funding of social care. There is a strong case for funding preventative support for people with autism in order to prevent needs from escalating, as recent research has shown that autism costs society £28 billion a year. A significant proportion of this is the result of lost earnings by adults with autism.²³

Unfortunately, at the moment many adults with autism are denied access to the types of support they most need.

Local authorities should fund social support services, including befriending, social programmes, social skills and life skills training for adults with autism.

²⁰ Department of Health. (2006). *Our health, our care, our say: a new direction for community services*, page 9. London: DH

²¹ Department of Health. (2006). *Best practice guidance on the role of the Director of Adult Social Services*. London: DH

²² Department of Health. (2006). *Better services for people with an autistic spectrum disorder*, page 16. London: DH

²³ Knapp et al. (2007). *The economic consequences of autism*. London: Foundation for People with Learning Disabilities

Kingston Asperger Syndrome Service

In 2007, The Royal Borough of Kingston upon Thames developed an Asperger Syndrome Service to help adults with Asperger syndrome live more independently. The impetus for developing this service was the identified need for a clear pathway and point of contact for adults with Asperger syndrome, who had previously received a service either from the Community Mental Health Team or Community Learning Disability Team.

Due to changes in the eligibility criteria in Kingston under the Fair Access to Care banding scheme, only those with a critical or substantial need receive support from community care services. Therefore, the Asperger Syndrome Service operates as a signposted specialised service which aims to meet the needs of adults with Asperger syndrome, including those who do not meet the eligibility criteria for community care services. The service works closely with the Community Learning Disability Team and Community Mental Health Team and also with 'Kingston Workstart', the local employment service for disabled people.

The service offers two training programmes – 'Personal Development' and 'Preparing for Work' – as well as individual appointments, a carer support group and a monthly social group that gives people with Asperger syndrome the chance to meet each other and take part in social activities.

The importance of person-centred planning

Even for those people who already receive some level of support, that support is not always what they want or even appropriate to their needs.

"I live in a residential home for people with autism and learning disabilities and I have a weekly timetable of events planned for me. The problem is I have different care staff all the time which frightens me because I don't like change. Also a lot of my activities are cancelled due to staff problems."

Adult with autism

"He has a reasonable amount of support but not necessarily the right sort. He does need more specific support."

Parent

Services should be built around individual needs, rather than on the assumption that what suits one person will also suit another. While this is true for all people, the diversity and individuality of autism means that no two people will be affected in quite the same way. A person-centred approach is required, which involves listening to the individual and making sure that they are always at the centre of planning and delivering services. Unfortunately, there is still a long way to go before person-centred planning becomes a reality for adults with autism. Only 27% of adults with autism currently have a person-centred plan or care plan.

Direct Payments and Individual Budgets

Direct Payments are cash payments, designed with the intention of giving people greater choice and control over their lives. Since 1997, individuals who qualify for services from their local authority have been able to choose whether to receive these in the form of a Direct Payment instead of services from the authority. The Government is committed to extending the scope of Direct Payments to those who are currently entitled.

Following a similar principle, Individual Budgets bring together separate funds from a variety of agencies, including local authority social services, Access to Work, Independent Living Funds, disabled facility grants and the Supporting People programme. After making an initial assessment of how much money is needed to meet the needs of an individual (known as the Resource Allocation System) a single sum is allocated to an individual and they can decide how to spend the money.

Individual Budgets were originally trialled through the 'In Control' pilots for people with learning disabilities. Thirteen further pilots were then sponsored by the Department of Health, with an evaluation of these pilots due to be published in April 2008. We need to see the results of this evaluation to gain a broader understanding of the impact they would have on people with autism.

If Individual Budgets are to work for people with autism, the money they receive should be sufficient for them to be able to afford the support and services that they need. There will also need to be a range of services and support readily available. Support workers with the right expertise must be on hand to help people determine how their budget should be used and to help them to manage their budget, if needed.²⁴

²⁴ In December 2007 the Government declared its intention to allocate £520 million to personal budgets, which refers to an upfront, transparent allocation of predominantly social care funding.



Receiving support from people who understand autism

It is vital that social care staff and others who provide support have an understanding of autism. When they do not, the support they provide is often inadequate.

"He has a 24-hour carer in his home, but they are not appropriately trained or aware."

Parent

The majority of local authorities believe that support workers need more training in autism. 63% say that support workers have insufficient training in autism in their initial professional training while 56% say that support workers have insufficient training in autism in their ongoing professional development.

The Department of Health notes that "commissioners of staff training and education should contract so that an appropriate level and type of training is provided for all relevant staff... Staff in regular contact with people with an ASD need more than awareness-training and should fully understand an individual's support needs and issues relating to diversity."²⁵

Local authorities should ensure that social care support workers who come into regular contact with adults with autism are trained in autism.

²⁵ Department of Health. (2006). *Better services for people with an autistic spectrum disorder*, page 11. London: DH

The impact of the right support

When an individual receives appropriate support it can transform their life.

"For the past seven years my daughter has received a superior service, funded jointly by the NHS and social services. Prior to this, while she lived at home with us until the age of 36, we had an increasingly difficult experience of services which were unable to provide adequate support for day care and respite. The staff did their best but staffing ratios and accommodation were very lacking... The change in our daughter's behaviour and the improvement in her quality of life since moving has been impressive."

Parent

"My son is very well supported in his supported tenancy. He's very happy, doing lots of interesting activities."

Parent

"Overall, I have been delighted with the generous amount of care my son has been receiving from his team. The result has been a remarkable increase in his confidence. He can now engage in conversation, with eye contact, which he once found very difficult. This, in turn, has enabled him to go out and be with people, for example at his community centre and church. The appointment of an Asperger specialist care coordinator has made a vast difference for me. Happily the two social workers he sees now have known him for a long time and are very helpful."

Parent

Oldham Metropolitan Borough Council

Oldham is a leading local authority in terms of autism provision. They have a high-level commitment to autism and the current Director of Adults and Communities in Oldham is the Chair of the Greater Manchester Autism Consortium. The authority's work includes:

> obtaining autism accreditation²⁶ for their learning disability services

All Oldham's learning disability supported tenancy provision, day service provision and respite provision have, since 2006, been autism accredited.

> producing a training strategy

There has been a huge investment in an autism training strategy, with three levels available for staff to complete, from basic to very specialised training. This is undertaken not just by those directly providing support but also by staff who carry out assessments of need. Other agencies such as the police, housing providers, the Acute Health Trust, the primary care trust, mental health services and probation services can also access the training and receive advice on specific cases and issues.

> a specialist autism post

Oldham has appointed a specialist post that enables them to achieve and maintain accreditation.

> a Vulnerable Adults Team

In recognition of the fact that some adults were not fitting into existing teams, Oldham has developed a Vulnerable Adults Team for people up to the age of 65. They take people who are eligible for support following a FACS assessment but do not fit into other teams. A large proportion of those people have Asperger syndrome or high-functioning autism and the team includes a clinical psychologist who spends half their time working with people with Asperger syndrome and high-functioning autism.

> preventative services

Oldham has established preventative services which are accessible to people who do not qualify for support through Fair Access to Care Services. These include befriending and social groups.

²⁶ The Autism Accreditation programme was established by The National Autistic Society (NAS), with support from the Department of Health. The programme operates independently of the NAS and supports the expansion of high-quality services for people on the autism spectrum. For a service to achieve accreditation, it must undergo an evaluation to determine whether it meets a number of standards, based on autism-specific criteria.

Neil

Neil has autism and severe epilepsy. He is 28 and has been in a day service for almost seven years. He has not spoken since he was a toddler, although very occasionally members of his family have heard him speak a single word when he thought no-one could hear him. He communicates by writing.



Neil seems to be highly intelligent. He has a strong sense of humour and often teases staff by hiding something they clearly value or by making it unusable until they ask him to mend it. He also clearly experiences frequent and considerable anxiety and, in his communication with staff he trusts, he stresses the importance to him of feeling safe. He has a deeply felt sense of frustration and of isolation from others, and he is very negative about his disabilities.

What are your main interests and hobbies?

I like to watch other people doing things but I do like walking, swimming, ten-pin bowling and visiting places. My hobby is mischief.

How do you spend an average weekday?

At 8.20am I get up after being called. My Mum washes me. I brush my teeth. I get dressed with help from my Dad. Eat my breakfast. Go in the taxi to Day Care. At 4pm I come home with the taxi driver. I relax until dinner time. Have dinner, watch television. Have a bath and go to bed.

What would you like to do with your days, which you don't do now?

I would like to do some maths and learn about science.

If there is any support you feel that you need, but are not getting, what is it?

Speech therapy and music therapy.

Would you like to have more friends or more time with other people?

I would like to have friends but I don't know how.

How do you feel about having autism and how does it affect your life?

I hate having autism and because I am so frightened I don't have a life of my own. I watch other people's. It makes me feel an outsider.

How well do you think that people generally understand autism, and understand you?

It varies, some people know about it and some don't. I think they think I am thick and badly behaved.

Would you like a job and, if so, what would you like to do?

Yes. When I am better at coping. I would like to be a scientist.

Chapter four: Lead the way

Current Government policies do not adequately meet the needs of adults with autism. If this is to change, national leadership is required from the Government.

- 98% of local authorities and 100% of primary care trusts believe that the Government could provide them with more assistance to support adults with autism.

The Government should:

- > expand capacity, expertise and leadership on autism in the Department of Health
- > ensure that there is regional support to help local authorities and primary care trusts implement good practice
- > issue statutory guidance to local authorities that addresses the barriers that prevent adults with autism from accessing services and produce good practice commissioning guidance for local authorities.

The Health Select Committee should:

- > hold an enquiry into autism.

The Government has a crucial role in determining the experiences of adults with autism. Yet, until now, little has been done to consider specifically the needs of these adults. This has both contributed to and reinforced the barriers that those adults experience when trying to access support.

A recent welcome development has been the appointment of a part-time autism specialist post in the Department of Health. However, this post is at the moment only for one day a week and is due to end at the beginning of April 2008. If autism is to get the focus and attention it requires, this post needs to be extended and made full-time.

There also needs to be support for local authorities within each government region

to enable them to implement good practice for adults with autism. There is currently no support available on a regional or local level from the Government to assist local authorities in this way.

It is clear from this report that people with autism need considerably more support than they are able to access and that current services and policies are not addressing this gap in support. The Health Select Committee should explore the issues covered in this report further and ensure that the Government is held to account on the provision of services for people with autism.

What is the current policy position?

A range of existing national policies do apply, either wholly or in part, to adults with autism (as they apply to other groups). However, these are not specific to the needs of adults with autism. The only publication by the Department of Health that focuses specifically on government policies and adults with autism is *Better services for people with an Autistic Spectrum Disorder*.²⁷ The intention of this document is to clarify how a range of already existing policy documents and positions apply to adults with autism, and it usefully highlights the good practice that local authorities, primary care trusts and other bodies should be adhering to. Yet, on its own, this document cannot resolve the difficulties adults with autism face in accessing support, as it has no statutory force, and while it brings together existing policy, it does not present a complete and coherent strategy for supporting adults with autism. It is also clear that much of what this

document says local authorities and primary care trusts should be doing is still not happening.

Since the launch of the Government's learning disability strategy – the *Valuing People* White Paper²⁸ – in 2001, there has been some debate over how it applies to people with autism, and there is confusion about this at local level.²⁹

"The Valuing People White Paper could be more helpful if it was clearer around the issue of who has responsibilities for developing services for people with Asperger syndrome."

Local authority

²⁷ Department of Health. (2006). *Better services for people with an autistic spectrum disorder*. London: DH

²⁸ Department of Health. (2001). *Valuing People: a new strategy for learning disability for the 21st century a white paper*. London: DH

²⁹ The Department of Health launched a consultation in December 2007 to 'refresh' Valuing People policy. This document *Valuing People Now: From Progress to Transformation* sets out what the Government intends to do from 2008-2011. The main priorities are personalisation, what people do during the day, better health, access to housing and making sure that change happens. The consultation closes on 11 March 2008.

The position from the Department of Health is that "*Valuing People* only applies to people if they also have a learning disability", but that "adults with Asperger syndrome or higher-functioning autism are not precluded from using learning disability services ..."³⁰ For those adults with autism who are able to access the benefits that *Valuing People* has brought, it has been a very positive development.

"The Valuing People principles have influenced a person-centred approach to service provision, which has benefited service users, including those with ASD, and enabled choice and independence."

Local authority

"[Valuing People] had some positive impact in general association with the learning disability population."

Local authority

However, for some adults with Asperger syndrome or high-functioning autism, *Valuing People* has actually resulted in further exclusion from services because they are not covered by its remit.

"Initially it served to exclude some adults with ASDs and was used as an argument to do so. This situation has not improved locally."

Local authority

"Asperger syndrome is excluded and this is a key area of service deficit."

Local authority

What indicators apply to people with autism?

There are currently no levers on local services to encourage them to specifically meet the needs of adults with autism. In particular, there are no autism-specific indicators or inspection targets, and this has often been a contributory factor to adults with autism being excluded from local service provision.

The number of targets set by national government for local authorities has been reduced, but there are some opportunities for people with autism to be considered under existing targets. For example, a current Public Service Agreement aims to address social exclusion through improving access to accommodation and employment, education or training, and includes a priority action designed to "ensure specialised support is delivered for at-risk groups."³¹ The action includes the statement that "It will also be important for LDPBs (Learning Disability Partnership Boards) and social care services to consider the wider and more complex needs of those with autism and Asperger syndrome."

Local authorities are inspected to see how well they are meeting the needs of adults in their area in comparison to government targets and desired outcomes for all adults. During the inspection process, targets are often broken down to consider how well different groups of people, for example, those with a learning disability or a mental health problem, are meeting specific outcomes. Unfortunately, there is no group that specifically covers adults with autism, so although some will be covered by the monitoring of people with a learning disability or mental health problem, or through more general questions, in the main, adults with autism are excluded from the benefits brought by inspection. Inevitably, this further increases their exclusion from services and impacts negatively on the nature of the support they receive.

³⁰ House of Commons Parliamentary question (82712), answered by Jacqui Smith on 25 November 2002 (http://www.publications.parliament.uk/pa/cm200203/cmhansrd/vo021125/text/21125w36.htm#21125w36.html_sbhd5)

³¹ HM Government. (2007). *PSA delivery agreement 16: increase the proportions of socially excluded adults in settled accommodation and employment, education or training*, page 7. Norwich: HMSO



What are the views of local services?

Local authorities and primary care trusts both say that the Government needs to do much more to meet the needs of adults with autism. 98% of local authorities believe that the Government could provide them with more assistance to support these individuals. We asked those local authorities that thought the Government could do more, what form this support should take:

- o 64% want specific guidance
- o 91% want additional funding
- o 74% want good practice examples
- o 81% want more autism training in professional development.³²

"Identifying a champion [for people with autism] both at central government level and local level."

Local authority

"A clear logical strategy for ASD."

Local authority

"Specific services are required rather than trying to use the umbrella of mental health or learning disability."

Local authority

"Currently there are no clear directives from central government specifically relating to ASD... it is still not enough."

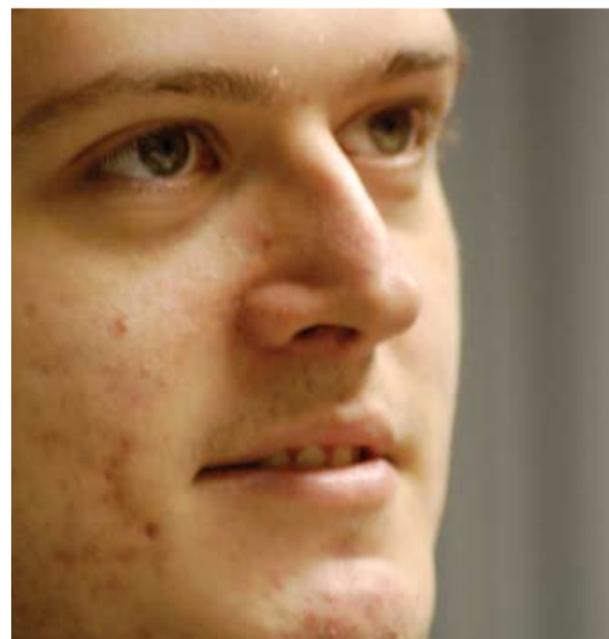
Local authority

"Services do not meet the needs of those who have ASD. Many who do not have a learning disability have no support as adult mental health services do not pick them up."

Local authority

Similarly, 100% of primary care trusts say that the Government could do more to help them support adults with autism. We asked them what the Government should do:

- o 88% want specific guidance
- o 96% want additional funding
- o 88% want good practice examples
- o 75% want more autism training in professional development.³³



³³ The figures in the text for this question are based on the total respondents for the questionnaire rather than those who answered this question. However, excluding those who did not answer the individual parts of this question, 100% of primary care trusts supported each of the suggestions - not one PCT said no to any of the suggestions.

³² The figures in the text for this question are based on the total respondents for the questionnaire rather than those who answered this question. However, excluding those who did not answer the individual parts of this question, these figures increase to: 94% want specific guidance, 98% want additional funding, 95% want good practice examples and 97% want more autism training in professional development.

"Unfortunately, where funding is involved, adults with an ASD still face many challenges, as neither learning disability or adult mental health services have funding available. The solutions are pooled budgets, joint training and good practice forums, closer client involvement and a nominated leader of ASD in the primary care trust and social health."

Primary care trust

We received an emphatic response from both local authorities and primary care trusts. The message from them is clear – more needs to be done by the Government to ensure that adults with autism are able to access the support they need.

The Government should expand capacity, expertise and leadership on autism in the Department of Health.

The Government should ensure that there is regional support to help local authorities and primary care trusts implement good practice.

The Government should issue statutory guidance to local authorities that addresses the barriers that prevent adults with autism from accessing services, and produce good practice commissioning guidance for local authorities.

The Health Select Committee should hold an enquiry into autism.

Mohamed



Mohamed is 22 years old and lives with his mum and dad. While he currently has some support, this has been patchy. He attends a number of youth groups, which provide him with leisure activities and social networks. However, he is concerned about his future, and in particular what will happen once he becomes too old for his existing support networks.

"I go out and about! I'm always busy. I'm going to be upset when I leave [names of schemes] soon... it's certain ages you see... it's going to be hard for me when I leave, either in 2009 or 2010. It's going to be very hard for me.

"I used to have three social workers, but they've all left... The last one left, it was in February last year, she left... I don't know what they're doing now with the social workers. Perhaps they're working with older people, or elderly people...

"I have a friend who's a psychologist who comes to my house sometimes and he asks me questions about things, about this and that, about things what I like to do and what I would like to do in the future... he helps me not to worry too much. You see I've been worried about the future lately. I mean my mum said to me nobody knows what's going to happen in the future... I'd like to leave home in the future, but I'm not ready to leave home yet, I'm too young to leave home... nobody knows what's going to happen in the future... but I'm still worried about the future quite a lot lately..."

Conclusion

The Government has endorsed seven outcomes for all adults.³⁴ These are:

- > improved health and emotional well being
- > improved quality of life
- > making a positive contribution
- > choice and control
- > freedom from discrimination
- > economic well-being
- > personal dignity.

We found that for most adults with autism these outcomes remain a wish-list.

Adults with autism do not have good health and emotional well being:

- 63% do not receive enough support to meet their needs
- 67% have experienced anxiety because of a lack of support
- over 60% of people who feel that they do not have enough support to meet their needs believe that with more support their general health would improve.

Adults with autism do not have a decent quality of life:

- 75% do not have any friends or find it hard or very hard to make friends
- 72% would like to spend more time in the company of other people.

Adults with autism are not given the opportunity to make a positive contribution:

- only 15% are in full time employment
- 66% are not working at all (including in voluntary employment).

Adults with autism do not have choice and control:

- only 14% live in their own flat or house with support
- 37% would like to live in their own flat or house with support
- only 27% have a person-centred plan or care plan.

Adults with autism do not experience freedom from discrimination:³⁵

- 60% have experienced problems trying to receive support from local authorities or health authorities
- 42% of these people were told this was because there were no appropriate services
- over 70% of those who live on their own have been bullied or harassed.

Adults with autism do not have economic well-being:

- over 60% rely on their family for financial support.

Adults with autism do not have personal dignity:

- only 20% of adults are receiving daily living support
- 44% of parents/carers believe that their son or daughter would benefit from this support.

It does not have to be like this. Our report has considered the actions that the Government, local authorities and primary care trusts need to take to make the desired outcomes for all adults a reality for adults with autism.

Think. Act. Transform lives.

³⁴ Department of Health. (2006). *Our health, our care, our say: a new direction for community services*. London: DH
The White Paper endorsed these outcomes as those towards which social care services should be working, with their partners.

³⁵ Defined as "equality of access to services. Not being subject to abuse."

Methodology

The statistics in this report result from research undertaken in 2007. There were four strands to this research, each considered below:

Questionnaire for adults with autism

A questionnaire was produced for adults with autism (18 or over) and their families/carers. There were 1,412 responses from individuals in England.

There were three sections to the questionnaire:

The first section asked for details about the person with autism. These included the age and gender of the person with autism: 68% of the people to which the responses referred were male and 32% female, 36% were between 18-24 years of age, 31% were between 25-39, 30% were between 40-64 and 4% were aged 65 or over. 1,412 people filled in this part of the questionnaire.

The second section was the longest in the questionnaire and asked about the experiences of adults with autism. 1,179 people completed this part of the questionnaire. We encouraged adults with autism to complete this section themselves but parents and carers were also able to help adults to complete it or complete it on their behalf. Of those who responded to this section, 42% were adults with autism who completed this section by themselves, 18% were adults with autism who completed it with support and 40% were parents/carers/others who completed it on behalf of someone with autism. Data that refers to what adults with autism have said is taken from all those who replied to specific questions in this section, so

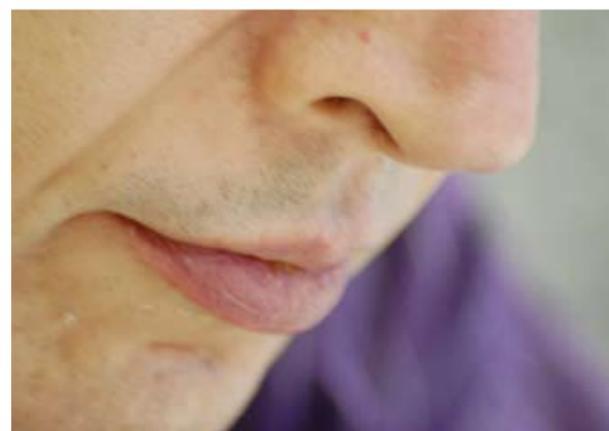
therefore includes the views of parent/carers about the experiences of their son or daughter.

The third section asked parents and carers about their own experiences and their views on the experiences of their son or daughter. 788 people responded to this section of the questionnaire.

The questionnaire was distributed by a variety of means, including being sent to National Autistic Society (NAS) members and organisations on the NAS Autism Services Directory and being available to complete online via the NAS website.

The figures in this report are based on the number of respondents who answered each question in the survey.

The quotes in this report that are from adults with autism and parents and carers are taken from responses to this questionnaire. All 'parent' quotes are from parents of adults with autism.



Questionnaire for local authorities

The figures in this report relating to the views of local authorities are based on a survey of local authorities. A questionnaire was sent to the 150 local authorities with social services responsibilities in England asking about the support and services they provide. 53 responses were received, a response rate of 35%.

Percentages drawn from the survey of local authorities are based on the number of respondents who answered each particular question. Those local authorities who chose not to answer a specific question (non-stated) were not included in the total figures for that question. Any exceptions to this are referenced in the text.

For those figures which excluded the non-stated figures, the non-stated rate varied from 2% to 19%.

Questionnaire for primary care trusts

The figures in this report relating to the views of primary care trusts are based on a survey of primary care trusts. A questionnaire was sent to 148 primary care trusts in England asking about the services and support they provide. 24 responses were received, a response rate of 16%.

Percentages drawn from the survey of primary care trusts are based on the number of respondents who answered each particular question. Those primary care trusts who chose not to answer a specific question (non-stated) were not included in the total figures for that question. Any exceptions to this are referenced in the text.

For those figures which excluded the non-stated figures, the non-stated rate varied from 0% to 21%.

Case studies of adults with autism

The case studies are based on 13 in-depth interviews with adults with autism. These interviews were with people from across the autism spectrum and represent their circumstances at the time the interviews were conducted in 2007.

Glossary of terms

Befriending: a befriender is a trained volunteer who spends time with an individual on a regular basis to enable them to take part in social activities.

Director of Adult Social Services: based within a local authority, the Director has responsibility for the provision of social care for adults. They may also share a number of responsibilities for the commissioning and/or provision of other services within their local authorities.

Learning Disability Partnership Boards: the Valuing People White Paper, the Government's learning disability strategy, includes the establishment of Learning Disability Partnership Boards. These Boards ensure that the strategy is implemented by local authorities in partnership with other organisations in their areas that have a responsibility for helping people with a learning disability. People with a learning disability and their parents/carers should also be encouraged to contribute to the work of the Boards, as well as local independent providers and the voluntary sector.

Local Area Agreements: these set out the priorities over a three year period for a local area, agreed between central government, local authorities and other key partners at the local level.

Local authorities: local authorities run day-to-day services and local matters within their geographical area. In this report, the term 'local authorities' is used to refer to those authorities which have social services responsibilities. Residents often refer to the local authority as "the council".

NHS continuing healthcare: this is the name given to a package of services which is arranged and funded by the NHS for people outside hospital with ongoing health needs. Individuals can receive continuing healthcare in any setting, including their own home or a care home.

Primary care trusts: a primary care trust is the local NHS organisation with overall responsibility for the planning and securing of health services and for improving the health of the people within its area.

Public Service Agreement: this sets out the priorities and indicators against which individual government departments' performances are measured. The Comprehensive Spending Review in October 2007 produced 30 PSAs for the spending period from 2008-2011.

Social groups: groups which enable individuals to meet and take part in social activities in a supported environment.

Social skills training: training which aims to improve an individual's ability to participate in social situations and interact with others.

