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# A life less ordinary

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## **People with autism**

A guide for donors and funders



Lloyds TSB  
**Foundation for Scotland**

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**Cover Photograph supplied by Prior's Court**

# Summary

An estimated one in every hundred people in the UK has autism. This means roughly 540,000 people have problems communicating and interacting with other people. Some will have repetitive behaviours and narrow interests. People with autism are more likely to have sensory problems, learning difficulties, mental health problems and epilepsy.

## Autism and charities

Charities are increasing our understanding of autism; helping individuals with autism; and improving their environment. Although 86% of the sector's funding comes from government, private donors can make contributions that add enormous value to the sector.

## A role of a donor

Donors have many opportunities to improve the lives of people with autism. Finding the best options involves donors asking a number of questions: what type of activity they want to fund, which group they want to help, at what level they want to operate and what issue they want to tackle. Underlying all of this is the need to find effective charities having real impact.

## Helping the individual with autism

**Diagnosis:** The earlier diagnosis occurs the better. Children with autism need specialist help. Without this, they can get stuck in repetitive routines, lose their skills and become depressed and anxious. Diagnosis helps people get their needs recognised so that they are eligible for support. Charities are devising better diagnostic tools to identify more people; they are working with government to improve the process; and they are providing help and advice to parents and individuals along the way.

**Education:** Education is the only intervention commonly accepted as successful for autism. It helps children to overcome impairments and develop strengths. Yet for too many children with autism, school is part of the problem rather than providing the solution. At school they become bullied, excluded and depressed, and they often leave unprepared for later life. Charities are working to improve all points of the system. They are running specialist

schools, training teachers, advising parents and lobbying government.

**Employment:** Only 6% of adults with autism are in full-time employment. While for many people with autism work will never be an option, there are others who are missing out. Lack of employment leaves people poor, depressed and isolated. Charities are preparing people for employment and helping them find and keep jobs.

**Housing and support:** Half of adults with autism are unhappy with where they live. Either people with autism are deemed too capable to require support, or so incapable that they often have little choice over how they live. More effort is spent controlling their behaviour, rather than tackling the root of the problem. Charities are helping people to live how they want to, with the right support and encouragement in place.

**Friends and leisure:** Taking part in social and leisure activities helps people with autism develop skills; enjoy themselves; make friends and feel less isolated. Many people with autism lack the ability to take part in leisure activities to have a fulfilling social life. Charities are helping develop social skills, improve existing social opportunities and run specialist programmes.

### Autism facts

- 540,000 people in the UK are estimated to have autism.
- 40% of children with autism have no friends.
- Only a fifth of teachers working with children with autism have had training.
- A quarter of children with autism are excluded from school.
- Half of adults with autism are unhappy where they live.
- Only 6% of adults with autism are in full-time employment.
- Three fifths of people with autism have a mental illness.
- Just under half of parents of children with autism experience mental distress.
- Autism is estimated to cost the UK £28bn each year.

## Addressing the wider picture

**Families:** Although each family is different, they all have to care for their relative with autism; fight for better services and support; and deal with the emotional impact. Parents of children with autism are twice as likely to have mental health needs than parents in general. Charities help families to cope: providing information and advice; practical help and emotional support.

**Government:** Government plays a central role in people's lives. It is responsible for people's health, safety, education, housing and care. Autism does not fit easily into existing government structures or funding streams and often falls through the gaps. Charities are making sure that government does not overlook autism and has the necessary information and commitment to provide better support and services.

**Public attitudes:** Poor public understanding adds to the challenges that people with autism face. If doctors, police officers, or the general public have little awareness or knowledge of autism, it makes it harder for people with autism to live their lives and be part of their local community. Charities educate people about autism, teaching police officers and GPs about it and how to respond to it.

**Research:** Knowledge is power. Research provides the knowledge to address the effects of autism, ranging from genetic research to developing practical strategies, eg, effective education and employment schemes. Charities not only raise money for high-quality research, but also influence other funders. They improve capacity and communication between researchers and those affected by autism.

**Conclusions:** Arguments can be made for addressing many of the areas in someone's life. However, NPC has identified four priorities where we feel that a donor can have the greatest impact:

- research;
- transition from school to adulthood;
- supporting adults with autism and normal or high IQs; and
- equipping parents and individuals with autism with information and advice.

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# Introduction

## Rachel's story

Rachel is a woman in her thirties with autism and complex needs. Her speech is impaired and she has learning disabilities; often her carers have to interpret her speech.

Rachel lived in a residential home with two other people. Due to her extreme hypersensitivities to sound, Rachel would throw severe tantrums at least four times a week, often lasting five hours at a time. Sometimes her fits were dangerous. She threatened a member of staff with a knife and succeeded in ripping out the toilet fittings. She needed three to five staff caring for her at any one time and was rarely allowed to leave the house.

Fortunately a charity that specialised in supporting people with autism agreed to take Rachel on. They listened to what she had to say and encouraged her to use pictures and videos to express what she wanted. The charity says:

*'We finally heard what she had been telling us for years. Rachel wanted her own home, one where she could have control over the things that caused her so much pain and despair: songs in the 'wrong' key, fans, washing machines, boilers....We can easily control such things by turning them off; a person with autism in a residential setting with other people cannot. Once we listened to Rachel and understood her aspiration to live in her own home, we took the plunge and began the planning process.'*

When the charity had helped Rachel to move into her own home, the impact was huge. In Rachel's own words:

*'At my school the staff used to hold my legs and arms and wouldn't let go. They used to lock me in my room. I moved to my new house. I've got lots of colours and new lights, presents, cards and balloons, a notice board ... I had a house-warming party. I planned it for a year before I moved in. This place makes me happiest. I like it because I can see Thomas the Tank Engine. He lives nearby. I make speeches about my life. I went to Parliament to talk about my house.'*

NPC met Rachel in her house, where she gave us tea and showed us her videos. She only needs one person caring for her now at any one time, and has given 13 speeches on her house at conferences around the country.

## Hussain's story

Hussain is a highly intelligent and engaging man in his early 20s with autism. Hussain has a biology degree from Cambridge University but recently decided to train as a furniture maker. He also has bipolar disorder.

Hussain grew up in Asia, and as a child coped well with his difficulties because he was clever and he was in familiar surroundings. But he always knew he was different: the sound of the school clock was too loud, and he had trouble dealing with large groups of people.

His family moved to England in his teens and Hussain found it difficult to adjust to a new home, new school and new friends. His mental health problems, hitherto quite mild, worsened and he was diagnosed with bipolar disorder. Since diagnosis seven years ago he has seen 17 different psychiatrists.

Simon Baron-Cohen, an expert in autism based at Cambridge University, has diagnosed Hussain with autism. But here in London, Hussain cannot get this diagnosis recognised: his GP refuses to believe him, because he is articulate and well-mannered. His psychiatrist seems only able to acknowledge his bipolar disorder.

Hussain is convinced he has Asperger syndrome: he always eats the same food; he craves familiarity and order. He has difficulty filtering sights and sounds and opted to work in furniture making because it is quiet and focused. Socially he appears well adapted, but he works extremely hard to keep up: he has to consciously interpret all the visual cues and decide how to react. Hussain says: *'When I go to the pub I see people chatting, making small talk, and it is like there is this invisible ether between them. I just don't get it. I can't be part of it.'*

Taking everything at face value, he is naïve and trusting. He offered a cigarette to a gang of youths and they nearly drowned him in a canal. He has been conned out of money by 'friends'. Each traumatic saga lands him in a psychiatric unit.

Hussain is an example of someone who has had considerable difficulty getting the support and help that he needs and which would massively improve the quality of his life. Difficulties over his diagnosis and his high IQ and obvious abilities mean that few sources of support are available to him. Often he has to make his way alone, without anyone to ask for advice.

### Daniel's story

Daniel is a 15-year-old boy with autism and behavioural problems. He was diagnosed when five years old. He was unable to speak and had very challenging and aggressive behaviour.

His father left the family when Daniel was seven, and he lives with his mother and two older sisters. Often they were unable to cope with his aggression and he would punch and bite his sisters. He also had difficulty using the toilet and would smear faeces on the wall. When he was upset he would run away from home.

As Daniel grew older and bigger his family found it harder to deal with his behaviour. When he was twelve he was attacked by a man in the park, and as a result was reluctant to leave the house. When he was not at the local special needs school he stayed in his room drawing. He was isolated and depressed.

A local charity was asked to help and provided a volunteer to help the family and Daniel. The volunteer was able to build up a relationship with Daniel, taking him out to play football and go to the cinema. This also gave Daniel's mother time to spend with her daughters.

Overtime the family noticed a huge change in Daniel. They felt his communication and self-confidence improved a great deal as did his ability to form friendships and independence.

The family say:

*'Everyone has benefited as it made the family happy to see Daniel happy. He has more confidence when going out in the community now and isn't as nervous or as anxious when out.'*

### The purpose of this report

At first glance, Hussain, Rachel and Daniel look very different. However, putting aside their different skills and different opportunities, their lives have been indelibly shaped by having autism.

Autism does not automatically consign a person to loneliness, joblessness, mental health problems and poverty, yet people with autism often end up like this. The situation for people with autism and their families is often dire; with an estimated one person in every hundred suffering from autism, the cost to society is huge. The question is, why? And then, what can be done about it?

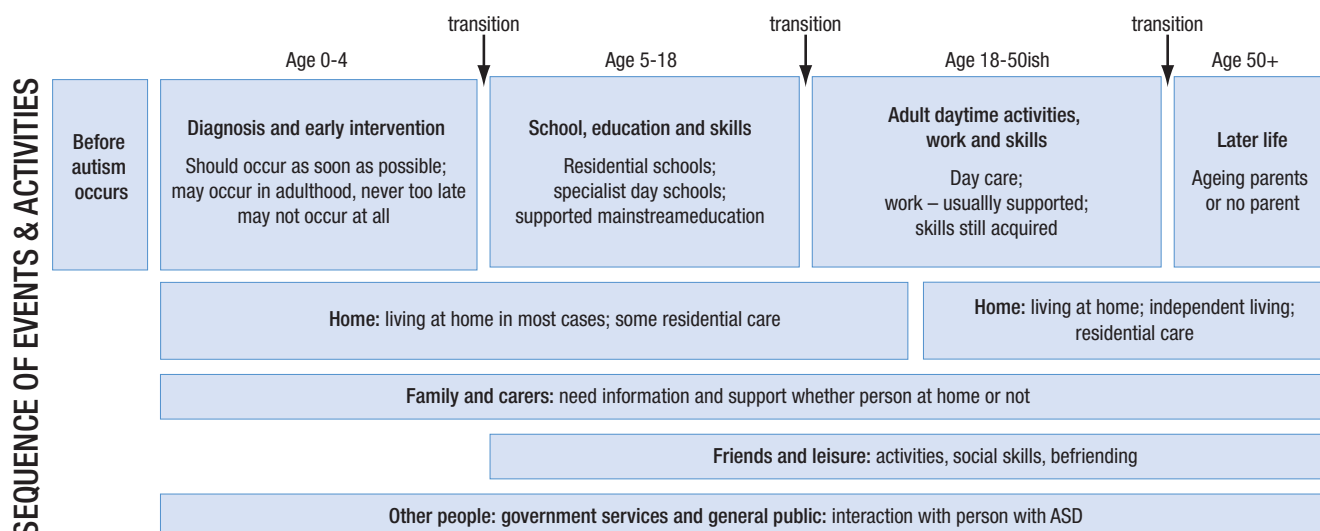
This report helps donors and funders to think about the role that they can play. It looks at the opportunities for private philanthropy and how this fits in within government funding. It helps donors to think about what makes an effective autism charity and what they can achieve with their money.

Figure 1 shows a person's needs as their life progresses. There is ample scope for private philanthropy. This report outlines why donors should care about autism; what charities are achieving; and where private money can make the most impact. As we have seen with Rachel and Daniel, charities can play a significant role. For those, like Hussain, who do not have access to this support, life is harder.

### Scope and content

The scope of this report is extremely broad. It includes everyone with autism, from those with very complex needs like Rachel, to those with a normal or high IQ, such as Hussain. It looks at the needs of infants, as well as those of older people, and all the points in between. It considers charities that work directly with

Figure 1: Diagram showing areas of need





individuals or their families. It also considers charities influencing services and government, and carrying out research.

The charities that this report identifies come from across the UK. However, the focus has been on England, Scotland and Wales.

## Structure

This report traces a path through the different issues that confront people with autism over their lifetime. It looks at the ways that charities are meeting their needs and the role that private philanthropy can play in improving the lives of people with autism, and all those affected by the condition.

### Section 1: Background

Section 1 provides a brief account of ASD: what autism is; how many people are affected; who has it; and what it means for them and others.

### Section 2: Charities and the autism sector

This explains the history of the autism sector, and how it is structured. It identifies different types of charities and interesting characteristics of the sector as a whole.

### Section 3: What should a donor fund?

This section looks at the specific role that a donor can play within the sector, and what types of questions should be asked when allocating private philanthropy.

### Sections 4 to 11

Having discussed the underlying themes and issues, the report then looks at the specific needs, and picks up the story of people's lives. Each of the next eight sections asks the following key questions.

- Why should a donor care about the issue?
- What is happening now?
- What are charities doing about it?
- What can donors fund?

Each section focuses on the work of charities, and explores the impact that they are having.

### Section 4: First steps

Section 4 begins with the process of **diagnosis**, the initial information that people with autism and their parents get. This is the start of the journey.

### Section 5: Education

The first stop on the journey is **education**, and this section looks at schools and educational techniques and the role they play in the development of children with autism. It also covers the transition to adult services.

### Section 6: Skills and work

Many adults with autism will leave education wanting a job, yet face several barriers to entering the workforce. The support they receive to get into **employment** and stay there is vital.

### Section 7: Home

Also when people leave school the question arises: where do they live? Where will be **home**? If they have particular care needs, who is going to provide them? If they need help to access the community, who is going to give it to them?

### Section 8: Friends and leisure

People with autism may want to participate in society in other ways. **Friends and leisure** are important here.

### Section 9: Family

The focus of the report then draws back from the individual to look at what happens to the **family**, and the impact of having a relative with autism.

### Section 10: Government and public attitudes

A section on **government** is necessary to explain how the work of charities fits with government policy, at both local and national levels. This section also looks at **public attitudes**.

### Section 11: Research

The report finishes by looking at **research** and what is being done to understand, treat and support this condition.

### Section 12: Conclusion

This summarises the funding options for donors and guides them in deciding what to prioritise.

# Background

One in every hundred people is estimated to have autism—roughly 540,000 people in the UK.

An estimated one in every hundred people in the UK has autism. This means roughly 540,000 people will have problems communicating, interacting with other people, and some will have repetitive behaviours and narrow interests. In addition, people with autism are more likely to have sensory problems, learning difficulties and epilepsy.

Autism has a significant impact on people's lives: only 6% of people with autism are in full-time employment;<sup>8</sup> 61% develop mental health problems;<sup>9</sup> 40% of children have no friends;<sup>10</sup> and 27% have been excluded from school.<sup>11</sup> Family life is also disrupted, with 44% of parents of children with autism experiencing mental distress.<sup>10</sup> The aggregate national cost of autism to the UK is estimated at £28bn.<sup>12</sup>

NPC's research found that it does not have to be like this. There are a number of effective methods that improve the quality of life for people with autism. Yet few people have access to this support. Instead, people with autism either fall through the gaps, or get inadequate and inappropriate support. Services are sometimes more concerned with containing and controlling people with autism, rather than allowing them to develop their own skills and capabilities.

Government, the private sector, charities and donors all have an important role to play in improving the lives of people with autism. While government provides the bulk of the money going into the sector, there is still a vital role for private funding. It allows charities to think strategically and flexibly, developing new services, sharing good practice, and helping families, government and the general public to support more people with autism.

## Box 1: 'Triad of impairments'

The 'triad of impairments' is a concept put forward in the 1970s by Lorna Wing and Judith Gould.<sup>7</sup> It identifies three areas of behaviour where people with autism have difficulties.

**Communication**, such as inability to speak, monotonous intonation and a literal interpretation of words.

**Social interaction**, including an inability to read facial expressions or body language, poor eye contact, and difficulty understanding basic social rules.

**Mental flexibility and creativity**, such as lack of imagination, inability to understand other people's emotions and repetitive behaviours.

## What is autism?

There is no physical test for autism: no blood test or brain scan that can show whether someone has autism, or how severe the condition is. Instead it is diagnosed through people's behaviour, specifically the problems they have with communication, social interaction and imagination (see Box 1).

Autism is a spectrum condition, which means that, while everyone shares the same basic types of impairments, the severity and the nature of these symptoms vary for each individual. Difficulties with communication can range from not being able to speak, to monotonous intonation and a very literal interpretation of language. Telling people with autism to 'pull their socks up', may mean that they actually physically pull up their socks.

Each person with autism will have a unique combination of strengths and impairments. For example, a PhD student might not be able to use the washing machine; a child who cannot speak may be able to spot complex patterns.

Some people even feel that talking of a spectrum is too prescriptive: as one expert says:

*'The word autism describes a constellation of behavioural attributes that are really quite diverse. In fact, the borders are so obscure that no one can be sure where the centre is. Beyond the definitions that are given for the syndrome, there is little one can say for autism as an homogenous or biologically meaningful disorder.'*<sup>13</sup>

There are attempts to break down this broad spectrum into recognisable and manageable sub-types. International diagnostic criteria break autism down into five different autistic spectrum disorders (ASDs), which include childhood autism or Asperger syndrome (see Box 2). Yet whether these divisions stand up to scrutiny, and how useful they are is disputed. Experts still debate about where the spectrum ends, or how distinct Asperger syndrome is from childhood autism.<sup>14,15</sup>

Another way that people divide the autism community is into 'high-functioning autism' or 'low-functioning autism'. Normally this is done on the basis of IQ; anyone with an IQ below 70 is defined as low-functioning, while those with an IQ above 70 are high-functioning. Sometimes it is based on language skills. It is thought that these two groups will often have distinct social, educational, occupational and residential needs.<sup>16</sup>



Others find this division unhelpful, offensive and misleading. By labelling someone as high-functioning because of their IQ, it may prevent them from getting support for their crippling social and communication problems. A label of low-functioning may mean a person's abilities and potential are overlooked. Adults with autism who are considered to be high-functioning have reported a lower quality of life than those with learning disabilities.<sup>17</sup>

Instead, some people prefer talking about people with autism and more complex needs. This can include learning disabilities, but puts the emphasis on their support needs, such as mental health and social problems.

### Associated conditions

As well as learning difficulties, people with autism are more likely to experience other physical and psychological problems. By adulthood, around a third of people with autism will have developed epilepsy.<sup>18</sup> There is also a suspected link with gastro-intestinal problems.<sup>19</sup>

They often experience extreme sensory problems. With autism, the brain seems unable to balance the senses appropriately. Some children with autism are oblivious to extreme cold or pain. A child may fall and break an arm, yet never cry, while the ticking of a clock can be as distracting as a fire alarm and clothes can feel like sandpaper.

Studies also suggest that 61% of people with autism have mental health problems.<sup>9</sup> Whether this is due to genetic susceptibility or as a result of the strain of the condition remains unknown.<sup>20</sup>

### How many people have autism?

One of the key debates in the sector is just how many people have autism and whether this number is growing. At the time of writing, the widely accepted prevalence rate is 1%. This is based on both a survey by the Office of National Statistics and a recent large-scale study of a population of children between the ages of nine and ten.<sup>10, 21</sup>

Extrapolating these figures to the whole UK population would mean that there are around 540,000 people with autism. Based on 2005 UK population figures, this means that there are 107,000 children under 18, and 433,000 adults with the condition.

These numbers are significantly higher than previous estimates.<sup>22</sup> Newspapers often speak of a 'hidden epidemic' that is engulfing the children of the UK. Pollution, the measles, mumps and rubella vaccination (MMR), older fathers and pesticides have all been suggested as a potential factor.<sup>23-25</sup>

#### Box 2: The different autistic spectrum disorders (ASDs)

There are two main diagnostic criteria for autism, one produced by the World Health Organisations and the other by the American Psychiatric Association.<sup>46,47</sup> Although they use slightly different names (reflected in the brackets below) they are largely identical.

When someone has **childhood autism** (or **classic autism**), they have a moderate to severe range of communication, socialisation and behavioural problems that are apparent before the age of three years. Roughly three quarters will also have a learning disability, so an IQ below 70.

**Asperger syndrome** (or **Asperger's disorder**) is characterised by problems with social interaction and stereotyped, repetitive interests and activities. There is no general language delay, but there may be difficulties understanding the subtleties used in conversation like irony or humour. Most individuals will have average or above average intelligence.

When someone has impaired social and communication skills and/or behavioural problems, but does not fully meet the criteria for any of the other conditions they can be diagnosed with **atypical autism** (or **Permanent Developmental Disorder-Not otherwise specified—PDD-NOS**).

Two other conditions that also come under the banner of ASD are:

**Rett syndrome** (or **Rett's disorder**) is diagnosed primarily in females. After a period of normal development, symptoms become apparent between the age of six and eighteen months. These include a loss of abilities, such as walking and speech, and the development of repetitive behaviour. It affects one out of 10,000 to 15,000 people.

Children with **Childhood Disintegrative Disorder (CDD)** develop normally for the first two years of life, and then before the age of ten they experience severe regression of skills, such as the ability to move, bowel control and language skills. It is very rare and research suggests that it affects fewer than two children per 100,000.

Some suggest that the increase in numbers is better explained through a broader definition of autism and better identification and diagnostic processes.<sup>26, 27</sup> The debate is still ongoing and is unlikely to be settled in the near future.

Studies differ considerably on the breakdown of this group. It is currently thought that 45% of this total group will have an IQ above 70.<sup>21</sup> Figure 2 shows a rough estimation of how people with autism are divided between those with an average IQ and those with learning disabilities, and whether they are children or adults.

Figure 2: Estimated breakdown of UK population with autism<sup>12</sup>

107,000 children		433,000 adults	
<b>48,000 children</b> 100% live at home		<b>195,000 adults</b> 79% live in private households 16% live in residential care 5% live in supported accommodation	45% of people with autism have an IQ above 70 = 243,000
<b>59,000 children</b> 98% live at home 2% live in residential placements		<b>238,000 adults</b> 52% live in residential care 35% live in private household (normally with parents) 7% live in supported accommodation 6% live in hospital	55% of people with autism have an IQ below 70 = 297,000

People with autism are more likely to have sensory issues, learning disabilities, mental health problems and epilepsy.

“To me the outside world is totally baffling incomprehensible mayhem which terrifies me.”

Person with autism<sup>114</sup>

## Who has autism?

One half of the population is much more likely to have autism than the other half. For every woman who is diagnosed autism, there are around four or five men. Autism has been called ‘extreme male brain’.<sup>28</sup> However, for some reason there are proportionately more women with classic autism. With Asperger syndrome the ratio is closer to 8:1.

Several ideas have been proposed for this. These include the role sex hormones play during pregnancy and autism’s genetic component being located on the X-chromosome.<sup>28, 29</sup>

Another theory is that more girls have autism than is commonly thought, but they are just better at hiding it. Better at mimicking other people and unlikely to become aggressive and violent, they are more prone to turn inwards and develop problems like self-harming or anorexia.<sup>30</sup>

No other group is clearly more susceptible to autism. When autism was first identified by Leo Kanner in 1943, he stated that parents of children with autism are more likely to be in a high socio-economic class.<sup>31</sup> This is not the case. It is likely that children of middle-class families are more visible, since their families have the time and the resources to fight for services and raise awareness.

There is also the question of ethnicity. We know that autism has an important genetic component. However, there has been no comparative research between ethnicities. Differences in autism rates in specific countries could be down to different diagnostic mechanisms or ranging levels of access to diagnosis.



Photograph supplied by Autism Speaks

While people from black and ethnic minority (BME) groups in the UK are not more prone to autism, they are much less likely to have access to help and support. This is partly due to difficulties with English, poor knowledge of autism, and a cultural tradition of keeping disabilities hidden.

## What causes autism?

One of the first explanations for autism was parental neglect.<sup>32</sup> ‘Refrigerator mothers’ (normally those who had a job) denied their children the love and attention they needed. Fortunately, this theory has been debunked. Instead, scientists look towards genetic and environmental factors.

The existence of a genetic component to autism is clear. If an identical twin has classic autism, there is a 60% chance that the other twin will too. This increases to 92% if you include the whole autistic spectrum. For non-identical twins, the likelihood is 10%, while for siblings this drops to 6–8%.<sup>33</sup> This is still considerably higher than the risk to the general population.

In a minority of cases (roughly 6–10%), the causes of autism can be traced to an identifiable medical condition. Normally this is a single gene disorder such as Fragile X Syndrome or tuberous sclerosis.<sup>22</sup> Yet in the vast majority of cases, the current consensus is that several genes may interact to create the susceptibility to autism.<sup>34</sup>

While genes are important, they do not necessarily tell the full story. Identical twins, who share the same DNA, do not always both have autism. There may also be an environmental component that contributes to someone developing autism, or triggers a genetic response.

What a possible environmental trigger could be is uncertain. It possibly occurs during a key moment of mental development, although experts disagree over the exact timing. Different theories cite sex hormones, viruses, heavy metals or carbon monoxide as contributory factors.

## The impact of autism

While little is understood about its causes, more is known about the profound impact that autism has, both on the lives of the people with the condition and their families. Attempts have also been made to spell out the greater costs to society and the state.

### Individuals

Each individual experiences autism differently. However, everyone with autism will have a different perception and understanding of the world.

Common symptoms include:

- difficulties speaking or repetitive use of language;
- difficulty understanding other people's emotions, body language or facial expressions;
- limited interests and preoccupation with certain topics, such as train schedules or computers; and
- a need for sameness and routines.

On top of this, people with autism often have additional challenges, such as sensory problems, learning disabilities or a medical condition like epilepsy.

All of these issues can have a serious impact on an individual's quality of life. For many the world is constantly confusing and makes little sense; the things people say and do seem random and unexpected. People with autism can often put themselves in dangerous or vulnerable situations, for example stepping out into a busy road or trusting strangers. People with complex needs may be unable to care for themselves or carry out basic tasks.

Some people with autism and their families also point to the benefits of their condition. They see autism as simply another way of seeing the world rather than a disease. They highlight strengths such as their intense focus, truthfulness and eye for detail.

However their impairments can still stop people with autism from getting health and education services and going out and taking part in their local community. Leisure centres can be too loud or bright, people's attitudes can be hostile and unforgiving. Repetitive behaviour and preoccupations can make it harder to fit into a job.

## Families

Autism also affects families. They are much more likely to be poor, separated, unemployed and have mental health problems. This is partly due to the challenges of dealing with a person with autism. Families also have to come to terms with having a family member with autism. Many families receive little practical, financial or emotional support, face constant struggles to access services and have few breaks.

## Community

People with autism are often excluded from their wider community. The local environment can exacerbate their sensory problems, while people's attitudes and behaviour can be distressing and confusing. In a very small number of cases and without getting the right support, people with autism can end up exhibiting anti-social behaviour, such as aggression or even arson.

Companies miss out on employing talented and committed individuals. The community as a whole suffers from a lack of understanding and diversity.

## Society

A recent report has looked at the economic consequences of autism for the UK as a whole. It puts the aggregate national cost of autism at just under £28bn each year. The lifetime cost of each individual with high-functioning autism is £3.1m, which rises to £4.6m for someone with low-functioning autism.<sup>12</sup>

The national costs of supporting children with autism each year is estimated at £2.7bn, mainly for their education. The £25bn annual costs for adults is divided into £15bn for providing services, and a further £9.2bn for lost employment. The remainder is put down to family expenses.

These considerable costs are based on estimates of what is being spent, not what should be. The possibility that these figures can be reduced by providing better and earlier support is tantalising on both an economic and an emotional level.

## What can be done?

Work in three main areas can improve the quality of life for people with autism:

- understanding autism better;
- addressing the needs of individuals with autism; and
- improving their surroundings.

## Understanding autism better

There is still a basic lack of understanding about autism: what causes it; how it influences brain development and function; and its interaction with other physical and mental

The causes of autism are still unclear; the impact is not.

Photograph supplied by Autism Initiatives



“We have tried everything: chelation, diets, and therapies of every sort. Fortunately our son has progressed, but we have no idea why. Is he just growing up? Or has one of our interventions had a special impact on him? We have no idea, and research tells us little.”

Parent of child with autism<sup>140</sup>

conditions. This has impeded the development of effective approaches that can help minimise the negative impact that autism can have.

Each year throws up another theory, relying mainly on hearsay and hope, rather than any lasting scientific research: Auditory Integration Therapy; Son-Rise Programme; chelation therapy to remove heavy metals from the body; facilitated communication; and dietary interventions. All of these promise to tackle the root causes of autism. Few have any scientific basis. None has any scientific backing, and some are actually harmful.

### Addressing the needs of the individual

All people with autism will need some form of support and help at some point in their lives, whether it is a tailored education or specialist employment advice. The quality and the consistency of this support will have a significant impact on an individual's quality of life and future prospects.

There are two main ways of providing direct support:

- addressing impairments and building on strengths; and
- tackling the secondary problems that arise from autism.

### Addressing the core impairments

People with autism process information in a distinct way, which often leads to unusual behaviour such as repetitiveness or being gifted in narrow fields. This accompanies an absence of usual development, such as instinctive social behaviour, language and communication.

There are a number of approaches and interventions that target these problems and help people to learn the skills to overcome them. These range from specific tools, such as the Picture Exchange Communication System (PECS) or social stories, to more complex educational approaches like TEACCH or Applied Behavioural Analysis (ABA). (See Section 5 for more details.)

Specific deficits, such as an inability to recognise facial expressions, can be taught through computer programs. Attempts can be made to break repetitive thought and behaviour through cognitive therapy, interaction and supported play.

### Tackling associated issues

Many people with autism will experience further problems due to their impairments and the lack of support and services currently available for them. This can range from mental illness to poor employment prospects.

They will need support and help targeted at those issues, which still takes their autism into

account. When people with autism receive counselling for depression and anxiety it should reflect their specific needs; likewise when they receive employment support.

### Addressing their surroundings

Many of the issues that face people with autism arise from the environment around them: how other people treat them; sounds and lights; the structures and rules that shape their lives.

Evidence from people with autism suggests that the most important factors they require from the world around them are:

- structure and predictability;
- low arousal levels; and
- informed assistance and support.

This is not as drastic as it sounds. A lot of problems merely require a change of attitudes and a better understanding of autism. Ensuring that carers are properly trained; that people have control over where they are and how they live; that teachers understand autism. All these steps would be a tremendous help. Changing the design of some buildings or modifying existing ones, for instance, including quiet rooms for people to rest in when they are stressed, may also help.

### What works?

Autism research can be difficult to carry out and rarely produces conclusive results. While there are strict scientific criteria for genetic research or brain scans, research into interventions or educational and behavioural approaches is much harder to do. It is difficult to isolate the particular impact that programmes have, as distinct from dietary changes, medication or just simply growing up.

To counter this, scientific studies usually require a large sample size, large-scale longitudinal studies, and control groups. This is expensive and time-consuming to do. There are also serious ethical issues surrounding using a control group.

Much of the research being done does not meet basic experimental criteria. The recent New York Health State Department Review of interventions for pre-school children highlights that only around 8% of 400 articles met basic scientific criteria.<sup>35</sup>

This is not to say that there are no indications of what works. Enough rigorous research has been done to provide the basis of an opinion. For example, we know that a supported employment programme produces better results than letting people battle on alone. We know that a structured education programme can help people to learn new skills and develop their capabilities.

The rest of the report will discuss in more detail the evidence and impact of different interventions.



## Who is involved?

Government, the private sector, charities and donors are all involved in providing services, carrying out research and supporting people with autism and their families

### Government

Government has the main responsibility to meet many of the needs of people with autism. This includes school fees, extra support costs and benefits, many of which are set out in a range of legislation, national policy and white papers.

Government funding for autism is channelled through central government departments and local authorities. For example, while housing benefits come directly from the Department of Work and Pensions it is the local educational authority (LEA) who is responsible for dispersing money to schools.

Having autism does not automatically make someone eligible for government support. Instead, eligibility for different services is judged on the basis of need. Normally it is people with autism and complex needs, such as learning disabilities or mental health problems, who receive the bulk of support. Although government then provides the funding, it does not always directly manage service provision. This can be outsourced to charities or even the private sector. See Section 10 for a more detailed look at government.

### Private sector

Private companies, such as the Priory Group, are playing an increasing role in the sector. This includes running schools, care homes and mental health hospitals.

The bulk of these services are paid for by the government. However, there is also the option for the costs to be met by the individual or the family. For smaller services, like play schemes or leisure activities, this is normally the case.

### Charities

Charities play a key role in the autism sector. They are an important source of expertise and experience. Much of the specialist autism provision that government provides is delivered through charities.

On top of this statutory work, charities use their experience to fulfil a wide range of charitable objectives. The next section, on charities and the autism sector, will look at this work in more detail.

“Autism is both a disability and a difference. We need to find ways of alleviating the disability while respecting and valuing the difference.”

Professor Simon Baron-Cohen<sup>139</sup>



# Charities and the autism sector

Charities that started as small parent-led organisations have now grown into multi-million pound service providers.

## History of the sector

Autism was first 'discovered' in 1943, but took a long time to be properly understood. Until the 1960s, cold or bad 'refrigerator' mothers were blamed for the condition. Asperger syndrome was only widely accepted by society as a condition in the 1990s.

Many autism charities have their roots in parents who formed small groups in the 1970s and 1980s to educate their children and then to house them as they grew up. Specialist services are still under-developed and reach what appears to NPC to be only a small proportion of those affected.

## Role of the charities

Charities are often at the forefront of the autism sector. The voluntary sector was one of the first to draw attention to the condition and has developed into an important source of expertise and experience. It fulfils a number of key roles, which include:

- delivering government services;
- providing training;
- developing innovative projects and pilots;
- funding and providing services not covered by government;
- improving communication and discussion in the sector;
- helping individuals and their families to campaign for better services; and
- lobbying and campaigning with government at all levels.

The rest of this report will look in more detail at these different roles. However, it is useful for a donor first to understand the structure of the sector and the different types of autism charities that exist.

## Structure of the charity sector

Table 1 shows the structure of the charity sector, the size of charities and what they cover. NPC consulted Guidestar UK, an online directory of UK charities, and found just over 250 charities that listed autism in their objectives. However, many of these were general disability charities that include people with autism in their services.

## National charities

The **National Autistic Society (NAS)** is the main autism charity in the UK. Founded by a group of parents in 1962, it was the first national society for autism in the world. Today it has an annual income of over £80m.

The main focus of the NAS's activities is services paid for by government. These include six schools and residential and supported living services. Ninety per cent of its income comes from providing these services. The NAS also provides services that are not funded by government, such as advice and support to parents, campaigning and lobbying, and training.

The NAS has also established the Autism Accreditation scheme. This is the only internationally recognized accreditation scheme running in the UK. It provides a quality assurance programme for over 300 organisations, including local authorities, NHS trusts, and local autistic societies.

Over the years, the NAS has become increasingly professionalised. As the original parents became less involved, it moved into campaigning and policy work in the late 1990s.

While the NAS has a presence in each of the different nations in the UK, there are also specific national charities. These are: the **Scottish Society for Autism**, **Autism Northern Ireland** and **Autism Cymru**. While the Scottish Society for Autism shares the model of the National Autistic Society, both Autism Cymru and Autism Northern Ireland have taken a different path. Instead of providing services they work at a strategic level, often focusing on devolved national governments.

The three national charities from Scotland, Wales and Northern Ireland have recently formed the **Celtic Nations Autism Partnership** to share best practice and experience, knowledge and skills across each of the devolved governments. It looks to promote the development of national policies and programmes to support individuals and families living with autism.



**Table 1: Different types of charity working in the autism sector**

Type of charity	Services to individuals: care; education; housing; day care and activities	Family and carers: support and information for families and individuals	Policy and campaigning	Research
<b>National Autistic Society (NAS)</b> founded in 1962. Income of around £80m (2006). A member organisation with 17,500 members and 61 local branches. It has local branches and projects that vary, but can offer everything from education to housing and day care, mostly paid for by the state. Its services are spread across much, but not all, of the UK. Its campaigning work is paid for by private donors, as are 'soft services' such as befriending schemes, supported employment and social skills.	✓	✓	✓	✓
<b>Large regional autistic societies</b> eg, Autism West Midlands, Autism Initiatives. Five have an income of £5m–£15m; ten have an income of £1m–£5m. Independent of the NAS. Larger charities deliver a full range of education, housing, day care, mostly paid for by the state. Smaller charities specialise in particular services. Some regional charities also have other projects (not necessarily paid for by the state), eg, supported employment or social skills.	✓	✓		
<b>Charities addressing particular issues</b> Education charities, most of whom run a special school, eg, Treehouse, Prior's Court. Specialist housing and support charities eg, Kingwood. Nation specific campaigning charities, eg, Autism Cymru	✓	✓	✓	
<b>Small local charities</b> (income < £1m) eg, Resources for Autism. Many smaller initiatives fill in the gaps not met by the state or the bigger organisations, eg, parent support groups, small locally run play schemes. Some are tiny. This part of the sector is quite fragmented.	✓	✓		
<b>Research charities</b> Two main charities are Autism Speaks and Research Autism, with a combined income < £1m.				✓
<b>Disability charities</b> Disability charities often find people with autism form a sizeable proportion of the users. 17% of Contact a Family's enquiries are related to autism. 30% of enquiries for Sibs are related to autism.	✓	✓	✓	

The combined income of the top 50 charities in the autism sector is over £175m.

Little voluntary funding goes to the sector: just £22 for every person with autism.

## Regional charities

There are a number of large regional charities across the UK. These include charities such as **Autism West Midlands**, the **Wessex Autistic Society** and **Essex Autistic Society**. They generally arose through dissatisfaction with local services, and normally started with a school, then, as the original children grew up, they started providing residential housing and diversifying.

Scotland also has regional charities, such as the **West Lothian Autistic Society**, **Strathclyde Autistic Society** and the **Grampian Autistic Society**. However, these have a limited income and their services are largely restricted to play groups, social activities and respite care. Wales and Northern Ireland do not have any large regional charities.

Because of their core business of schools and housing, many of these major charities look the same. They all have an income between £1m–£15m, of which about 90% comes from the government in the form of school and residential fees.

Some of these regional charities have grown beyond their initial geographical focus. The main example of this is **Autism Initiatives**, which used to be the Liverpool and Lancashire Autistic Society. It now has a presence in Scotland, Northern Ireland and is expanding into Wales. It has an annual income of around £11.5m.

Within each region, the National Autistic Society runs a network called Partners in Autism. This brings together representatives of the voluntary, public and private sector.

A number of regional charities have also grouped together to form **Autism Alliance UK** in order to share their experiences and expertise. This also includes the Scottish Society for Autism.

## Issue focused charities

There are also a number of charities that focus on a particular issue and area of expertise. For example, both **TreeHouse** and **Prior's Court** focus on improving education, while **Autism Speaks** and **Research Autism** concentrate on research issues.

## Local charities

Below this are a number of smaller charities, which range in size from city-based charities, such as the **Autistic Society Greater Manchester Area (ASGMA)** to small parents' groups or nursery schools. These normally provide an ad hoc number of services, or concentrate on a particular issue. For example, **Resources for Autism** in Barnet, North London concentrates on providing play groups and social activities.

## General disability charities

Other charities are not autism specific, but provide services for people with autism as part of their wider remit. NPC identified several disabled children's charities that offer services to children with autism and their families. There are 700,000 disabled children in the UK, which suggests that children with autism might account for around 20% of the users of general disabled children's charities. One charity indicated that the autism group was disproportionately represented: 30% of its families had children with autism. NPC's report into disabled children, *Ordinary lives*, provides examples of the work of many of these charities.<sup>36</sup>

There are also adult disability charities, such as the **Disability Law Service**, the **Disabilities Trust** and **Mencap**, which are all involved with people with autism.

## Funding for autism charities

NPC identified over 50 charities with income over £25,000 that specialise in autism. NPC used data from Guidestar UK, combined with the latest accounts available from the Charity Commission, to analyse how these charities are funded. Most accounts were for the financial year 2005 or 2006. Total income for these charities amounted to just over £175m.

### Dominated by statutory funding

Although on average government accounts for 86% of the sector's income, many of the 'service delivery' charities receive over 90% of their income from local authorities (LAs) or primary care trusts (PCTs).

The vast majority of regular government funding to autism charities goes towards:

- special school fees; and
- housing and support services.

The funding is often on a per person basis, and provided under service level agreements. The eligibility criteria and how this funding is distributed vary between different local authorities. It is normally only people with autism and complex needs, such as learning disabilities or mental health problems, who qualify for these services.

Often there is little expertise or strategic thinking that underpins the allocation of these resources. Instead of basing funding decisions on outcomes, local commissioners often decide it on immediate concerns over costs.

Autism charities also receive government funding for:

- providing training;
- running employment programmes;
- family support;
- research;
- information; and
- leisure activities.

However, there is little statutory obligation to provide these services, so funding is often limited and sporadic.

### Little voluntary funding

There is little voluntary funding currently going into the autism sector. In 2005-6 NPC judged it to make up only 7% of the income—£12.7m. This is considerably less than other sectors. This equates to about £22 for each person with autism. Voluntary donations in the last decade have been dominated by the Shirley Foundation, estimated at £35m-£50m cumulatively.

In 2006, the combined income of the three largest children's cancer charities totalled around £39m. Nearly all of this funding came from voluntary sources. These charities cater for around 11,000–12,000 children with cancer: around £2,500–£3,000 per child. Figure 3 shows this graphically.

It is difficult to prioritise giving to a cancer charity or autism charity on an emotional, practical or financial level. However it does seem striking though that a hundred times more money is given to a child with cancer compared to a child with autism.

The reasons why autism attracts such little funding have not been analysed. NPC can only speculate that autism has a low public profile, is not easily comprehensible and is not something that people fear they will develop.

### Other striking characteristics of the autism sector

The sector has a number of characteristics that donors need to be aware of when looking at funding alternatives.

#### Autism charities provide few people with direct services

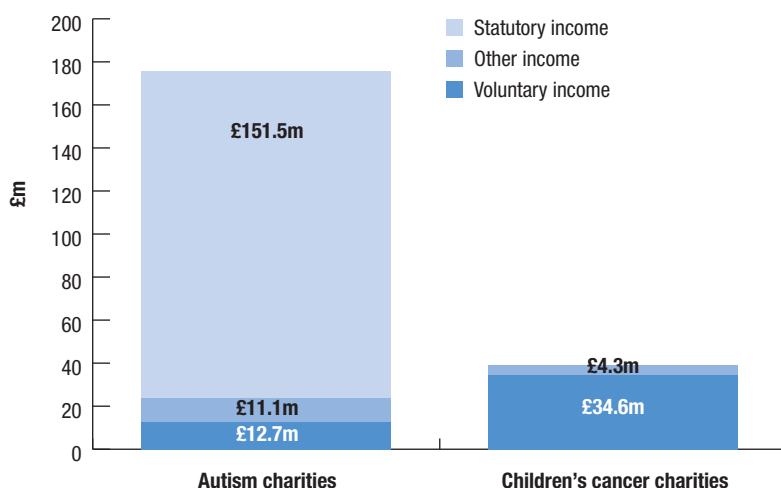
There are few specialist autism charities. Although often these charities have considerable incomes (see Table 1) they are only able to reach a small number of people. Specialist autism schools normally teach around 30 pupils; specialist employment services have roughly 60 people on their books.

Partly this is because of the high costs involved, residential school fees can be as much as £120,000 a year, while the costs of housing and supporting an adult with particularly complex needs can rise to £500,000 a year. Government often prefers to fund cheaper generic placements within their own services, or general disabled charities. They do not necessarily have the expertise to offer effective support to people with autism.

The majority of people with autism will not need special services, and could be supported within mainstream education, health and other services if these services knew how to cope.

Supporting a person with autism can cost as much as £500,000 a year.

**Figure 3: Comparing sources of funding for autism and children's cancer charities**



**Growing professionalism**

There has been a growing trend of professionalism in the autism sector. Many of the major charities were set up by parents and with minimal organisational structures. In the face of increasing government contracts, a high turnover, and a large number of staff, charities that provide services have had to adapt to their new circumstances.

The major regional and national autism charities have become more business-like in their approach. There have been challenges in negotiating this shift.

**Poor coordination**

NPC has noticed there have been problems coordinating between autism charities. This is partly due to competition between service providers for government funding. NPC heard anecdotal evidence about services being developed in areas without proper coordination between charities on the ground.

Although forums such as Partners in Autism, Autism Alliance UK and the Celtic National Autism Partnership are leading to improvements, some issues still remain.

**Few recorded outcomes**

Few autism charities capture their outcomes and results in a collated or accessible format. Most services track individual improvements and progress against personal goals. This makes it difficult to judge success across services, or compare between different services.

This is partly because measuring progress for people with autism is challenging (see Section 1). But also few charities have had to collect their results. Local commissioners rarely ask for that information, basing decisions either on cost or on personal experience of the charity.



Photograph supplied by TreeHouse

# What should a donor fund?

There is considerable scope for private philanthropy within the autism sector. However, a donor must consider several key questions when deciding where and how to allocate resources.

- What are the opportunities for private funding?
- Who should donors target?
- How should they be helped?
- What issues should be addressed?
- What charities should be supported?

## Private funding opportunities

Although the government plays a major role within the autism sector, there are three key areas where private money is vital.

### Improving specialist autism services

While government has statutory responsibility to cover specialist services such as school fees, care costs; and diagnosis, there are often flaws in how this is delivered. These include:

- lack of innovation;
- lack of expertise;
- lack of provision; and
- government evading its statutory responsibility.

A private donor can help to correct this. This could include funding an innovative pilot project, helping share good practice, or supporting parents to campaign for better services.

### Making mainstream government services more welcoming for people with autism

Not everyone with autism will need a specialist service. For example, most children with autism will attend mainstream schools. Everyone with autism will come into contact with public services, whether it is the health system or the police.

Again, while the government is responsible for these services, often the specific needs of people with autism are overlooked and lost. Private funding can help:

- develop training schemes;
- improve awareness of autism; and
- lobby government.

### Covering areas where government provision is inadequate or not involved

There are a number of areas where statutory responsibility is uncertain, under funded or beyond the remit of the state. These include:

- social and leisure provision;
- family support; and information;
- research; and
- public awareness.

While charities may get some government funding for these programmes, this varies and is often uncertain and quick to be cut.

One group which is often overlooked are people with autism who do not have complex needs or learning difficulties. They are therefore often ineligible for government services.

### Who to help

The reasons for helping people with autism are compelling, whether it is improving their quality of life, ensuring that their rights and dignity are respected, or pursuing more tangible and economic returns.

Donors can choose to target their funding at certain groups within the autism community. This can be based on level of IQ or complexity of need, or adults as opposed to children.

Or then again they might want to look at the wider context, through tackling general issues such as research, lobbying and public attitudes.

The reasons for helping people with autism are compelling, whether it is improving their quality of life, or pursuing more tangible and economic returns.



Photograph supplied by Resources for Autism

Autism is a pervasive and life-long condition; in some way it will affect all areas of a person's life.

Current provision for people with autism is limited, and good practice is not widespread.

### People with complex needs

Most resources are targeted at people with autism and complex needs. Their needs are more visible and they are eligible for more government support. Often this support is both intensive and expensive.

Still, not everyone with autism and complex needs get this support. Some are in psychiatric hospitals or living with elderly parents, others are placed in services for general learning disabilities that lack autism-specific support. Current provision is limited, and good practice is not widespread.

A donor can play a key role in improving the allocation of government resources for this group and developing more and better provision.

### People with less complex needs

People with autism and less complex needs do not necessarily need specialist support and can often be included in mainstream services. Yet when these mainstream services cannot cope with their specific needs there are few specialist services that can cater for them and they are rarely eligible for government support.

Private funding can improve and extend the services available for this group, either through improving mainstream services or by developing specific services. It often requires only a small intervention to stop this group from spiralling out of control.

### Children

There is a strong argument for intervening early. Structured education programmes have been shown to lead to improvements in cognitive ability and IQ. Working with children can stop behavioural problems before they become entrenched. The current cost of caring for a child with autism and learning disabilities until they are 17 is £420,000. It drops to £300,000 for children with autism, but with an average of high IQ.<sup>12</sup> Increasing resources into this area and improving capabilities and skills, may reduce the future costs of care and support.

Although the government has the major role in the education section, a donor can help improve the process. He or she can also become involved in other areas, such as social and leisure activities, or supporting the family, which can improve the quality of life.

### Adults

Most money in the autism sector is directed at adults. The cost of care and support is so expensive and last for so long that the average cost for an adult with low functioning autism is

£3.15m, while the average for an adult with high functioning autism is still £1.95m.<sup>\*12</sup> Yet despite the huge sums involved supporting adults with the most complex needs, quality and the innovation is often lacking.

Without this support into adulthood, the benefits of education can be wasted or even reversed. Often the emphasis is on controlling and containing adults, rather than building on their education, interests and skills.

Private funding can help redress this balance, improving services for those with care needs and expanding services to meet the needs of those with less complex requirements.

## How to help

NPC often uses the triangle in Figure 4 to illustrate potential options. Normally the intervention that is closest to the individual will produce more certain results, although for a fewer number of people. If you provide good care to somebody with autism their lives will improve. If you do good campaigning and lobbying it might not necessarily result in any changes, though if it did the numbers affected could be huge.

Often improving a particular situation will require concerted efforts across each level. For example improving education for people with autism will involve:

- running autism-specific schools;
- supporting parents to campaign for better services;
- training teachers on how to teach pupils with autism; and
- lobbying government for improved policy.

Sometimes a charity will operate on all levels of the triangle, while others prefer to focus on a particular level.

## Issues to address

Autism is a pervasive and life-long condition; in some way it will affect all areas of a person's life. The following sections of this report look at several key issues for an individual with autism: diagnosis; education; employment; housing and support; leisure and friends. It then looks at the wider picture, their family, government and public attitudes and research; all areas which have a vital impact on people with autism.

\* These figures are based on the work of Martin Knapp, which assumes that 36% of the costs for adults relate to economic loss due to unemployment. If the economic loss is stripped out, then the lifetime costs for adults in terms of services, care and family costs are as follows:

For people with low functioning autism:  
£4.262m x (1-36%) = £3.15m

For people with high functioning autism:  
£2.641m x (1-36%) = £1.95m



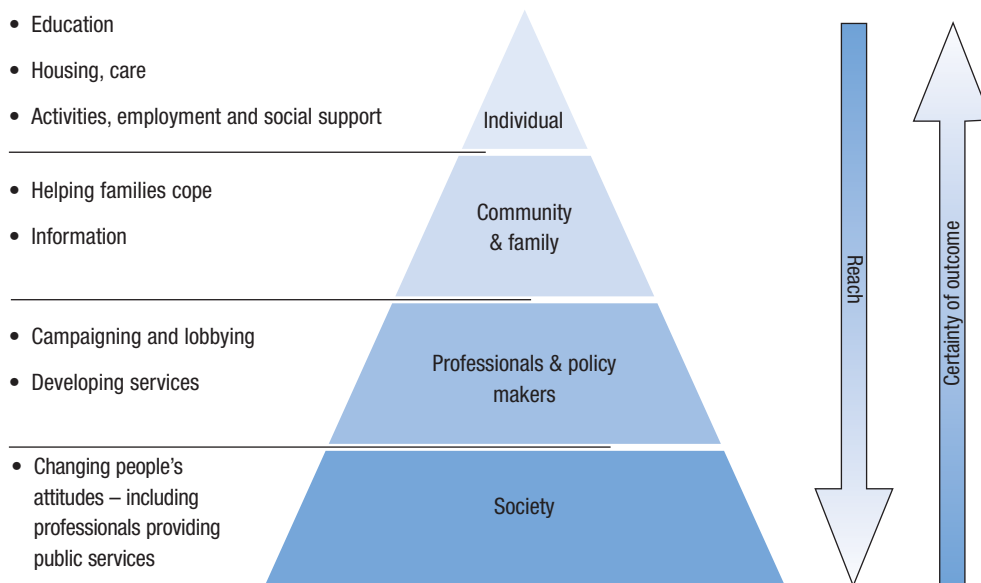
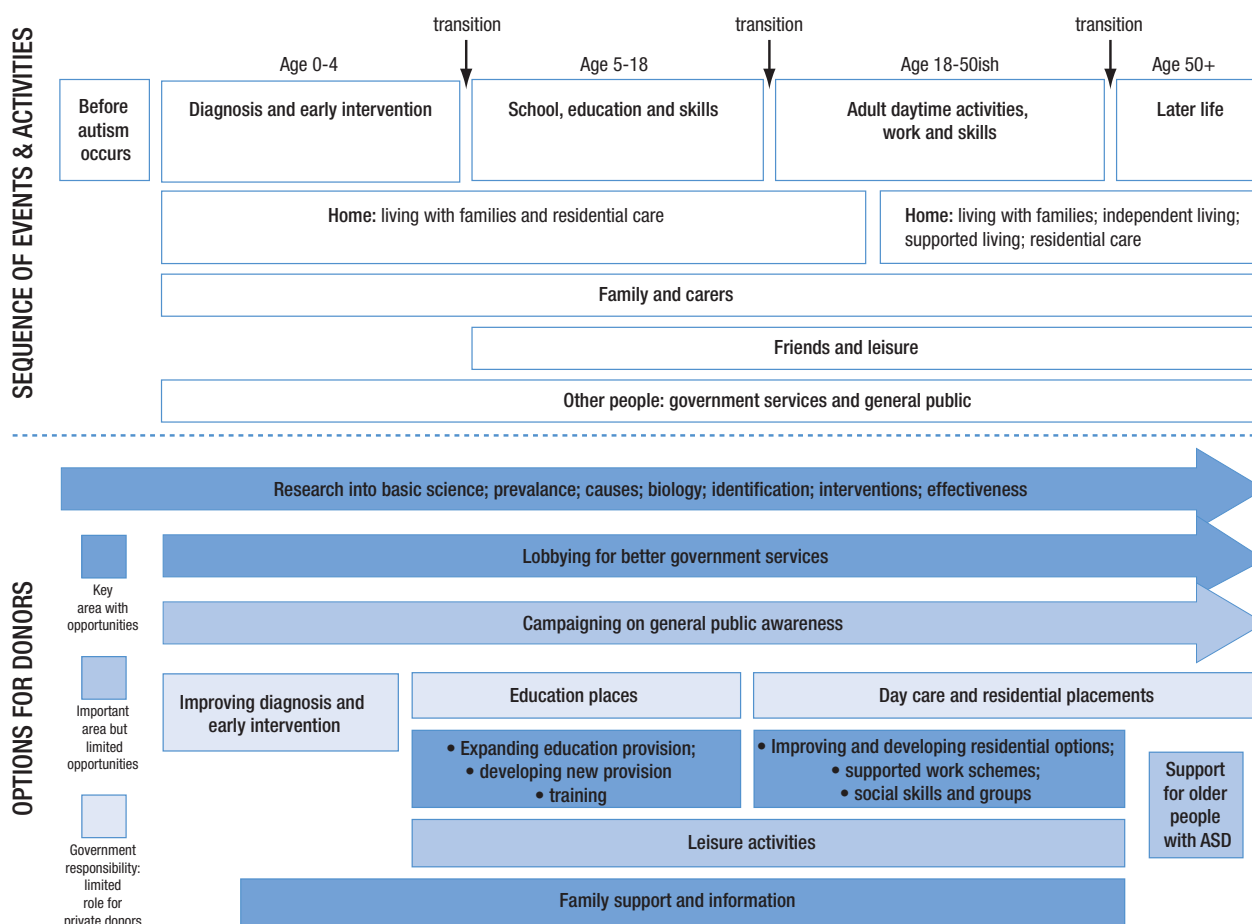
**Figure 4: Diagram showing different levels of activity**

Figure 5 represents the different issues which build up and interact throughout a person's lifetime. It also highlights areas which provide opportunities for private funding.

What is clear is that there is considerable need, rationale and opportunities for private funding across the eight main issues. These are explored in detail in the rest of the report, but in advance of this, Tables 2a–2h provide

quick summaries of the reasons to fund each area and also examples of possible initiatives and their impact.

NPC has also highlighted four priorities within these topics: research; transition from school to adulthood; supporting adults with autism and normal or high IQs; and equipping parents and individuals with autism with information and advice. These are explored in more detail in Section 12.

**Figure 5: Funding opportunities for donors during a person's lifetime**

**Tables 2a–2d: Funding examples for donors by issue**

Table 2a: First steps	For two out of five children with autism, it takes three years for a clear diagnosis. Some adults with autism still remain undetected.		
Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>• Diagnosis opens up the opportunity for understanding, support and therapy.</li> <li>• The earlier this happens, the greater the impact.</li> <li>• Good early information helps people to make informed choices.</li> <li>• Government has the main responsibility for diagnosis, but charities play an important supporting role.</li> </ul>	Individuals	Research into improved screening tools	More people with autism are detected sooner
	Families	Information website and helpline on autism services	Parents feel less isolated and children get quicker access to support and help
	Services	Advice to GPs on identifying someone with autism	Referral process to specialist diagnostic services is smoother
	Government	Lobbying government on better diagnostic process	Diagnostic process is simpler and better resourced

Table 2b: Education	Six out of ten children with autism are in the wrong schools for them. Teachers do not have the right training and pupils end up bullied or excluded.		
Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>• Education is likely to improve the skills and abilities of people with autism.</li> <li>• Better skills will enable people with autism to live more independently and take advantage of opportunities, such as employment.</li> <li>• Fees are funded by the state. However private donors can expand provision and improve the system.</li> <li>• Education already attracts private donations, but more are needed.</li> </ul>	Individuals	Capital projects for special schools	More children with complex needs will have access to specialist education
	Families	Resources for parents to campaign	Putting pressure on local government to fulfil its obligations
	Services	A pilot and evaluation of a teacher training course	Teachers in mainstream schools are better equipped to teach children with autism
	Government	Sensitive lobbying of national government	The specific needs of children with autism would gain higher priority in government

Table 2c: Employment and skills		Only 6% of people with autism are in full-time employment. The UK cost of lost employment is estimated at over £9bn a year.	
Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>• Employment can improve quality of life, but mainstream employment services are rarely able to help people with autism.</li> <li>• Despite the high costs of lost employment, current government funding does not reflect the need for specialist autism support; in particular the need for support in employment.</li> <li>• Charities have developed programmes that demonstrate how people can get jobs and with support, keep them.</li> </ul>	Individuals	Employment schemes to help people with autism find and keep a job	More people with autism achieve sustained employment
	Families	No direct support but:	Help more people to live independently if employed long term
	Services	Training for mainstream employment services on autism	Employment advisors are able to provide better support for people with autism
	Government	Lobbying to improve funding for employment services	Increase government funding to support people with autism in employment

Table 2d: Home and support		Half of adults with autism are unhappy with where they live. In the face of little choice or support, people end up living with their parents or in unsuitable provision.	
Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>• Where people live, and how, are vital to a person's quality of life.</li> <li>• Charities pioneer best practice in residential care and support in imaginative and courageous ways.</li> <li>• The state covers individual placements, but does not pay for developing new ideas or expanding provision.</li> <li>• Eligibility criteria for state support often overlook people with autism and an average or high IQ.</li> <li>• Private money is needed to give charities the flexibility and security to provide better services.</li> </ul>	Individuals	A pilot and evaluation of specialist support service for older people	Older people with autism will have housing and support designed for their particular needs
	Families	Training for families on how to care for people with autism	Families feel more confident and capable and individuals with autism receive better care
	Services	Training for professional carers	Professional carers are better equipped to offer the right care and support
	Government	Advice for local commissioners on improving funding of services	Commissioners plan more strategically and in ways that prevent crises

**Tables 2e–2h: Funding examples for donors by issue**

Table 2e: Friends and leisure	Four out of ten children with autism have no friends. A third of adults are not involved in any social activities.		
Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>Social activities give people the opportunity to have fun, develop skills and meet other people.</li> <li>People with autism face considerable obstacles to making friends and taking part in local leisure activities.</li> <li>Charities are helping overcome these barriers and give people with autism the chance to take part in a range of activities.</li> <li>There is very little government money available and private funding is often needed.</li> </ul>	Individuals	Social clubs for teenagers with autism	Teenagers with autism are able to make friends, have fun, and learn skills like art or football
	Families	Social activities for children with autism and their siblings	Brothers and sisters have fun with their siblings with autism and relate to them in a more positive way
	Services	Advice for mainstream leisure services on improving facilities for people with autism	Leisure centres become more hospitable and welcoming places for people with autism
	Government	Working with local commissioners to allocate funding for social activities.	Government funding provides more stability and support to autism-specific leisure projects

Table 2f: Families	Families face practical, emotional and financial challenges with little support. Nearly half of parents of children with autism are under severe mental distress.		
Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>Having a family member with autism can affect the quality of life of other members of the family.</li> <li>There is little government support for families of people with autism.</li> <li>Supporting families helps them to provide better support for their relative with autism.</li> <li>Charities mainly rely on private donations to offer valuable services.</li> </ul>	Individuals	Information to parents on how to care for a child	Parents understand how to care for the child better: the child is happier
	Families	Sibling groups for brothers and sisters of children with autism	Siblings of children with autism will feel happier and able to cope with other issues, such as bullying at school
	Services	Autism training for carers providing short break services	More children with autism and their families benefit from short breaks
	Government	Lobbying for better services	More funding available for services such as short breaks

Table 2g: Government and public attitudes	Government plays a central role in the lives of people with autism. The funding it provides and the decision it makes can make the difference between contentment and misery.		
Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>Government provides most of the funding for autism services; sometimes it can lack expertise or strategic vision.</li> <li>Charities can lobby and work with government to prioritise autism and improve services.</li> <li>They can also equip individuals with autism and their families to be campaigners.</li> <li>Lobbying and campaigning work is not government funded initially, although government sometimes 'buys' expertise.</li> <li>Charities also try to improve public attitudes, mainly by targeting groups that have regular contact with people with autism.</li> </ul>	Individuals	Information for individuals with autism to help them become advocates and lobby for better services	People with autism receive more support and assistance
	Families	Resources for parents to become campaigners at national and local levels	Parents persuade local authorities to fund a specialist autism resource in the local school
	Services	Training on autism for police services	Policemen know what to do when they meet someone with autism in trouble, preventing unnecessary trauma
	Government	Providing information and advice to government departments	Government policy is more strategic and aware of the specific needs of people with autism

Table 2h: Research	Knowledge is power. Research can provide us with the tools we need to combat the negative effects of autism.		
Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>Better knowledge is urgently needed in medical research. More data is needed about the effectiveness of interventions.</li> <li>This can help design and develop better support and services for people with autism.</li> <li>Co-ordinating research and communicating research findings is vital, but this is left to charities.</li> <li>Funding for research has been inadequate so far. However, funding by private donors can leverage increased funding from government bodies and large foundations.</li> </ul>	Individuals	Scheme to encourage individuals with autism to get involved in research	Access to more brain tissue and study participants may speed up research
	Families	A seminar bringing together families with researchers	Parents learn about the latest research and can make more informed decisions about treatment for their children
	Services	Improve funding, capacity and coordination of research	The quality and quantity of autism research will improve
	Government	Work to access government funding streams	More funding for research

## Charities to support

Throughout this report, NPC describes some of the activities of the different charities it has come across. We have also pulled out a limited number of charity recommendations that we think provide a good cross-section of the effective work going on in the sector. They represent a balanced portfolio of options for donors across a number of dimensions. Factors include:

- issue the charity addresses;
- geographical range;
- risk;
- size of charity; and
- level of activity.

To view an updated version of these charity recommendations a donor should access the NPC website, [www.philanthropycapital.org](http://www.philanthropycapital.org). Charity recommendations will be updated as the situation changes.

## Criteria for good local charities

Local projects and groups were too numerous for NPC to research. However a donor might want to support a charity in his or her area, in which case the following criteria for a good project may be useful:

- Are the people it is trying to help consulted as far as possible?
- Is the project flexible and person-centred?
- If the project involves a physical place, is the environment appropriate for people with autism?
- Is there a good level of expertise among staff in order to offer good services to people or support volunteers?

For more details about the criteria for effective charities, donors may wish to consult *Funding success: NPC's approach to analysing charities*, also available on the NPC website.



Photograph supplied by Prior's Court



# First steps

# 4

Most children with classic autism could be identified by the age of two; the actual average age of diagnosis in the UK is five years.<sup>37</sup> Around half of people at the higher end of the autistic spectrum had to wait until after they were 16 before they got a diagnosis.<sup>8</sup> Even if a child's autism is identified early on, it can take a considerable time for a diagnosis to be confirmed. For two out of five children with autism, it takes three years for a clear diagnosis.<sup>38</sup>

Being diagnosed with autism can be hard; yet struggling on without a diagnosis is harder. While the process is stressful and the truth can be painful, the potential benefits massively outweigh the difficulties.

The earlier a diagnosis occurs the better. Children with autism need specialist help. Without this, they can get stuck in repetitive routines, lose their skills and become depressed and anxious. Diagnosis is pivotal in making sure that children get the support they require. It ensures that their needs are recognised and that they become eligible for government or charitable support.

It is not just children who can benefit from diagnosis. A large number of adults have struggled on, without the support and understanding they need. It is not too late to help them.

Yet detection and diagnosis are only the first steps on a daunting and confusing life-long journey. Parents of children with autism, and newly diagnosed adults, are suddenly confronted by a huge number of questions. What does having autism mean? What can be done? What is going to happen in the future? What support can I get? The answers and the help they receive help to shape the rest of their lives.

Charities play an important part in this journey. Behind the scenes, they help to improve the identification and diagnosis process through research and advising government. They also have a more visible role providing support and advice to parents and those who have just been diagnosed.

Donors can support this work. Funding research into better identification and diagnostic tools will help make sure that more people with autism are picked up. There is considerable scope to improve the information available about local sources of support and help.

## Why should donors care?

Receiving a diagnosis of autism provides answers. It makes difficulties more understandable and the need for support much clearer. Parents want to know why their two-year-old child is ignoring them. Children with autism want to know why they feel different from other children in the playground.

A diagnosis indicates what type of help might be needed and makes parents more confident in requesting this support.<sup>39</sup> Often it is needed to qualify for services, like specialist schools. Or open up information and support, including government benefits, such as the Disability Living Allowance or the Carer's Allowance.

The earlier this support is put in place the better. Early childhood is a time of considerable brain and behavioural development. Early interventions have had promising results in improving cognitive, communication and social skills (see Box 3).<sup>3</sup> Putting effective management techniques in place can stop children from developing associated behavioural problems.<sup>40</sup>

The long-term consequences of non-diagnosis can be considerable. These include: exclusion from school; problems with the police; and mental illness. The preliminary findings of a study in Hackney suggest that a third of excluded children have undiagnosed autism.<sup>41</sup> Half of people with autism who were diagnosed after 30 had a mental health problem.<sup>8</sup> The burden falls on their families and the state, which has to pay the cost of people needlessly getting caught up in the criminal justice system, providing psychiatric help and paying benefits.

## What is happening?

Increased awareness of autism in the 1990s led to more people, both adults and children, looking for a diagnosis. This increased the strain on the system, which was highlighted by a series of articles and reports, from charities, researchers and government.<sup>37, 42</sup>

For two out of five children with autism, it takes three years for a clear diagnosis.

With diagnosis come a huge number of questions. What does having autism mean? What can be done? What support can I get?

Although examples of good practice do exist, accurate identification of those with autism is often haphazard and poorly organised.

Since then, initiatives have been introduced to improve the system. These include the autism exemplar for the National Service Framework for Maternity, Children and Young People's services, and The National Autism Plan for Children<sup>43, 44</sup> (see Box 4 for more details).

In response to a report by the Public Health Institute of Scotland (PHIS) in 2001, the Scottish Executive has funded a number of initiatives to improve diagnosis. These include a quality standard for autism diagnostic services, development of awareness and information packs for GPs, and a directory of the different diagnostic services in Scotland.<sup>45</sup>

Anecdotal evidence from parents and charities suggests that things have improved. However, not all challenges have been overcome, and provision remains patchy and inconsistent throughout the UK.

### Autism is difficult to diagnose

Diagnosing autism is not straightforward; there are no blood tests or conclusive brain scans. Instead, diagnosis relies on a detailed study of developmental history and behaviour, following internationally recognised standards. (These are set out in DSM-IV, which is issued by the American Psychiatric Association and the World Health Organisation's ICD-10.<sup>46, 47</sup>)

Scientists have developed a number of diagnostic tools to help them detect signs of autism. Using these tools, it is thought that a reliable diagnosis can be made by the age of two or three.<sup>48</sup> However, autism will look different in each person, and will change as people develop. Even trained professionals can disagree about a diagnosis, as can be seen in Hussein's case study in the Introduction.

Those with Asperger syndrome or with an average or high IQ might exhibit less obvious symptoms, have no delay in speaking and no obvious repetitive behaviour. Problems will only develop when they are put under more social pressures at school and may initially be misdiagnosed.<sup>49</sup>

Autism can also be confused with other conditions. A low IQ, Attention Deficit Hyperactivity Disorder (ADHD) or mental

health problems can obscure symptoms of autism. In an American study, 74% of children with atypical autism had previously been erroneously diagnosed with ADHD.<sup>50</sup>

### Problems with the process

Figure 6 shows the process that people have to go through in order to get a diagnosis.

#### Poor identification

There is no universal screening tool that will identify children with autism. There have been attempts, such as the CHAT (Checklist for Autism in Toddlers). This is made up of a brief set of questions to ask parents, as well as directly observing a child's behaviour. While it does not identify all children with autism, it can provide a useful guide.<sup>51</sup> In some places in the UK, health visitors are using it at the 18-month/two-year developmental check.<sup>52</sup>

Generally it is parents who first notice problems with their children.<sup>37</sup> Health workers or nursery teachers also identify possible candidates, but often they lack the necessary expertise. Four out of ten English GPs did not feel that they had sufficient information to make an informed assessment about whether a patient had an ASD.<sup>53</sup>

In Scotland the situation in 2001 was not much better: *'although examples of good practice do exist, accurate identification of those with autism is often haphazard and poorly organised.'*<sup>42</sup>

While people working with children might expect to come across cases of undiagnosed autism, this is unlikely to be the case for those working with adults. Prison officers, homeless workers, and even GPs rarely consider the possibility of autism, and know even less about identifying it.

#### Inadequate services

There is no set process for people suspected of having autism. There are a number of paths that can be taken, which largely differ according to the area and can be confusing. More than one in eight GPs did not know how or where to refer a patient with a suspected ASD.<sup>53</sup>

### Box 3: Early Intensive Behavioural Interventions<sup>3</sup>

Research led by the University of Southampton assessed the effect of early intervention (EIBI) for autism. EIBI is a comprehensive form of intervention, in which pre-school children are taught a wide range of skills by a specially trained group of teachers, normally including the parents of children. The teaching methods are based on Applied Behaviour Analysis (ABA). (See Box 10 for a full explanation of ABA.)

The two-year intervention examined how EIBI affected the skills and abilities of children with autism, and looked at the impact on the parents. It found that EIBI:

- led to gains in intelligence, language and daily living skills, as well as motor and social skills;
- tended to be more effective with children with higher IQ and mental age; but
- did not lead to major reductions in the diagnostic symptoms of autism or in problem behaviours.

#### Box 4: Diagnosis and assessment guidelines

**National Standards Framework for Children, Young People and Maternity Services—Autism Exemplar (2004):** The Children's National Standards Framework (NSF) sets integrated standards for children's health and social services. To accompany this, the Department of Health produced a set of exemplars to illustrate how these standards relate to particular groups. The autism exemplar outlines a clear mechanism and timeline for diagnosis and assessment.

**Autistic Spectrum Disorders: Needs Assessment Report (2001):** In 2001, the Scottish Ministers commissioned the Public Health Institute of Scotland to look at available services for people with ASD. The report detailed an inconsistent patchwork of provision and highlighted diagnosis as a particular problem. It also set out what 'ideal' services for diagnosis and assessment would look like.

**National Autism Plan for Children (2003):** This is a set of guidelines produced by the National Initiative: Autism Screening and Assessment (NIASA). NIASA was made up of a group of professionals, academics and voluntary groups, and was funded by the National Autistic Society, the Royal College of Paediatrics and Child Health, and the Royal College of Psychiatrists. It sets out a vision of what good services for children with ASD or suspected ASD would look like.

Attempts have been made to standardise and clarify this process through diagnostic and assessment guidelines (see Box 4). While these have resulted in improvements, there are still issues surrounding capacity and coordination.

There are often few professionals with specialist knowledge of autism; this is particularly apparent in tertiary services, where a much higher level of knowledge is needed to deal with particularly difficult cases.<sup>54</sup>

Moreover, many cases require assessment from a number of different professionals, often leading to problems with coordination and sharing information. This can make the whole process even more confusing and stressful for individuals and their families.

Recently, there has also been a trend to centralise services, particularly in areas with low population densities. This means that people have to travel huge distances. At the moment there are plans to close the only tertiary diagnostic service in Wales.

#### Long wait

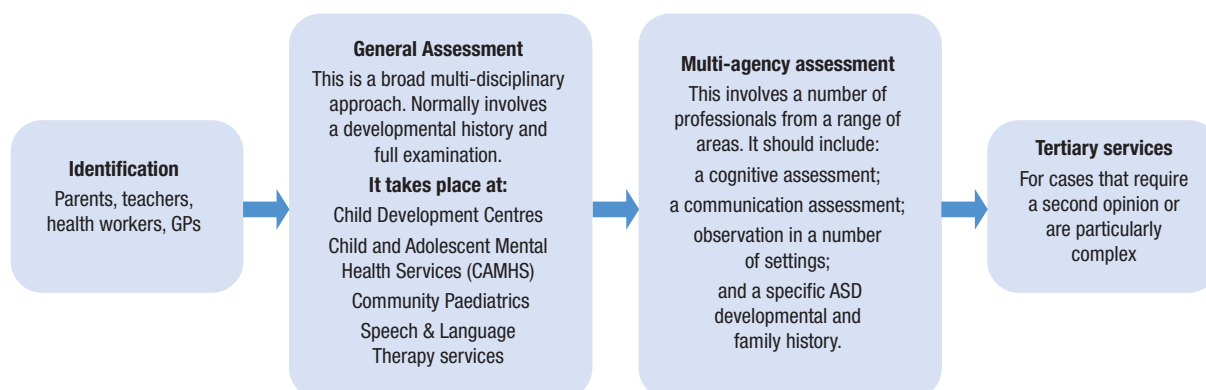
Even when possible problems are recognised it can still take a long time for a diagnosis to be made. In 1997, a study showed that, on average, parents of children with classic autism see something wrong at 18 months. However, their child is five by the time a diagnosis is made. For parents of children with Asperger syndrome, their concerns emerged at 30 months, yet diagnosis only happened, on average, at age 11.<sup>37</sup>

In a survey in 2001, 30% of parents said that delays in diagnosis and services placed great stress on the whole family, and 23% said that there was disruption to their family lives.<sup>8</sup>

Since then, there have been improvements. However, as with most services, provision is patchy across the UK, particularly concerning the initial identification of autism. NPC has heard that in some areas there is still a two-year wait to get a diagnosis for particularly complex cases. Some families try and circumvent the system by getting a private diagnosis. But then a private diagnosis is not always accepted by local authorities.

30% of parents said that delays in providing a diagnosis and services placed great stress on the whole family.

Figure 6: Process of identification and diagnosis



Many adults still struggle on without a diagnosis and not getting the support and the understanding they need. It is not too late to help them.

### Little information on autism services

Diagnosis opens up a world of information and support, but it is a confusing, complex and challenging world. Parents and individuals, often dealing with huge emotional shock, need help to navigate their way around and make some sense of their new surroundings.

*'Parents' early experiences may set the tone for their later relationships with health and education services.'*<sup>59</sup>

Information at the point of diagnosis has traditionally been poor. GPs are often unaware of local sources of support. In 1999, the NAS surveyed its membership to judge the quality of support and information they were getting at diagnosis. Just under half of respondents were not given any advice about where to go for help, support or further explanation. Of those who got information, half of them rated the help they got as 'very poor'.<sup>55</sup>

Again, recent government action seems to have improved this situation. At a national level, an information booklet for parents of newly diagnosed children has been published as part of the Early Support Materials.<sup>6</sup> The Scottish Executive provides a similar booklet for parents in Scotland.<sup>56</sup>

The diagnosis guidelines also recognise the need for better information during and after diagnosis. The autism exemplar called for a family support worker who can provide follow-up support and advice. Although some local authorities are looking at ways to implement this, provision appears extremely patchy.<sup>57</sup> Instead parents often have to rely on local charities and parents' groups to provide advice and support.

### People slipping through the gaps

We do not know how many people remain undiagnosed. There is no centralised registry of people with autism. Even Health Authorities do not keep information: in 1999, a survey found that only 17% of respondents had detailed data about how many children had autism.<sup>58</sup> However, based on what little information we do have, and an estimated prevalence rate of one in a hundred, it is pretty clear that not everyone is being picked up.

It is thought three main groups are particularly likely to be overlooked: adults, people with less complex needs and women.

**Adults:** A number of adults have grown up before the broad spectrum of autism was recognised and before the diagnostic process improved (see Box 5). As adults, it is often harder to be diagnosed. Most diagnostic tools rely on a detailed analysis of early childhood development. Although this can be pieced together by talking to parents and looking at childhood pictures, it is not straightforward.

### Box 5: Gemma's story<sup>4</sup>

When she was four years old, Gemma was diagnosed with dyspraxia—a condition that can affect intellectual, emotional and physical development. Yet for a long time she knew she had something else. All through school she was badly bullied and had difficulty communicating with people. Even her teacher called her names in front of the class and ripped up her work.

She made it to college, but in her third year—at the age of 19—she was diagnosed with Asperger's syndrome. As she says:

**'Finally we have an answer for all the problems I have and it's helped me to move on from all the bullying and hurt I've experienced. It's definitely been a positive step. It's also helped with my depression as well. It's helped me to see that my dyspraxia and Asperger syndrome are nothing to be upset about, but something to be proud of.'**

Anecdotal evidence suggests that a number of those adults are found in prison, or in psychiatric wards, or being cared for at home by increasingly elderly parents.

*'Adults are particularly poorly served in terms of both diagnostic services and post diagnostic support ... There are virtually no services in Scotland geared up for the identification, diagnosis and assessment of adults with ASD and few professionals are skilled in this area.'*<sup>42</sup>

**People with autism and an average or high IQ:** For those with less obvious needs, no learning difficulty or language delay, it is easier to pass through the system unnoticed. There can also be considerable disagreements over whether they fit into a diagnosis of autism, or do not fulfil all the criteria.

**Women:** The common ratio of diagnosis between the sexes is 4:1. However, some clinicians think that women are overlooked, and make up the 'invisible end of the spectrum'.<sup>59</sup>

Women may be better at coping and camouflaging their problems. Girls are more likely to watch and imitate other behaviour and act as part of a group. Their symptoms may look different, and contribute to behaviour such as self-harm or anorexia.<sup>60</sup>

### Where does the spectrum end?

Autism is a broad spectrum, and it is hard to identify a limit point. There are also those with 'autistic traits' who are part of what is called the 'Broader Autism Phenotype' (BAP). While they may have social and communication deficits, they do not necessarily fulfil the criteria of a diagnosis of autism.<sup>61</sup> Although they may have some considerable need, they will not get the help that comes from diagnosis.

## What are charities doing?

Diagnosis and initial information support are too important to leave to government. Charities are acutely aware of the issues and are often set up by parents who have gone through the process. They know what is needed and what can help to minimise the distress and uncertainty. They provide an important bridge between the medical model of diagnosis and the system of support and help that exists beyond it.

Charities are providing three main areas of support:

- improving identification and diagnostic tools;
- improving the diagnostic process; and
- improving initial support and information.

### Improving identification and diagnostic tools

There is exciting work being done into ways to pick up autism more quickly and more reliably:

- developing screening tools for the general population, or certain sections; and
- refining the diagnostic instruments for trained professionals.

**Research Autism** is a charity that funds research into improving the quality of life of people with autism. One of its priority areas of research is the identification of people with autism. In the past it has funded the Autism Research Centre in Cambridge to devise a test to identify autism earlier.

It has also just devised a screening tool for prisoners. It can be used by prison officers to identify inmates who are likely to have autism; they can then be referred to trained professionals. The charity is currently in talks with the Scottish Executive to roll this out across all prisons in Scotland. If successful, this could then be extended to the rest of the country.

**Autism Speaks**, the other major UK research charity in the sector, is channelling funds into research into baby siblings of children with autism. As siblings are more likely to develop

autism, they provide a source of information about children pre-diagnosis. By tracking their early development researchers hope to identify clinically predictive behavioural and biological markers and to correlate them with the onset of autism (see Box 6).

Since 2003, Autism Speaks' sister organisation in the US, Autism Speaks Inc, has part-funded the High Risk Baby Siblings Research Consortium, along with the National Institute of Health. This is a group of 19 researchers in the US, Israel and Australia who discover the earliest behavioural and biomedical markers of autism spectrum disorder. Autism Speaks UK is currently helping to establish a Baby Sibs Network in the UK, based at Birkbeck College.

### Impact

Better and earlier identification and diagnosis will ensure that more people get picked up and their needs properly assessed. This will help them to get the support and help they need.

Research has led to better diagnostic tools in the past. It is not always clear which research will pay off. That is why it is important to channel money through research charities, which use scientific advisors to review projects.

### Improving the process of diagnosis

Although the Department of Health has overall responsibility for diagnosis, charities play an important supporting role. This can include influencing government policy and strategy, and expanding capacity and working directly with GPs.

Charities have fed into the recent round of different guidelines and reports on diagnosis. Both the **Scottish Society for Autism (SSA)** and the **NAS** were on the working group for the Public Health Institute of Scotland ASD: Needs Assessment Report. In England, the NAS provided much of the impetus and the funding to produce the National Autism Plan for Children (NAPC).

“Finally we have an answer for all the problems I have and it's helped me to move on from all the bullying and hurt I've experienced.”

Person with autism

#### Box 6: 'Babysibs' project

The High Risk Baby Siblings Research Consortium was established in 2003 with the goal of bringing together the major research groups in the field to discover the earliest behavioural and biomedical markers of ASD. The research will lead to the identification of early markers and the development of treatments for preventing or improving symptom development and expression, optimising developmental outcomes and enhancing family adaptation.

As the recurrence rate of autism in families where one person is affected is possibly ten times higher than that seen in the general population, this group has the unique opportunity to study autism at the earliest stages of life. This makes possible the identification of the underlying neurobiological mechanisms that lead to the development of autism. In addition, these projects can have a collective impact on the research and clinical communities by developing recommendations and guidelines that inform clinical practice and policy.



Both the NAS and the SSA have their own diagnosis facility. The SSA is based in their centre at New Struan, while the NAS runs the Centre for Social and Communication disorders, set up in 1991. These are largely paid for by government.

There are also a number of charities that work with their local GPs and health workers to raise awareness of the condition. This could be in the form of leaflets or training sessions. These are largely ad hoc and sporadic.

### Impact

How diagnosis is actually delivered to people on the ground, and their experience of the process has a considerable impact on their quality of life. Having a diagnostic tool is no use unless there are enough trained people to use it.

The process seems to have improved recently, and charities have been involved as members of advisory panels or working groups. Whether this would have happened without them is doubtful.

Closer to the ground, the diagnostic facilities that the SSA and the NAS provide have proved to be important focal points of expertise. The Centre for Social and Communication disorders also trains 100 professionals from around the UK and overseas every year. It no longer has to make any diagnosis itself as it has already trained all the doctors in the area to do it.

### Better initial support and information

Not surprisingly, it is often the national charities, like the **National Autistic Society**, the **Scottish Society for Autism** and **Autism Cymru**, that parents turn to first.

Both the NAS and Autism Cymru have websites that include comprehensive information on the diagnosis process and information for the newly diagnosed.

**Research Autism** has just launched a website that provides up-to-date information on the many approaches and interventions used to help people with autism. It provides information on what they are, what they are supposed to achieve and whether there is any scientific evidence to support them.

The NAS also runs a specific programme called *Help!* for parents and carers immediately after diagnosis. It develops their knowledge and understanding of ASDs, teaches them strategies and techniques they can use and connects them with local services.

There are several different types of programme available to suit different parents' needs, including two-day programmes and one-day programmes. The NAS has also developed *Help! 2* for parents who already have a basic level of understanding.

**Peach** is a parent-led group aiming to encourage, support and inform parents of children with autism about early intervention using Applied Behavioural Analysis (ABA, which is described in the next section). Peach also monitors the standards and quality of the ABA services available.

At a wider level, the NAS and **TreeHouse Trust**, an education charity, contributed to the autism handout, as part of the Early Support programme. This again gives parents advice about treatments, sources of support and where to go for help.

Local charities and parents' groups provide local information and support through helplines, fact sheets, or drop-in sessions. **Resources for Autism** based in Barnet, and the **Autistic Society Greater Manchester Area (ASGMA)** also produce information packs.

**Autism Argyll** is the local autism charity for Argyll and Bute. This has a population of 90,000 people spread over Scotland's second largest authority and including 16 populated islands. One of the reasons it was set up in 2000 was the lack of post-diagnosis support available. So it put together an information pack that provided an introduction to autism and the local services available.

The idea proved so successful that the Scottish Executive commissioned the charity to write a guide that covered the whole of Scotland. This involved surveying what support was available and talking to clinicians and parents about what was needed. The guide was produced in summer 2006 and sent to every diagnostic centre in Scotland. There is space in each copy to insert a handout giving specific local details.

### Impact

Equipping parents with the skills and the information they need immediately after diagnosis minimises the problems they have connecting up with support. Parents we met stressed the trauma of not knowing what to do and where to go, and spoke of the benefits of finally receiving some guidance.

This need is demonstrated by the huge demand for information from charities: 40,000 people use the NAS helpline. Before it ran out, Resources for Autism handed out around 100 copies of its guide to local services every month.



## What can a donor fund?

Donors can get involved at all stages of the process, from helping to devise tools that identify who has autism, to providing help and advice immediately after a diagnosis.

There is no obvious strategic point to target private money. Improvements can be made at all stages of the process. Where a donor gives will largely depend on what they want to achieve and the level of risk and returns they are seeking.

The most direct and immediate way for a donor to get involved is through funding **better information and support**. A donor can go to a national autism charity and fund their information services, or find a more local charity with a more targeted reach.

A number of charities are experimenting with new ways of sharing information. This includes developing internet-based tools, chat rooms and CD-ROMs.

Donors can also approach the issue from the other end of the process by funding research into **diagnostic and screening tools**. While this will help more people get picked up more quickly, research is uncertain and it may take time to produce concrete results.

The final area for a donor to fund is **improving the process**. This ranges from training GPs to lobbying central government or the Department of Health. Yet while it is important to smooth out problems in the system, there are limited opportunities for a donor to get involved. Much of what charities do, both at a national and local level, is ad hoc and irregular; standalone projects are few.

Donors may also be uncomfortable with paying for what could be seen as the responsibility of the state. Although on one occasion private funding was used to set up a diagnostic clinic before the NHS took it over.

**Table 3: Examples of funding and impact**

Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>• Diagnosis opens up the opportunity for understanding, support and therapy.</li> <li>• The earlier this happens, the greater the impact.</li> <li>• Good early information helps people to make informed choices.</li> <li>• Government has the main responsibility for diagnosis, but charities play an important supporting role.</li> </ul>	Individuals	Research into improved screening tools	More people with autism are detected sooner
	Families	Information website and helpline on autism services	Parents feel less isolated and children get quicker access to support and help
	Services	Advice to GPs on identifying someone with autism	Referral process to specialist diagnostic services is smoother
	Government	Lobbying government on better diagnostic process	Diagnostic process is simpler and better resourced

It is estimated that there are over 100,000 children with autism in the UK.

Only a fifth of teachers in schools where there are children with autism have received any training about the condition.

Education is the only commonly accepted intervention for autism. It helps children to overcome their impairments and develop their strengths. It offers a way to overcome antisocial behaviours and provides the basis for a happy and independent life.

Yet for too many children with autism, school is part of the problem rather than providing the solution. The education system is often unable to cope with the specialist needs of children with autism. And the rising number of children being diagnosed is only exacerbating the situation.

Six out of ten children with autism are not in the right school.<sup>62</sup> They are being taught in schools that do not have any knowledge of autism and how to teach children with the condition. Only a fifth of teachers in schools where there are children with autism have received any training about the condition.<sup>62</sup>

Children with autism find it hard to fit in, both within the social world of the playground, but also in the strict structures of school. Four out of ten children with autism ends up bullied, while one in four is excluded, normally because their school just cannot cope with their needs.<sup>11, 63</sup>

Parents have to fight hard to get their child the extra support they need, whether it is speech and language therapy, or a place in an autism-specific school. Often their efforts are undermined by the attitude of local education authorities or individual schools.

Government has a statutory obligation to provide an education for all children, including pupils with autism. However, it often lacks the necessary expertise, so charities often run specialist autism schools. Charities' schools and training programmes also provide an important source of expertise and experience for government to draw on.

Yet more needs to be done, and this often requires private funding. Charities need to keep innovating and developing better education services. They also have a role influencing government and improving the system as a whole. At a local level this involves working with parents, while national lobbying and campaigning has the potential to make a broader impact.

## Why should donors care?

The lives of people with autism can be improved through education. The right kind of education can help overcome children's impairments, build on their strengths, and ensure that school is a positive and happy experience. Just as with all children, school can become a place to gain qualifications, improve health and develop as a person.

However, providing a good education for children with autism presents challenges to the education system. All children with autism will require some kind of support, whether this comes from a place in an autism-specific school, or from a teaching assistant in a mainstream school. It matters where they are taught, what they are taught, and how they are taught. Too often, the emphasis in schools is on controlling children rather than helping them to develop their skills and abilities.

The rewards of getting education right are significant. There are immediate impacts on skill levels and academic achievement. Behavioural problems can be headed off and managed. Schools provide a vital opportunity, whether it is to teach a child to use the toilet, or to get qualifications, like GCSEs or A-levels.

There is also the potential for long-term benefits. Having a better education is thought to provide the basis for better outcomes as adults. With the skills and the self-confidence they develop at school, people with autism lead happier and more independent lives. They require less support from families and from the state. Even small improvements have the potential to create considerable savings over a lifetime.

However, there has yet to be a comprehensive study on the long-term impact of education for children with autism. Without proper transition programmes and support, young people with autism leaving school experience major problems settling into a new environment. This can undo some of the benefits of a successful education.

## What is happening?

Children with autism are found in a range of different educational settings, from specialist schools to mainstream schools. An unknown number are also being taught at home (see Box 7). The exact situation is unclear. Only the Scottish Executive and the Special Educational Needs (SEN) West Midlands Regional partnership have officially audited provision of autism education in their areas.<sup>52, 64</sup>

Autism charities supplement this knowledge by producing a stream of surveys and reports (described later in this section), representing the experience and attitudes of their members or the parents and children with whom they work.

There is more information on the wider issue of Special Educational Needs (SEN) in the UK. After all, roughly one out of every six children has an SEN, and SEN funding makes up around 30% of the total education budget.<sup>65</sup> Autism is often highlighted and delineated within this. The NPC report *Making Sense of SEN* looks at the SEN sector in more detail.

Although there are many instances of successful education, there still appear to be significant challenges facing current autism educational provision. These include:

- strain on the education system;
- children not in the right schools;
- teachers not trained;
- problems in schools;
- difficulties getting the right support; and
- little preparation for life after school.

Because the education system is complicated, we now go on to explain the situation and what charities are doing in some detail.

## Strain on education system

### Growing numbers

There are an estimated 100,000 children in the UK with autism. Better identification and diagnosis has led to increased demands on the education system. In a 2001 survey of Local Education Authorities (LEAs), 87% of respondents perceived an increase in children being diagnosed over the last five years.<sup>66</sup> In that same year, a government strategy on learning disability mentions 'a sharp rise in the reported number of school-age children with autistic spectrum disorders.'<sup>67</sup>

It is not known exactly how many children with autism there are in schools; this data is not kept. However, we can get an indication from looking at government statistics on children with a statement of SEN, or who are part of School Action Plus—a scheme that supports children who are making little or no progress at school over time. Members of both of these groups require extra support from the LEA, whether this takes the form of an educational psychologist, or a place in a special school.

In 2006, roughly 30,000 children in England had autism as their primary need in the statement of SEN; a further 10,000 children were part of School Action Plus.<sup>65</sup> However, this does not include children with autism who are being catered for in school or whose needs are not yet recognised.

### Limits to funding

Most children with special educational needs are educated by the state. The state however only has finite funds to pay for this. If the state directly linked funding levels to the numbers of pupils with SEN within each LEA, there would be an incentive for each LEA to increase the numbers of pupils with SEN in order to increase the funding they receive.

Instead the Department for Children, Schools and Family (DCSF) allocates funding to LEAs based on a number of underlying factors that correlate to SEN, such as the number of families on income support and pupils for whom English is an additional language.

The LEAs then devolve as much money as possible to individual schools. This is usually based on a mixture of social deprivation factors, schools results, and only occasionally based on the numbers of children with SEN. There is little consistency between different schools on how this money is used, whether for Special Educational Needs Coordinators (SENCOs), or learning support assistants. There is rarely a specific allocation for meeting the needs of children with autism.

If the needs of children with autism, or any SEN, cannot be funded by the school, they are assessed for a statement, which spells out what support is needed. This is then a legal responsibility for the LEA, which is meant to retain a budget to cover the costs of an assessment and pay for the support spelled out in it.

The cost of this extra support varies, from a few hours of speech and language therapy every week to 52-week residential schools, with one-to-one support that can cost up to £130,000 every year.<sup>68</sup> When children are in residential school for more than 38 weeks of the year, part of the costs should be met by either social or health services, but often there is resistance to this.<sup>69</sup>

The right kind of education can help overcome children's impairments, build on their strengths, and ensure that school is a positive experience.

### Box 7: Where pupils with autism are educated

- ASD specialist schools (residential and day);
- specialist schools for pupils with learning disabilities;
- specialist units within mainstream schools;
- mainstream schools; and
- at home.

There are no exact figures available for the breakdown between these different groups.

Over half of parents think their child is in the wrong school.

### Box 8: Two main educational approaches<sup>6</sup>

**Applied Behavioural Analysis (ABA):** ABA breaks down skills into small steps and uses positive reinforcement to motivate the child. The programme assumes a heavy commitment of time and one-to-one teaching. The Lovaas approach, which is one of the main ABA programmes, involves working with a child on a one-to-one basis for up to 40 hours a week. Other families use many of the same techniques in a less time-intensive way, and find that the underlying principles of ABA can be applied successfully to more general areas, like behaviour management, social interaction and communication.

**Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH):** This provides children with strategies for coping and understanding their environment. The strategies help to make their world a less confusing and more predictable place. The TEACCH approach organises environments and learning situations to be consistent with what is known about how people with autism think and learn. Professionals who use TEACCH focus on the whole child and tend not to specialise in the way that speech and language therapists or psychologists do. The TEACCH approach actively involves parents.

### Lack of knowledge

While there is convincing evidence in favour of structured educational approaches (such as those in Box 8), there is little indication of which particular method is best and at what age this support should be delivered.<sup>70</sup>

*'We do not yet know how early that intervention needs to be, how intensive, nor with which children. Still less do we know what kind of intervention it needs to be, although we have some idea of likely characteristics.'*<sup>71</sup>

In spite of decades of research, there has never been a well controlled study, carried out by people independent of the promoters of the approach that indicates which approach is more effective. In 1999, a survey of different educational techniques found that only 8% of the behavioural/educational approaches surveyed met even basic experimental criteria.<sup>35</sup>

That same survey, carried out by the New York Health Board, came down in favour of Applied Behavioural Analysis (ABA). This has been backed up by recent studies on the short-term effectiveness of ABA for some children.<sup>72, 73</sup>

However some of the more extravagant claims in favour of ABA have been contested by others in the sector. They point to the lack of data on adult outcomes, and to research that suggests ABA is only effective for a relatively small group of children.<sup>74</sup>

The current consensus within the UK is that different groups of children with autism will respond best to different types of educational approach. How to identify these groups, and match them up with a range of educational options remains the challenge. All agree that more research is needed.

### Box 9: Autism Trust

The Department for Children, Schools and Families (DCSF) is piloting a system of 'trusts', where interested organisations are brought together to work on a particular problem and help provide training and expertise. Charities will play an important role in this.

One objective of the trusts is to create demand and interest from teachers in a subject, rather than force feeding schools/teachers with yet more requirements. One of the trusts will be on autism. It is likely to start at the end of 2008.

### Lack of strategy

Although LEAs normally have written SEN policies, not all of them have specific autism policies.<sup>39</sup> Without any in-depth knowledge or well thought-out strategies, LEAs often ignore the needs of autism or respond in a knee-jerk manner.

Problems are ignored until they spiral out of control at great cost to the individual and to the LEA. Instead of building up local specialist provision, such as resources in a mainstream school, LEAs continue to fund expensive out-of-area placements.

One of the biggest questions has been whether LEAs should fund Early Intensive Behavioural Interventions (EIBIs) (described earlier in Box 3 in Section 4). A West Midlands survey in 2002 found that eight out of 14 local authorities were funding home-based programmes such as Lovaas (see Box 8). This costs between £7,500 and £24,000 per year, compared to £1,000 for a part-time nursery placement.<sup>52</sup>

LEAs have begun to engage with this issue, and 11 of them have provided some funding for a recent study on the effectiveness of EIBI (see Box 3 in Section 4). The DCSF is about to set up an autism trust looking at improving autism awareness in schools (see Box 9).

### Children are not in the right schools

#### Type of school

Current government policy stresses the need to include children with disabilities in mainstream schools (see Box 10).<sup>75</sup> For many children with autism, this is the best option. Others will need the level of support that can be supplied only through specialist provision.

A recent report by the Office for Standards in Education (Ofsted) highlighted the success of mainstream schools with specialist resources in achieving high academic, social and personal outcomes for disabled children.<sup>76</sup> This view is shared by parents of children with autism. Staff in these settings were perceived as helpful and knowledgeable, classes were specifically designed for children with autism and there were small numbers in classes.<sup>39</sup>

Often a child's needs will change over time. In some cases a child might spend a couple of days a week in a mainstream school and the rest of the time in a specialist environment. This requires a flexible continuum of provision that takes into account the individual needs of each child.

At the moment, this range is not available, and over half of parents think their child is in the wrong school.<sup>62</sup> For these parents, the main problem is the fact their child is not in autism-specific provision, whether a specialist school or a unit within a mainstream school. The majority of parents



of children with autism in general disability specialist schools think their child would be better off in mainstream school with proper support.

Half of parents blame a lack of provision for their child being in the wrong school.<sup>62</sup> One mother had to visit 28 different schools to find one that could meet the needs of her child.<sup>39</sup> There are still only 7,500 places for children in autism-specific schools.<sup>77</sup>

Approximately one in ten children with a statement for autism cannot be catered for in their own LEA.<sup>66</sup> While this could just involve travelling a few miles into another borough, it often means a traumatic daily commute or having to attend a residential school far away from family.

As a result, many children with autism end up not going to school. In the face of poor provision and with no school that can meet their needs, they end up at home. While no one is keeping statistics on how many children with ASD are out of school, there is strong anecdotal evidence that this is happening.<sup>78</sup>

### Unsuitable surroundings

Often schools need to adapt their environment for children with autism. This does not have to be complicated. It could just involve taking down a clock, or turning off a light. Or even allowing a child to go to a quiet room and calm down when he or she get distressed. Ideally, when new schools are built, they should take into account pupils with autism as well as physical disabilities, providing quiet spaces as well as wheel chair ramps and hearing aid loops.

### Box 10: Inclusion

One of the major debates in special education over the last 20 years is whether disabled children should be integrated into mainstream schools, or should go to specialist schools.

The current trend is for children with disabilities to be included in mainstream educational settings, rather than 'segregated' in specialist schools. This has led local authorities to close specialist schools and channel children into mainstream schools. However, some argue that being in a mainstream school does not always lead to proper inclusion, as a child becomes educationally and socially isolated.

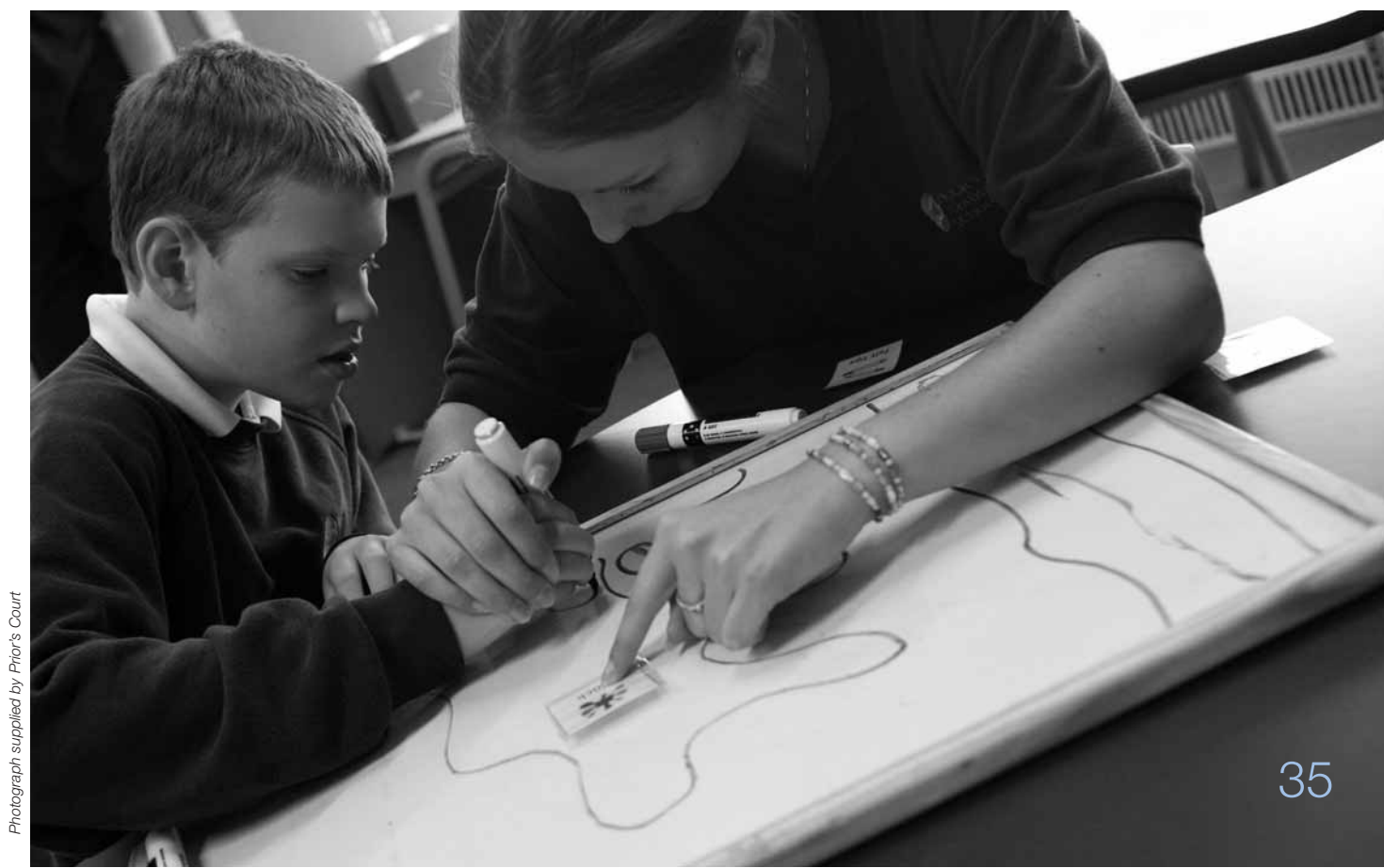
Increasingly, there is a more pragmatic approach based on an analysis of each child's need. Often this requires a more flexible approach to education, such as a specialist resource in a mainstream school, or dividing a child's time between a mainstream and specialist school.

Children with more complex needs benefit from being taught in schools that are designed specifically for their needs. This can involve having wide corridors and lots of windows, so that pupils do not feel closed in.

In many cases it is not just the physical surroundings, but also the way the day is structured that makes a difference. One of the most stressful times of the day for children with autism is break time and lunchtime, when there is no set structure.

Secondary schools can seem particularly chaotic. In primary school, children are often in small classes, and stay in the same classroom with one teacher. This all changes in secondary school and pupils have to move from classroom to classroom, facing different teachers and classmates.

One mother  
had to visit 28  
different schools  
to find one  
that could meet  
the needs of  
her child.



Photograph supplied by Prior's Court



Photograph supplied by TreeHouse

For a child with autism, having a teacher who knows about autism is vital. All teachers should be able to adapt their teaching styles to meet the needs of their pupils with autism. Although each child might have specific needs, there are common approaches that reflect the nature of the condition. The DfES outlined some of these in *ASD: Good Practice Guidance*, issued in 2002.<sup>79</sup> These include:

- For children with more complex needs, the training that a teacher needs is often highly complex and specialised. As one mother said:

The level of autism training varies between LEAs and among schools. Some LEAs have a policy of autism awareness training made available for at least one person in each school. Others make training available only on request.<sup>80</sup> As many LEAs do not keep central records of staff training, it is difficult to know which schools know about autism.

that while 70% of mainstream teachers had worked with children with autism, only 5% had had specific training in their teacher training, and a further 5% had been on subsequent training days. Even in special schools, only 50% of teachers and 40% of other staff had received special autism training.<sup>81</sup>

Even when there is training, this is often insufficient, lasting only an afternoon or an evening. An NAS survey in 2001 showed that of those teachers who had received autism training, the majority of this training lasted for just one to four hours.<sup>8</sup> There are no common standards across the country and little attempt to track what impact it has on teaching practice.<sup>66</sup>

*'There is a danger...that attendance on a short-course on autism is seen as adequate training and that knowledge of one approach will meet the needs of all pupils with an ASD.'*<sup>52</sup>

Current efforts are not working. In mainstream secondary schools, only 13% of parents say all their child's teachers adapted their approach to take into account their autism, and 16% do not believe that any of their child's teachers adapted their approach at all.<sup>62</sup>

## Bullying

The problems children with autism face in school are often compounded by bullying. Children with autism find it hard to deal with the complex and shifting social rules of the playground and are often unable to protect themselves or deflect unwelcome attention. Four out of every ten children with autism get bullied at school,<sup>63</sup> as compared to one in four children without autism bullied at secondary school.<sup>82</sup>

This has an immediate impact on self-confidence and can lead to problems in the future. Eight out of ten parents say that the bullying had a negative impact on their child's self-esteem and two thirds said that bullying led to mental health difficulties.<sup>62</sup>

Problems at school cause many children with autism to develop behavioural problems and become constantly anxious and depressed. This can lead to exclusion, as schools simply do not know how to cope.

One in four children with autism will experience exclusion from school at some point in their life.<sup>11</sup> Many of these will have been excluded more than once. In a survey of excluded children, two out of three had more than one fixed-term exclusion, and one in six had been excluded either more than ten times or so many times that their parents had lost count. A quarter of those children who had been excluded were excluded permanently.<sup>62</sup>



As mentioned in the previous section, a recent survey carried out by the Institute of Child Health, suggests that a third of children excluded in Hackney have autism.<sup>41</sup>

There is a high financial cost of exclusion—roughly £40,000 over a child's life time, as calculated in NPC's report *Misspent Youth*. This is compounded by the lack of support they receive after being excluded: 71% of parents say that their local authority did not put any support in place, although they are required to do so after 15 days.<sup>62</sup>

### Problems getting extra support

For most children with autism, initial attempts to provide support and help will happen through school. This could involve extra attention from a learning assistant, or specialist sessions with a speech and language therapist. Recent government policy has been aimed at strengthening this support, and diverting funding directly to schools.<sup>83</sup>

If a child needs more support than the school can provide, and the LEA is unwilling to provide extra help, children have to apply for a statement of SEN. Roughly four out of every five children diagnosed with autism have a statement.<sup>62</sup> This then places a legal responsibility on LEAs to provide external support.

### Confusing and obstructive process

However, getting a statement can be a highly stressful process. Due to its financial repercussions, LEAs often drag their feet and delay. Children can be refused either an assessment or a statement at the end of the process. Even when there is a statement, the LEA can try to restrict the entitlements spelt out in it so as to reduce their liability.

Parents may appeal to the Special Educational Needs and Disability Tribunal (SENDIST) if they are unhappy with the provision offered in a statement or to force the LEA to carry out an assessment.

The number of cases going to SENDIST involving autism has risen steadily, from 402 in 2000/2001 to 788 in 2005/2006. ASD cases are now the largest single group heard at SENDIST and comprise just under a quarter of total appeals.<sup>84</sup>

This is a hugely stressful process. In a survey of parents who had been through it, four out of five rated their own stress levels at eight out of ten or above. Almost a third put their stress level at a maximum score of ten. Some parents talked of feeling bereaved when it was all over.<sup>85</sup>

It is also expensive; the average cost of legal representation is £4,300. Three out of five parents thought the process caused them financial hardship, involving mortgaging their house, taking out loans or spending their savings.<sup>85</sup>



Photograph supplied by Prior's Court

Many parents feel they are made to go to tribunal because LEAs are hoping to delay payments. In a significant number of cases, the LEA backed down and settled at the last minute.

### Limited support

Even when a child does have a statement, the LEA does not necessarily provide the support it is legally obliged to provide. Even after going through the tribunal process, around four out of ten parents still experienced difficulty getting the LEA to implement the result of the tribunal.<sup>86</sup>

In a major survey carried out by the NAS, 45% of parents said it took over a year from receiving a SEN statement for their child to receive any kind of support. Only 55% of children who need speech and language therapy actually get it. Parents identify social skills support as being particularly difficult to access, despite its importance for children with autism.<sup>62</sup>

Two thirds of parents say a delay in accessing support had a negative impact on their child's behaviour and a third say it had a negative impact on their child's mental health.<sup>62</sup>

“The right education can make all the difference – between a lifetime of dependency and a lifetime of involvement in the world around them.”

All-Party Parliamentary Group on Autism

“We had to get him into that school—nothing else mattered. Now, at six, he is a completely different child: he doesn’t bang his head and he’s learning to play.”

Parent of child with ASD

## Preparing for life

### Poor planning

Even where there has been a successful experience at school, this can be undermined by a poorly thought out transition from school. A significant obstacle is ensuring sufficient cooperation between local authority children’s services and their adult counterpart to ensure a smooth transferral of support. There are often particular problems when a child is returning back home after going to school in a different local authority.

All children with disabilities should receive transition planning from the age of 14. Yet very few children with autism get a plan. Only half aged between 14 and 19 have transition plans. If you look only at pupils in mainstream schools, this falls to a third.<sup>62</sup>

### Little access to further education

There is little opportunity for children with autism to go on to further education. There is insufficient provision of specialist further education (FE) colleges and little support for students at mainstream universities. Research has also shown that students with autism need to be better prepared for what they can expect from college. FE colleges have been identified as the service that needed the most development in order to meet the needs of children with autism.<sup>67</sup>

## What are charities doing?

Within this complex education system, charities play a pivotal role. They provide important centres of excellence on autism-specific education. Through their specialist schools they provide places for those with the most challenging needs. They share these lessons through teacher training and working directly with schools.

As well as being part of the system, they also help to regulate and improve it. By supporting parents to campaign, they ensure that children get the support they deserve. By campaigning and lobbying, they help to influence government policy and funding.

Their work can be separated into the following categories:

- running specialist schools or units;
- providing teacher training;
- improving mainstream schools;
- supporting parents;
- managing transition and the path to further education; and
- working directly with local and national government.

## Providing specialist education

Most of the major regional and national autism charities have their own schools, such as the New Struan Centre at the **Scottish Society for Autism**, or Peterhouse School for Autism Initiatives. The **National Autistic Society (NAS)** now has six schools in Scotland and England.



Photograph supplied by TreeHouse

These have been joined by a new wave of schools that were set up during the 1990s in response to the high demand for autism-specific specialist education. These include **Prior’s Court** and **TreeHouse**. (See Box 11 for a brief history of autism education.)

They were often founded to introduce new educational approaches to the UK, like Applied Behavioural Analysis (ABA). Numbers of both primary and secondary schools have steadily increased. A charity in Northern Ireland, **Special Provision for the Education of Autistic Children (SPEAC)** has helped set up an autism-specific resource within a special needs school.

In most cases each school has developed its own approach. They tend to integrate a range of styles where appropriate, and tailor these to the needs of their pupils. Many of the schools share their expertise and good practice through the Confederation of Service Providers for People with Autism (CoSPPA).

The cost of each child placed in specialist schools is paid for by the state. However the state rarely covers the costs of developing schools and expanding their infrastructure.



## Impact

Charities are running specialist schools that provide autism-specific education to more children. They are also important repositories of knowledge and experience.

Unfortunately the numbers of pupils at these schools are small. On average there are about 35 pupils, many of whom have serious needs and require one-on-one support.

Pupils enter these schools at different levels and at different ages. Each school claims that they take the most challenging children, but there is no universal scoring system to provide a baseline of difficulties. Equally, the true potential of each child is uncertain. There is no way of determining how a child would have fared elsewhere.

Instead, most schools measure results at a detailed individual level, with what is normally called an Individual Educational Plan (IEP). This normally consists of a detailed analysis of the child's needs and identifies skills and areas that ought to be developed. This could range from learning to greet people and say hello, to not spitting. Progress is measured at regular intervals and the plan is changed accordingly.<sup>77</sup>

This produces a convincing number of anecdotes about individual progress. Particularly when the child is coming from mainstream school, the changes can be remarkable and instant.<sup>71</sup> For specialist schools, which have relatively few pupils, this level of evaluation is normally enough. Yet, it is almost impossible to compare IEPs within schools, let alone between them.

NPC would have liked to have seen more effort from individual schools to capture results and chart progress in a more standardised manner. This could capture improvements in behaviour, cognitive ability and independent living skills across the school. Over time it could provide for judging the comparative success and impact of individual schools and approaches.

Academic research has proved inconclusive. What little has been done has been small scale and remains contested. Although Applied Behavioural Analysis has probably undergone the most analysis these studies are still criticised for poor methodology.

Other ways of judging the success of individual schools is by looking at academic success and reports from government inspectors, such as Ofsted and HM Inspectorate of Education in Scotland.

Each school has a legal requirement to teach the national curriculum. For those with learning disabilities, P-scales are often used\*. Yet the criteria for these are rather vague, and do not easily distinguish between different levels of

## Box 11: Brief history of autism education

Our understanding of ASD is only very recent, so education is taking time to catch up. In the 1960s and 1970s desperate parents set up schools to separate distressed children from overwhelming mainstream schools. This allowed parents and educationalists to start experimenting with different education techniques. Although the benefits of one technique over another were not proved conclusively, the general evidence pointed to some specialist education being better than none.

By the 1990s the next wave of sophisticated specialist schools were established (eg, TreeHouse, Prior's Court), starting at primary level. These schools have increased their age ranges as pupils have grown up, and it is only recently that pupils are starting to graduate.

attainment. Also academic qualifications do not necessarily reflect individual ability in areas such as social skills or independent living.

Reports by Ofsted and HM Inspectorate of Education in Scotland ensure that schools are being run to a minimum standard. They are often able to look in depth at the combined results of individual pupils, and make informed judgements. However, the emphasis of these reports is often on the immediate quality of the provision rather than assessing longer term success or outcomes.

## Training teachers

Charities disseminate the expertise and the knowledge they have by establishing training programmes for other teachers.

Charity-run specialist schools, such as **TreeHouse** and **Prior's Court**, are increasingly developing themselves as centres of excellence and often provide training resources and support for other schools. Prior's Court has recently started a Research and Development Centre to train its own staff, parents and teachers from other schools.

One of **Autism Cymru**'s main projects is the inclusive education programme, which aims to provide intensive training in autism to every mainstream school in Wales. At the moment it has worked with 13 out of the 22 LEAs in Wales, and has reached over 100 schools.

It runs training sessions for groups of teachers from the same area. These last for two days and cover the main aspects of autism and autism education. When the teachers go back to their school they have to do an 'autism audit'. They then report back on what they have done to fill those gaps, and the impact that this has had on the school.

It also runs three yearly forums that bring together teachers from primary, secondary and specialist schools. They can share experiences, tactics and best practice. There is also an internet network they can use.

“Something as straightforward as letting him stay in the computer room during break times made the difference between him enjoying his mainstream school, and being excluded.”

Parent of child with ASD<sup>78</sup>

\* P-scales are used to measure the progress of pupils for whom the early levels of the National Curriculum are not appropriate.

OSSME is a vital outreach service. There is nothing like it anywhere else in the country.

Autism Accreditation Service

### Impact

Training teachers helps to spread knowledge of autism education to a wider audience, and helps benefit children in their care. Most teachers appreciate the opportunity for training, and in all the training schemes that NPC has looked at, there has been good feedback on the quality and the utility of the information. However, often little follow-up work is done to see what the long-term impact of the training was.

Autism Cymru's training programme was particularly impressive for building into the scheme follow-up sessions. It also monitors the ways in which improved awareness has changed teaching provision in schools.

### Improving schools

While training is important, sometimes schools and teachers need specific help for particular cases. Specialist schools often have good relationships with mainstream schools in the area. Often pupils may spend a few days at mainstream school with the support of an assistant. These informal relationships often provide a way of helping to improve the strategy and the provision of mainstream schools.

In 1998, **Autism Initiatives** was the first charity to set up a specific education outreach service, the Outreach Support Service for Mainstream Education (OSSME). It provides support to individual children with autism to ensure that they get the most from their school.

This includes stepping in when there is a danger that a child might get excluded from school and working with the child, the family and the teachers to improve the situation. It also stops problems from developing by helping pupils at various transition times in their education. This includes the move from primary school to secondary school, or moving from specialist schools to mainstream schools.

In 2006/2007 it helped 132 pupils from 103 different schools from Liverpool, Manchester and the Isle of Man.

OSSME's expertise has been developed by carrying out individual research projects such as the Autism Transition Toolkit (ATT) and Facilitated Autism Friendly Socialisation (FAFS). It has disseminated what it has learnt at both international and national conferences.

**Autism West Midlands** has funding from Children in Need for a part-time coordinator providing support to children who are at risk of exclusion. It is predominantly aimed at young people between the ages of 14-18 who have Asperger's. The coordinator supports around ten children at any one time, and works with them, their schools and their families. This involves providing training, giving talks about autism, working against bullying and improving opportunities for inclusion.

### Impact

Although teacher training is important, often schools need advice on dealing with individual pupils. OSSME has developed a strong reputation, as the leading education outreach service in the UK. In its evaluation by the NAS's Autism Accreditation service, it was called 'exciting and forward thinking' and a 'ground breaking outreach service.' Each of its projects has been evaluated by a third party, and found to have improved the education of the children it has helped.

There is continued demand for its services from schools and LEAs, and since it began, it has tripled the numbers of children it works with. As a teacher from one mainstream primary school said:

*'Because each child is different it has been extremely helpful to be able to call on the professional expertise of the OSSME team.'*<sup>88</sup>

Representatives from the scheme have spoken at the 4<sup>th</sup> International Conference on autism and taken part in a prestigious fellowship in the US.

### Supporting families

Charities are helping parents to navigate the education system and ensure that their children get the education they deserve. It is often those who push and complain who get the places that they want for their children.

Parents often need specialist legal advice to take their case to SENDIST, and then to ensure that the statement is upheld.

Since 2000, the **NAS** has run a project called 'Advocacy for Autism Education'. It has three main components.

**The Education Advice Line:** a telephone service provided by volunteers. It offers advice and information on special educational needs to ensure parents and carers understand their rights and entitlements.

**Tribunal Support Scheme:** a telephone advice line run by volunteers for parents who wish to challenge the decision made at SENDIST. Volunteer case-workers help parents to lodge their appeal and prepare their case.

**Representation at Tribunal:** aims to help families to represent themselves at Tribunal. However, when this cannot happen, the law firms Clifford Chance and Addleshaw Goddard provide free legal representation.

The **Disability Law Service** runs a helpline for all disabled people to answer their legal questions and provide advice and support. A number of their clients are parents of children with autism who are denied their right to a proper education.



**The Independent Panel for Special Educational Advice (IPSEA)** provides free independent advice and support for parents of children with disabilities, including those with autism. As part of its work, it helps parents to prepare and present cases to SENDIST, as well as providing an independent witness panel, which gives a free second opinion on a child's needs and assess his or her level of support needs.

In 2005, **Parents Autism Charity for Education (PACE)** produced a guidebook for parents called *Constructive Campaigning for Autism Services*. This provides tools and strategies for parents to use in campaigning for better education services in their area.

PACE has since merged with **TreeHouse**, and in September 2006 TreeHouse started a new Parent Support Project based on the lessons of the guidebook. It is supporting ten parents' groups across the UK to influence their local authorities. At the end of three years it will be evaluated to see what type of approach to campaigning works best.

### Impact

Providing parents with support helps them to get their child into the right school with the proper support. In some cases, their campaigning can set a precedent for the area.

A parents' group in Richmond used TreeHouse's handbook to persuade the council to train 60 mainstream teachers a year in autism. Other feedback stressed the impact of the information in the book on getting different parents to work together and persuade LEAs to take them seriously.

## Transition and further education

Charity-run schools are waking up to the need for a proper transition when their pupils leave school. Daldorch School near Glasgow, which is run by the **NAS**, has just opened a transition centre for young adults aged 17-21. It provides accommodation for 27 people to live together and learn skills such as horticulture and carpentry. It provides an important intermediate stage for young people, between being in a specialist residential school and becoming adults.

It is not just pupils at specialist schools who need support. Often it is those in mainstream education who are most likely to leave school and disappear from sight. The **King Egbert Integrated Resource** is an autism-specific centre in a mainstream school in Sheffield. It has set up a charity to match pupils with autism to jobs in the local area.

As part of their attitude to transition, charities often get involved in further education. Having experienced problems in successfully placing its pupils at further education colleges elsewhere, **Prior's Court** is developing plans for its own agricultural and horticultural college. Plans are in early stages, but it hopes to capitalise on the talents displayed by many of its pupils in gardening and looking after animals. **Autism Initiatives** also has plans for its own FE college.

Some charities provide support to students in university or college. **Autism West Midlands** runs a support group for students at the University of Birmingham, to give them advice and help. The **NAS** offers support to students throughout the UK, subject to funding, but it helps students to seek that funding.

Even when there has been a successful experience at school, this can be undermined by a poorly thought out transition.



Photograph supplied by Prior's Court

### Impact

Better transition and further education opportunities are helping to ensure that education and learning does not stop when children leave school. Education for people with autism should be a life-long process, yet opportunities are limited.

This is still a relatively new area for autism charities to be involved in, and the impact is not yet clear.

### Lobbying

There are a few charities—mainly the national ones— that directly lobby central government about autism education. The **NAS**, **Scottish Society for Autism**, **Autism Cymru** and **Autism NI** all have policy and campaigning teams that highlight the education needs of children with autism. **TreeHouse** is rare among smaller charities in having a dedicated policy and campaigns team.

In the beginning of 2006, the NAS launched its '*make school make sense*' campaign. This uses information from its members to present a picture of autism education in the UK and what needs to be done about it.

The campaign involved lobbying local MPs as well as government ministers. Individual documents were targeted at Wales, Scotland and Northern Ireland to take into account the different situation in each country. In Scotland, it largely coincided with the publishing of a major report into the state of education for pupils with ASD by HM Inspectorate of Education.<sup>89</sup>

There are a number of groups that have been set up to advise the government on issues associated with autism education. These include the Autism Working Group, set up by the DfES to produce the *ASD: Good Practice Guidance*, issued in 2002, and the All-Party Parliamentary Group on Autism (APPGA).

### Impact

Measuring the concrete impact of lobbying is not easy. Even if policy changes, it is hard to work out whether this was the result of lobbying, or whether it would have changed anyway. Delineating the impact of an individual charity is even harder. There is then the question of how the policy change is implemented and how much impact it actually has. Often schools are under a number of different funding and performance pressures; it is important not to alienate them or their teachers.

Increased government interest in autism education is part of a general trend in government, which is becoming increasingly engaged with disabled children in general. There are certain indicators that the NAS '*make school make sense*' campaign has been able to build on this trend and highlight the particular needs of children with autism.

Specific returns from this have been:

- Special Educational Needs Coordinators (SENCOs) in schools to be qualified teachers and have autism training; and
- autism packs will be produced for schools by the DCSF.<sup>90</sup>



Photograph supplied by Prior's Court

## What can a donor fund?

There is a broad range of options for donors who are interested in improving education for children with autism. The most obvious is to fund a special school. Although government funds each child's fees, there are a number of associated costs and services that fall outside of this.

Schools may need **development capital**, perhaps to build more classrooms, to develop new services such as a gardening or woodwork course, or even to set up a teacher training course. For building projects this can involve a significant amount of money. For example, TreeHouse's latest capital appeal seeks to raise £11.5m.

In some cases charities cover these costs through loans that they then pass on to the LEAs through higher fees. However, loans do not necessarily cover all of the costs of development, and some charities are unable to negotiate fees that cover their costs.

Private funding, or even soft loans, can help smooth over this process. These would help more schools to increase the number of places available and the quality of the educational provision. This could ensure that more children with particularly complex needs get access to a good education.

A donor might want to fund their local autism specialist school, or conversely contribute to an established centre of excellence.

A donor can also use their funds to help charities **share good practice and carry out training**. This can involve special schools disseminating their results and sharing their

knowledge with other schools, but also improving training for mainstream teachers.

This is a difficult subject, as a donor might think that it is government's responsibility to pay for autism training. While in some cases this is happening, and schools and LEAs are using money from their SEN budget, this is highly patchy throughout the UK.

As this is such an important area, there is an argument for a donor to support this activity when a convincing opportunity arises and, despite willingness from the teachers, there is no possibility of government funding.

A donor can also **fund research** to work out which educational approaches are most effective and for which groups of children. This can include providing resources to specialist schools to capture their data, as well as funding academic researchers.

As well as directly supporting provision, donors can also **help parents to campaign and advocate** on behalf of their children. Equipping parents with the skills and the resources they need to deal with their schools and LEAs can help ensure their children get a proper education. It can also have a wider impact, setting a precedence for the local area.

A funder can also help charities to **lobby and advise government**. This should happen at both a local and national level, to ensure that the needs of children with autism are taken into account when determining education policy and strategy. While it is always uncertain how much charities contribute to changes in policy, the potential returns from this are considerable.

**Table 4: Examples of funding and impact**

Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>Education is likely to improve the skills and abilities of people with autism.</li> <li>Better skills will enable people with autism to live more independently and take advantage of opportunities, such as employment.</li> <li>Fees are funded by the state. However private donors can expand provision and improve the system.</li> <li>Education already attracts private donations, but more are needed.</li> </ul>	Individuals	Capital projects for special schools	More children with complex needs will have access to specialist education
	Families	Resources for parents to campaign	Putting pressure on local government to fulfil its obligations
	Services	A pilot and evaluation of a teacher training course	Teachers in mainstream schools are better equipped to teach children with autism
	Government	Sensitive lobbying of national government	The specific needs of children with autism would gain higher priority in government

Only 6% of people with autism are in full-time employment—this only rises to 12% for people with autism and normal or high IQs.

Only 6% of people with autism have a full-time job.<sup>8</sup> This compares to an employment rate of 49% for all disabled people, and 75% for the UK as a whole.<sup>91</sup> For people with autism who have average or above average IQs, the employment rate is still only 12%.<sup>3</sup> A recent report by a leading economist estimates the cost of lost employment to be over £9bn a year to society.<sup>12</sup>

This is not because 94% of people with autism are incapable of full-time work. While for many people with autism, work will never be an option, and should never be a necessity, there are others who are missing out. They have skills and talents that are often overlooked as people concentrate on their problems. Many have benefited from improved autism education over the past ten years, yet they still confront barriers to getting a job.

Lack of employment leaves people poor and depressed. They draw benefits, rather than pay taxes; they use their skills to play computer games, rather than contributing to the economy. Having no job contributes to psychiatric and behavioural problems.

Although the government has emphasised the importance of getting people into work, it continues to ignore the specific needs of people with autism. It is largely left to the charitable sector to provide the necessary support to get people with autism into a job and keep them there. Focused employment schemes run by charities show very promising results, but expansion is hampered by lack of government funding.

Private money can help sustain the few existing specialist programmes helping people with autism, until government funding is procured. It can also fund charities pursuing exciting opportunities to set up social firms and enterprises.

## Box 12: Rob's story<sup>2</sup>

Rob was diagnosed with Asperger syndrome in 2003. He attended mainstream primary and secondary schools and has completed a higher education qualification in computer studies. However, he had low self-esteem and was very anxious that he could not get a job. This was heightened by the fact that he had left home and was sharing a flat with his girlfriend, adding both financial and emotional pressure.

Rob also had difficulties with communication, motivation and using the telephone in particular. With the help of a local charity he realised that many of his problems were easy to overcome when tackled one by one.

The charity helped him to address these problems, recognise his own strengths and realise that he was not always to blame when things went wrong. Rob now works full time in the electronics industry and has held down this job for over a year.

## Why should donors care?

People with autism often want to work. A job brings self-respect, a sense of purpose and the opportunity to learn new skills, meet new people and bring in a pay cheque.

Depending on their abilities, there are a broad range of jobs that people with autism can do: volunteering, supported employment, part-time or full-time work. People with autism hold down many different types of jobs—from professors to gardeners and from office managers to cleaners. Often their particular aptitudes, such as spotting patterns and intense concentration, lend themselves to particular jobs from packing travel bags for airlines to complex logistics.

Employing people with autism can bring huge benefits to employers. They can be trustworthy, hard working and maintain a high level of accuracy. Managers have commented that, by thinking about the way they communicate to employees with autism, they have learned to communicate more effectively with their whole team.

The annual cost of lost employment to the UK has been calculated at £20,000 for each adult with autism and a normal and high IQs. As a whole this adds up to £3.85bn a year.<sup>12</sup> If those with low IQs are included this rises to over £9bn.

Often people with autism need help to prepare for a job and to find one. Employers also need advice on how to tailor their recruitment procedures and office environment accordingly. There are few sources of support and advice. In particular, there is serious need to provide continued support to people with autism who are in a job.

Without this support, people with autism struggle to find any useful and satisfying employment. If they do get a job, it is often below their educational level and, without the proper support, it can be distressing. Having to leave their job is a further blow to self-confidence that many people find hard to recover from.



## What is happening?

Employment and autism has not been the topic of much research. The traditional focus has been on supported employment schemes for people with learning difficulties. The needs of people with autism and normal or high IQs have been largely overlooked.

The **National Autistic Society (NAS)** has helped to shed light on the situation. Surveys of its membership were among the first to draw attention to the lack of employment. In 1995, it also started *Prospects*, the first employment scheme designed to help people with autism with normal and high IQs to get into paid employment. It has used the information and the expertise it has developed through this programme to shed light on the area.

A recent government priority has been getting people into work. Disabled people are one of the groups it is targeting, through Jobcentre Plus and the New Deal programme (see Box 13). The success of this for people with autism is yet to be assessed.

The general picture for people with autism can be summed up as follows:

- Few people are in employment.
- They are unprepared for the job market.
- There are significant barriers to employment.
- There is little support getting work.
- There is little support once in work.

## Few people in employment

A study by the NAS in 2001 found that only 6% of people with autism are in full-time employment and a further 4% work part-time. Even those at the higher end of the spectrum, with an average or above average IQ, are unlikely to work, with only 12% in employment.<sup>8</sup>

Further smaller studies have confirmed these low levels. If a person with autism does have a job, it is likely to be well below their educational qualifications.<sup>16</sup>

## People are not prepared for the job market

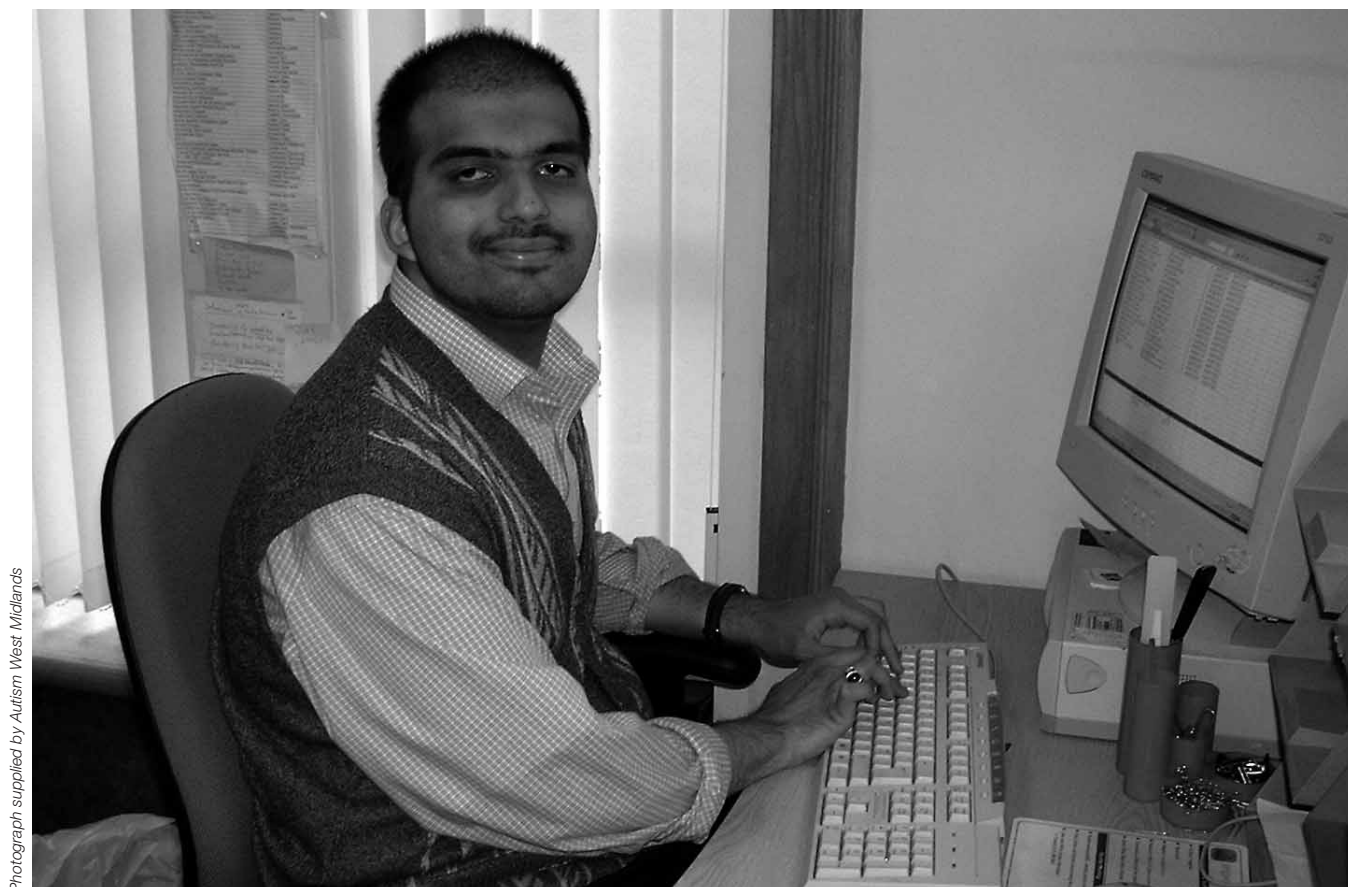
Having the right qualifications is not enough for people with autism to get a job. They need to be well prepared for the work place, and need life skills and confidence, for instance the confidence to board a bus to get to work. Talking to charities and experts, it seems that education only prepares people with autism for work if it specifically focuses on this aim (see Box 12).

## Barriers to employment

Barriers to employment may not be immediately obvious. Job adverts routinely stress qualities like being a 'team-player' and having 'developed inter-personal skills'. These are often not an integral part of the job, but make people with autism unlikely to apply.

Applying for a job requires filling out application forms and undergoing interviews. These are

The cost of lost employment to the UK has been estimated at over £9bn a year.



Photograph supplied by Autism West Midlands



Employers are frequently unaware of the needs of people with autism, employers' legal responsibilities and how easy it would be to adapt the working environment.

both activities that people with autism find hard to do. In the illness box of one application form, a man with autism detailed every single minor illness he had experienced since birth—a list that ran for three pages. It had no bearing on his capabilities as a computer programmer, but stopped him from getting a job.

Employers are frequently unaware of the needs of people with autism, employers' legal responsibilities and how easy it would be to adapt the working environment. For example, instead of requiring an interview there could be a short trial period.

The benefits system can also be a disincentive for people with autism to get a job. If people work for more than 16 hours a week they lose their Incapacity Benefit (see Box 13). If the job does not work out, it takes time to reapply and receive the benefit. People are reluctant to take the risk of losing a secure income stream.

### Poor support getting employment

Government provides support to disabled people who are getting a job through Disability Employment Advisors (DEAs) in job centres and the New Deal programme (see Box 13).

However, few of these have any knowledge about the specialist needs of people with ASD. Although 86% of DEAs had supported someone with autism in the last two years, only a third of all DEAs thought they had sufficient knowledge to support clients with an ASD to find suitable employment.<sup>92</sup>

Although DEAs can refer people on to specialist advisors, there is a tendency when contracting out these services to commission large general disability providers. While these are cheaper, they rarely have specialist knowledge of autism.

NPC has found only two employment programmes specifically for people with autism. These are the **NAS Prospects**

programme, mentioned above, and **Autism West Midlands's ASpire Programme**.

Government contributions to these programmes is very limited (as we see later in the section).

### Little support in work

Once in a job, people with autism continue to face challenges: interacting with other colleagues, adapting to a changing workplace and handling office politics. Employers need advice on how to support someone with autism, and how to deal with problems as they arise.

One man was doing really well in his job, yet did not know how to ask for a day off. After a year without a single holiday, he became so overworked he had a nervous breakdown and had to leave.

The six-month support available under the government's New Deal is not long enough for people with autism. The Access to Work programme (see Box 13) potentially provides funding to employers, but is a difficult scheme to access.

### What are charities doing?

Most efforts to help people with autism to get employment are being made by charities. There are three main areas of activity:

- preparing people for employment;
- running structured employment programmes; and
- social enterprises.

### Preparing people for employment

Schools equip pupils with vocational skills and qualifications. Converting skills into real jobs, however, needs effort by specialists willing to provide the necessary support.

Schools can start by supplementing their education by arranging work experience programmes. The **King Egbert Integrated Resource** is an autism department in a school in Sheffield. It matches pupils with employers in the local area, and arranges work experience opportunities. It has set up a charity and runs a centre in the local mall to help provide continued support to adults.

Qualifications and vocational skills need to be supplemented with practice in social skills and support in adapting to the work environment. Social activities and resources can help equip people with the information, the self-confidence and the personal skills that they need to get a job.

*Number 6*, a one-stop shop in Edinburgh run by **Autism Initiatives**, provides advice about employment. While its members have qualifications and skills and want to work, they

#### Box 13: Government support for people looking for employment

- **Jobcentre Plus:** This is a government agency supporting people of working age from welfare into work, and helping employers to fill their vacancies. It is part of the Department for Work and Pensions (DWP).
- **Disability Employment Advisors (DEA):** Most job centres have a DEA. They provide extra support for people with disabilities—including help finding a job—and also offer advice about available financial and practical support.
- **New Deal:** The New Deal is a government programme designed to get people into work and administered through Jobcentre Plus. It funds disability specialists as 'job brokers' to provide tailored support and also six months of support once in employment.
- **Access to Work:** This is a government grant to employers to pay any extra employment costs of hiring someone with a disability. For people with autism, this could include the costs of ongoing support. At the end of three years the grant is reviewed.
- **Incapacity Benefit:** Incapacity Benefit is a set rate of benefit that gives people of working age a replacement income when they cannot work because of ill health or disability. It does not take account of particular financial needs.

often do not have a good idea of what work actually entails and what kind of job they want to do. The advisors at *Number 6* help people to think about this and then refer them on to a local charity, **Intowork**, which runs a disability employment service and has a specific autism department.

### Impact

Measuring the impact of these activities on employment is going to be hard. While these programmes help move people towards a job, they do not necessarily get people directly into employment, and there can be a number of stages in between.

Of the 33 people at *Number 6* who got employment support, 19 of them are now in paid employment.<sup>93</sup> Yet how much of this is down to *Number 6* as opposed to the work of Intowork is hard to say.

### Structured employment programmes

Two charities that run autism-specific employment programmes are the **NAS's Prospects** service, which is run in London, Leeds, Glasgow and Manchester, and **Autism West Midland's ASpire** programme, which is based in Birmingham. These schemes usually get the bulk of their costs paid through Jobcentre Plus. However, they find it extremely

hard to get any government money for continuing to support in employment over the long term. They either have to bear the cost themselves or try to pass it on to a sympathetic employer.

The *ASpire* programme has three main stages:

**Work preparation:** This starts with a personal development programme, which identifies and fills skills gaps like CV writing, anger management and communication. A work placement programme then gives some real experience of work.

**Job club:** When people are ready to work they attend weekly Job Clubs and access resources and support to help them find and apply for work.

**Workplace support:** Individuals who have found work or who are already employed can receive support within the workplace. Support packages are designed to meet the needs of the individual and the employer and can include training for managers and colleagues.

The **NAS's Prospects** programme is broadly similar. It has also diversified the types of support it offers. In 2005, it started its transition project, helping students at university to find work once their studies had finished or as they approach their final year.

NPC has only found two employment programmes specifically dedicated to adults with autism.



“The job has helped me meet people and become more independent.”

Person with autism<sup>94</sup>

The results of employment programmes are promising, but the numbers involved are small. Scaling them up is difficult given government's unwillingness to foot the bill.

### Impact

Getting people into employment is one measure of the success of employment programmes, but there may be interim steps to measure as well. Some people are starting from a lower position than others. If the emphasis is only on numbers of people in jobs then programmes start to pick only the strongest applicants, and neglect those who might need a bit of extra work. There is a need for more nuanced and scientific evaluations to include these benefits. However, in the meantime a very thorough evaluation of the NAS's *Prospects* programme provides many valuable insights.

### NAS Prospects

The NAS's *Prospects* programme has had several evaluations since it began in 1995. The most recent of these was in 2003.<sup>94</sup>

Between 1995 and 2003, two thirds of clients got a job. Of those who had a job after the initial pilot stage in 1996, 68% of clients were still in permanent jobs in 2003.

Members of *Prospects* got jobs that were appropriate to their skills and abilities, ie, higher level and better paid. Of the *Prospects* clients placed in employment, 84% were satisfied with their jobs, and their comments back this up:

*'I feel much more confident than before and better able to cope with my present job.'*

*'Prospects have helped me realise who I am.'*

*'I suffered from severe bullying in my previous job and developed insomnia and depression. Now I am much more secure and happy.'*

*'The job has helped me meet people and become more independent.'*

There was a 10% increase in the number of people living independently as a result of *Prospects*.

Employers were enthusiastic: over 80% of line managers felt they had gained personally from the scheme; 98% of senior managers or employers were satisfied or very satisfied. Comments bear this out:

*'I've gained pleasure from seeing the employee grow in confidence.'*

*'It has increased my ability as a manager in general.'*

*'I'd love to do it again.'*

However, employers admitted they needed *Prospects* for the scheme to work: 93% would not have coped without support.

The *Prospects* scheme helped improve awareness of autism: 81% of line managers stated that they had no prior knowledge of

autism or Asperger's prior to *Prospects*. After taking part in *Prospects*, 92% said they understood the condition.

Fiscal savings to the Exchequer are less clear cut. Reduced benefits together with increased tax and National Insurance contributions showed net benefits of £4,339\* per person in work over the three-year period 2000-2003. However, the average cost per job found by *Prospects* is estimated at £4,281 in 2002/2003. The cost of continued support for each person in employment is estimated to be around £2,500-£3,000 per person per year. So it seems that in total running such schemes probably results in a small immediate cost.

However, the calculations do not include the benefits to the clients of increased earnings and improved well-being. Increased earnings benefit the economy; improved well-being may result in savings in health and social care, because of greater independence, confidence and reduced depression. If these benefits were included, the case for supported employment could be very strong.

The NAS has used the expertise it has developed from the project to provide guidelines and leaflets for people with autism looking for employment, and potential employers.

Autism West Midland has not undertaken a full evaluation of its *ASpire* programme. It is waiting for the end of its current government contract to do so. It does monitor user satisfaction, however, which is uniformly positive.

It has also trained a member of the local authority's disability employment service, about the specific needs of people with autism.

### Social enterprises

More charities provide direct employment for people with autism, normally for those with learning disabilities who need more specialist support. The work provides useful experience, and a launch pad to go on to further employment.

The *ASpire* project is looking to set up a small business in the new Custard Factory development in Birmingham, where it is based. This would provide office support for businesses in the building and an opportunity for people to have direct experience of employment.

Other small projects have been set up to provide employment opportunities. These include a café run by the **Scottish Society for Autism** in South West Scotland.

\* £494,686 split between 114 respondents to questionnaire.



Photograph supplied by Autism West Midlands

**Autism Initiatives** is pursuing a number of different opportunities in its different national offices in Liverpool, Edinburgh and Belfast. It has just received funding for a social firms coordinator, who would help advise organisations about setting up new social firms, as well as work with existing social firms to increase their awareness and recruitment of people with autism.

### Impact

Most social firms and enterprises working with people with autism are in their initial stage and yet to be evaluated. While there is evidence in favour of social enterprises helping disadvantaged and vulnerable people, NPC has not come across an evaluation that has specific reference to autism.

### Barriers to achieving wider impact

Readers may have noticed that, whilst there are promising results, the numbers on these employment programmes are tiny. These programmes need to be scaled up so that more people with autism can be employed.

Let us suppose that there are around 170,000 people with average or above average IQs who are unemployed.<sup>†</sup>

Let us suppose a quarter of them want to work. Say they join something like the *Prospects* scheme, and that 38% of them retain jobs with permanent contracts.<sup>‡</sup> This would mean that 10,000–20,000 people get into long-term work.

However, scaling up these projects is difficult in the face of government unwillingness to foot the bill on long-term employment support.

It currently costs the NAS £500,000 to run *Prospects* each year, which ties up a significant amount of unrestricted voluntary income. The NAS understandably feels the government should pay. The *Prospects* programme in Sheffield has recently been transferred to a local charity.

“The major problem I am experiencing at the moment is the assumption that there will be a “recovery”. I have to apply for further government funding every three months.”

Disability Employment Advisor<sup>92</sup>

<sup>†</sup>195,000 (see Figure 2 in Section 1) x 88% unemployment rate.

<sup>‡</sup>56% permanent contracts; 68 job retention rate = .56 x .68 = 38% permanent retentions



## What can a donor fund?

Getting people into employment is obviously an important issue. The social benefits are clear. Yet it is also a frustrating area, due to the limited options for private funding.

The most obvious projects with an established and recognised model are the **structured employment programmes**. Giving people the support they need to get a job and to keep it is necessary and relatively straightforward. But there still remains the question about how sustainable and appropriate this is for private funding.

Some might argue that employment support is a statutory responsibility. Yet government is often reluctant to pay for expensive specialist support and to fund continued support in a job. In this environment, private funding is necessary, but in the past it has proved difficult to find the amounts or the commitment needed.

In light of this, there seems to be an argument to fund charities to run **social enterprises**. These can provide both employment experience and a stream of unrestricted income. This mirrors a larger trend within the voluntary community to set up social enterprises.

However, this is still a new development and most current initiatives are small and uncompetitive. Projects that cater for those with fewer skills, and produce pots or bird-boxes, have proved unable to make a profit. There are currently few, if any, social firms in the UK that employ people with competitive skills, although successful international examples do exist.

A third area that a donor might like to concentrate on is helping charities to **prepare people for employment**. This is a slightly grey area, and includes the work of schools and social centres as well as general support and advice.

It is unlikely to produce any immediate pay-offs in the form of jobs, yet can provide an important stage in moving people down the path to employment.

**Table 5: Examples of funding and impact**

Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>• Employment can improve quality of life, but mainstream employment services are rarely able to help people with autism.</li> <li>• Despite the high costs of lost employment, current government funding does not reflect the need for specialist autism support; in particular the need for support in employment.</li> <li>• Charities have developed programmes that demonstrate how people can get jobs and with support, keep them.</li> </ul>	Individuals	Employment schemes to help people with autism find and keep a job	More people with autism achieve sustained employment
	Families	No direct support but:	Help more people to live independently if employed long term
	Services	Training for mainstream employment services on autism	Employment advisors are able to provide better support for people with autism
	Government	Lobbying to improve funding for employment services	Increase government funding to support people with autism in employment



There are estimated to be 540,000 adults and children with autism in the UK, but where do they all live? There are 30,000 individual places in the UK providing accommodation and support for people with autism and learning disabilities; only 3,000 of these are autism specific.<sup>95</sup> Most people with autism and less complex needs are ineligible for government support, yet only 3% are able to live fully independently.<sup>8</sup> Without any other choice, over half of adults with autism end up living with their family.<sup>8</sup>

Half of adults with autism are unhappy with where they live.<sup>96</sup> Without the support and the care they require, they often end up developing behavioural or mental health problems. More effort is spent controlling and managing their behaviour, rather than tackling the root of the problem and helping them to live how they want to.

Charities help arrange the accommodation and put in place the support that people with autism need. They step in when people's needs prove too complex for other services or their families. They help put together the right housing, with the right level of support to help people achieve their potential and exercise their choice.

While government pays for accommodation and support through housing benefits and community care packages, private funding is still vital. It can provide charities with the flexibility they need to develop new services. It can also help extend support to people with average or high IQ who are ineligible for government support.

## Why should donors care?

People with autism are heavily affected by the world around them. Where they live and the support they receive is vital in helping them to lead happy and fulfilling lives. If done well, it provides the basis to enrol in further education courses, take part in leisure activities in the community, and live more independently.

Too few people with autism are able to live in the way they choose. They are put in unsuitable residential care or placed in psychiatric wards, where often their wishes

are disregarded and their rights can be abused. While some people with complex needs will need constant support, this must be tailored to the needs of each individual and be focused on helping them to develop their capabilities and achieve their own goals.

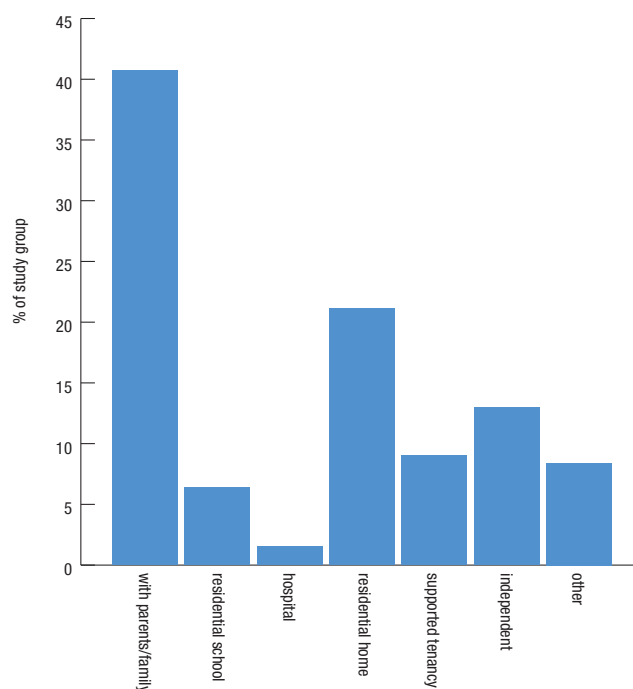
For those with less complex needs, helping them to lead a happy life requires less effort. It could just require a couple of hours a week sorting out bills or clearing up misunderstandings with neighbours. Few people get this basic help, and without it their lives can quickly disintegrate around them.

Providing support for people with autism requires a level of resources, expertise and awareness that is currently only sporadically available across the UK. Without it, the quality of life for people with autism suffers.

The burden of care often falls on the family. Unwilling to leave their child in unsuitable and dangerous care, nearly half of parents keep their children at home, even when they are adults.<sup>8</sup> This normally imposes significant financial, emotional and practical burdens.

As parents grow older, they are less able to care for their child, and more worried about what will happen when they die.

**Figure 7: NAS survey of where people live, 2005.**



*This chart is based on a survey of 480 NAS members. While all surveys differ slightly they present a relatively coherent picture of where people with autism live.*

## What is happening?

The true state of housing and care for people with autism in the UK is largely unknown. There is no comprehensive collection of data at a national level. Even local authorities rarely collect information about how many adults with autism are living in their area.

There have been few attempts to shine a light on the situation. A number of small studies have highlighted the different places that people with autism end up living. Although these all differ slightly, they present a largely similar picture. Figure 7, a survey of 480 members of the **National Autistic Society (NAS)**, represents a typical example. A recent study on the economic impact of autism on the UK has also attempted to collate the information available on accommodation arrangements for adults with autism (See Table 6).<sup>12</sup>

**Table 6: Estimated place of residence for people with autism**

Place of residence	High-functioning	Low-functioning
Private household	79% (153,842)	35% (83,304)
Supporting people accommodation	5% (9,737)	7% (16,661)
Residential care	16% (31,158)	52% (123,767)
Hospital	-	6% (14,281)

The most comprehensive survey of the situation so far has been the report *Tomorrow's big problem*, funded by the Shirley Foundation and published in 2004.<sup>95</sup> This highlighted the need for better government planning and the importance of allowing people with autism to choose where to live.

There are a number of factors that shape the current housing situation for people with autism:

- growing numbers;
- high costs;
- a lack of strategy;
- restricted choice;
- inadequate support; and
- poor training of professionals and carers.

## Growing number needing housing support

Based on prevalence studies and a ratio of one in a hundred, there are an estimated 433,000 adults with autism in the UK. An increasing number are coming to light, due to improved diagnosis and a growing trend to move people from psychiatric and mental wards into the community.

## Patchwork of funding

There are three main sources of government funding related to housing and support (see Box 14). People with autism are not automatically eligible for any of this support, and instead have to fulfil separate sets of criteria, which often differ between local authorities.

In 2002, the Department of Health published *Fair Access to Care Services: guidance on eligibility criteria for adult social care* to establish a more consistent approach to determining eligibility for social care. It sets out four bands of eligibility. These are defined by the risk to a person's independence if their needs were not met.

A major problem for people with autism is falling between the mental health and learning disability teams in local social services. If they have neither of these conditions, they often end up shunted between teams. This makes getting an assessment difficult, and while they may qualify for care due to their needs, there may be issues working out who is responsible for funding this support.

## Potentially high costs

The total costs of housing and care for people with autism will vary hugely, from a couple of hours a month support to 24-hour care involving two staff. While for some people it can cost as much as £500,000 a year, on average the cost of residential care is just under £65-75,000 a year.<sup>12</sup>

Residential care and day care facilities cost roughly £3.5m\* on average for each person with learning disabilities and complex needs over their lifetime.

### Box 14: Government funding related to housing and support

There are three main sources of government funding for housing and support costs for people with autism:

- **Housing benefits:** This is money from the Department for Work and Pensions (DWP) for people with a low income in order to pay their rent.
- **Social care packages:** These are provided by local authorities' social services and health departments. Eligibility is determined by an assessment of need.
- **Supporting people:** This is a pool of money from central government, which is given to local authorities to pay for housing related support for vulnerable people. It is not supposed to take the place of social care.

\* Using figures from Knapp study (2007) for residential care and other services, adults with complex needs cost around £65-75,000 per annum, multiplied by 50 years.<sup>12</sup>

## No concerted strategy

Despite the huge costs involved, few local authorities have a local housing strategy for people with autism. All local governments should have a housing strategy for people with learning disabilities.<sup>67</sup> However, few of these strategies refer to autism.

Without a concerted strategy and under immediate funding pressure, local government often make ad hoc and short-term decisions. They fail to fund the full costs of developing new services, or put in place preventative measures. Because they step in too late and provide insufficient support when they do, the costs are higher and prolonged.

There are exceptions. Some local authorities, like Surrey County Council, have a strategy for autism that uses population needs assessment to plan future housing and support needs.<sup>97</sup> A number of local authorities have a pooled support fund to meet initial support needs and prevent people requiring more intensive support in the future. Where this occurs, the benefits have been evident, as in the Liverpool case described later in Section 10 on Government.<sup>95</sup>

## Restricted choice

There are two main reasons why people with autism often have little choice about where and how they live: people with autism are rarely listened to; and there is a lack of provision.

Normally, little effort is made to ask people with autism where they want to live or to help them to express their choice. To make matters worse, people with autism often have difficulties articulating what they want.

Even when they are able to communicate a preference, it is often dismissed as unfeasible and beyond their capabilities. Yet, with the right support, people with autism can live successfully in many types of housing: independent living, supported living, shared accommodation, and group homes (see Box 15).

An important part of this decision-making may involve their family. Yet the NAS found that only 35% of carers had had a discussion with a professional about current or future housing options.<sup>96</sup>

The lack of available housing options limits this choice. There are only 30,000 residential places for people with autism and a learning disability. Only 3,000 of these are autism specific, while the rest are for general learning disabilities. One estimate for the number of additional places needed for those with autism and a learning disability is about 8,500.<sup>95</sup>

Residential placements can be unsuitable. Specialist care for people with learning disabilities does not necessarily include the expertise needed for people with autism. Even autism-specific care can be unsuitable. Many of the original services were started 20 years ago, and put large groups of people together in one building, cutting them off from the community. This might not be suitable for people who often find social interaction stressful and disruptive.

The current trend is to help people live in their own homes, or in independent flats. This often requires negotiating with social services, housing associations and mortgage providers. Many local authorities are put off by the initial expense and outlay required and are worried about possible risks if things go wrong. Often it is just easier to put people in a residential home and leave them there.

## Insufficient support

People with autism need support on how to live as well as where to live. This does not just involve physical care and supervision, but also support and encouragement to do what they want. This can include help going out into the community, getting work experience, or meeting up with friends.

As in the school environment, too often the emphasis is placed on containing people and managing their behaviour, rather than helping

Little effort is made to ask people with autism where they want to live.

### Box 15: Mark's story

Mark was diagnosed with classic autism during childhood and attended local specialist schools. He has very limited spoken language, but does use some signs. After leaving school he lived with his parents, but as he grew older and bigger they were unable to continue looking after him. He moved to a group home that included 11 other people with different types of challenging behaviour.

Over the next few months there were several serious aggressive outbursts, including head-butting staff. Staff did not know how to communicate and deal with him. They came to dislike him and made little effort to make his environment predictable. They thought he should move into a secure psychiatric hospital.

A local charity became involved and started looking at what Mark would like and what would be possible. Mark wanted to move back to his parents, which was not an option. However, there was the possibility of moving back to his hometown, near his parents, and living there with support. A house was acquired through shared ownership and Mark was able to take part in recruiting the staff who would be supporting him. After he moved in to his new home, incidents of challenging behaviour reduced from two to three each week to virtually none.

Over half of all adults with autism remain living with their families, often because of inadequate choice, provision or support.

More effort is placed on controlling people than helping them to live as they want.

them to achieve their goals. People need to take part in activities during the day and be able to continue their learning.

It is not just people with complex needs who need help. Even people at the higher end of the autistic spectrum, without learning disabilities or mental health problems, find living independently confusing and challenging. They may need help dealing with their neighbours, paying bills or registering with their local GP or dentist. For around a quarter of people with Asperger's syndrome it would only need a few hours of support each week in order to be able to live fully independently.<sup>8</sup>

Initiatives such as *Supporting people* (see Box 14) provide housing support for people with less complex needs. It was specifically not designed to take the place of social care. Instead it was supposed to be a short-term intervention to reintegrate people back into the community and relearn useful skills. Eligibility differs between local authorities. While this can be useful for people with autism, often they need more continuous support.

### **Lack of training of professionals**

Although carers require a qualification in social care, they do not have to have any autism-specific training, even if they are caring for someone with the condition. Even in places where there is a high likelihood of finding a person with autism, there is rarely autism-specific training.

In psychiatric hospitals, often a specialist team is on hand at the first sign of trouble and jumps on the individual and wrestles them to the ground. Staff trained in autism would know not to do this to people with autism—who dislike surprise, loud noises and physical contact—and would be able to recognise warning signs and diffuse the situation before it escalated.

Opportunities for autism training are limited by a lack of courses and qualifications. Most autism-specific organisations provide their own in-house training. Even in autism-specific organisations, there are issues concerning staff turnover, the quality of training and a reliance on agency staff.

### **Limited specialist services for specific groups**

People often have other support needs separate from their autism. They could have a mental health problem, be elderly, or have a physical disability. They require specific care and support that reflect all of their needs. Often they fall through the gaps; older people end up in care homes which do not have any experience of autism, or in autism-specific facilities that cannot cater for older people.

Specific groups, such as people from ethnic minorities, might need tailored support and advice to help accessing services.

Even caring for people without learning disabilities can pose problems. Charities have told us that it is often hard to know where their responsibility of care ends. It is difficult to know what to do when they see someone taking part in potentially risky behaviour, without infringing on their privacy or personal liberty.

### **Living with family**

Over half of all adults with autism remain living at home in the face of inadequate choice, provision or support.<sup>8</sup> They are unable to move on and parents are unwilling to let them go to live where they will not be looked after properly.

For many people with autism, living with their family is not the right option. Although parents will have a unique knowledge of their children's needs, they are not always best placed to deal with them. Dealing with the violent tantrums of a six-year-old is easier than dealing with someone in his twenties who is six feet tall.

Many of the experts and charities that NPC met spoke of a coming crisis as these parents became too elderly to look after their children.

### **What are charities doing?**

Most regional and national charities have grown up providing autism-specific housing and support. These have been supplemented by charities that concentrate solely on providing housing support. These charities are often able to pursue three main objectives:

- listen to people and help them achieve their choice;
- increase the housing options available; and
- increase care and support for people to achieve their personal goals.

By providing and combining these three options, charities are able to make a significant impact on individual's lives. They are then able to use this experience and expertise to benefit a wider group of people. They can:

- provide training to other professionals or carers;
- share knowledge and best practice; and
- work with local and national government to help them think more strategically.

Too often, local government turns to charities when things go wrong, eg, when people have developed mental health problems or behavioural problems and are too 'challenging' for local services. Charities are looking to get involved earlier in the process.

## Providing a choice of where to live

Charities are widening the choice available for people with autism, providing residential placements, and also helping people with autism to buy or rent their own home. They are also providing the support and encouragement that people with autism need to develop their skills and live active and involved lives.

The **Kingwood Trust** gives people with autism the chance to choose where and how they live. Since 2001, it has been providing supported living services for people in their own homes. Kingwood's clients may part-own their own homes, or rent from housing associations, or their home may be bought for them by a family member.

They might be living alone (with care), or rent along with other people in individualised flats. In almost all cases, Kingwood helps the individual in their negotiations with housing associations or to apply for a mortgage. It also enables them to personalise their homes, changing colours, furnishings and lights.

**Autism Initiatives** has a system called 'What I Need', which captures individual wishes. This is devised by a member of the Practice Support Team (PST) in close consultation with the individual and members of their family. This document looks at what each individual wants to achieve, and outlines ways to help them reach these goals.

There are a number of other examples of autism charities giving people their right to a choice. Sometimes the smallest thing can make the biggest difference. Before helping people move into their new homes, **Autism West Midlands** takes them round all the furniture stores, and helps them to design and choose everything for their new house, from colour of walls to types of furniture.

### Impact

Having a choice of where to live is an outcome in itself. People who are not disabled sometimes take for granted their ability to choose, subject to income, where and how they live. Often the greatest pleasure is being able to make the simplest decisions, like when to turn the light off, or what to do during the day.

### Improving provision

There is a shift in the way that most charities are providing housing. They are selling off their buildings, and freeing up the money they have tied up in property. Increasingly they work with housing associations to provide housing that they can then either manage or rent to individuals. Many of these are purpose-built, which are better suited to the particular needs of people with autism.



Photograph supplied by National Autistic Society

In Wales, the **National Autistic Society (NAS)** has worked with a local housing group and Newport City Council to develop new accommodation for six adults with autism. Each tenant will have their own individualised flat designed to take into account the needs of people with autism. It also has movement sensors to detect any possible epileptic fits and reduce the need for staff to intrude.

**Autism West Midlands** is prioritising its Autism Outreach Service. This provides support to people early on about their choices of where to live, negotiating with local councils and exploring different packages. This means that the right support is slotted in at the right time and prevents problems from developing.

They currently have a coordinator who is helping 24 people to negotiate a package of care. One of the main groups of people it is helping is those with elderly parents, and putting a plan in place before matters get out of control.

### Providing specialist care

Specific groups will require specific support needs. The **NAS** runs a secure psychiatric hospital called the Hayes in Bristol. This provides care for twelve people with autism who are sectioned under the Mental Health Act (1986). To be sectioned under the Mental Health Act your problems must be very serious: you must pose a danger to yourself or the public. Many people with autism are caught up in the mental health system, and only get diagnosed with autism late on in life, and without specialist support can be a danger to themselves and others.

The Hayes' specialist approach helps people to improve and move on. Six to seven people move on each year, some to satellite houses that they have in the community, others to

Charities often step in when people's needs prove too complex for other services or their families.



People with autism often need support on *how* as well as *where* to live: going out into the community, getting work experience, or meeting up with friends.

standard supported living, or residential care. There is massive demand for the Hayes' services.

**Autism West Midlands** is developing services for particular sub-groups, such as those people with autism who also have severe mental health problems, are deaf and those from black and minority ethnic communities.

It has recently started a new service for four young men who are starting at the local special needs college. This provides support to attend classes and offers an important stage in transition.

**Spectrum** (formerly the Devon and Cornwall Autistic Trust) is developing a service for older people with autism, making sure that they have access to geriatric care, and that houses are adapted with lifts and hand rails.

### Providing support

Care packages normally include a heavy support component, which will vary depending on the needs of the individual. Some will require 24-hour care, while others might only need two hours a week. Support should be tailored to the wishes and desires spelled out as part of their individual plan.

**Kingwood** has a community coordinator who helps the people it supports to integrate into the community and to take advantage of volunteering, education and other opportunities.

Often there may be specific support needs requiring professional help. This could include speech and language support, or psychological assistance. Often charities have dedicated teams that cover the different people they care for. **Autism Initiatives (AI)** has a Practice Support Team (PST) based in its headquarters in Liverpool. It is made up of two speech and language therapists, one psychologist and two assistants. They provide advice and help to AI's different services in England, Scotland and Northern Ireland.

The **Essex Autistic Society** has a clinical psychologist team to support its services. For each client, they carry out a sensory and communication analysis to work out their particular needs. For those with greater needs they can do more in-depth analysis.

**Autism West Midlands (AWM)** ASSET is an independent living service for people with Asperger's syndrome, helping them to live where they choose, enjoy a good quality of life and be an active member of the community. Support packages are tailored to individual need and are based on good practice approaches to autism.

AWM is currently supporting 20 people with funds from the *Supporting People* programme. This limits the type of support that it can provide. Instead of providing continued support, it is focused on teaching and achieving certain tasks.

Charities also provide a range of different resources and materials that people can use in their daily life. The **Autistic Society Greater Manchester Area** has produced a guide for people with autism on how to use the transport system.<sup>98</sup>

Other charities are providing less structured social groups, which often offer an important source of advice and encouragement. These will be looked at further in the next section.

### Impact

Case studies and anecdotes show individuals undergoing massive improvements after receiving support from charities. Staffing ratios for someone at Autism Initiatives have been reduced from 4:1 to 2:1. At Autism West Midlands, a man with complex needs went from requiring 24-hour care, to only requiring four hours support a week. These are impressive results, and demonstrate considerable savings.

The focus is very much on putting the person at the centre of the process. This emphasis means that there have been no real attempts to capture a charity's results on anything other than an individual basis. Again there is anecdotal evidence of individual improvements, and reduced staffing costs, a reduction in challenging behaviour such as breaking furniture. Yet this is never presented in a standardised and collated manner. Each charity has a favourite success story that it uses to illustrate its work.

This is not just a theoretical bias. It is also because charities have not been required to gather this information. The tendering process for government funding does not require or encourage aggregated evidence of results. Commissioners often come and inspect the service individually. And, due to the small numbers of people involved, commissioning is often done on a very individualised and personal basis.

However, there is a significant amount of anecdotal evidence showing the impact of having a choice and good quality support. People are happier and calmer, there are fewer violent incidences and there is often a reduction in the numbers of staff required.

## Improving training

Most charities provide in-house training for their staff, depending on their level of responsibility. Major charities, such as the **NAS** and the **Scottish Society for Autism**, also provide autism training for those that cater for more generic learning disabilities, which include people with an ASD.

**Spectrum** is pioneering training in Positive Behaviour Management. It gives all 54 staff training in techniques to ensure the least distress for the people it cares for. This includes recognising what things trigger bad behaviour, and learning ways to control any aggression.

As well as developing their own care expertise and training, charities are also providing training for parents, families and other professionals in ways of caring for their children. This takes a wide variety of forms and covers multiple areas, such as sexuality, managing violent behaviour and care techniques.

The NAS holds regular conferences and events, as does the **Scottish Society for Autism** and **Autism Cymru**.

### Impact

Carers are better trained and better able to cope with people with autism, whether they are in mainstream services, in specialist care or family members. This is a positive outcome in itself. People feel more secure and able to provide better support and services for people with autism.

## Sharing best practice and standards

Most charities are surprisingly shy of sharing details of what they do. NPC has come across a number of different charities tackling the same problems without sharing the lessons they have learned. Often charities are worried about competition.

However, there are charities that are sharing their lessons at conferences and publishing research. **Kingwood** has a particularly strong tradition of sharing good practice. In 2000, the charity brought together a multi-disciplinary group of professionals and parents to explore the future direction for residential services. It produced a report in September 2001, called *A Life in the Community*.<sup>99</sup> This provided the impetus for a change in direction towards supporting people in their own homes, with an emphasis on community involvement.

Since then it has carried out three major research projects:

**Community development project:** This was funded by the Health Foundation for three years and employed a Community Development Coordinator. It looked at what 'community' meant for people with autism, and how to get them involved in local opportunities.

**Research into training:** A project looking at new approaches for the recruitment, retention and development of staff to work with people with autism.

**Person-centred planning:** Funding from the Diana, Princess of Wales Memorial Fund went towards establishing guidelines for implementing person-centred support for people with autism.

It also helps the people it supports to travel to conferences and speak about the impact of successful services. Rachel, as described in the introduction, has travelled to the Houses of Parliament as well as a number of conferences to speak about her house.

### Impact

In the absence of any clear measurement or basis for comparison, it is hard to delineate the impact that sharing best practice has. There does seem to be a general move towards putting each individual at the centre of the process. How much this can be traced to an individual charity, or even shifts in government policy towards putting the focus on the individual, is impossible to say.



Photograph supplied by Autism Initiatives

## What can a donor fund?

Donors might not immediately think they have a role to play in improving housing and care for people with autism. Yet there are some important opportunities for a donor to make a key difference in this area.

Importantly, private money can be used to give charities the flexibility to **develop and improve services**. Charities are only paid when people step through the door, or start using a service. Often funding is tightly controlled and does not increase in line with inflation.

It can be expensive and time consuming to expand provision, train staff and devise better ways of providing care. Often local authorities will not pay the extra fees needed to fund these service developments.

A donor can also fund **evaluation of services**. Particularly when a charity is piloting a new service, or one targeted at a specific group of people, it is important that they capture the

lessons they learn and then share them widely. This can be through conferences, published materials or presentations.

It could help narrow down the different effective types of support and practices, whether it is improving choice, best types of training, or how to specialise services.

A donor can also look at ways to **support people with less complex needs** who might not be eligible for government support. There is a massive lack of advice and support for this group. Private funding is desperately needed to help charities to reach this overlooked group.

**Table 7: Examples of funding and impact**

Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>Where people live, and how, are vital to a person's quality of life.</li> <li>Charities pioneer best practice in residential care and support in imaginative and courageous ways.</li> <li>The state covers individual placements, but does not pay for developing new ideas or expanding provision.</li> <li>Eligibility criteria for state support often overlook people with autism and an average or high IQ.</li> <li>Private money is needed to give charities the flexibility and security to provide better services.</li> </ul>	Individuals	A pilot and evaluation of specialist support service for older people	Older people with autism will have housing and support designed for their particular needs
	Families	Training for families on how to care for people with autism	Families feel more confident and capable and individuals with autism receive better care
	Services	Training for professional carers	Professional carers are better equipped to offer the right care and support
	Government	Advice for local commissioners on improving funding of services	Commissioners plan more strategically and in ways that prevent crises

# Friends and leisure

# 8

Four out of ten children with autism do not have a single friend.<sup>10</sup> Some sit indoors, playing computer games, never leaving the house. Their parents are afraid to let them out in case they get beaten up, or in case they get in trouble with the police. They just sit there, growing older, not developing their skills, and moving further and further away from getting a job or living independently.

Going out, taking part in sports, or playing music helps people to develop their skills and abilities. It can distract them from negative repetitive routines and give them something fun and enjoyable to do. It provides an opportunity to make friends and feel less alone and cut off from society.

Being social is difficult for a person with autism. Their impairments often make being around other people and interacting with them hard and stressful. Sensory issues can exacerbate this, and stop people with autism from going to public leisure centres, or taking part in other social activities.

What little specialist support is available is mainly targeted at general disabilities, and does not always take into account the needs of people with autism.

Charities provide one of the few avenues to a fulfilling social life. There is very little government funding, and charities have to rely on voluntary funding or charging fees. Donors have considerable scope to widen provision and make sure that everyone can afford it.

“Contrary to what people may think, it is possible for an autistic person to love someone and feel lonely.”

Person with autism<sup>40</sup>

## Why should donors care?

Leisure activities provide important opportunities for both adults and children. They often need help to learn skills that other people take for granted.

Activities such as painting or sport can provide physical and creative outlets, which contribute to general health and well-being. Improved skills can be a source of satisfaction and pride, while an active social life reduces feelings of isolation and loneliness.

People with autism may require activities specifically tailored to their needs. This then can also provide a way for people to meet other people with the same condition, which in turn helps them to feel less cut off and alone.

Some argue that people with autism do not feel lonely or need friends and that it is social pressure that drives them to be social, exposing them to unnecessary stress and feelings of failure.

But some people with autism desperately want to be social. If they are not given this opportunity they retreat into their own world, or conversely will do anything to have friends and try and fit in.

Circumstances differ from one person to another, and social issues have to be addressed with a great deal of sensitivity and be tailored to the individual. There is currently little provision that meets this need.

## What is happening?

It is almost impossible to get an accurate picture of what the social life of people with autism is like. Research tends to overlook or underrate the benefits of social activities and friendships.

When the area is assessed, the emphasis is normally on disabled children. A number of the disabled children's charities, such as **Contact a Family**, have surveyed current social provision and opportunities for disabled children.<sup>100</sup> NPC's report *Ordinary lives* looks at these results and the barriers facing disabled children in more detail.<sup>36</sup>

This information provides a window on the situation for children with autism. While they face many of the same barriers as children with a general disability, these are often magnified by the nature of their condition.

Four out of ten children with autism do not have a single friend.



Half of parents say that their adult son or daughter has been unable to meet people and make friends outside their home.

The situation for adults with autism is almost completely unknown. The few limited surveys that have been done and individual anecdotes point to a high need and massive lack of provision. The **National Autistic Society (NAS)** is currently collecting data on the situation of adults for their next campaign. It is hoped that this will shed some light on the situation.

The basic situation can be summed up in three main ways:

- few opportunities to meet people;
- unsuitable public facilities; and
- difficulty accessing specialist support.

### Few ways to meet people

People with autism are unlikely to have many existing social opportunities or access to ready-made social networks. They are likely to be bullied or excluded from school. As adults they are unlikely to be employed or have access to the social opportunities that employment offers.

Four out of ten children with autism have no friends.<sup>10</sup> And in a brief survey of adults with autism and their parents, one third of the adults with autism said they were not happy with the number of friends they had.<sup>101</sup> Half of parents said that their son or daughter had been unable to meet people and make friends outside their home. In a similar survey, parents said that a third of their adult children were not involved in any social activities at all.<sup>8</sup>

### Unsuitable public facilities

In a survey of parents, fewer than half felt that there were appropriate play and leisure facilities in their local area for the person they care for. Only 58% of respondents felt that the person they care for was able to access mainstream play and leisure facilities.<sup>96</sup>

### Physical environment

The physical environment of public leisure facilities is often stressful for people with autism, due to the bright lights, noises and large numbers of people. Going to theme parks or theatres often involves distressing queues.

Under Part III of the Disability Discrimination Act (DDA), playgrounds, leisure centres and playgrounds have to 'make reasonable adjustments' to policies, practices and procedures that discriminate. Yet implementation is sporadic. Exactly what 'reasonable adjustment' means is often uncertain. Often the emphasis is on making buildings wheelchair friendly, rather than taking into account the sensory needs of people with autism.

### Attitudes

Public attitudes can make going out to mainstream facilities an uncomfortable experience for people with autism and their families. Staff and other people can be rude and obstructive, not understanding autism or what they can do to help.

*'Even on queue jumping schemes\* one has to undergo abuse and hurtful comments from the public which spoil the day for all.'*<sup>15</sup>

### Difficulty accessing specialist support

Due to the barriers that they face, people with autism generally need help going to public leisure facilities, such as visiting the local cinema or sports centre. Or they may need the opportunity to take part in specialist leisure services.

### Lack of autism-specific provision

The majority of this specialist social and leisure support is provided by general disability charities. While some of them have staff trained in meeting the needs of people with autism, many do not. One child with autism described being in a play group for children with disabilities as like being in a room with twenty phones going off at the same time.

There are few leisure opportunities specifically targeted at people with autism. For example, there are only three social groups for teenagers with autism in the whole of London. And only 28% of adults with autism had access to social groups for people with autism.<sup>8</sup>

Parents are not willing to leave their children in places that are not right for them. A mental health charity recently ran a session for autism in their big hall in Brent. Only one child stayed. The rest came, saw that it was unsuitable and then left again.

\* Some leisure facilities allow people with autism to jump queues because they get agitated if they have to wait.



Photograph supplied by Autism Initiatives



As one mother of an 8-year-old boy with autism and dyspraxia said:

*'It would be really nice to see some more activities available for children with disabilities. In the past I have tried to include Joseph in holiday activities run by local organisations and although they are happy to accommodate Joseph, the specialist help he requires is not readily available.'*<sup>102</sup>

### Specialist provision is expensive

The lack of specialist leisure services is underpinned by a lack of funding sources. Few areas of government regularly fund social activities. If they do, the high staff costs of autism-specific activities make them an unattractive option for commissioners. Instead available funding tends to go to generic services for disabled people and usually this means children.

Families and individuals are often the ones that end up paying the price. For those who are already struggling on a low income this is a further burden.

### What are charities doing?

Charities are often the only organisations addressing the social needs of people with autism. There has been a recent increase in private provision, such as special cinema screenings, but these are few and far between.

As shown in Figure 8, there are four main ways that charities can improve the social life of people with autism:

- help people with autism learn and develop social skills;
- provide friends or mentors;
- provide autism friendly environments where they can use and develop their social skills; and
- help people to access mainstream leisure services.

### Social skills programmes

Social skills programmes explicitly address lack of social awareness. This involves a number of different techniques, such as social scripts, which involve brief written scenarios concerning particular key interactions, like introducing yourself or answering common questions. People with autism can memorise them, and with practice scripts can be used fluently.

Similarly, role playing can be used to practise certain scenarios, and help improve perception of non-verbal cues, such as body language, facial expression and tone of voice.

A number of charities run social skills programmes, though these vary in quality and regularity. Both the **NAS** and **Autism West Midlands** run social groups.

### Impact

A number of studies have demonstrated the benefits of social skills training for people with autism in maintaining conversations, improving the ability to interpret other people's emotions and increasing self-confidence.<sup>103, 104, 105</sup>

However, there are still questions over how transferable these skills are. Even though people's abilities might have improved within the set context of a social skills class, there have been difficulties using these skills in daily life. Once they are in a different context, surrounded by different people, and without the support of a teacher, people find it hard to apply the skills they have learned. It is often important that people have an opportunity to practise their skills in a range of different settings.

### Providing friends and support

Charities also run schemes that provide people with autism with the opportunity to make friends and to do things like going to the cinema or bowling. The **NAS** and **Autism Initiatives** both run a befriending scheme matching volunteers with children or adults with autism. They can help them go out and take part in fun activities, such as swimming or shopping.

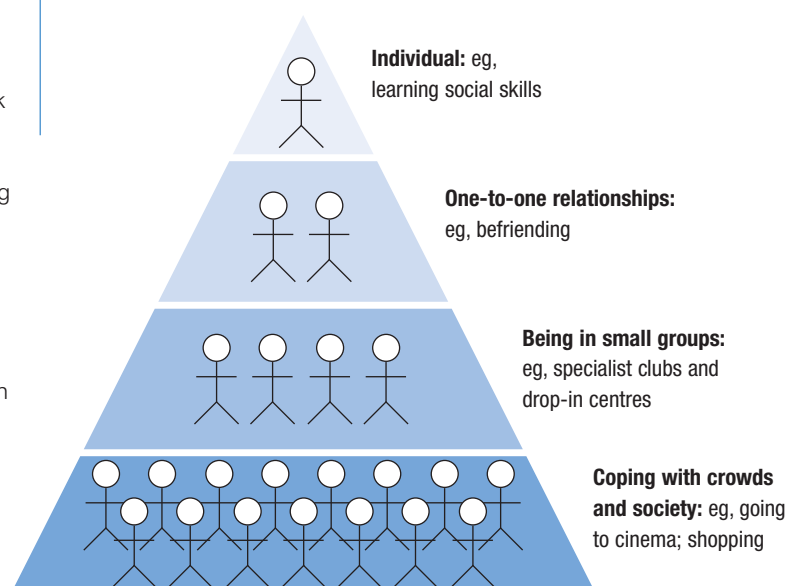
**Circles Network** supports disabled people to build social networks to ensure that they have an active social life.

### Impact

NPC has come across little evidence of the success of stand-alone befriending schemes. There have been suggestions that a typical befriending scheme is too loose and not structured enough to make a lasting impact.

People with autism often need help to learn social skills that most people take for granted.

**Figure 8: Different forms of social activity**



By providing specialist leisure activities or improving mainstream services charities are one of the few avenues to a fulfilling social life.

NPC is interested in the potential for mentoring schemes. In a scheme (not a charity) run by a psychotherapist in Essex, a mentee with autism and mental health problems described how she would have *'thrown herself under a train'* if she had not had a mentor to help her work through her problems.

NPC's report on mentoring, *Lean on me*, did not cover people with autism. However, it did find that one clear benefit of mentoring is that the objectives of the relationship, boundaries and timescales are clear cut.<sup>106</sup> Hard-to-reach groups value 'rules' being set and expectations being managed. This structured approach to a relationship might suit many people with autism. However, it would need commitment. Mentoring relationships that are broken by the mentor can be damaging.

### Providing supported social activities

The main way that charities help people to socialise is through directly providing social activities and services, such as workshops, art groups and theatre trips.

#### Children and young people

**Resources for Autism** runs a selection of social activities for children and young people with autism. This includes running a Saturday club for children aged 8-12, a Wednesday after school group for children aged 12+, and holiday clubs for those aged 8-19. Participants can take part in a programme of activities, led by a team of experienced staff and volunteers.

Some of these, like yoga and music, take place in a centre on the Finchley Road in London. Other activities, such as bowling and swimming, take place in the local area.

Resources for Autism is one of only three autism-specific play schemes in London and demand clearly outstrips supply. When it advertised its 2007 Easter play scheme, it was booked up within two hours. It currently has a waiting list of twenty times the number of places.

The charity gets almost no government funding to provide its play schemes. Instead it relies on voluntary income to supplement the fees it has to charge parents. This ensures that even those with a low income can afford a place.

As well as running arts sessions for adults with autism, **Turtle Key Arts** helps the Royal Opera House to run *Turtle Opera*, a series of half-day workshops over the summer holidays for children with autism. These involve singing and drama and physical exercise to help develop social skills, self-confidence and to encourage making friends. At the end of ten weeks the children put on a performance for friends and family.

In Manchester the **Autistic Society Greater Manchester Area (ASGMA)** has concentrated on its Aspirations programme. This started in 1999 to provide suitable social and leisure opportunities and support for people with Asperger's syndrome. It covers people from

Photograph supplied by Resources for Autism



the age of 10. The oldest person is 72, but most people are between 10 and 30 years old.

It now reaches over 200 people from its centre in Stretford. People aged ten and over are able to access facilities such as drop-ins and youth groups at the resource centre and outreach venues across the region. It runs a number of social activities, such as art clubs, discussion groups and bowling or swimming trips. It works with mainstream leisure services to help them adapt their services to take into account the needs of people with autism.

It also offers one-to-one support. Members are helped with the problems that they face and supported to apply for jobs or college.

It survives on a huge mixture of funding. Its main source of statutory funding is from local Connexions\* services. But it also needs a significant voluntary income.

### Adults

**Autism Initiatives** recently received funding from the Scottish Executive to set up a 'one-stop shop' in Edinburgh called *Number 6*. This provides a place for people with autism to come and get advice and meet other people. There is a wide range of activity groups, based on what people want to do, such as walking or playing pool. There are also discussion groups based around issues such as sexual behaviour, health and independent living skills.

Staff also provide a source of advice and support. People can come in and ask about any issues that are concerning them, whether it is problems getting benefits or trouble with their family. The centre also provides employment support and advice, helping people to think about their options and referring them on to people who can help them.

\* Connexions is a government run programme designed to help young people between 13-19 to access information and advice, and take part in social and leisure activities. This is extended up to the age of 25 for those with disabilities or learning difficulties.

### Impact

The impact of well-designed programmes can be varied and wide-ranging. These often involve a number of integrated activities, such as mentoring, befriending and the opportunity to meet other people and get out into the wider community.

A number of the social projects that NPC has looked at have been evaluated. This may well be due to the perceived need to provide proof of the impact of social and leisure activities.

An evaluation of *Turtle Opera* showed that by the end of the programme the children were found to have improved social skills and lower rates of emotional and behavioural difficulties. The children rated their social skills as significantly better by the final workshop than they had been at the first.<sup>107</sup>

When the Scottish Executive funded *Number 6* it included money for an evaluation by Strathclyde University. The mid-way evaluation has highlighted several benefits. It pointed to the welcoming atmosphere, the high quality of the social and activity groups and the impact it has on social isolation, skills and self-esteem.

Three quarters of service users felt that their overall experience at the one-stop shop was 'very positive' or 'positive'. All the parents and carers questioned felt that their family member had benefited from the service or support they received, and 85% felt that they themselves had benefited from the services received from *Number 6*.

In 2006, ASGMA undertook a highly comprehensive survey of the people benefiting from its services. Just over 90% said that Aspirations, the social project, was 'very good'.

Little government funding is available for social and leisure opportunities for people with autism. It is often the first thing to get cut and the last to be reinstated.

## What can a donor fund?

There is little government funding available for social and leisure opportunities for people with autism. What little there is goes primarily on children and is normally sporadic and ad hoc, depending on the attitude of local authorities and the state of the budget. It is often the first thing that gets cut and the last thing to be reinstated. The scope for donors to fund in this area is wide, without worrying that statutory services are being subsidised.

The most obvious and arguably the most important area for donor support is **specialist leisure activities**, such as teenage activity groups, play schemes or adults' activities.

These provide a way for people with autism to experience a rich and varied social life and can have a broad variety of benefits, from better mental and physical health, to improved self-confidence and employment prospects.

Funding specialist autism leisure services helps more people to develop a social life. Yet it also helps establish an effective template or model. When funding a leisure project a donor should always be aware of the potential for an **evaluation and assessment of success**.

For some people who might not be able to deal with being part of a larger social group, there will be a need for **social groups** and **mentoring**. These could need funding for evaluation to supplement the evidence base.

A donor might want to find a project that is operating in their local area. This could either be an autism-specific service, or a project for disabled people that has some autism specialism. Criteria for judging these organisations was discussed in Section 3.

**Table 8: Examples of funding and impact**

Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>Social activities give people the opportunity to have fun, develop skills and meet other people.</li> <li>People with autism face considerable obstacles to making friends and taking part in local leisure activities.</li> <li>Charities are helping overcome these barriers and give people with autism the chance to take part in a range of activities.</li> <li>There is very little government money available and private funding is often needed.</li> </ul>	Individuals	Social clubs for teenagers with autism	Teenagers with autism are able to make friends, have fun, and learn skills like art or football
	Families	Social activities for children with autism and their siblings	Brothers and sisters have fun with their siblings with autism and relate to them in a more positive way
	Services	Advice for mainstream leisure services on improving facilities for people with autism	Leisure centres become more hospitable and welcoming places for people with autism
	Government	Working with local commissioners to allocate funding for social activities.	Government funding provides more stability and support to autism-specific leisure projects

Just under half of parents of children with autism are under severe mental stress;<sup>10</sup> they are twice as likely to have significant mental health needs than parents in general.<sup>108</sup> Having a child or sibling or relative with autism can bring unusual pleasures, but it is also very challenging.

Parents are confronted with issues and problems that they may know very little about and be unprepared to tackle. They have to master complex medical issues, navigate their way through a maze of unconnected and unhelpful government departments, learn new techniques in dealing with their child, and apply for benefits—all while caring for a child who may have severe behavioural problems, suffer sleepless nights, and represent a danger to themselves and others.

Meanwhile the normal routine of a family life continues: clothes need to be washed, chores done, the rest of the family looked after. A parent may also have a job to worry about.

Siblings, daughters, sons, grandparents and spouses, as well as parents, all need support in living with and helping a relative with autism. Otherwise they risk being worn down and damaged by the experience. They need emotional, financial and practical support, to ensure that they can carry on. Supporting the family also helps the individual with autism.

Charities are well placed to provide this kind of support and assistance. Often they have been set up by parents who know the specific needs and problems that families face. However, they are normally limited in the amount of support that they can provide, as this kind of provision is largely outside of government responsibility and funding is scarce.

Donors can help to fund a variety of programmes that help parents and equip them with the skills and the resources they need.

## Why should donors care?

There are around one million people in the UK who are related to someone with autism. Although each family is different, they all face common challenges: the practical and financial costs of care, fighting for services and support, and emotional pressures.

Few families will have the financial or emotional resources to deal with the situation by themselves. They will need to be able to draw on different sources of support and help when needed.

Proper support can help families look after their relative with autism. It can help them to campaign for better services and equip them with the resources, the confidence and the multiple skills that they need. Support allows families to pursue activities that are central to their own health and happiness, such as holding down a job, having a social life, and being able to devote time to their other children.

Without help, advice and support, families experience extreme hardships: social isolation; poverty; poor mental and physical health; and the breakdown of family relationships. Extreme cases may lead to suicide.

If families are no longer able to cope, responsibility normally falls on the state, which then has to provide expensive residential schooling or care provision.

Without help, advice and support, families experience social isolation, poverty, ill health and family breakdown.

Photograph supplied by Autism Speaks





Almost half of parents of children with autism are under severe mental stress.

“Last year we were so stressed. I used alcohol to medicate my depression. My eyeballs hurt through lack of sleep. My liver hurt from alcohol.”

Parent of child with autism<sup>140</sup>

## What is happening?

The focus of attention is normally on the parents. The impact on siblings is increasingly recognised, but wives and husbands of carers are largely overlooked.

Data on the situation parents face largely comes from studies undertaken by disabled children's charities. Autism charities have also carried out surveys of their members, which are supplemented by numerous anecdotes and case studies. There has been a recent growth in the number of books written by parents of children with autism (see Box 19 in Section 10).

## Parents face emotional and practical challenges

Parents can find it hard to connect to their child with autism. A newborn child with autism does not have the same instinctive social reactions as most children. They do not reach out for their parents, point out new things or try and communicate with their parents.<sup>109</sup> Parents unsurprisingly feel inadequate if their child is more fascinated by a washing machine than by them.

Diagnosis may provide an explanation for this behaviour, but it does not necessarily end the guilt. While the original theory that autism was caused by parental neglect is thankfully disproved, it tends to linger even among those who should know better. Only five years ago a parent was told by a GP that his child's autism could have been caused by accidentally being burned on the stove.

Children with autism can need intensive practical care and supervision. Often they have little sense of personal safety or the repercussions of what they do. Their behavioural problems can be more traumatic than the core disability.<sup>110</sup>

Parents have to be constantly on guard, in case their child gets on the roof, or gets violent, or eats mud, or empties all the shampoo, conditioners, tomato ketchup and mustard around the house, because they like the way it feels in their fingers.

Childhood problems of autism are difficult to manage:

- 38% of children have significant problems sleeping;
- 51% have problems with eating;
- 26% have problems with toileting; and
- around 40% are hyperactive and have problems with temper.<sup>111</sup>

On top of this, the interventions that parents follow are often labour intensive and stressful. Early Intensive Behavioural Interventions (EIBIs) need a great deal of time and effort. Parents often feel that they are stretched beyond their limits on a regular basis.<sup>112</sup>

## Challenges growing up

*‘Having a child with autism is long-term – it’s a marathon not a sprint.’<sup>6</sup>*

An individual will always have autism. The difficulties parents have connecting with their child are often sustained as the child grows up. The challenges may vary, but the constant emotional, practical and financial pressure will remain. Even as an adult, a person with autism can still depend heavily on their family. As we have already seen, half of all adults with autism live at home.<sup>95</sup>

Meanwhile parents will be getting older, while their child will be growing up to be bigger and stronger than them. They might also have other caring needs, such as looking after their elderly parents. Parents worry about dying, and what will happen to their child when they are gone, as voiced by the following parent:

*‘What worries me is what’s going to become of him? Before I go to sleep I think, “Will [my son] ever get a job? Will he ever get married? When he’s thirty will he be in an institution? Or will he be living a normal life?”’<sup>113</sup>*

## Insufficient support

Families often need help to cope with the challenges they face. Yet, there are often few sources of support and help available.

## Short breaks

Short breaks benefit both the carer and the person with autism, allowing parents to have a rest from caring and maybe spend time with their other children. It takes the pressure off providing constant and intensive care. For half of all families who use short-break services, it provides their only form of support.<sup>114</sup>

There are currently insufficient short breaks for children with autism. Local studies highlight the lack of provision and the high demand for these services.<sup>108, 115</sup> This is similar for all disabled children, as spelt out in the NPC report, *Ordinary lives*.<sup>36</sup> In 1998, the Department of Health estimated that less than one in fifty children with disabilities benefited

### Box 16: Struggling for short breaks<sup>5</sup>

One single mother had three children with autism. The mother was struggling to cope but the children did not have the sort of complex needs required to meet social services' criteria for short-break schemes.

Nor did they show the 'severe challenging behaviour' required to be eligible for the short-break service run by the health services. In the end, the health services accepted the children into their short-break facility 'to help out', but not for long, because they could not help with the social need for a break from caring.

This is a classic example of how the division between health and social services creates confusion as to who should be providing what, and results in different departments offloading responsibilities to each other.

from short breaks.<sup>116</sup> Compared to any other group of disabled children, teenage boys with autism have to wait the longest.

Carers have no statutory right for short breaks. The Carers Act (1995) and Children Act (1998) state that the support needs of both the child and the carer should be assessed. Yet assessment does not necessarily lead to short-break provision, as funding pressures lead to high eligibility criteria and long waiting lists (see Box 16). A third of children on waiting lists for short breaks in the UK have autism.<sup>114</sup>

The mother of one teenage girl with autism said:

*'We enjoy the break and enjoy being back together. The change of routine has helped us all. Susie gets to be in another environment she loves and we get to relax in our home. It allows us to relax with our one-year-old son and get a relaxed night's sleep and an evening off duty.'*<sup>102</sup>

Where short breaks are available, the vast majority are generic services for disabled children. Care staff are rarely trained in autism. In a study of short-break services, over 80% wanted more information about autism, and over 60% required a specific training package.<sup>114</sup>

Staff-training is vital in order to help children with autism adapt to their new surroundings and be looked after properly. Otherwise short breaks can be intensely distressing for everyone concerned. Services break down and children become excluded. Short-break services are then reluctant to take on children with autism, while parents are unwilling to use them.

In May 2007, as part of a Comprehensive Spending Review for disabled children and their families, the government committed to spend an additional £280m for short breaks for families to supplement existing provision (see Box 17).

### Information and support

Parents often have to waste time looking for information about services and benefits. This causes delays and frustration, as expressed by the following quote:

*'The stress is not knowing. If you know a bit and you're actually doing something, even though there are 100 things you could be doing, you feel better about it.'*<sup>6</sup>

Often parents are not aware of their rights and those of their child. Without advice and support, they may be unable to argue their case with the local authorities.

### Financial support

Over half of families with children with autism receive a disability benefit.<sup>10</sup> Yet only one in five carers feel that all the additional costs to themselves or the person they care for had been met by their package of benefits.<sup>96</sup>

Over a third of carers openly admit that they do not understand the system.<sup>96</sup> A number of state benefits have to be applied for in a strict series of deadlines. Applications are time-consuming, complicated and can often be emotional. As part of the Disability Living Allowance (DLA), the parent has to detail every possible danger that can happen to their child.

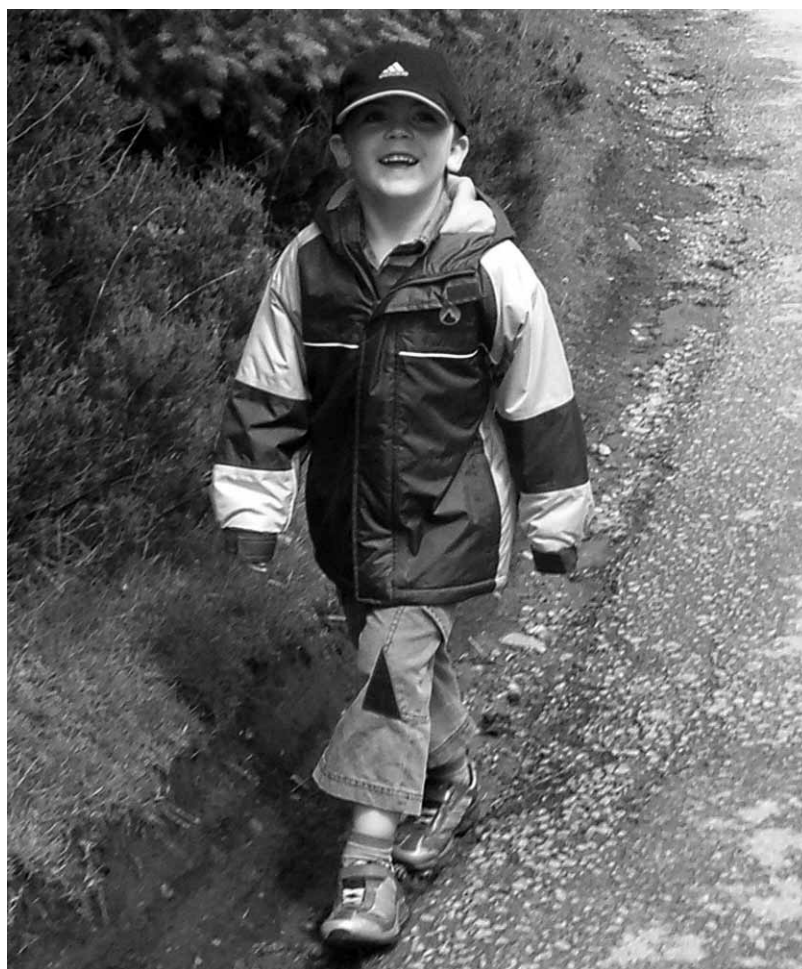
*'It's hard to describe autism within the questions and boundaries of the application form.'*<sup>6</sup>

It is not always obvious how autism fulfils certain criteria. There is a mobility component for the DLA, and while a child with autism may have no obvious physical problems, he may need constant supervision to walk down the street.

*'You just wish you had somebody to come and help you fill in these forms... they get put to one side and then you try to answer the questions and you think "What does that mean?" It would be easier if he was in a wheelchair. You could say what the problems are.'*<sup>6</sup>

“Having a child with autism is long-term—it's a marathon not a sprint.”

Parent of child with autism<sup>6</sup>



Photograph supplied by Autism Speaks

Siblings may have to take on extra responsibilities, making them feel older than their years and isolating them from their peers.

## Impact on family

### Isolation and loneliness

Parents often describe feeling cut off from society and alone. They feel they have no one to speak to and no one who understands their situation. Other people do not know much about autism or its effects.

Parents' caring responsibilities limit opportunities to follow their own interests and meet up with friends.

*'You feel so isolated. I tried to take my little boy to the park but he would run off and hit other children. So sometimes you're just stuck indoors with him, and you do start to get a bit depressed, really.'*<sup>6</sup>

### Poor physical and mental health

Parents of children with autism have significantly worse mental health than other people, including the parents of other disabled children. According to the Office of National Statistics just under half of parents of children with autism have an emotional disorder. This is twice as high as other parents.<sup>10</sup>

Other smaller studies showed that half of mothers with children with autism were experiencing 'significant psychological distress'; three out of five parents of children had a 'significant mental health need' and half of parents were 'highly aggravated'.<sup>117,108,118</sup>

Not surprisingly, it seems stress levels are compounded by a lack of support.<sup>119,120</sup> There are a number of individual anecdotes about suicide or total mental breakdown.

Mothers, who tend to be the primary carer, are more affected than fathers.<sup>113</sup> There are also indications that the physical health of parents is adversely affected.<sup>110</sup>

### Family breakdown

Having a child with autism often puts added strains on family relationships. In many cases it is the stress of constantly having to battle for services that does the damage.

A survey by the Office of National Statistics found that almost two out of every five children with autism live in 'unhealthy functioning families'.<sup>9</sup> This rate is twice as high as for other children.<sup>10</sup>

Strong anecdotal evidence supports these statistics. One North London charity puts the divorce rate of parents of children with autism at 80%.<sup>121</sup> While in one small study of 75 families, one in three children with autism was being brought up by a lone parent.<sup>108</sup>

\* This was measured using the General Functioning Scale of the MacMaster Family Activity Device (FAD), which gets families to rate the appropriateness of certain statements, such as: 'In times of crisis we can turn to each other for support' and 'We avoid discussing our fears and concerns.'

## Poverty

Caring for a disabled child is three times as expensive as caring for a non-disabled child. Families of children with autism face a range of extra costs. These include replacing clothing, not being able to use public transport, and having to adapt the house.<sup>122</sup>

Caring for a child with autism also has an impact on employment levels. Parents of a child with autism are less likely to have a job, compared to people with similar educational background: 30% of children with autism lived in families in which neither parent worked, compared with 14% of other children.<sup>10</sup>

A recent report on the economic impact of autism on the UK has placed the annual cost to all families at £1.3bn. This includes out-of-pocket expenses and lost employment opportunities and income, but does not take into account the time spent providing informal care. As the report says:

*'The question that these high costs raises is whether this burden—economic and otherwise—is reasonable for a society to expect of families.'*<sup>12</sup>

There is patchy evidence about how these added costs translate into family poverty. According to a local study in Manchester, half of the families bringing up a child with autism had a weekly take-home income (including all benefits) of less than £300.<sup>108</sup>

The Family Fund is a government funded charity that provides grants to families of disabled children. Eligibility is subject to income. Between 1999 and 2004 the biggest increase in applications came from families of children with autism.<sup>123</sup>

## Siblings

Brothers and sisters are also affected by autism. Their parents often have to spend more time caring for their siblings. Sometimes they may have to take on extra responsibilities themselves. This can make them feel old beyond their years and isolated from their peers.

Siblings' education may suffer as a result of being tired because of interrupted sleep. Doing homework may be impossible because of the disruptive behaviour of a sibling. They may be bullied at school and it is often siblings who find other people's attitudes most upsetting.

Children often have a lot of questions concerning autism, such as whether they will develop it when they grow up. Often, they feel unable to ask their parents for fear of upsetting them. There is also the wider impact from parent's mental health and possible divorce.

The national charity for the siblings of disabled children, **Sibs**, report that the siblings of children with autism make up roughly a third of callers to their helpline.



## What are charities doing?

Many of the autism charities set up by parents have a strong awareness of the challenges facing the families of people with autism and what is needed.

Donors might expect it is the government's responsibility to ensure that families of children with autism get the financial and practical support they need. At present this is not happening; services are non-existent or inadequate. Charities are needed to help improve these services, either by providing autism-specific expertise, or by lobbying the government to change policies, benefit levels and legislation. They also provide training and information, to give parents the skills to cope.

Charities have a much larger role to play providing emotional support where there is little government responsibility.

## Improving services

**Shared Care Network** is the umbrella charity for short-break services in the UK. In 2002 it commissioned research from the **Norah Fry Research Centre** into the short-break services available for children with autism and their families. The resulting report, *Better for the Break*, highlighted the huge shortfall in provision, and the lack of training for carers.<sup>114</sup> Since then, the Shared Care Network has produced a DVD, called *Getting to know me*, which provides information for potential carers about looking after children with autism.

Several charities for disabled children have been part of the *Every Disabled Child Matters* campaign. This has led to a government increase in funding of £280m into short-break services (see Box 17). This initiative will have a positive effect on families of children with autism if more short breaks are available as a result. However, immediate benefits might be constrained by a shortage of autism-trained staff.

Autism charities also provide short-break opportunities. This ranges from schools offering help over the holidays, to dedicated

respite facilities. Both **Autism Initiatives** and the **Scottish Society for Autism** have residential respite services for people with autism.

The **Wessex Autistic Society** provides both community-based and residential short-break services for people with autism and their families.

**Resources for Autism** provides a support programme called *Reach Out* in the North London boroughs of Barnet and Brent. It receives most of its funding for this through a Carers' Grant. This was originally based around a family outreach model, working directly with children with autism and their parents to improve their behaviour and skills.

Yet it was quickly found that this was not what parents wanted. What they wanted was someone who could look after their child while they went and had a bath; or helped their other children with their homework. The emphasis of the programme has now changed accordingly. In 2006, 31 families were supported.

## Impact

There is limited evidence of the outcomes of short breaks. Most of the literature focuses on the desire for breaks, characteristics of service users and the different models, rather than what they achieve. Shared Care Network's report, *Better for the Break*, consulted a small number of adults and young adults with autism about the impact of short-breaks. They highlighted the benefits of short-breaks to both individuals with autism and their parents if done well.

There is some evidence that short breaks reduce the stress on parents, particularly on mothers, and that it reduces the need for out of home placements. The NPC report *What price an ordinary life?* looks at this area in more detail.<sup>124</sup>

In 2006, the Wessex Autistic Society carried out a small survey of parental satisfaction. All responses were either satisfied or very satisfied, with the quality of care their child received; their child's social skills development; and their child's personal and self-help skills development.

“It wasn't having a child with autism that caused the most stress. It was the battle I had to access services for her that finished me off.”  
Parent of child with autism<sup>78</sup>

### Box 17: 'Aiming high for disabled children: more support for families'<sup>142</sup>

In May 2007 the government announced the results of a Comprehensive Spending Review for disabled children and their families. This was in response to a long-running campaign, *Every Disabled Child Matters*, co-ordinated by four charities: Council for Disabled Children, Contact a Family, Mencap, and Special Education Consortium. The government committed to spend £340m for disabled children and their families, spread over three years from 2008-2011, to improve services. The funding is to be allocated as follows:

- £280m for short breaks for families. This is for additional services—not to fund existing services.
- £35m to improve the provision of access to child care—to be implemented via Sure Start.
- £19m for support in the transition from childhood to adulthood.
- £5m to support parent forums.

The document also talks about the importance of a 'core offer' of a universal entitlement to a level of service. It also stresses the importance of early support programmes for children aged 0-5. Improving data collection on cases by local authorities and Primary Care Trusts is another priority. Families of children with autism will benefit from some of this spending, although there are no specific funds set aside for autism.

## Information and advice

Almost every local charity has some kind of advice service and helpline, either officially or on an ad hoc basis. The **NAS** is the largest source of information for families, through its helpline, website and publications.

A lot of charities provide training programmes for parents about a whole range of issues, such as sexuality and managing behaviour. The NAS has devised the Early Bird programme for parents of newly diagnosed children. It gives them a crash course on the skills that they need and techniques they can use.



Photograph supplied by Resources for Autism

The NAS has franchised the scheme out and runs a training school to teach people about these techniques. In December 2006, there were over 230 licensed teams comprising over 1,170 individual licensed users who have run the programme with more than 4,500 families.

The **Essex Autistic Society** has a Family Support Officer who helps out with whatever the parent wants, whether it is just a friendly ear, or more practical services, such as helping them fill out benefit forms, giving them advice about support they can get or directing them to people who can help them. This can involve intensive support, or just ringing up an over-stressed mother to remind her that the benefits form needs to be handed in.

There are also a range of charities that offer more specialist support, such as the **Independent Panel for Special Education Advice (IPSEA)** or the **Disability Law Service (DLS)**.

## Impact

Feedback from parents on the benefits of better information and having someone to help explain the situation is uniformly positive.

An evaluation of the Early Bird programme in 2003 showed that parents were significantly less stressed, that they were able to adjust their communication style and they were able to see their situation more positively. Parents were extremely happy with the programme and 95% would recommend it to other parents.<sup>125</sup>

## Emotional support

The main source of emotional support for parents is local parents' groups. They provide opportunities for parents to meet other people who have gone through the same thing, and who are dealing with the same issues. There are normally strong ties between the local autism charity and local parents' groups.

**Autism West Midlands** supports 31 parents' groups and also provides a training pack for those who want to set up a group for parents. These provide advice and guidance for around 450 parents.

The **National Autistic Society** has over 70 local groups across the UK that provide support and advice to parents and families.

The charity **Sibs** also offers an advice and support line for siblings and professionals, as well as providing help and training on setting up sibling groups. Due to the high number of brothers and sisters of children with autism getting in contact, it is looking at developing an autism-specific template.

## Impact

All of the parents that NPC spoke to stressed the importance of parents groups and the impact that it had had on their lives. Although there are been instances where parents groups have been hijacked by hard-line groups strongly advocating particular viewpoints or treatment, these are rare. In the vast majority of cases, parents groups provide a welcome opportunity for parents to share knowledge and feelings with other people who have had the same experience.



## What can a donor fund?

Families get little of the support they need through the statutory sector. Instead they often have to rely on each other and what provision charities can provide.

Donors can support families in three main ways. The first is by helping to **improve and extend services**. As government support is limited in this area there is an argument for charities to fill these gaps, and ensure that more people have access to better support.

The most logical way for a donor to be involved is through improving the capacity and the ability of the charity to provide services. This largely involves funding training so that people providing short-break services and other sources of support are trained and knowledgeable about autism.

A donor can also provide funding to those charities that are **providing information and training** to parents. This could be a national charity or more local sources of advice. Intensity of support could vary from websites to training courses.

Finally a donor can fund charities **providing emotional support**. This includes different types of support groups as well as more intensive and personal contact.

One of the ways to address all of these areas is by funding a family support officer or team, who can then provide a source of support and training to parents and advice to local services.

**Table 9: Examples of funding and impact**

Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>Having a family member with autism can affect the quality of life of other members of the family.</li> <li>There is little government support for families of people with autism.</li> <li>Supporting families helps them to provide better support for their relative with autism.</li> <li>Charities mainly rely on private donations to offer valuable services.</li> </ul>	Individuals	Information to parents on how to care for a child	Parents understand how to care for the child better: the child is happier
	Families	Sibling groups for brothers and sisters of children with autism	Siblings of children with autism will feel happier and able to cope with other issues, such as bullying at school
	Services	Autism training for carers providing short break services	More children with autism and their families benefit from short breaks
	Government	Lobbying for better services	More funding available for services such as short breaks

# Government and public attitudes

Autism does not fit easily into government structures. People often fall through the gaps.

Government plays a central role in the lives of people with autism. It is responsible for people's health, safety, education, housing and care. Its responsibilities are spelt out in a complex web of legislation, national policy and guidelines. However, as government is increasingly decentralised, actual delivery of these responsibilities generally lies with local government. How these policies are funded and implemented have a major impact on their success.

People with autism often pose particular challenges for government. Autism does not fit easily into existing government structures or funding streams. People with autism often fall through the gaps.

Even when people with autism are picked up by local government, the support that is provided is often inadequate and inappropriate. Local government commissioners may not know what makes an autism service good. Specialist autism services can often be expensive and lose out to cheaper and less effective alternatives because commissioners make

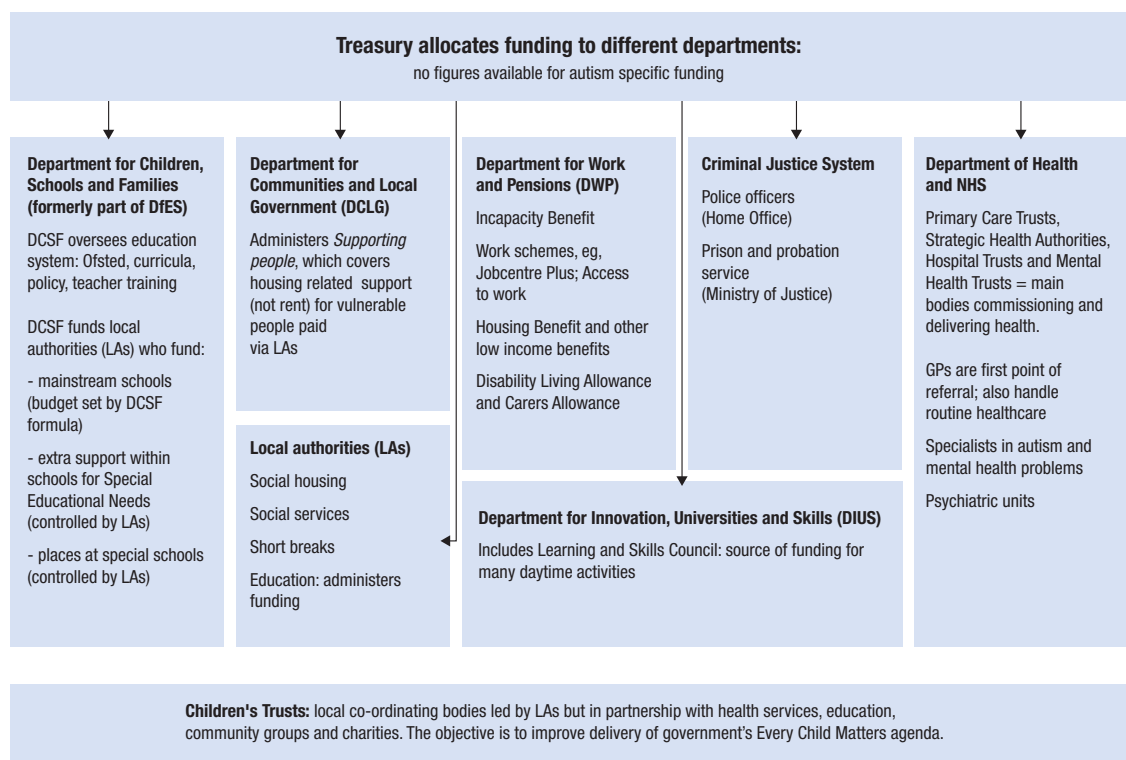
short-term decisions based on immediate costs rather than long-term benefits.

Charities help to address these shortcomings, not just by providing effective services, but also by helping government to think more carefully about its autism strategy. They provide expert advice, guidance and direct lobbying at all levels of government. They also equip people with autism and their families to become campaigners and advocates.

Poor public understanding adds to the challenges that people with autism face. If doctors, police officers, or the general public do not understand autism, it can lead to misunderstandings and exclude people with autism from their local community. Charities have a role to educate and inform the public about autism, dispelling prejudice and raising awareness.

Private funding is vital to allow charities to do all these activities. There is little other money available.

Figure 9: Government and how it affects people with autism: responsibilities of different departments



## Why should donors care?

As we have seen in previous sections, government plays a central role for people with autism. Figure 9 illustrates the activities of government affecting these people. On a day-to-day basis, the relationship can be intense. So although the subject of government might seem somewhat dry to a donor, for a person with autism who is dependent on government services, good government can be the difference between contentment and misery.

The government, or agencies or organisations acting on behalf of the government and using government funding, may house people with autism and care for them on a daily basis. Government is responsible for people's physical and mental health, and has a duty to educate them. Government officers are responsible for their safety. And government might also be involved in helping to employ people, or providing funds for medical research.

Government has significant financial and organisational resources at its disposal. However, NPC learnt from talking to many charities that this capacity could be allocated more effectively. There is no centralised or cohesive strategy for autism in the UK. Decisions are often made in an ad hoc manner, and with insufficient knowledge or awareness of the issues. With inadequate central direction, and uneven local expertise, the quality of services is patchy and inconsistent across the UK.

Legislation also affects people with autism, who have, for instance, joined the mental health lobby in criticising some of the provisions of the recently passed Mental Health Act (2007).

Public attitudes also need to change. Too often, too much pressure is placed on people with autism to 'fit in', rather than helping change society to make it more hospitable for people with autism. This is particularly vital for public officials, such as doctors and police officers.

## What is happening?

The responsibility for autism is spread out and diffused across government. We do not know how many people with autism government is supporting, what this costs, how services are being delivered and how much of a priority autism is. Awareness, expertise and provision seems patchy across all areas of government.

There have been attempts to clarify and standardise government responses. The Department of Health and the Department for Education and Skills, as was, commissioned a 'clarification note' on how central government policy relates to adults with autism (see Box

18).<sup>126</sup> At a local level, Surrey County Council has devised its own autism strategy.<sup>97</sup>

Public attitudes are even harder to judge. No large-scale surveys have been carried out. However, smaller samples, often looking at particular groups, such as GPs or employers, have highlighted considerable lack of awareness. Only 20% of employers knew anything about autism when surveyed by the NAS' employment scheme *Prospects*.<sup>94</sup> A number of personal anecdotes and news stories highlight the lack of understanding that people with autism face as part of their daily life.

## Legislation and national UK policy

A complex raft of legislation provides a framework of rights, guarantees and constraints for people with autism. This covers areas such as special educational needs (SEN), or disability discrimination (see Box 18).

Government pursues policy goals through a series of policy documents, directives and guidelines. No department has overall responsibility for autism. Policy relevant to autism originates from a broad range of government departments, including the Department of Health and the Department for Children, Schools and Families (DCSF) (formerly DfES).

There is no overarching UK national strategy for autism but there is the autism manifesto produced by the All-Party Parliamentary Group on Autism (APPGA).<sup>127</sup> The APPGA is made up of a cross-party group of MPs and peers interested in autism. This provides a useful platform for important and topical issues around autism to be discussed and raised in parliament.

The manifesto sets out four general principles and 11 specific objectives to deliver better services and support for people with autism, to be achieved in the next ten years.

Personal accountability and responsibility often seems to be the best way to ensure that issues are dealt with and carried forward. Within some government departments there are individuals who are responsible for autism, but this practice does not appear to be common.

However, there seems to be growing political interest in autism. This is complemented by the success of the disabled children's lobby in its *Every Disabled Child Matters* campaign.

## Funding

It is vital that funding backs up both legislation and policy. Yet it is impossible to say exactly how much government funding is going on autism. Current estimates put the total annual costs of providing services for people with autism at just under £15bn.<sup>12</sup> However, there is

There is no cohesive strategy for autism in the UK. With inadequate central direction and uneven local expertise, the quality of services is patchy.

no central stream of autism funding and money is rarely ring-fenced within departmental budgets. Instead it is often subsumed into other categories such as disabled children, learning disabilities, or mental health.

Increases in funding to one of these areas, can produce knock-on benefits. Families with autistic children are likely to benefit from the extra £340m that has been allocated to disabled children through the recent Comprehensive Spending Review for England (see Box 17 in Section 9).

### Devolved governments

Devolved governments seem to present further opportunities for action and influence. They have control over certain funding streams and areas of policy such as health, education and care.

#### Scotland

A Public Health Institute of Scotland (PHIS) report in 2001 highlighted the lack of services for people with autism in Scotland and problems with government. Following this, the Scottish Executive set up the National ASD Reference Group in June 2002 to agree priorities and identify the best way to

develop good practice. There were specific sub-committees on diagnosis, information and training.

Based on the advice of the reference group, the Scottish Executive funded a number of autism projects. This includes the Scottish Autism Service Network, two pilot projects to provide 'one-stop shops' for adults with autism and quality standards for autism diagnostic services. It has also set up a working group to improve autism respite care by dispersing £150,000 for better training. The Scottish Executive has not articulated the results of these initiatives.

The effect of the recent changes in the Scottish Parliament has yet to be analysed. It is hoped that the new government, led by the Scottish National Party, continues to recognise and fund the support needs of people with autism.

#### Wales

The Welsh Assembly has just produced a draft of the All-Wales Autism Strategy for consultation. This is the first of its kind in the world and provides a clear direction for how services in Wales should develop in order to meet the needs of people with autism. It provides clear action points for commissioners, service providers and local government.

It also commits the Welsh Assembly Government (WAG) to appoint an autism coordinator, who will undertake research into the needs of older people, issuing autism-specific guidance documents on education and transition to further education. The WAG will commission an accredited course on autism, to ensure that those who work with people with autism have a minimum level of expertise.

The strategy has been accompanied by a pledge of £1.7m from the Welsh government to help local authorities evaluate current provision and implement improvements. More significantly, autism will also be part of the Welsh budget for the next ten years as a priority area.

### Local government

As government is increasingly decentralised, local government is taking the leading role in allocating funding and delivering services. However, people with autism present several challenges to the way that local government delivers services because their needs are:

- specific and complex;
- multiple; and
- life-long.

#### Box 18: Disability legislation and policy affecting people with ASD

##### Legislation

**Children's Act (2004):** This aims to improve the coordination of service providers and government departments through initiatives such as a Children's Commissioner for England and setting up Children's Trusts.

**Disability Discrimination Act (2005):** This protects all disabled people from 'less favourable treatment' in access to education, services, employment and transport, and puts a new duty on the public sector to 'promote disability equality.'

**Mental Health Act (2007):** This new act will determine under what circumstances a person with a mental disorder can be detained compulsorily. Critics see that it has the potential to deprive people with autism of their liberty.

##### Policy

**Valuing People (2001):** This policy aims to improve the lives of people with learning disabilities, their carers and their families. It is underpinned by four principles: rights, independence, choice and inclusion.

**Our Health, Our Care, Our Say (2006):** This aims to make services more responsive, focus on people with complex needs and shift care and support closer to home. It seeks to give people choice and control over their life and the health and social care they receive.

##### Clarifications

**Autism exemplar, National Service Framework for Children, Young People and Maternity Services (2004):** This document illustrates how the standards and key themes of the NSF for Children, Young People and Maternity Services should be applied to a child with autism.

**Better Services for people with ASD: a note clarifying current government policy and describing good practice (2006):** This document clarifies the nature and intent of existing government policy in relation to adults with autism and explains what this means for local commissioners and providers.

Local government does not necessarily have the expertise and the knowledge to provide or commission services for people with specific and complex needs.

Charities explained to NPC that services are allocated by different teams, covering mental health or learning disabilities, so people with an average or high IQ and without mental illness often fall between departments and funding streams. They are often refused assessment or shuttled from department to department, without anyone taking responsibility.

Children's Trusts in England are supposed to develop and coordinate children's services at a local level. However there is no blueprint for how Children's Trusts operate, and no requirement for autism to be a priority. So, as in national policy, local implementation and delivery relies heavily on the commitment of individuals as well as funding availability.

Children's Trusts do not extend to adults, despite the need for improved coordination of local services such as health, housing and social care. The transition between different services is difficult. As people move from child services to adult services, and then on to geriatric services, their social worker often changes. Yet people with autism have needs throughout their life and find change difficult.

Autism services can be expensive and the numbers of people being diagnosed with autism is growing fast. NPC heard that it is tempting for social services to try and reduce the strain by cutting costs, or raising the level of eligibility. Often assessors do not take into account the nature of the condition and the need to prevent crises.

People with autism are not the only people to face these problems, and addressing them has been a focus of recent government policy.<sup>67, 128, 129</sup>

*'Having a clear, locality wide structure through which ASD is championed has been shown to help'.<sup>126</sup>*

In Scotland and Wales, the devolved administrations led calls for local autism strategies. In Scotland, all local governments have to outline plans to develop services and meet the needs of people with autism, as part of their Partnership in Practice (PiP)\* targets for 2004–07.<sup>130</sup> In Wales, as part of the national ASD strategy, there is a responsibility on local government to develop a strategy for autism.

\* Partnerships in Practice are local government strategies for addressing the needs of people with learning disabilities.

### Box 19: Autism Lit

There has been a recent growth in books and films about autism. These include *The Curious Incident of the Dog in the Night-time* by Mark Haddon, and the film *Snow Cake*, starring Sigourney Weaver.

There have also been a number of accounts written by people with autism and their parents. These help to illustrate the different experiences and obstacles that people with autism face. They include: *George and Sam* by Charlotte Moore; *Send in the Idiots* by Kamran Nazeer; *Born on a blue day* by Daniel Tammet; and *Joe: the only boy in the world* by Michael Blastland.

In England, concerted autism provision and strategies depend on the attitude of local government, and the willingness of individual departments to pool their resource and expertise. Examples include:

- The Liverpool Primary Care Trust and Social Services set up a team to provide diagnosis and support for people with Asperger syndrome. The Liverpool Asperger Team now run managed pathways to connect individuals with the right public service.
- Surrey County Council has an autism strategy, devised by all the different government departments. It also set up a system of Autism Champions, to promote the dissemination of autism information throughout all local government services.

Anecdotal evidence suggests the success of these initiatives, although NPC has been unable to locate any formal evaluations.

### Public services

People with autism often come into contact with public services, such as the police or the local health service. However, employees in public services appear to have low levels of awareness of people with autism, and what to do when someone has it.<sup>53, 92</sup>

People with autism have greater health needs than the rest of the population, and so have regular contact with the NHS and may use emergency services. An American study found that average annual health care costs were 45% higher for children with autism than children without autism.<sup>131</sup>

People with autism come into contact with the Criminal Justice System in various contexts: as victim, witness, suspect or offender. There is a considerable amount of anecdotal evidence of situations where policemen have misinterpreted actions and people with autism have ended up traumatised and in jail.



I had a case recently of a seven-year-old girl. Her school marked her out as difficult and spiteful—fellow pupils call her “little pig.” But I see a troubled child with Asperger’s and needing help.”

Child psychologist<sup>141</sup>

A person with Asperger’s describes being stopped for driving with a milkshake, and then arrested for being rude, which resulted in enormous stress and escalation of circumstances:

*‘At the station, my friend tried to explain my disability but the police didn’t understand what Asperger’s was and were not open to her explanations.... I felt I was being treated as if I were mad.’<sup>132</sup>*

Another recent news story told of a young man with autism who was served an Anti-Social Behaviour Order for staring over a neighbour’s fence.<sup>132</sup>

### General awareness, stigma and discrimination

The majority of people in our society know little about autism. People may expect an autistic savant like the Dustin Hoffman character in the film *Rain Man*, or a child obsessed with Thomas the Tank Engine. They are surprised when someone with autism is a middle-aged woman buying bread in the local shop. People do not know how to accommodate people with autism and make them feel comfortable.

*‘The concepts of physical and mental impairment are fairly easy for people to grasp, but the idea of social impairment is much more difficult to understand (and to explain).’<sup>6</sup>*

Levels of awareness and interest are increasing with books and articles written about autism (see Box 19). Yet there is still prejudice and stigma: children being bullied at school, or a person struggling to take a bus because people stare.<sup>133</sup>

## What are charities doing?

Charities can support and improve the government system at a number of different points. They can:

- campaign at a national level to improve legislation and policy;
- lobby local government so that they do not overlook the needs of people with autism;
- offer workable solutions to specific problems and show how these can improve services;
- help government to determine where to spend resources by demonstrating what works;
- feed practical experience from delivering services into policy discussions;
- represent people affected by autism—individuals and parents—and feed their views into policymaking and practice; and
- empower individuals and families to pursue their legal rights.

Figure 10 shows the ‘policy loop’, and the steps required to achieve policy change.

Charities can also improve society’s understanding of autism and help professional groups who regularly meet people with autism, such as policemen, to recognise and understand the condition.

### National campaigning and lobbying

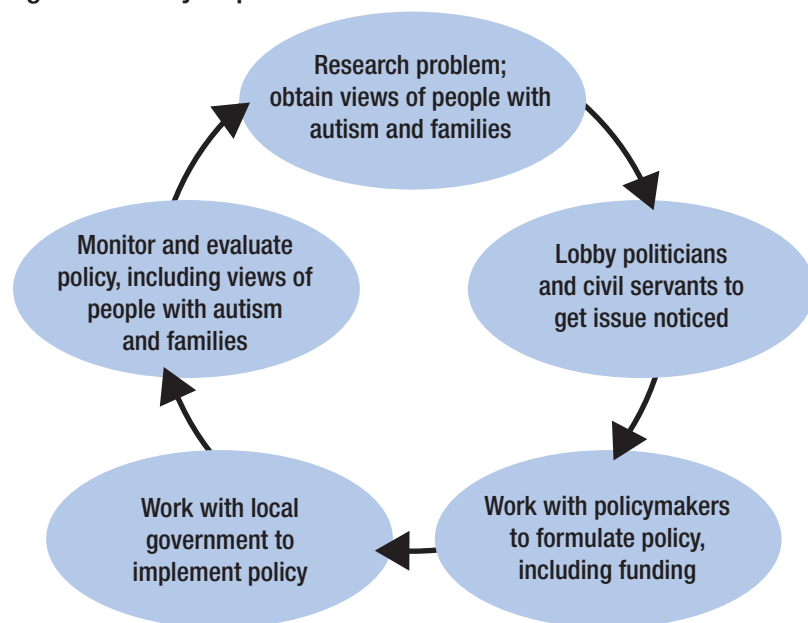
The national charities, such as the **National Autistic Society (NAS)**, **Scottish Society for Autism**, **Autism Cymru** and **Autism Northern Ireland**, carry out most of the lobbying at a national level. Single issue charities, such as **TreeHouse** and **Autism Speak** pursue specific areas, such as education or medical research.

Unpicking the different ways charities influence government is difficult. The two most obvious methods are membership of an advisory group or direct campaigning. Personal relationships with civil servants are also valuable.

The APPGA (All-Party Parliamentary Group on Autism) is supported by an advisory group, which includes the NAS, Autism Speaks and TreeHouse. The APPGA has commissioned research into education and the impact of autism.

Charities have also been involved in advisory groups set up on specific issues. The NAS, Autism Speaks and TreeHouse are members of the Autism Research Coordinating Group, along with representatives of government departments, funders and experts. The group helps government to play a greater role in coordinating information on autism research and identifying priorities.

Figure 10: Policy loop



In Scotland the main advisory group has been the Autism Reference Group. Its members include the Scottish Society for Autism and NAS Scotland. It had £2m to spend on projects to improve autism provision in Scotland.

The NAS has had a campaigning office since 1999. Every year it organises a campaign around a particular issue, normally based on research it carries out with its members. The campaign for 2006 was '*make school make sense*', which is mentioned in this report's section on education.

When Autism Cymru was founded, one of its major strategic goals was to persuade the Welsh Assembly to devise a national strategy for people with ASDs. This would be the first national strategy for people with autism in the world and provide an integrated strategy for people from birth to the grave. It lobbied individual civil servants and ministers on the need for an integrated national strategy and its financial and practical benefits.

In March 2002, it was asked by the Minister for Health and Social Services to present to members and officials in the National Assembly of Wales (NAW). In December 2002, the Health Minister announced the development of a national strategy for autism.

The Chief Executive of Autism Cymru, Hugh Morgan, chaired the Expert Working Group that fed into the strategy from July 2003–September 2004. This involved over 100 different professionals, parents and people with autism. He presented the final report to officials in September 2004. It required further lobbying and work to produce a draft of the strategy in January 2007.

### Impact

Teasing out the impact of lobbying on policy, and identifying the steps described in Figure 10 is best illustrated by the following examples:

### Wales

Autism Cymru's role in developing an ASD strategy for Wales demonstrates effectiveness at several points in the 'policy loop'. Politicians are now noticeably more engaged with autism. It has resulted in specific policy development, in the form of the All-Wales Strategy for autism described earlier, which has been out for consultation since January 2007.

While there are some flaws and limitations to the document, it is an important step forward. It contains clear action points at both national and local levels, and identifies a post within government that would take responsibility for actions.

As it has only just been launched for consultation, there is still some uncertainty about how this will be implemented. However, the initial £1.7m pledged by the Welsh Assembly Government shows financial commitment and will be of practical help to local authorities evaluating current provision and implementing improvements. This is equivalent to over £70,000 per local authority.\* Autism will also be part of the Welsh Budget for the next ten years as a priority area.

### Every Disabled Child Matters

Government recently promised £340m for disabled children and their families under the Comprehensive Spending Review. This arose as a result of a sustained and very well coordinated campaign by four charities for disabled children. The *Every Disabled Child Matters* campaign involved the entire disabled children voluntary sector, and gained support from key politicians, MPs, and also civil servants within the then DfES and Treasury who were persuaded by the campaign's arguments.<sup>143</sup>

\* £1.7m ÷ 22 local authorities



\* Photograph supplied by Autism Cymru

However, the promised money must now be spent. Charities will be monitoring this closely: there is a risk that some of the funds will be used to subsidise existing services provided by local authorities rather than expand them.

### Working with local government

Charities are working with local authorities to help them think about their autism strategy, as well as look at ways they can commission better services for people with autism.

Part of **Autism Cymru's** lobbying work is focused at local government, for instance convincing local authorities of the need to have a local strategic plan. Autism Cymru then pulls together a multi-disciplinary group, including local practitioners, social workers, parents and individuals with autism to formulate the plan. So far Autism Cymru has worked with four out of the 22 Welsh local authorities.

**Autism West Midlands** has trained three development officers in Solihull, Sandwell and Shropshire. They are mainly funded by the local authority and have varying briefs, but all carry out autism training and awareness among different local government agencies.

The **NAS** has regional offices that work closely with local authorities. The **Tyne and Wear Autistic Society** holds specific training sessions for local government commissioners.

### Impact

Autism Cymru helped Ceredigion local authority to develop a local strategic plan and appoint a development officer for autism. In the two years since he was appointed, the number of adults with autism being supported has doubled.

### Helping individuals with autism and their families to campaign

Organisations can help individuals and their parents to campaign for the services that they need and that they are eligible for.

The **Essex Autistic Society** employs a family support officer. One of her jobs is to help parents to navigate the government system, reminding them when to fill in their forms.

The **Disability Law Service (DLS)** runs a helpline and takes on individual casework. In 2006, about a tenth of the calls it received were about autism, and it took on ten autism-related cases.

### Impact

Equipping people and families with the resources and the information to apply for services and support ensures that more people have access to the support they are eligible for. In some cases, individual cases can set a precedent for the future.

The DLS won a case for a boy with autism concerning the payment of the higher level of the mobility component of the Disability Living Allowance (DLA). The DLS argued that IQ tests were not a useful measure of intelligence for people with autism and their social intelligence should be taken into account too. The Court of Appeal agreed and the decision means a potential increase in weekly income of over £23 for many people with autism. This individual case sets a legal precedent that may help others in future.

**autism • west midlands**  
0121 450 7582  
(Monday-Friday, 9am-5pm)

**ATTENTION!**  
**POLICE / EMERGENCY SERVICES**

I have an **Autism Spectrum Disorder**  
*turn over for more information and help*

---

I have an **Autism Spectrum Disorder**

This means:

- I have social communication difficulties.
- I am likely to be extremely anxious in unfamiliar situations.
- My behaviour may appear strange or threatening.
- I will need the support of an appropriate adult / intermediary.

My name is \_\_\_\_\_ Card No. **0236**

Please contact \_\_\_\_\_ Tel \_\_\_\_\_

Photograph supplied by Autism West Midlands

### Increasing awareness of autism within targeted groups

Charities target groups of people who have a specific responsibility for people with autism or regular contact with them. As we have seen earlier, they work with parents, teachers and employers to improve understanding. However other groups are also immensely important to people with autism, eg, health workers and the police.

The **Scottish Society for Autism** has worked with the NHS to provide a website for frontline health workers about dealing with people with autism.<sup>134</sup>

**Autism West Midlands** runs a forum on ASDs for people who work in the criminal justice system. The forum includes local bodies such as the Youth Justice Board and the Crown Prosecution Service.

The charity has also helped develop an 'attention card' for people with autism, which identifies them as having an ASD and gives a number to call for advice. People have to register for this card to make sure that it is not abused. **Autism Cymru** is using a similar system. The card is useful for the police, emergency services and general public. As part of these schemes, both charities provide

Too often the emphasis is on changing the person with autism, and not enough on changing the world around them.

training and information for local police services on ASD.

The **NAS** has a general awareness card, although this does not require registration. It has also produced a guide on autism for criminal justice professionals.

### Impact

The 'Attention Card' programme run by Autism Cymru has been evaluated by the University of Bangor. Feedback from participants, those with ASDs, their families and police officers implies success. Around 90% of the police officers interviewed indicated a need for more cards, and around 60% asked for more training.

Autism West Midlands also evaluated the success of its attention card scheme after its first year. Two thirds of the respondents with autism said that having a card made them feel safer, while 96% of family members thought that carrying the card had made their relatives safer. The evaluation also included a number of positive anecdotes and instances where carrying the card had cleared up potential problems and misunderstanding.

Here are some comments from people with autism who use the card:

*'As I am unable to communicate with others clearly, the card enables me to show people I have a problem speaking to them if I am on my own.'*

*'I feel safer because it helps me to explain that I have difficulties, which I can't do when I'm stressed.'*

*'I showed the card to a shop assistant who thought I was stealing. Now he knows I do not shop like everyone else.'*

Comments from families:

*'My son had an incident where the police were involved and once they realised he was autistic and had the card to back him up, their attitude changed and they said that if they had known to begin with, they would have handled things differently. I feel reassured that things will be different in future.'*

*'This card really is a godsend.'*

### Public awareness

Charities point out that too often the emphasis is on changing the person with autism, and not enough on changing the world around them. Better awareness and small changes in behaviour would help to make the environment more sympathetic to people with autism.

In 2002, the **Disabilities Trust** and the **British Institute for Brain Injured Children (BIBIC)**

launched an autism awareness year. This was supported by the 800 other charities, including the **National Autistic Society (NAS)**. It involved a series of events, including a conference at the King's Fund.

Media coverage of autism also helps to disseminate information about the condition. In 2006, **Autism Cymru** was named charity of the year for S4C, the Welsh language channel. This led to a series of television programmes on different issues concerned with autism.

The **NAS** also works closely with the media to increase coverage of the condition, and in 2005 held an 'autism day' in Leicester Square, which was attended by over 8,000 people. It is currently planning a more concerted awareness push around adults.

### Impact

More public awareness campaigns could increase knowledge and understanding of the condition and give the public:

- a clear idea of what autism actually is and the impact it has;
- an understanding that there are many people with the condition and members of the public are likely to meet them; and
- what to do if you meet someone with the condition.

Changing public attitudes is a vital area of activity, yet frustratingly intangible. It is hard to measure the success of individual efforts to raise awareness of the condition, and what impact this has on people's behaviour.

I showed the card to a shop assistant who thought I was stealing. Now he knows I do not shop like everyone else.

Person with autism

### Box 20: £340m for disabled children: a donor's role

In 2005, the True Colours Trust commissioned *Ordinary lives*, a report by NPC on charities working in the disabled children sector, which described the need for funding for a sustained lobbying campaign to improve services for families of disabled children. Short breaks for families was one of the pressing issues on the agenda.

In 2006, the True Colours Trust agreed to fund the *Every Disabled Child Matters* campaign, via grants to the Council for Disabled Children and Contact a Family. The resources helped the charities consolidate early progress and provide more information and evidence to support the campaign's case.

In 2007, the campaign reaps its reward: the charities reported that they were 'very happy with the amounts allocated to short breaks as a result of the campaign.'

The campaign has not stopped: the government will need help implementing the policy in the Comprehensive Spending Review and spending the money allocated. However, this result is a major milestone in progress.

We cannot say for sure whether the True Colours Trust grant either:

- helped the Comprehensive Spending Review to exist; or
- influenced the amounts of money contained within the review.

However, without a fully funded campaign team carrying out all the necessary work, success would have been a struggle.



Charities have a role to educate and inform, dispelling prejudice and raising awareness. Private funding is vital: little other money is available.

### What can a donor fund?

Private donors play a leading role in funding campaigning, policy and awareness work. There are opportunities to get involved in lobbying all levels of government.

A donor can fund charities engaged in **campaigning and lobbying**. This could include high-profile national campaigns or behind-the-scenes lobbying and advice. There are few charities working in this area at the moment. The national charities have the main presence, yet there are also issue-focused charities that have a targeted presence.

The potential impact of lobbying and campaigning is that the needs of people with autism are recognised and taken into account in national legislation and policy. This provides the basis for improved service provision for people with autism. Box 20 shows how a funder can have a significant role in a lobbying campaign.

There are also opportunities for **lobbying at a local level**. Almost all charities are involved in working with local government in some sense, whether it is national charities or local service providers. This could involve providing strategic advice or informing them about the best way to commission services, and the benefits that result.

A donor may find it more satisfying to fund charities that **empower families and individuals** with autism to **campaign on their own behalf**. This could involve training in campaigning skills, or providing specialist knowledge.

There is also the question of improving **public awareness**. The most established and well recognised approaches are targeted awareness, such as attention card schemes, or work with GPs. There is also the scope for a wider push. Imagine if there was an equivalent public campaign in autism to Jamie Oliver's campaign on healthy eating at school. It could really help people with autism to be better understood.

**Table 10: Examples of funding and impact**

Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>Government provides most of the funding for autism services; sometimes it can lack expertise or strategic vision.</li> <li>Charities can lobby and work with government to prioritise autism and improve services.</li> <li>They can also equip individuals with autism and their families to be campaigners.</li> <li>Lobbying and campaigning work is not government funded initially, although government sometimes 'buys' expertise.</li> <li>Charities also try to improve public attitudes, mainly by targeting groups that have regular contact with people with autism.</li> </ul>	Individuals	Information for individuals with autism to help them become advocates and lobby for better services	People with autism receive more support and assistance
	Families	Resources for parents to become campaigners at national and local levels	Parents persuade local authorities to fund a specialist autism resource in the local school
	Services	Training on autism for police services	Policemen know what to do when they meet someone with autism in trouble, preventing unnecessary trauma
	Government	Providing information and advice to government departments	Government policy is more strategic and aware of the specific needs of people with autism



**Knowledge is power. Research into autism provides the understanding and the tools we need to address the negative effects of autism. This does not just involve genetic research in a laboratory, but also developing and testing practical strategies, like more effective education and getting people into employment.**

**At the moment we still know too little. Autism is a complex condition, which has only recently been the focus of rigorous biomedical and social research. Although the amount of research into autism is increasing, there are still important gaps in our knowledge.**

**Initial signs are promising. Technologies such as brain imaging and genetic analysis are now being successfully applied to autism. Long-running research into better interventions is producing results. In time, this will hopefully lead to improved support and services.**

**Unfortunately, what little is known is not always shared with those directly affected by autism. Parents often feel cut off and isolated, with little access to the latest relevant information and research.**

**Charities provide a catalyst for research. They direct more funds into the field and ensure it is spent on high-quality and necessary research. They help improve the capacity and the practical capabilities of the research community. They can also help disseminate and publicise the results of research to a wider audience.**

**Private funding helps charities to achieve these goals. Donors can channel money to research projects, or build up the capacity of research charities.**

## Why should donors care?

Research can give us the tools we need to combat the issues facing people with autism, such as late diagnosis, sleeping difficulties and poor employment prospects. It can also address the physical and mental problems that people with autism experience.

Research is wide-ranging; from investigating genes and brain structure in the laboratory to evaluating the efficacy of employment programmes. See Box 22 for a description of the different types of research taking place. Much of this research informs and complements each other. Better knowledge of autism's different symptoms could help design a more effective supported living programme.

Biomedical research lies at the root of our understanding of autism. Without unpicking the causal factors of autism and the impact they have on brain development and structure, we will never truly understand the condition. Despite some controversy (see Box 21) it is commonly accepted that research will provide a vital basis for designing better interventions and systems of support.

Other research looks at meeting the immediate needs of people with autism, whether this involves interventions or treatments or better services and support. This could involve research into educational approaches, the best way to treat associated medical or psychological problems, or even the best way to get them a job.

If this research is not done, we will never get to the bottom of autism, the impact that it has, and what can be done to improve the quality of people's lives.

### Box 21: A search for a cure?

**There is opposition among the autism community to research that is aimed at finding a 'cure' for autism. Some people with autism, and some parents, feel that autism is not a disorder, but simply a different way of being and an intrinsic part of their identity, which should be respected and tolerated.**

**They worry that looking for a 'cure' will eradicate these different ways of looking at the world. Instead they believe more effort should be placed on making society more tolerant.**

**The opposing argument is that biomedical research is not looking to eradicate autism, but rather reduce its negative effects. People with complex autism can have a very low quality of life due to the severity of their condition. A better understanding of autism will lead to better interventions and support.**

## What is happening?

The research environment is constantly shifting and developing, with new information being uncovered on a regular basis. There is a growing number of specialist neurodevelopment and autism journals, which record and share this information. Both international and national conferences provide the opportunity to share information and establish consensus.

It is hard to keep up with a constantly changing situation, and sometimes research and the implications of this research can appear fractured. Two important pieces of work have helped to establish some common understanding across the whole field. These are the Medical Research Council's *Review of Autism Research: Epidemiology and Causes*, in 2001, and the Institute of Child Health's *Mapping Autism Research: Identifying UK priorities for the future* in 2004.

Research into autism can provide the tools we need to address the negative effects of autism.

**Box 22: Areas of autism research**<sup>136</sup>**1. Causes**

- Genetic causes: eg, chromosomal abnormalities and candidate genes.
- Environmental causes: All factors other than genetic susceptibility, including obstetric and perinatal factors, gastrointestinal abnormalities and immunological causes.

**2. Epidemiology/prevalence**

- The number and distribution of cases of autism in a population.

**3. Diagnosis and assessment**

- All aspects of the identification of autism, from initial screening to the specific diagnostic assessment and tools that are used to measure the degree of impairment.

**4. Symptoms**

- Neurology: Research investigating brain abnormalities in autism.
- Neuropsychology: Research investigating how abnormalities in cognitive and developmental processes and functioning affect behaviour.
- Behavioural: All aspects of behaviours that are associated with autism eg, stereotyped and repetitive behaviours, sleep difficulties and toilet training.
- Associated medical and psychiatric disorders: eg, epilepsy, anxiety and depression.

**5. Intervention/treatment**

- Psycho-educational: Including behavioural interventions (eg, ABA), communication and language-focused interventions (eg, PECS), play-based approaches and educational programmes (eg, TEACCH).
- Psycho-pharmacological: Prescription drugs used to treat the symptoms of autism.
- Biomedical: Including non-mainstream, complementary treatments such as vitamin therapy, chelation therapy, secretin, diets and sensory integration approaches.

**6. The family and services**

- Including a wide range of studies associated with the family function, effects on parents and siblings etc.
- All research into services available to individuals with autism (eg, supported work schemes, community support and families' experience of diagnostic and intervention services).

**Understanding autism****Causes**

Autism is a complex neurological condition. What exactly causes it is still uncertain. It is believed to be the result of a complex interplay of genetic and environmental factors. Exactly what these are is still unknown. Scientists are starting to talk of separate 'autisms' across the spectrum, which have distinct and different causes.<sup>135</sup>

Some of the most cutting edge research that is being done is on which genetic factors make people susceptible to autism. The Autism Genome Project, an international project scanning the human genome (see Box 24), has already identified two genetic areas that merit further research.

Research into environmental factors that might possibly trigger a genetic response is still relatively limited. A number of possible candidates have been put forward such as heavy metals, vaccination, or even pre-natal influences, such as testosterone or alcohol abuse.<sup>34</sup> One of the most notorious of these

is the MMR vaccine (see Box 23). While some of these are scientifically more plausible than others, none has a substantial body of evidence behind it.

**Symptoms**

There is also important work going on in looking at what the symptoms of autism actually are. While the behavioural symptoms are relatively well catalogued, scientists are beginning to get a better idea of autism's impact on brain structure and brain development.

Recent work has looked at the implication of mirror neurons, which are activated when someone performs an action, or when they see someone else performing the same action. These are thought to be implicated in understanding other people's intentions, language and empathy. Some researchers claim there is a link between mirror neurons and autism.

Research can highlight possible windows of opportunity for interventions, and may also provide a way to measure their impact. Understanding the neurobiology of autism could lead to a targeted drug or therapy.

**Prevalence and diagnosis**

We still do not know how many people have autism. What information we have is from studies focused on children. There is still little known about prevalence amongst adults. Better data might help to establish whether there has been a rise in prevalence.

**Overcoming the negative effects****Interventions**

There is little evidence about which interventions work to reduce the negative symptoms of autism. There are three main sub-sections of research:

**Box 23: MMR**

In 1998, an article in the *Lancet* by Dr Andrew Wakefield claimed the measles, mumps and rubella vaccine (MMR) triggered autism. This led to a significant drop in the numbers of children in the UK being vaccinated.

The validity of this research has been called into question, and Dr Wakefield and two of the other authors of the article are facing charges of serious professional misconduct. No other research has proven the link between MMR and autism. In Japan, the numbers of children diagnosed with autism continued to rise, even after the MMR vaccine was withdrawn.

Some parents continue to believe strongly that MMR causes autism. Although there is no evidence proving a link, scientists are unable to rule out the possibility that MMR was involved in a tiny number of cases.

Autism is a complex neurological condition. Although we are getting closer to an answer the exact causes remain uncertain.

- Psycho-educational approaches: these include approaches such as Applied Behavioural Analysis (ABA) and TEACCH (see Box 10 in Section 5).
- Drugs: these are often used to treat the symptoms of autism, including depression, behavioural problems and hyperactivity.
- Bio-medical treatments such as diet or vitamins: have had a popular following, despite little scientific proof.

It has proven difficult to produce research that convinces everyone. There are several issues that cloud the problem. In particular, there is the difficulty in isolating exactly what impact a particular intervention has had. How do we know that it is the change in diet that is having an impact, and not another factor, such as the person's social environment, or even simply growing up? Control groups raise ethical concerns, but these can be overcome through a creative approach to research.

The area with most evidence is the educational area. As mentioned in the section on education, there is a variety of research on the impact of educational approaches. The recent results from the EIBI project point to increased IQ as a result of early behavioural therapy (see Box 3 in Section 4).

### Services

Over the years services have been built around people with autism, to combat the problems they face. Many of these have been described earlier on in the report. Most need better data on effectiveness.

Proper and rigorous research is helping to isolate the most effective programmes, and helping to validate and share this knowledge. However, more research is urgently needed.

### Research priorities

There is no overall strategic direction for autism research. Funding comes in from different directions and is spent in different places. The funding mechanisms for research sometimes result in funding not being allocated to the priorities of either those affected by autism or even the scientists themselves. In any case, the priorities of scientists, people with autism and their families are not always aligned.

In 2004, the Institute of Child Health (ICH) did a survey of the current research environment.<sup>136</sup> This involved canvassing the opinion of 184 academic researchers, as well as 123 members of the non-academic community. This included parents, professionals in the field and people with autism. It compared their perspectives on autism research with current activity in the field.

### Box 24: Autism Genome Project

Launched in 2004, the Autism Genome Project, or AGP, is the largest study ever conducted to find the genes associated with inherited risk for autism. Many of the world's leading genetics researchers pooled their resources to scan the human genome in the search for the genetic causes of autism.

The project is a public/private research partnership involving approximately 50 academic and research institutions that have pooled their DNA samples in a collaborative effort. It is designed to enable doctors to biologically diagnose autism and enable researchers to develop universal medical treatments and potentially a cure.

Phase one of the project, a research partnership with the US National Institute of Health, consisted of two scans of the human genome searching for autism susceptibility genes. The scans analysed DNA samples from nearly 1,200 families. Phase one came to an end in February 2007. After analysing 10,000 genes, it identified two of the many genetic factors that were linked to autism.

Phase two will expand on the results of the first phase and allow researchers to confirm or deny the role of genes previously identified as possibly harbouring autism susceptibility. It will look at one million genes and massively expand the knowledge we have. Due to technological advances, the second phase, involving a hundred times as many genes, will be done more quickly and cheaply than the first phase.

Over half the focus of research activity in the world and in the UK was on symptoms. Yet both parents and scientists believed that research into causes and interventions was more important. Figure 11 shows a discrepancy between actual research and what the lay community seeks.

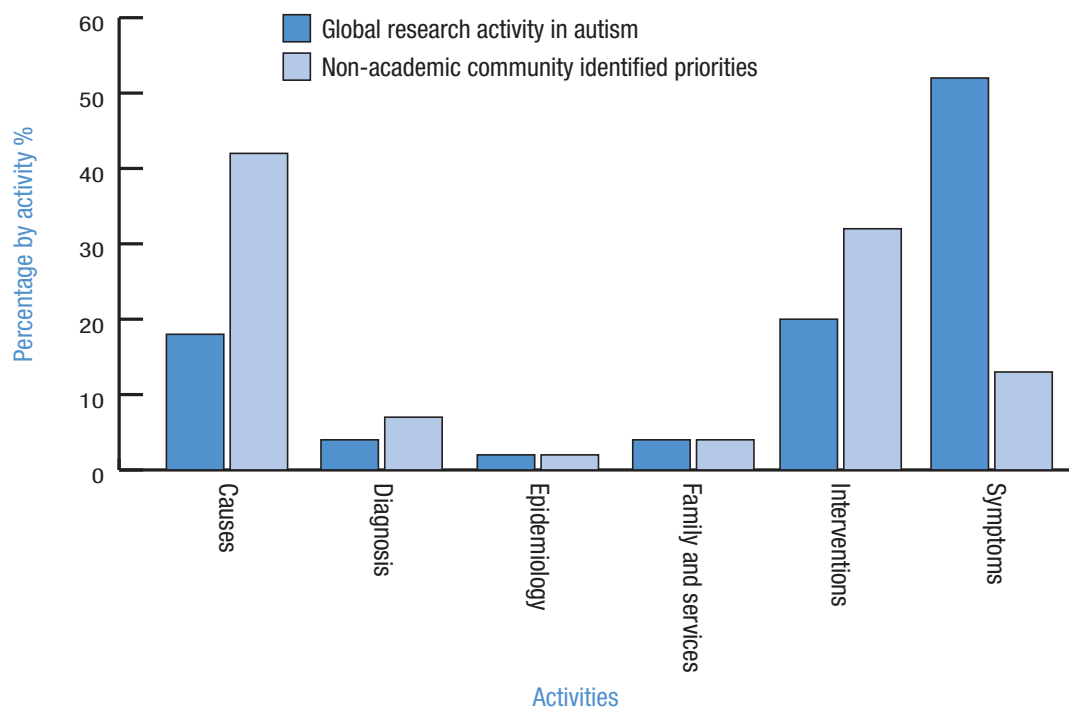
The non-academic community would like to focus on environmental factors, when looking at both causes and interventions. Academics have different priorities. For them the main focus of research on causes should be genetics. Both are important, but the non-academic community wants to understand the environmental risks of triggering autism, regardless of genetic predisposition.<sup>136</sup>

There can be a tension between the scientific demands of a peer review process and the wishes of parents. A good example is the question of diet. Research shows that around half of parents are putting their children on special diets at significant practical and financial cost. For parents that NPC has spoken to, it is an issue of vital importance.

However, there are significant challenges that need to be overcome in relation to researching the impact of diet:

- using a big enough sample;
- putting in place proper controls;
- ensuring that the change in diet is followed; and
- isolating the impact of diet from other factors, such as education and growing older.

The priorities of researchers, people with autism and their families are not always aligned.

**Figure 11: Current global research activity compared to priorities of non-academic community**<sup>136</sup>

In 2005, only £2m was spent on research—just £3.70 per person with autism.

A recent proposal, *Can Diet Affect Autism?* (CANDAA), which was designed to look at the impact of diet, recently failed the MRC peer review criteria.

Although NPC recognises the need for quality controls and scientific peer review, it seems unfortunate if this diverts attention away from issues that need to be understood. Often it is useful to know what does not work, as well as what does.

Largely in response to the ICH report, the government set up the Autism Research Co-ordinating Group. This is made up of representatives of the main government departments, the Wellcome Trust, the MRC and charities. Its aim is to help co-ordinate and direct government spending on autism research.

### Funding

Underlying many of these issues is a lack of funding. More money would break through the complexity of autism and would help to build up research capacity. In 2005, only £2m was spent in the UK from all funding sources on research into autism, despite the fact that one in 100 people is affected. That is just £3.70 per person with autism.\*

At present, funding for biomedical autism research comes from a mix of public and charitable sources. State funding comes primarily from the MRC, with small amounts from the Economic and Social Research

Council (ESRC) and the National Institute of Health Research (formerly NHS Research and Development). The Big Lottery Fund also supports medical research.

Charitable funding comes from a number of different sources, ranging in size and activity. These include the Wellcome Trust, Autism Speaks, Baily Thomas, and the Health Foundation. The Three Guineas Trust also supports research into education.

NPC compared the low funding for autism with spending on cancer research in the UK. There are a million people with cancer in the UK at any one time, so the £1bn spent on cancer research equates to £1,000 spent on each person with cancer,† or £50 per person likely to develop cancer.\* Half of this £1bn comes from donations from the general public.

The comparison shows baffling priorities in research spending. Autism costs the UK over £18.8bn a year for the cost of services (housing and education), which is roughly three times the £5bn costs of cancer care each year. An adult with autism costs society, on average, between £13,000 and £75,500 a year. The average cost per year of a person with cancer, while they have it, is £5,000.

But people with autism have the condition all their lives. A person who develops cancer costs, on average, £300 per year over their

† £1bn spent on the one million people living with cancer implies £1,000 per person.<sup>137</sup>

\* £1bn spent on cancer; 20 million people will develop cancer (assuming one in three people) = £50 per person.

\* £2m spent on ASD research; assuming 540,000 with ASD at any one time = £3.70 per person.



entire lifetime.\* So it would appear to be in the interests of government to increase spending on research on autism in order to reduce future care costs.†

It is extremely difficult to prioritise either cancer or autism research. The categories are too wide; the impact is too varied and wide-ranging. Autism is life-long, while cancer usually occurs later in life. Cancer is life-threatening yet autism can have serious negative impacts. However, both require and deserve significant funding. It does not appear that autism research is getting this.

The reasons for the low funding for research into autism are not clear cut. For private donations, one explanation might be that most of the population considers themselves 'at risk' of developing cancer, so there are strong political and private motives for funding cancer. By contrast the general population meets autism much less frequently. Another explanation might be the long history of cancer knowledge and the efforts of Imperial Cancer Research Fund and Cancer Research Campaign (now merged to form Cancer Research UK) since the early 1960s.

## Capacity of UK research

### Researchers

The position of research in the UK is relatively strong. In 2004, UK researchers accounted for 16% of active autism researchers in the world.<sup>136</sup> This percentage is likely to have gone down in the last couple of years, as autism research in the US has increased.

Autism researchers are spread out across universities, NHS Trusts and research centres throughout the UK. Important centres are based in Cambridge, Oxford, Birmingham, Sheffield, Manchester, Newcastle, Edinburgh, Southampton and Strathclyde. In London, King's College London, University College London and the Institute of Child Health are important centres of autism research. There are often strong links between researchers in the UK and overseas.

### Subject matter

The UK provides several opportunities for autism researchers. In particular the existence of a central national health service makes it easier to undertake large cohort studies, involving large numbers of people over long periods of time.

There are limitations. All scientists need something to study; in this case it will be people with autism and their family. They need brains, and DNA, and people who are

willing, and able, to consent to taking part (see Box 25 for examples). More participants and material are needed.

## Communication

Too often, at present, the research that is being done is not reaching those affected by the condition. Parents often complain that they feel lost and adrift, without being told what has been discovered and what is being done. They have to wade through complex medical articles or journals and decipher scientific jargon and statistics.

What little is known has been lost in a cloud of confusing and conflicting information. Anecdotes and hearsay get passed eagerly among internet chat rooms, while small and unscientific research is blown up out of all proportion.

Organisations and individuals can be unwilling to get involved and make definitive statements about specific interventions or approaches in case it opens them to attack.

Without anyone providing an impartial and authoritative lead, parents are left adrift and at the mercy of conmen and clinics that promise miracle cures. Unfortunately, even when scientists try to communicate with parents, a significant number remain unconvinced. Often this is because it does not tally with their own experiences. The recent MMR debate is a case in point.

## What are charities doing?

Charities are helping to develop autism research. They are doing this in a number of ways:

- fundraising for autism research;
- influencing other funders;
- directing money to high-quality and necessary research;
- increasing UK research capacity;
- undertaking research; and
- improving communication and discussion on research.

Parents often feel isolated, with little access to the latest information.

Fragile anecdote and gossip about the latest autism treatment drives desperate people.

Parent of child with autism<sup>144</sup>

### Box 25: Understanding the autism brain

#### Autism Tissue Programme

The Autism Tissue Programme makes post-mortem brain tissue available to as many qualified scientists as possible to advance autism research. Using brain tissue, scientists can go far beyond the constraints of other technologies and study autism on both a cellular and molecular level. The resource is rare however. The necessary ethical approval has just been issued in the four UK centres to take part in the programme.

#### Brain imaging

At the beginning of 2007, Oxford University opened the first brain imaging centre that is purpose built for autism. The MEG scanner can look at brain activity while a particular task is performed. This allows researchers to compare the brain activity of someone with autism with someone without autism. It can also be used to see how the brains of children with autism develop.

\* £6bn cost of cancer care a year; 20 million people will get cancer in their lifetime (one in three out of a population of 60 million in UK). £6bn ÷ 20 million = £300, ie, £300 per year spread over a person's life.

† £18.8bn cost of ASD a year = £34,800 per person (assuming 540,000 with ASD).



This work is being led by the two major autism charities, **Autism Speaks** and **Research Autism**. However, other charities are also involved in building up our knowledge base.

Research Autism was founded by the NAS and the Autism Research Centre in Cambridge. Its Chief Executive is also the Director of Research at NAS, and he is seconded across for three days a week.

Autism Speaks in the UK was founded by Dame Stephanie Shirley. It is a sister charity to the larger organisation in the US.

Determining the impact of funding research can be seen on different levels. These would be the indicators:

- getting funding for research in the first place, either directly or indirectly;
- directing funding into high quality, priority projects, likely to be well-run, thereby increasing the chances of success;
- evaluating the results of the research; and
- translating these results into concrete action, eg, better interventions or services.

### Fundraising for research

The history of charitable involvement in autism research in the UK is short. **Research Autism**, which is mainly concerned with improving interventions, was originally set up in 2003, while **Autism Speaks**, which focuses on bio-medical research, was set up in late 2004.

Both charities have had a slow start, gradually building up resources, experience and exposure. The momentum is only starting to show in 2006 and 2007. This is contributing to more funding for autism research, which is then being channelled to high-quality research.

Both organisations are developing their fundraising strategy, which largely involves targeting wealthy individuals and the major trusts and foundations.

### Impact

It is still too early to have a full picture of the impact of fundraising. Both of the charities are still relatively young, particularly for fundraising charities. It takes time to establish the infrastructure, the fundraising networks, and awareness of the issues. Both charities are finding fundraising slower than hoped.

Yet there are promising signs. In the 18 months before the end of 2006, Autism Speaks committed £115,000 for autism research. In the next year this is expected to rise to £300,000.

Research Autism is administering a grant worth £127,000 that is looking at Learning Environments for Children with Autism (LECA). It has also raised money for specific projects such as £17,410 for a bullying project.

### Influencing funding

Influencing other funders is also a major goal of both **Autism Speaks** and **Research Autism**. The government and major trusts, such as the Wellcome Trust, are sitting on considerable resources. Charities can influence their funding through persuasion, but also by using other funds as leverage.

### Impact

While it is hard to delineate the impact of influence, initial signs are encouraging. Autism Speaks is currently working with the Wellcome Trust on a major high-profile UK and international workshop on the neuro-biology of autism.

It also recently co-hosted a research meeting with the MRC, which led to a proposal for the creation of a UK Infant Sibs Research Network, described in Box 5. Funding has recently been secured for the first phases of the network from two UK trusts.

The MRC's annual report referred to its good relationship with Autism Speaks and spoke of 'establishing mechanisms to allow potential co-funding of autism research projects in the coming year'.

Research Autism has also managed to bring in more money to the sector. After organising a research forum on sleep and autism, it persuaded an existing research project into the impact of melatonin on sleep to include people with autism. The original project funders contributed the extra £100,000 needed.

It has also used seed money or its endorsement to bring in funding for a range of projects. These include leveraging in £10,000 for a pilot study investigating diet, as well as a study looking at the impact of music on autism.

### Funding quality research addressing the right priorities

It is not enough to get more money into autism research; it also needs to be well spent. Both **Research Autism** and **Autism Speaks** have scientific advisory boards that ensure that the projects they direct money to are both of high priority and scientifically robust.

Autism Speaks shares the Scientific Advisory Board of its sister organisation in the US. When research proposals are submitted, there is a process of peer review, and they are ranked in order of quality. Only the best are funded. There are four main areas of interest:

- aetiology (including genetics, environmental factors and epidemiology);
- treatment;
- diagnosis (including phenotyping); and
- neurobiology.

Autism Speaks also has a Scientific Affairs Committee, which has a specific role identifying breaking areas that are ripe for discovery.

Research Autism also has a scientific advisory committee, which is again made up of international experts in autism. It also carried out a survey of 8,000 members of the NAS affected by autism to find out which interventions they were using. This was used to influence Research Autism's funding priorities. They were:

- comparison of different interventions;
- autism and mental health; and
- challenging behaviour in autism.

On a more strategic level Research Autism, Autism Speaks, the NAS and TreeHouse Trust are all members of the Autism Research Coordinating Group (see before).

### Impact

It is still too early to see the practical impact of the research that both Research Autism and Autism Speaks are funding. These projects take a considerable amount of time to design, fund, carry out, peer review and then publish.

There have been important stages that have been reached. The first stage of the AGP has highlighted two possible genetic factors, while Research Autism recently publicised the results from the EIBI study.<sup>138</sup>

### Increase UK capacity

Charities are improving UK research capacity. Most of this involves directing more funds into UK research, which then attracts new researchers. However, work is also being done improving autism research infrastructure by establishing autism research chairs, and improving communication and collaboration between researchers.

**Autism Speaks** has helped to advise UK researchers on the availability of grants from its sister organisation. It is working with **Autism Cymru** to found an autism chair in Wales, to stimulate research there. It is experimenting with other tools, such as mentored fellowships, to attract young scientists into the area.

Autism Speaks has also helped researchers to engage and collaborate with each other. In May 2007 it part-sponsored the Open University to organise a conference that brought together autism researchers from across the UK.

**TreeHouse** is working with the Institute of Education to get funding for a research and practice group for autism education. This would involve a professor and senior lecturer based at the Institute of Education, and a research associate based at TreeHouse. They

will then carry out research into how to remove barriers to learning and participation in schools and society for people with autism.

The **Autism Research Centre** in Cambridge University is developing its own charity to help supplement its work. This raises money for costs such as travel expenses to international conferences, which would not be covered in its research grants.

### Impact

Developing research capacity helps improve the quality and the quantity of autism research. It is difficult to measure growth in capacity, but individual examples can be isolated. Autism Speaks has helped triple funding flows from its sister charity in the US into the UK from £175,000 to £580,000.

Autism Speaks and Autism Cymru have recently persuaded the University of Cardiff to agree to set up a Chair in Autism. Initial funding will be split between foundations, with the University taking over all costs after five years.



Photograph supplied by Autism Speaks

## Charities doing research

Charities have a role in carrying out research themselves. This can be done by using internal expertise or bringing in external assessors. The important thing is that it is done to research standards that makes the lessons learnt robust and transferable.

The report has already looked at a number of these evaluations, such as Professor Pat Howlin's evaluation of the **NAS's** Prospects employment project, and Professor Allen's evaluation of **Autism Cymru's** Attention Card Scheme. The National Centre for Autism Studies (NCAS) at the University of Strathclyde is half way through an evaluation of **Autism Initiative's** one-stop shop, *Number 6*, in Edinburgh.

Charities are also well placed to do research looking at the people that they help. As mentioned above, **Research Autism** did research into the priorities of those affected by autism. The NAS has also carried out a number of research projects looking at the lives and experiences of its members. These included: *Autism: Rights and Reality*; and *Ignored and Ineligible: The Reality for Adults with Autistic Spectrum Disorders*.<sup>8, 96</sup>

**TreeHouse** has just started a research project building on its work helping parents' groups to campaign for better education. It has received funding from the DfES to study ten different parents' groups and evaluate what type of support produces the best results.

More generally, operational charities provide a useful source of detailed individual case studies. These can suggest possible successful approaches. However, NPC would have liked to have seen more in the way of collated data on indicators such as distress, communication and independence.

### Impact

Research is vital to show that the projects run by charities actually work. Ideally it means that successful projects are highlighted, shared and funded, and unsuccessful projects fall by the wayside.

## Improve communication and discussion

Charities can provide the bridge between the research community and the rest of the autism sector. They have a role in increasing contact between the scientific and non-scientific community.

One of the major recent developments is the launch of **Research Autism's** website. This has collated the results of all of the scientific research into autism interventions and communicated it in an accessible, understandable and impartial way. It can be accessed at any time and by anyone.

Research Autism also runs regular fora that bring together experts and people directly affected by autism, like parents or individuals with the condition. They can discuss research priorities and compare notes on practical experiences.

**Autism Speaks** is running training courses for scientists on how to communicate their research more effectively and in a media friendly way. It is also running a programme to get people with autism and their families involved in research, by donating their brain tissue at death or by taking part in the 'Baby-sibs' research.

There are also a number of charities that run conferences where international experts present to parents and professionals. One of the most innovative of these is **Autism Cymru's** online conference. It has run this every year since 2004 and reaches about 10,000 people around the world.

Before the conference, around 60 international experts publish a paper on some aspect of autism research. Then over the week of the conference there are times when delegates can pose direct questions to them over the internet. There is even a café where delegates can meet to chat online about what they have heard.

### Impact

There is a huge desire from parents to be kept up to date and involved in autism research. Demand for information and the opportunity to attend conferences are high.

It is still too early to see if Research Autism's website is meeting that demand. It will be something to watch closely.

## What can a donor fund?

Research is vital. Yet, what type of research should be prioritised is debatable and contested.

**Biomedical research** lies at the heart of the matter, unpicking the possible genetic and environmental factors that cause the condition of autism; understanding exactly how the brain develops and operates. Funding biomedical research will require some patience, although there is the potential for significant returns.

Alternatively, research into better **interventions** and service for people with autism has the potential for more immediate returns, although with less breadth.

There is a wide range of activities that a donor can fund. One of these is the option to channel funding to a **specific research project**. Both Research Autism and Autism Speaks have a selection of projects that have gone through their rigorous peer review mechanism. These can appeal to the different interests of a donor.

If a donor has no particular interest in which topic to fund, both research charities are also developing **discretionary funds**. These can then be disbursed by the charity to meet immediate needs.

Donors can also fund the **central costs** of research charities. This can help to leverage in more money for research, by paying for fundraising costs and influencing other funders. There is also the need to cover costs such as administration and governance.

Private money can also be used to develop **research capacity**. Again this is likely to be channelled through the two research charities, although other charities often do play a role by working with their local universities or research institutions.

If a donor funds a charity to carry out an innovative or pilot project, they should also be prepared to fund a **proper evaluation**. It is important to properly and rigorously collect and evaluate the lessons of the project. Funding should then be made available to disseminate the results to a wider audience and make sure it is actually used.

Donors also have the important role of funding **information sharing and discussion** for both academic researchers and also parents and professionals. This can involve a number of different activities from a national information website, to individual conferences and seminars.

**Table 11: Examples of funding and impact**

Rationale for support	Level of activity	Examples for donors	Possible impact
<ul style="list-style-type: none"> <li>Better knowledge is urgently needed in medical research. More data is needed about the effectiveness of interventions.</li> <li>This can help design and develop better support and services for people with autism.</li> <li>Coordinating research and communicating research findings is vital, but this is left to charities.</li> <li>Funding for research has been inadequate so far. However, funding by private donors can leverage increased funding from government bodies and large foundations.</li> </ul>	Individuals	Scheme to encourage individuals with autism to get involved in research	Access to more brain tissue and study participants may speed up research
	Families	A seminar bringing together families with researchers	Parents learn about the latest research and can make more informed decisions about treatment for their children
	Services	Improve funding, capacity and coordination of research	The quality and quantity of autism research will improve
	Government	Work to access government funding streams	More funding for research

The scale of autism is significant: an estimated 540,000 people have autism, and many more are affected, as family members or working directly with someone with the condition. The impact the condition has on the quality of people's lives makes it an important issue for society. The scale and the nature of the issue has only recently come to light. Many of the autism charities are still quite young, and the sector as a whole is comparatively underdeveloped and overlooked.

Public attention is increasing but voluntary funding for autism is still limited. The availability of only small sums of voluntary funding could be construed as an opportunity for ambitious donors wanting to make a substantial impact on the sector. The Shirley Foundation has had a tangible impact on setting up schools, residential housing charities and a research charity. Other donors could make their mark on this sector too.

## Priorities

Throughout the report we identify issues that need resolving and suggested ways in which donors can help. In Section 3 we look at the specific role that a donor can play within the sector. The rest of the report expands on important areas of charitable activity and private philanthropy.

Despite the need to address all of the issues in the report, NPC believes there is still value in identifying priority areas. To this end we have highlighted four areas within the sector where we believe that private funding can make the most difference.

## Research

Too little is known about autism and how to minimise the negative effects of the condition. Research is helping to unpick and clarify key issues that could lead to considerable improvements in quality of life. This includes genetic research, comparative studies of educational approaches and the interaction of autism and mental health issues.

While government funds autism research, private philanthropy is needed to supplement these efforts and ensure that autism is prioritised. A donor can support a particular project or area of research, or fund a charity to help coordinate research activity, improve capacity and influence other funders.

## Transition from school to adulthood

Education is vital for improving the skills and potential of people with autism. Yet too often children leave school and have nowhere to go. Little effort is put in managing this change and supporting people to move successfully on to further education, employment or a home of their own.

Private funding can work from both directions. A donor can support schools offering vocational training and independent living skills. This may

involve developing a further educational college, or even transitional housing. Conversely, a donor may work with a charity providing housing and support to help them manage transition into their services.

## Supporting adults with autism and normal to high IQ

People with autism and normal to high IQs are often overlooked by services. While they may receive support at school this often drops away as they become adults. Mainstream services are often ill-equipped to help them, while they are not often eligible for specialist services. They end up unemployed, isolated and unhappy, often still living with their parents.

Private funding can support initiatives that cater for this group, whether employment programmes or social activities. Successful projects will improve their quality of life and can then be replicated. In certain cases, successful evaluations can lead to future government funding.

## Equipping parents and individuals with autism with information and advice

NPC has found that parents and individuals with autism often have to fight to get access services. Although government policy and legislation guarantees them certain services and benefits, there can be considerable obstacles to actually receiving them. Overcoming these barriers often requires considerable effort, knowledge, and resources. Other responsibilities, such as having a job or doing the housework, limit the time that can be spent campaigning.

A donor can fund a number of initiatives that improve the capacity of families and individuals with autism. This could involve direct support, such as legal advice or help filling out benefit forms. Or a donor might prefer a more indirect approach, funding charities that reduce the general strain on a family or generally improve the advocacy skills of individuals with autism.

## Role of government and the general public

Underlying all of these four priorities is the need to involve and engage government and the wider public. Considerable effort is needed to make the world a more hospitable and understanding place for people with autism. Too often the emphasis is directed at changing the person with autism. Instead, government, public officials and the general public have a key part to play. Helping them to understand and respond to the needs of people with autism will play a major part in meeting these four priorities and improving the lives of people with autism in general.



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# Other publications

## Community

- **Not seen and not heard:** Child abuse, a guide for donors and funders (2007)
- **A long way to go:** Young refugees and asylum seekers in the UK (2007)
- **Home truths:** Adult refugees and asylum seekers (2006)
- **Inside and out:** People in prison and life after release (2005)
- **Grey matters:** Growing older in deprived areas (2004)
- **Side by side:** Young people in divided communities (2004)
- **Local action changing lives:** Community organisations tackling poverty and social exclusion (2004)
- **Charity begins at home:** Domestic violence (2003)

## Education

- **Misspent youth:** The costs of truancy and exclusion (2007)
- **Read on:** Literacy skills of young people (2007)
- **On your marks:** Young people in education (2006)
- **What next?:** Careers education and guidance for young people (2005)
- **School's out?:** Truancy and exclusion (2005)
- **Making sense of SEN:** Special educational needs (2004)

## Health and disability

- **Don't mind me:** Adults with mental health problems (2006)
- **Valuing short lives:** Children with terminal conditions (2005)
- **Ordinary lives:** Disabled children and their families (2005)
- **Out of the shadows:** HIV/AIDS in Burundi, Democratic Republic of Congo and Rwanda (2005)
- **The hidden assassin:** Cancer in the UK (2004)
- **Caring about dying:** Palliative care and support for the terminally ill (2004)
- **Rhetoric to action:** HIV/AIDS in South Africa (2003)

## Cross-cutting research

- **Striking a chord:** Using music to change lives (2006)

## Improving the voluntary sector

- **Going global:** a review of international development funding by UK Trusts and Foundations (2007)
- **Funding success:** NPC's approach to analysing charities (2005)
- **Surer Funding:** Improving government funding of the voluntary sector (2004, published by acevo)
- **Full cost recovery:** A guide and toolkit on cost allocation (2004, published by NPC and acevo)
- **Just the ticket:** Understanding charity fundraising events (2003)
- **Funding our future II:** A manual to understand and allocate costs (2002, published by acevo)

Forthcoming Research	
Violence against women (2007)	How to fund (2007)
Out of school hours (2007)	Environment overview (2007)
Financial exclusion (2007-2008)	Advocacy and systemic change (2007-08)
Homelessness and housing (2007-08)	Child mental health (2007-2008)
Young offenders (2008)	Substance abuse (2008)
Degenerative diseases (2008)	

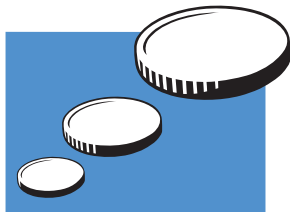
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# New Philanthropy Capital

New Philanthropy Capital (NPC) helps donors understand how to make the greatest difference to people's lives. We provide independent research and tailored advice on the most effective and rewarding ways to support charities.

Our research guides donors on how best to support causes such as cancer, education and mental health. As well as highlighting the areas of greatest need, we identify charities that could use donations to best effect.

Using this research, we advise clients (including individuals, foundations and businesses) on issues such as:

- Where is my support most needed, and what results could it achieve?
- Which organisation could make the best use of my money?
- What is the best way to support these organisations?

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