The National Autistic Society

ADULTS WITH AUTISM NEED

- a JOB WHEN THEY CAN WORK
- BENEFITS WHEN THEY CAN'T
- AND A GOVERNMENT THAT LEADS THE WAY

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The National Autistic Society

Don't Write Me off

MAKE THE SYSTEM FAIR FOR PEOPLE WITH AUTISM

Accept difference. Not indifference.

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The photographs used in this report were taken by Adrian Turner, with the exception of the photo on page 30 which was taken by Mark Ferguson.

How the research was conducted

In late autumn 2008, The National Autistic Society set out to research the barriers people with autism and their families face when seeking services and benefits provided through Jobcentre Plus.

To do this, we conducted three pieces of UK-wide research. These were:

- in-depth interviews with ten individuals who have applied for Employment and Support Allowance (ESA)
- a follow-up survey of *I Exist*[1] respondents
- phone interviews with individuals who have had contact with a Disability Employment Adviser.

This report examines the major themes that came out of our research and makes recommendations based on the data we collected, secondary sources and the larger policy context.

For more information on methodology, please see page 40.

About autism

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. It affects around one in every 100 people. Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support. The three main areas of difficulty (sometimes known as the 'triad of impairments') are:

- Difficulty with social interaction: this includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships.
- Difficulty with social communication: this includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.
- Difficulty with social imagination: this includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow, repetitive range of activities.

People with autism may also experience some form of sensory sensitivity, being over- or under-sensitive to sounds, touch, tastes, smells, light or colours.

Asperger syndrome (AS) is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language. People with AS do not usually have learning disabilities but may have specific learning difficulties, including dyslexia.

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[1] In 2008 The National Autistic Society launched the *I Exist* campaign to improve services and support for adults with autism. This campaign included a survey of over 1,700 adults with autism and their families across the UK.

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We followed the experiences of a group of ten individuals as they applied for Employment and Support Allowance, and you will see quotes and comments from all of them throughout this report. Thank you to Aly, Craig, Kate and Conrad, Paula and Jamie, and Tom for sharing their experiences with us.

Executive summary

Too many people with autism[2] find themselves written off; receiving neither the support they need to work nor the support they need from the benefit system.[3] UK-wide research for *Don't Write Me Off* shows that of the adults with autism we surveyed:

- one third are currently without a job or benefits
- over half have spent time with neither a job nor benefits, some for over ten years

- just 15% have a full-time job
- 79% of those on Incapacity Benefit want to work
- 82% who have applied for benefits say that they needed support to apply.

These findings reveal a stark reality for the hundreds of thousands of people living with autism in the UK. However, there are simple steps that the Government can take to make the system work better, and to unlock the potential of so many. Adults with autism need:

Employment and Support Allowance to work for them, by:

- making sure people are asked about their autism when they apply
- telling people that they have the right to an advocate
- scrapping the need for people to produce a 'sick note' when they apply.

Jobcentre Plus staff to understand and meet their needs, by:

- introducing a network of Autism Coordinators across Jobcentre Plus districts to work with frontline staff, local employers, and employment support services
- making sure that medical assessments are carried out by doctors with a proven understanding of autism
- ensuring there is better awareness of autism among frontline Jobcentre Plus staff, particularly Personal Advisers and Disability Employment Advisers.

A national strategy to transform access to employment:

- in England, through an Adult Autism Strategy that establishes Specialist Autism Teams in every local area
- in Wales, through the Welsh Assembly Government Autism Spectrum Disorder Adult Task and Finish Group Report
- in Scotland, through an updated Scottish Government *Working for a Change?* strategy
- in Northern Ireland, through a new Northern Ireland Assembly employment strategy for people with autism.

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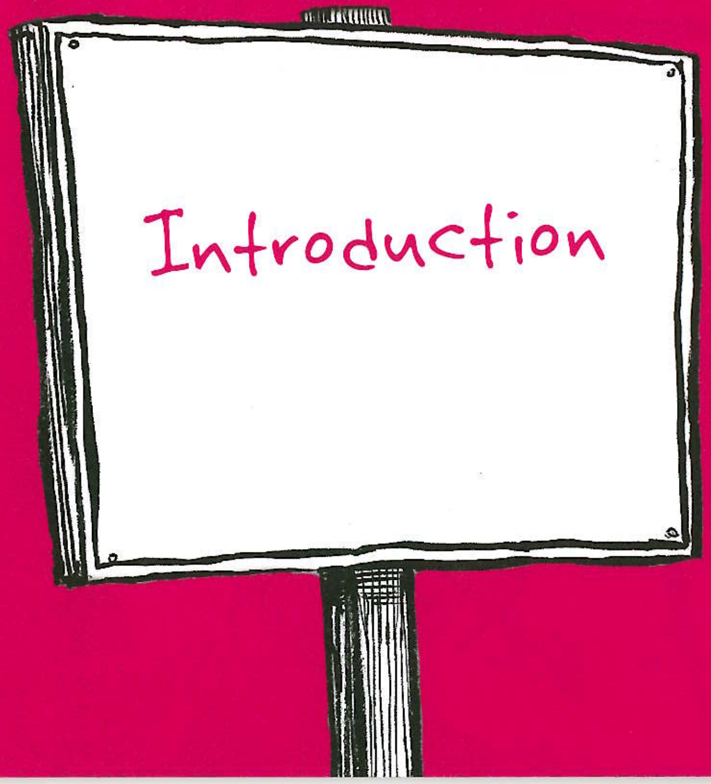
[2] In this publication we use the term autism to refer to all diagnoses on the autism spectrum (including Asperger syndrome and high-functioning autism). However, we sometimes refer to high-functioning autism or Asperger syndrome alone.

[3] Unless otherwise stated, the benefits referred to in this report are work-related benefits, primarily Incapacity Benefit, Employment and Support Allowance and Jobseekers Allowance.

The number of people with autism in employment is alarmingly low, with our research showing that just 15% of adults with autism in the UK are in full-time paid work. We also found that many of those not in work were also excluded from the benefits system: one third are currently without a job or benefits.



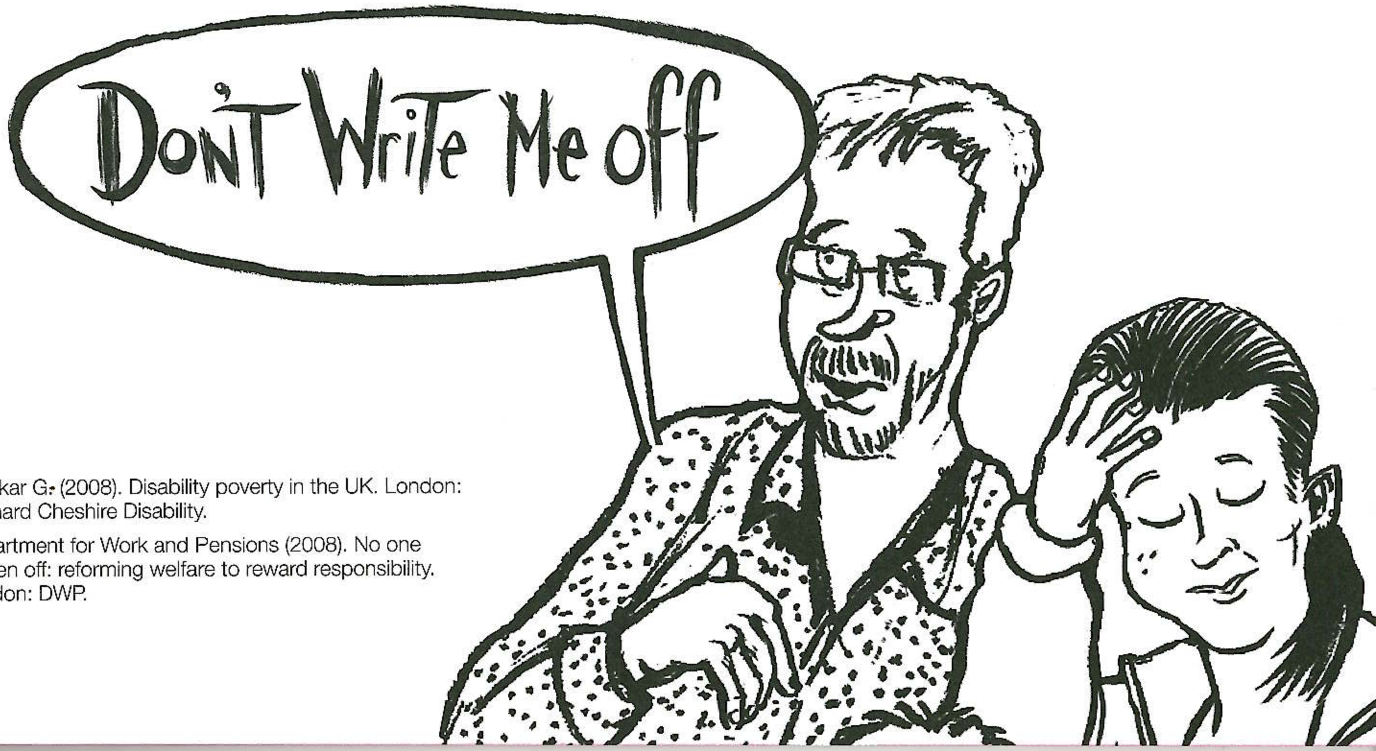
Research shows that 30% of people with disabilities live below the poverty line.[4] This will include people with autism.

More needs to be done to ensure that people with autism can access benefits and support to find work.

The Government's new benefit, Employment and Support Allowance (ESA), is meant to provide that support. This is a benefit for people across the UK who find it hard to work due to their disability; the Government aims to give more money to those facing the greatest barriers to accessing work and more support to those looking for work.

The Government's reason for introducing ESA is that no one should be written off;[5] however, this vision is not yet a reality for adults with autism.

The National Autistic Society followed a group of adults with autism as they applied for ESA. As the report progresses you will read their stories, they will tell you what does and does not work in the system, and what needs to change to make sure that adults with autism are no longer written off.



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[4] Parckar G. (2008). Disability poverty in the UK. London: Leonard Cheshire Disability.

[5] Department for Work and Pensions (2008). No one written off: reforming welfare to reward responsibility. London: DWP.

Chris & Carole

Chris is 21, a prolific science fiction writer who lives with his mum Carole and his sister Emma in Surrey. He was diagnosed with Asperger syndrome in 2007.

In the past, Chris has worked as a shop assistant but, due to his autism, found the interaction with the public hard to cope with. After a short time, Chris had to leave. Since then, Carole has worked tirelessly to help Chris find a job that meets his needs, at one point even reducing her own hours to part-time to help him with his search.

> "It's been really tough trying to get help and support for Chris, only having the weekends to do things with him... the only way I could do that was if I wasn't working full-time. There are not enough hours in the day."

Chris and Carole then heard about Employment and Support Allowance (ESA) and decided to apply in the hope that this might deliver the support Chris needs to find work. To apply, Chris had to call Jobcentre Plus; like many people with autism, he is not comfortable using the phone so he asked Carole to call for him. However, Jobcentre Plus refused to speak to Carole and would only deal with Chris directly. Chris took the phone and answered questions as best he could. It wasn't until Chris put the call on speakerphone that Carole realised that the Jobcentre was trying to claim the wrong benefit for him.

> "They said 'are you too sick to work?' and of course he said 'no' because he's not too sick to work but he wants the help to get into work. So they said 'oh no, you've got to claim Jobseeker's Allowance' and that's when I piped in: 'No, he's claiming Employment Support Allowance, not JSA.'"

There were more problems to come. With no warning, Chris' benefit payments were stopped and a letter arrived requesting a sick note from Chris' GP. Carole got the sick note and sent it on to Jobcentre Plus but was frustrated that Chris' benefit had been stopped with no warning.

At this stage Carole had to return to full-time work because it was "the only way to keep the household running". When it came to his medical, Chris went to see the doctor alone, but after "a bombardment of questions" the doctor asked Carole to join them. Chris had not really been able to answer the questions and the doctor then went through the assessment with Carole.

A week later Chris was awarded ESA. He is now in the Work Related Activity Group.

Looking back, Chris says he could not have gone through the process without Carole. As Carole says:

> "I think they should start by establishing what the diagnosis is first and then talk to the person appropriately."

Applying for help is not a choice, it is a necessity.

Half of our interviewees told us that they had to apply for ESA out of financial necessity. The majority of our interviewees also reported having their benefit either withheld or significantly delayed, resulting in weeks, and in some cases months, without any income at all. As Aly told us:

> "Any vulnerable person can be left with no money for food, for rent, for anything."

While in the assessment phase for ESA, applicants are supposed to receive a basic rate depending on their age. However, Jamie, Craig and Chris were all left without any money until well after the 13-week assessment phase had ended and they had received a decision on the benefit.

As Craig put it, he didn't receive money or a decision until "about the seventeenth week of the 13-week assessment."

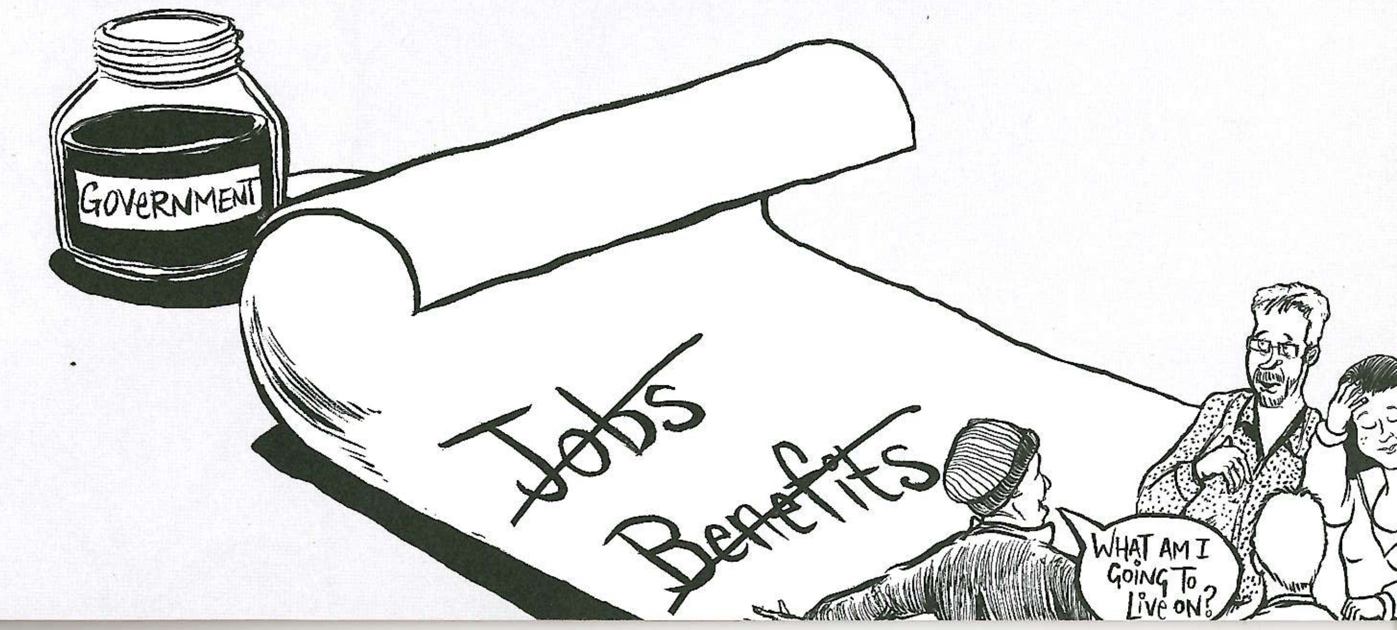
Asking about someone's autism is essential.

Autism is a hidden disability and communication is often a challenge for people with the condition. As it may not be immediately obvious to people who do not know about the condition, it is critical that people applying for ESA are asked about their diagnosis so adjustments can be made to support them. This is especially important if the Department for Work and Pensions (DWP) is to meet its commitments under the Disability Discrimination Act.[6] Jobcentre Plus staff must make any reasonable adjustments that people with autism need to enable them to access the system. These could include using different forms of communication, providing an advocate, or allowing a person's advocate, friend or carer, if they have one, to help the individual answer questions or attend appointments.

Requiring 'sick notes' is demoralising and inappropriate.

Despite autism being a lifelong disability, claimants applying for ESA are required to produce a sick note from their doctor as evidence that they are unable to work. For many of the people we spoke to, this resulted in delays receiving their benefit.

Jamie's doctor told his mum Paula he couldn't give her a sick note "because Jamie's got something that's a lifelong condition, I can't give him a sick note because it's something he's not going to recover from in six months' time." Finally, when a consultant gave her a letter saying "Jamie's condition is a lifelong condition and he will continue to need ongoing care and support throughout his life," Paula thought "OK that's in black and white" but in the end, "it wasn't good enough! I just didn't know what to do." Because Jamie was not able to get an actual sick note, his benefit was withheld until he received a decision on the benefit.



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[6] Disability Discrimination Act (1995). Article 21, Duty of Providers of Services to Make Adjustments.

Understanding autism is critical

Many people we spoke to told us that they didn't feel that Jobcentre Plus staff or the Atos[7] doctors really understood autism. When Janet's son Bob, who has autism and behavioural problems, applied for ESA, she recalled thinking "it's like these people haven't got a clue what the circumstances are."

What needs to change?

Had Carole not been there, Chris' claim could easily have gone wrong at the earliest stage, simply because no one asked if he had a disability that might affect his claim. It is crucial that **people applying for benefits are asked at the start of their application whether they have a disability in order that the necessary adjustments can be made during their application process.**

Autism is a lifelong disability, so the requirement for people to provide sick notes when applying for ESA adds an unnecessary barrier for people with autism who are trying to access the benefit. As claimants are already required to undergo a DWP medical, there is no need for sick notes and **the Government should scrap them.**

There are further challenges once people are receiving ESA and the Government needs to put safeguards in place to ensure that people with autism are not unfairly affected. For example, people currently face a cut in their benefit if they fail to attend a Work Focused Interview. However, as autism is a communication disability, people may not fully understand what they are being told and may not themselves be understood. The National Autistic Society is worried that this breakdown in communication could lead to people with autism facing an unfair cut in their benefits.

One simple way the Government could stop this happening would be to introduce **a written warning instead of a benefit cut the first time someone misses an interview.** This reduces the danger of people losing their benefit simply because they do not understand the system. Another way of making sure that everyone understands ESA is to **ensure that all written communications that concern sanctions or meetings at Jobcentre Plus are automatically provided in easy read and plain English formats.**

In the next chapter we will hear from Stefan and Gail as they discuss the need for advocacy through the benefits process.

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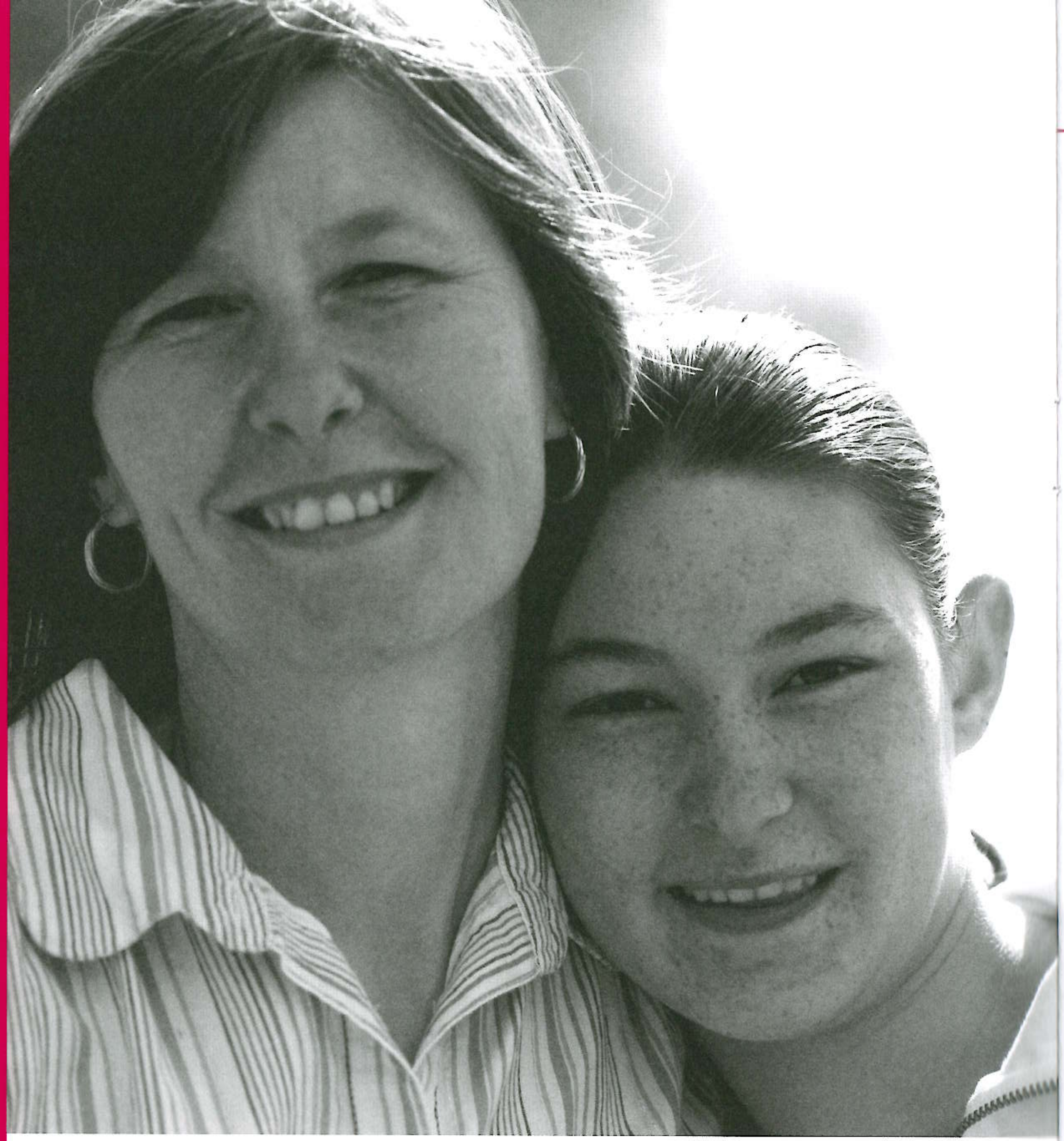
[7] Atos Healthcare is the company paid by the Department for Work and Pensions to carry out medical assessments for Employment and Support Allowance, Disability Living Allowance and Incapacity Benefit.



Stefan & Gail

Stefan is 20 and lives in Sheffield with her parents. She has autism, epilepsy and associated learning difficulties. Stefan enjoys dancing, going to college and working in a local shop.

Stefan's mum, Gail, first learned about ESA after finding out that they would be losing all child-related benefits[8] when Stefan turned 20. Because they would no longer be able to support Stefan, they had to apply for ESA.

Gail went with Stefan to the medical assessment. However, she was worried that her support could hide Stefan's difficulties.

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[8] This included Child Tax Credit, the disability element of Child Tax Credit and Child Benefit.

"My intention was not to speak for Stefan. Stefan was going to answer every question herself. When we went in, the doctor asked Stefan questions and all I did was translate. That's how I see what I do, I translate. So if he asked her a question like 'What are you doing at the moment?' then I just translated that into 'Can you tell us what you've done this week?' So I translated the questions and Stefan answered. At this point Stefan had not answered one question directly, only through me. He came to the last question and he said, 'How do you see yourself, Stefan, in three years time?' and I started to speak to try and explain what he meant because Stefan didn't understand. It's too abstract for Stef. Then he said 'I don't want you to do this anymore. I want Stefan to now answer questions from what I'm saying.' She really just didn't understand how he was putting it, and he said 'This is just what I wanted to know, that she really wouldn't understand everyday conversation from an unfamiliar person.'"

Stefan was awarded ESA. She is now in the Support Group.

Afterwards, Gail and Stefan talked about whether Stefan could have applied without Gail's support.

Stefan: "Could do, depends though don't it?"

Gail: "Depends on what?"

Stefan: "If I could or not."

Gail: "If you could or not. Well that's what we're asking. Could you go to town and find where we needed to go, by yourself?"

Stefan: "I could if I get used to it for like a year."

Gail: "She's not very good at just going to unfamiliar places."

Stefan: "I would need to go there quite a few times for me to remember where it is and I would be able to go there on my own then if I knew where it is."

Gail: "So what about answering all the questions... by yourself?"

Stefan: "I wouldn't be able to do it."

Who needs advocacy?

Our survey found that 75% of respondents have applied for benefits at some point, 82% of whom, across the autism spectrum, needed help applying. The Department for Work and Pensions' own research describes the disability benefits system as "extraordinarily complex"[9] and this is backed by recent National Audit Office research, which found that this applies equally, if not more so, to people with autism.[10]

Whether it was making phone calls to Jobcentre Plus, completing claim forms, having someone to go to appointments with, or interpreting the meaning of questions in a medical assessment, all our interviewees needed some help to get through the ESA process. This support came from many different sources: parents, partners, advocates and carers. As Scott told us, "it probably would have been very difficult for me... I often can't get my point across very well so my mum helps me with that... I tend to be focused on one thing and sort of find it difficult just to express my problem." Without Kate's support, Conrad would have simply given up on the process because of the stress it caused him, "the medical form… caused absolute riots in our house: 'Why can't they leave me alone? Why do they want to know all this? I've got Asperger syndrome. Don't they know what it is?'" Further challenges were posed by the complexity of the system. As Lesley told us, "there is no continuity. You should be dealing with one person that will process [your claim] and that's your point of contact. They hold all the information and are not sending you off here and there because, apart from anything else, it's the stress."

Most of the time people relied on family for this support and several of our interviewees reported that those who supported them through the process had to either take days off work or reduce their hours to help. Others we spoke to relied on parents who are either full-time carers or retirees. As we have seen with Gail and Stefan and Chris and Carole, even where people have a willing advocate, that person can be actively prevented from helping the person they are trying to represent.

This refusal to allow a friend or family member to help when applying for ESA goes directly against Jobcentre Plus guidance, which makes it clear that people applying for benefits have the right to an advocate.[11] Not only must all staff be made aware of and follow this guidance, but people must also be offered the support of an independent advocate. As Carole says:

"It would be nice if there was a third party rather than just me because I think I'm biased, because he's my son. It would be better if there was another person there for him. But we weren't allowed to have another person because he's not eligible for anything."

What needs to change?

Like Stefan, most of the people taking part in our research needed help applying for benefits, and this help was usually provided by a parent, family member or carer. It is **important that everyone applying for ESA is informed of their right to have someone help them through the process. Those who want an independent advocate must be supported to access one.**

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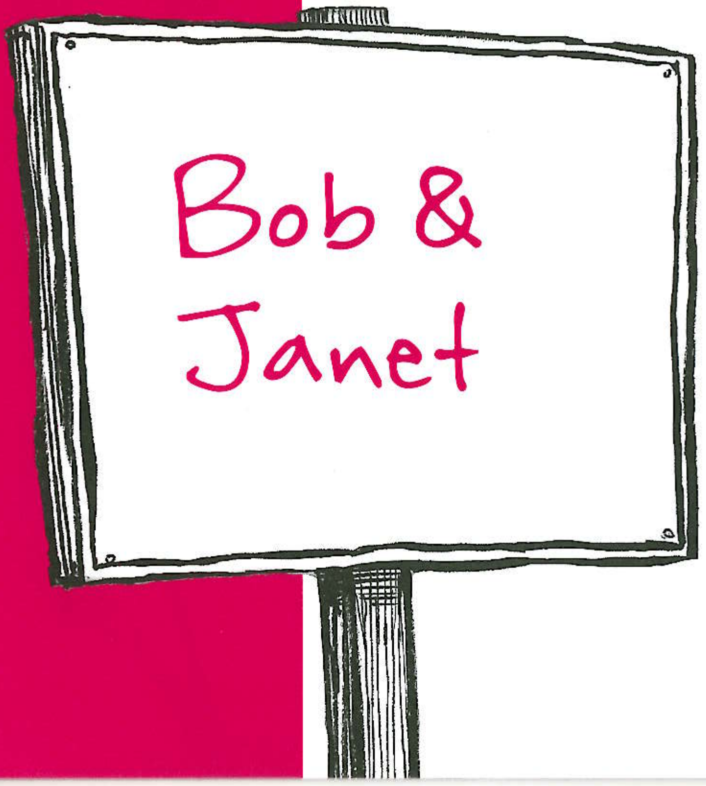
[9] Freud, D (2007). Reducing dependency, increasing opportunity: options for the future of welfare to work. Leeds: Corporate Document Services.

[10] Forsythe, L., Rahim, N., and Bell, L. (2008). Benefits and employment support schemes to meet the needs of people with an autistic spectrum disorder. London: National Audit Office.

[11] Department for Work and Pensions (2007). A Guide for Staff, www.dwp.gov.uk/docs/repsguide.pdf, last accessed 17 August 2009.



Bob & Janet

Bob is 19, enjoys woodwork and IT, and lives at home with his family in North Wales. He was diagnosed with autism and behavioural problems at the age of 2 and would need constant support in order to work.

Shortly after his 18th birthday, his Benefits Liaison Officer told Bob and his mum, Janet, that he should apply for ESA. Janet called Jobcentre Plus but the staff refused to allow her to apply on Bob's behalf over the phone. Instead Janet had no choice but to request and complete a paper form. When she was filling it in she found it hard to see how Bob's disability fitted with the questions being asked.

> "All they're talking about is somebody being sick and being ill and if you have autism you're not ill, you've just got a condition... It seems they're not looking at it from the right perspective."

Janet had the same problems when it came to getting a sick note for Bob. She tried explaining to staff at Jobcentre Plus that Bob isn't sick but has a lifelong disability. Their response was to say that Bob didn't fit with their criteria and to question why Janet thought he was eligible for ESA.

> "It has to be exactly as it is on the form rather than somebody using their common sense and saying 'oh OK then, it doesn't actually fit into these criteria but it still is a valid claim.'"

Eventually, Janet managed to secure a letter from Bob's doctor explaining his disability. Soon after, Bob and Janet received two letters on the same day from Jobcentre Plus. One said that Bob was not entitled to ESA, the other that he had been awarded the benefit.

Confused, Janet called Jobcentre Plus to ask which letter was correct. She was told that Bob had been awarded the benefit, but the payments had been suspended because the doctor's letter had no end date. Jobcentre Plus then suggested that Janet should go back to the doctor every six months to get a new letter for Bob. Again, Janet tried to explain that Bob has a lifelong disability.

It took five months for Bob to receive his benefit and Janet admits that had she not been given the initial advice that he was entitled to ESA she might not have continued fighting.

> "I think you'd just give up. If they were saying you're not entitled to it I'd just think, 'OK we tried, if we're not entitled to it then fair enough.'"

Bob now receives ESA. He is in the Support Group.

Knowledge is power

Of the people we surveyed, 93% who received information about benefits from a professional, such as a Jobcentre Plus adviser, then went on to apply for benefits. However, less than half of the respondents (43%) were receiving this information.

A recent report commissioned by the Department for Work and Pensions (DWP) describes how many people find the process daunting and decide to seek professional help from local charities or from the Citizens Advice Bureau. This advice enables claimants to answer questions more fully, increases their confidence in their eligibility and reduces their anxiety about the process.[12]

The importance of having professional advice and information is made clear by Janet's experience of applying for ESA for Bob. This was also true for Craig, who told us that he was advised by his Personal Adviser at Jobcentre Plus that, because he had a disability, "ESA would be more appropriate because you get more support than as a... jobseeker [on Jobseeker's Allowance.]" This helped him feel more confident about applying for and fighting for his benefit. Tom was also convinced to apply for ESA after hearing about it from the consultant who initially diagnosed him with Asperger syndrome. Reliable information is vital in ensuring that people can access the benefits they need.

What needs to change?

The experiences of the people we talked to shows the **importance of raising awareness of ESA among people with autism and their family or carers.**

The Department for Work and Pensions should run an accesible communications campaign for people with autism, their families, and carers to ensure that everyone is aware of the support offered by ESA.

In the next chapter Paula will tell us how important it is that people within Jobcentre Plus and Atos Healthcare understand autism.

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[12] Goldstone, C., Hawkins, J., and Bhagat, M. (2007). Knowing and understanding Disability and Carer's Service customers. London: Department for Work and Pensions.

Paula

Paula is 21, a talented writer who lives with her parents and three siblings in Lancashire.

Paula has worked in two different jobs but had to leave both because she couldn't cope with being "around people and loud music and busy environments." This was before her diagnosis of Asperger syndrome and it wasn't until she began to learn more about the disability that she began to understand why she was finding it so hard to find a job.

"I don't think that applying normally for jobs works because on all of their adverts that they put up it says 'you must have strong communication skills' and staff at Jobcentre Plus are telling me that I've got to apply for jobs that say this on them. Well I can't!"

Convinced she needed more support to get a job, Paula decided to find out what other help was available to her. It was at this point that she found out about ESA.

At first, the ESA assessment process went very smoothly. Paula received her weekly payments and had her first Work Focused Interview. Her Personal Adviser was very helpful; she understood Asperger syndrome and Paula felt that she was at last receiving the right support.

"I don't have to apply for a certain amount of jobs a week. If an interview comes up, I'll get help... instead of just being sent to it."

Then came Paula's medical. Her doctor rushed through the assessment in only 15 minutes, focusing not on her Asperger syndrome, but on her balance and coordination, both of which she had mentioned in her medical form. Despite handing him a seven-page psychiatrist's report about her diagnosis, the Atos doctor still recorded that he saw no evidence of communication difficulties. "It was like he thought I could just 'get over it' or something."

Six days later, Paula's application for ESA was rejected. Paula had been scored zero points on her assessment.

After appealing and having her application refused again, Paula took her case to a tribunal, with the support of her local Citizens Advice Bureau. The tribunal was very relaxed and it was clear that the people there had read all of Paula's written evidence, including her psychiatrist's report. The questions they asked were direct and Paula felt as if they were genuinely trying to understand her difficulties.

Paula was told at the tribunal that she would receive ESA. Although she has had no confirmation from Jobcentre Plus, the amount she receives shows she is in the Work Related Activity Group.

Who needs to understand autism?

Paula's experience applying for ESA shows how important it is for all professionals involved in the benefits system to understand autism. Autism is a complex disability, which presents differently in each individual. People with autism have complex social and communication needs, and some have limited or no language. It is vital that Jobcentre Plus staff get the training and support they need to work with people with autism.

Atos doctors

The failure of the Atos doctor who carried out Paula's medical assessment to understand autism resulted in her being denied ESA. It is vital that these doctors understand autism and how it affects an individual's ability to communicate. However, recent National Audit Office research found that 80% of doctors admitted that they needed more training to help people with autism.[13]

Personal Advisers

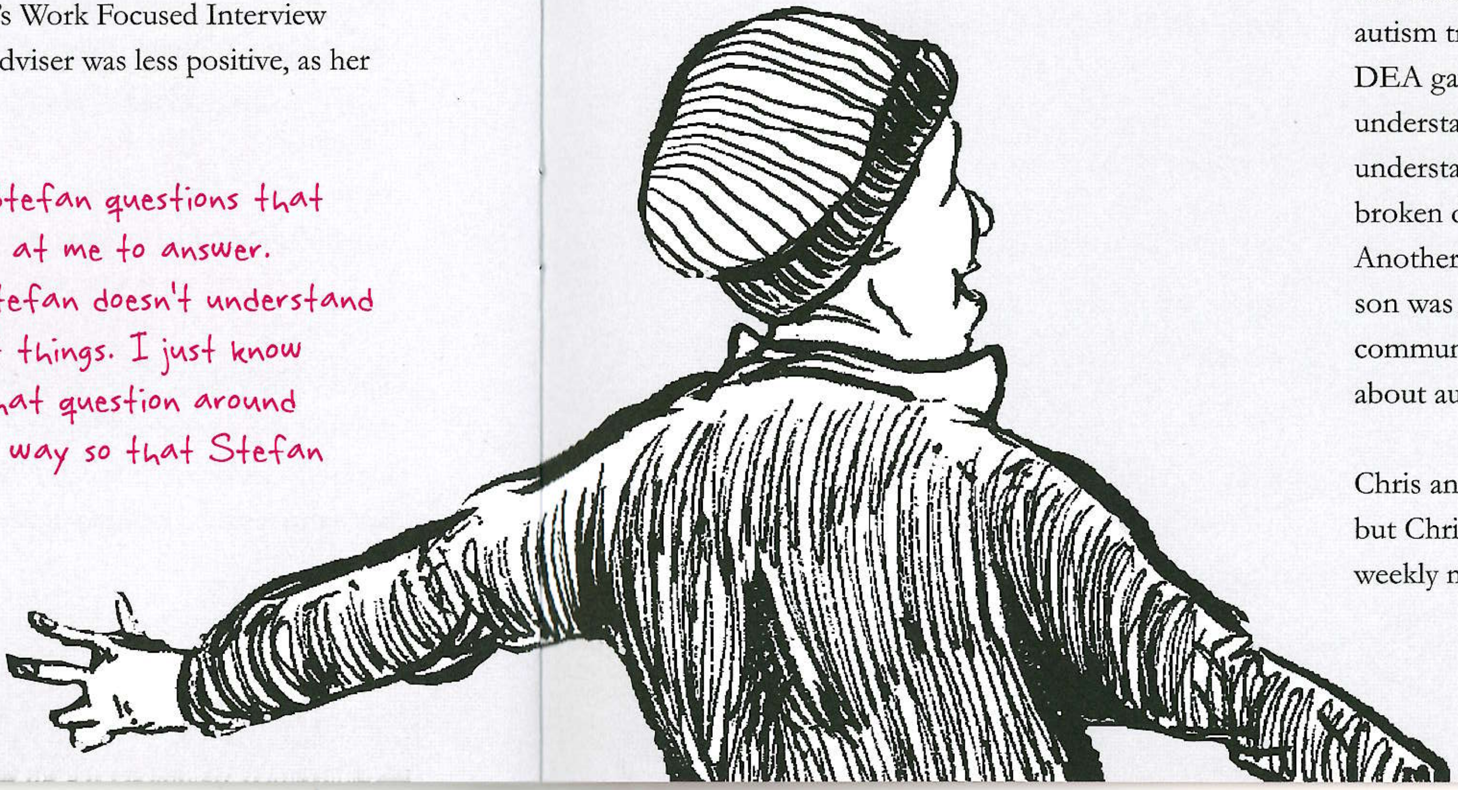
Personal Advisers are the first point of contact for people with autism at the Jobcentre. Research conducted by the Department for Work and Pensions (DWP) found that some staff felt that there was a significant lack of awareness of autism among co-workers, noting that advisers were not able to understand the needs of their claimants with autism who, in turn, had difficulty describing them.[14]

As part of ESA process, people have to attend Work Focused Interviews, which are carried out by Personal Advisers. The success of these interviews rests on each adviser's understanding of autism. Paula's Personal Adviser had a good understanding of Asperger syndrome, which made a real difference. Stefan's Work Focused Interview with a Personal Adviser was less positive, as her mum describes:

> "They asked Stefan questions that she just looked at me to answer. Sometimes, Stefan doesn't understand how people put things. I just know how to turn that question around in a different way so that Stefan can answer."

Personal Advisers are able to signpost people with more complex needs to a Disability Employment Adviser (DEA), but again, this requires them to understand autism and the accompanying support needs people have. Research for the DWP indicates that individuals are "lucky" to make it through to a DEA and our phone survey supports this.[15]

Training for Personal Advisers needs to include help to recognise autism, advice on how to best communicate with and deliver support to people with autism, and how to refer people on to more specialist provision.



Disability Employment Advisers

A report commissioned for the DWP found that training among current DEAs is inconsistent and the research found a number of examples where DEAs had been in post for up to two years without any formal training.[16]

The responses of our phone interviewees also suggested that training among DEAs was inconsistent: 34% of phone respondents thought their DEA's knowledge of autism was "bad" or "very bad". One person from our phone survey noted, "they obviously had knowledge of people with disabilities, but not specifically autism", while another reported that "the DEA was asking a lot of questions, and the type of questions he was asking meant it was easy to tell he hadn't had autism training". Another person noted that "the DEA gave no evidence that he had any understanding of the condition. He didn't understand the need for information to be broken down, to use literal language and so on." Another said that "the DEA didn't see that my son was not understanding and having difficulty communicating, but this is a well-known fact about autism".

Chris and Carole also sought help from a DEA, but Chris found the DEA "intimidating" and the weekly meetings very stressful.

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[13] National Audit Office (2009). Supporting People with Autism Through Adulthood. London: NAO.

[14] Forsythe, L., Rahim, N., and Bell, L. (2008). Benefits and employment support schemes to meet the needs of people with an autistic spectrum disorder. London: NAO.

[15] Goldstone, C (2008). Disability Employment Adviser (DEA) Organisation in Jobcentre Plus. London: Department for Work and Pensions.

[16] Ibid

Like Paula, over 70% of the people we surveyed by phone had met a DEA alone at some point. Because adults with autism may have difficulty expressing how their autism affects them, it is vital that the Jobcentre Plus staff supporting them to find work have a clear understanding of the disability.

We welcome the fact that, since November 2005, the Government has included autism training for all new DEAs. However, more still needs to be done to ensure that they are equipped with the skills to support people with autism. Currently only half of all DEAs have received the new training, so the DWP must make it a priority to extend this training to all existing DEAs as quickly as possible.

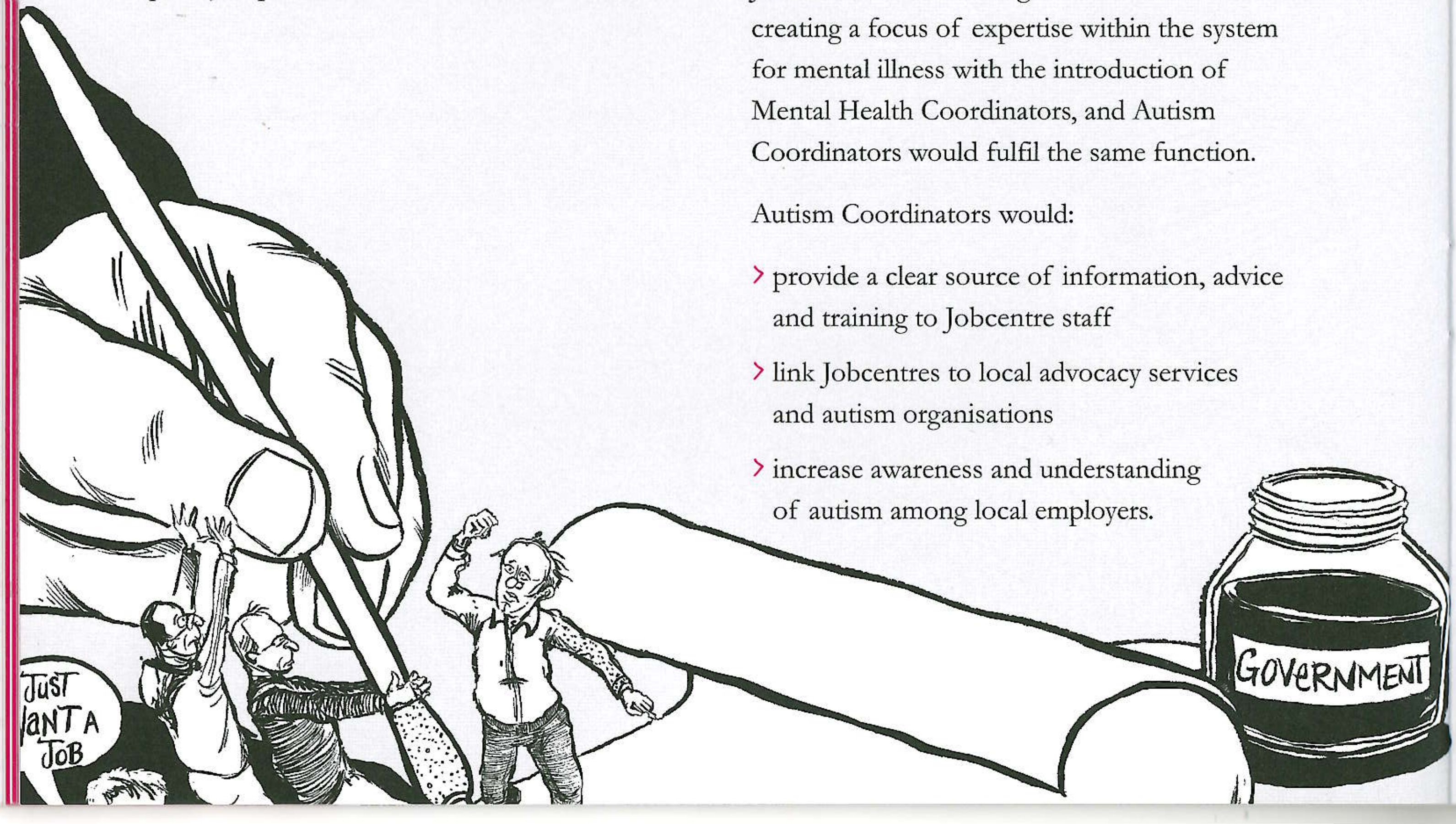
Introducing Autism Coordinators within Jobcentre Plus

Autism is a complex disability and we recognise that it is not practical for every member of the Jobcentre Plus staff to become an expert. Therefore it is important to establish a recognisable progression of expertise, so that staff who do not have the knowledge or confidence to support a particular client can turn to someone else for support. Thus, just as Personal Advisers are able to seek support from DEAs, Autism Coodinators could add a further level of expertise.

Jobcentre Plus has recognised the value of creating a focus of expertise within the system for mental illness with the introduction of Mental Health Coordinators, and Autism Coordinators would fulfil the same function.

Autism Coordinators would:

- provide a clear source of information, advice and training to Jobcentre staff
- link Jobcentres to local advocacy services and autism organisations
- increase awareness and understanding of autism among local employers.

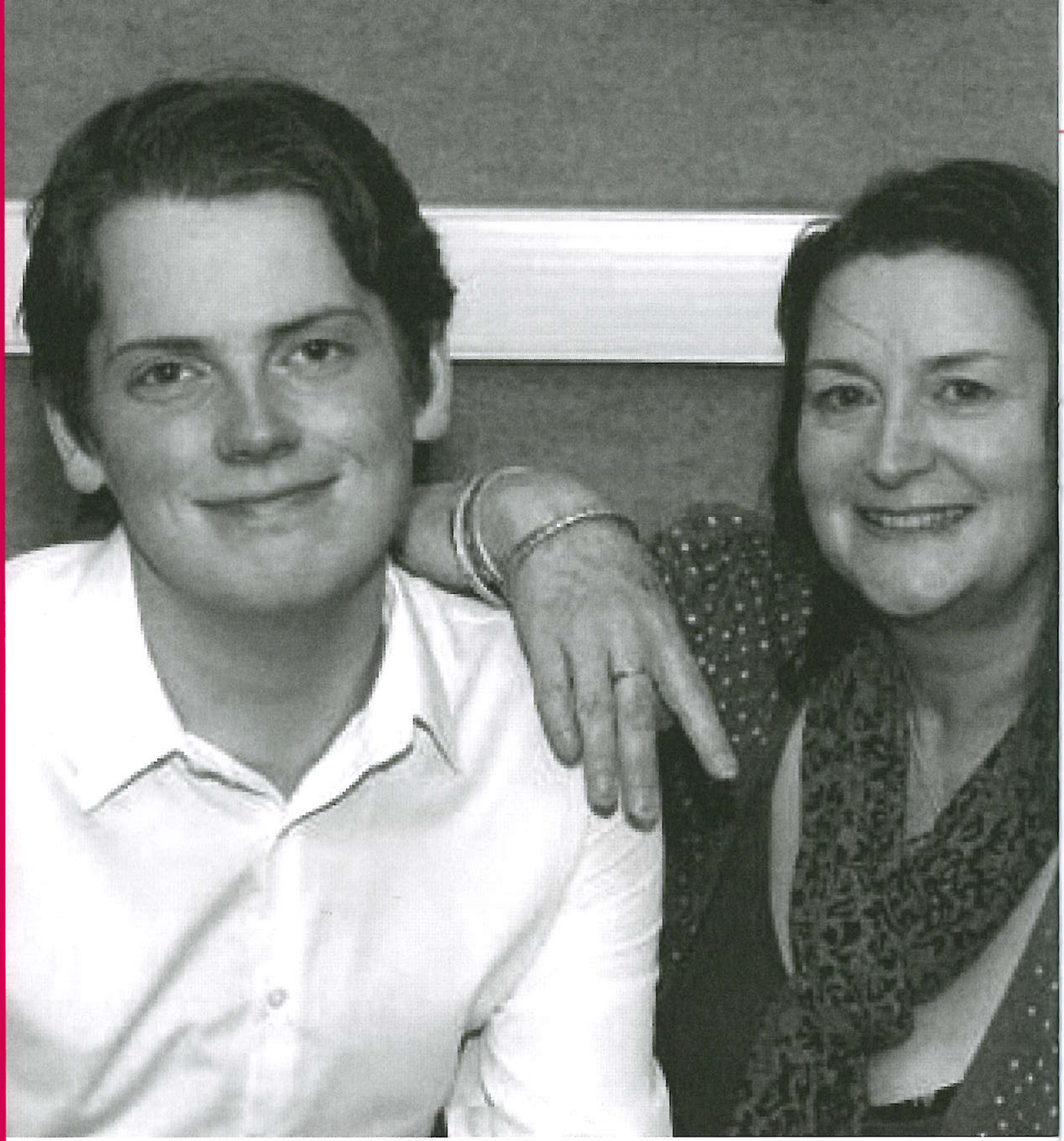


There are roughly 350,000 people with autism who are of working age, and only 15% of them are in full-time paid work. These people need Jobcentre Plus to work for them. The complexity of the condition requires staff who have a further level of expertise; it is unrealistic to expect Jobcentre Plus staff to meet their obligations to all individuals on the autism spectrum, including those with complex behaviours and communication difficulties, with only limited training and no additional support.

What needs to change?

What is clear from the experiences of all the people we talked to is that **those involved in delivering Jobcentre Plus services require training in autism.** Atos doctors need knowledge of autism to enable them to carry out accurate assessments; Personal Advisers need improved awareness of autism so that they can provide the right support or refer a person to someone with the appropriate expertise; and Disability Employment Advisers need a better understanding of autism to ensure they are able to meet the needs of those coming to them for help in finding work.

Autism is a complex disability, affecting each person differently, and not all frontline staff can be experts in the condition. In order to provide extra knowledge and advice to frontline staff, and to build practical links locally between health services, employment support services, employers and others, **a new network of Autism Coordinators should be established.** A similar system is already in place with Mental Health Coordinators, and this model should be replicated for autism.



Scott & Lesley

Scott is 20 years old and wants to work in the media. He lives with his mum, Lesley, just outside Glasgow. Scott has Asperger syndrome.

Applying for ESA was a particularly stressful experience for Lesley and Scott but they had to continue as they had "no options, financially, no options".

Lesley filled in all the ESA forms with Scott, because, as he said:

"When it gets to a particular question that may not apply I have... problems. I tried my best but it helps when you've got someone else as well to sort of bounce back the problems with."

At the Work Focused Interview, the Personal Adviser had no knowledge of Asperger syndrome. "So as far as he was concerned he was communicating with someone who had no difficulties."

It looked unlikely that Scott was going to get the support he wanted to work. As Lesley said:

"I offered an overview of Scott's specific difficulties, but made the assumption that, because the person giving the medical assessment was a doctor, I wouldn't have to explain Asperger syndrome. But Scott felt that the doctor really misunderstood him."

The Personal Adviser Scott met clearly didn't understand the impact of his Asperger syndrome. Lesley tried to explain that Scott was working towards a clear career goal and that he needed specialist autism support. However, in the end, Scott and Lesley left his Work Focused Interview feeling:

"He's not going to be able to do anything for us, he just let us go and get on with it."

Scott was awarded ESA. He is in the Work Related Activity Group.

Since Scott's decision, he has been sent to several employment support services, but Lesley does not feel that he is yet receiving the right support to fulfill his ambition to work.

DON'T WRITE ME OFF

Employment for people with autism

In our 2007 *I Exist* survey, 15% of people responding were in full-time paid employment and our new research for *Don't Write Me Off* shows no change to this figure. Despite this, when asked about work, 61% of those not working said they wanted a job. When we asked those on Incapacity Benefit if they wanted to work, 79% said they did. People with autism want to work, but they need support to get a job.

People with autism can face significant barriers when looking for a job or trying to stay in employment. Some of these difficulties may include:

> **Problems with job advertisements.** Many job adverts ask for such things as "good communications skills" or that a person be a "team player". Where these skills are not necessary, such adverts discriminate against people with autism, for whom social communication and interaction can pose real difficulties.

> **Understanding both verbal and non-verbal language.** Someone with autism may struggle to understand body language, make eye contact or answer hypothetical or open-ended questions. This presents particular difficulties for people in interviews.

> **Recognising and understanding other people's feelings and expressing their own.** This may make it difficult for people with autism to fit in with their colleagues. All jobs have mutually understood unwritten rules and expectations, such as making tea and coffee for everyone if having one yourself. A person with autism may not grasp these unwritten rules unless they are explained to them.

> **Understanding and predicting other people's behaviour, and imagining situations outside their immediate daily routine.** People with autism may find it difficult to plan their time and structure their working day.

Accessing support to find work

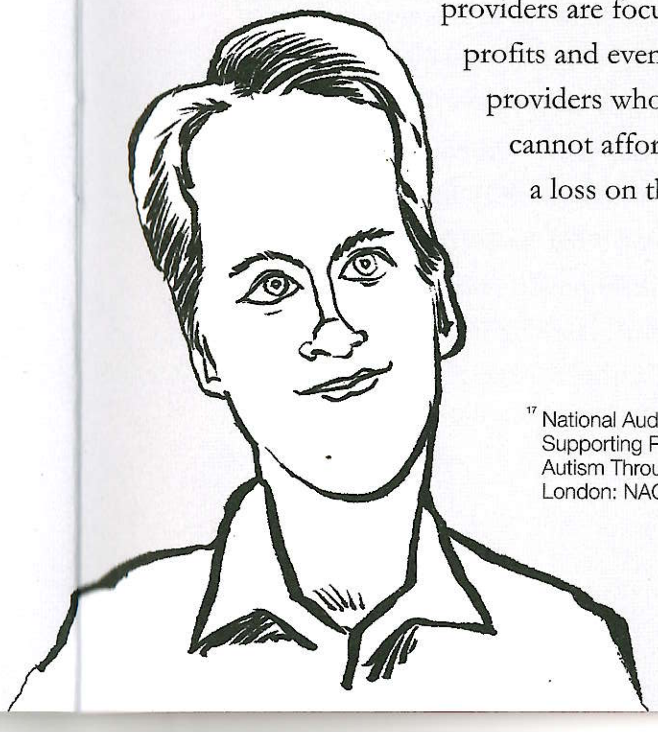
There are two important ways in which people with autism should be able to access support to find work through Jobcentre Plus.

> **Through Pathways to Work**: People receiving ESA who are in the Work Related Activity Group are referred to the Pathways to Work programme; people in the Support Group can volunteer to access Pathways to Work. This programme includes a series of Work Focused Interviews where a person talks about what they are doing or could do to find a job.

> **Through specialist disability employment services:** Disabled people seeking work can be referred to specialist disability employment services (soon to be known as Work Choice) through a DEA at Jobcentre Plus. People hoping to see a specialist disability employment service do not have to be on benefits.

Is employment support working for people with autism?

The Department for Work and Pensions (DWP) currently relies on contracts with businesses or charities to provide most of its employment support for disabled people looking for work. These providers are paid to get a set number of people into work and they are paid the same amount for everybody. Many providers are focused on profits and even those providers who are charities cannot afford to make a loss on the contracts. This means that there is no financial incentive for providers of employment support to focus their efforts on people who may take a long time to support into work or require more intensive support to get a job – such as people with autism.

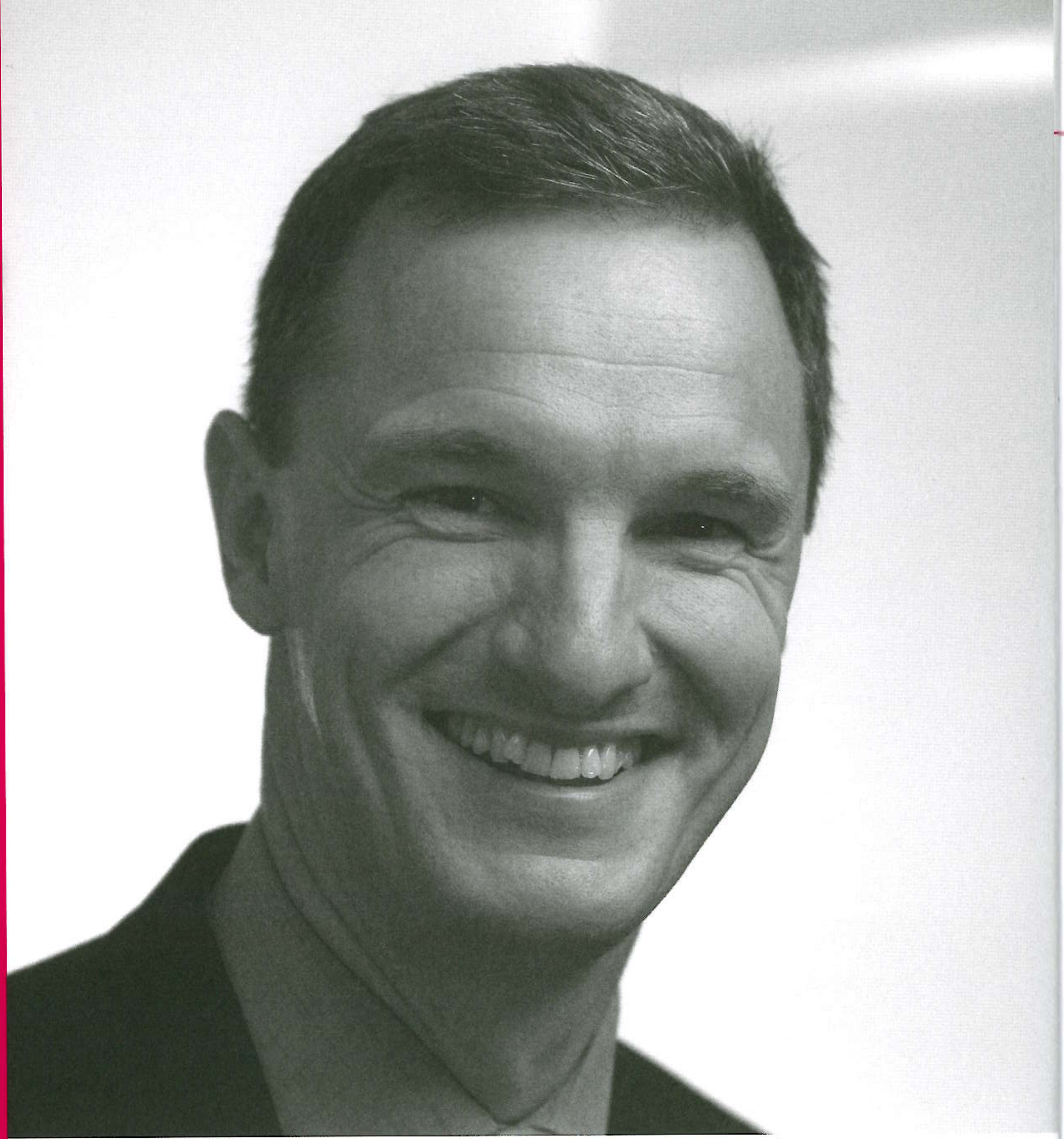


There is also very limited access to specialist autism employment support. Recent National Audit Office research found that specialist schemes "can result in significantly higher rates of employment, more appropriate employment, greater job satisfaction and higher employer satisfaction when compared to generic disability employment services".[17]

What needs to change?

Like many people with autism, Scott wants to work but is not yet receiving the support he needs to do this. If the DWP is serious about its commitment that no one should be "written off" then **it needs to ensure that contracts for employment support work for everyone with autism.** This means recognising that some people will cost more and take longer to support into work than others. It also means monitoring existing contracts to make sure that they are working for people with autism and that people are not simply being "parked", or in effect, written off. The DWP can do this using data it already collects.

[17] National Audit Office (2009). Supporting People with Autism Through Adulthood. London: NAO.



Mark Lever
Chief Executive, The National Autistic Society

Behind the statistics in this report there are real lives and individual stories of people trying their best to avoid poverty and to make their own contribution to society. Although everyone in this report is different, what unites them is a struggle to have their autism understood, and for the welfare system to support them to work or access benefits.

They are not alone. There are hundreds of thousands of adults with autism in the UK. The National Autistic Society (NAS) believes that each of them deserves the opportunity to live with dignity and to fulfil their individual potential. For some, this means to work, for others it may not, but they too should be able to live in financial independence. The majority of people with autism are not given these opportunities.

I am grateful that the people featured in this report have shared their experiences of applying for Employment and Support Allowance. In doing so they have demonstrated that there is a need for stronger safeguards in the system and for professionals to have a better understanding of autism. Unless those individuals whose job it is to assess people with autism for benefits or to support them into work are able to communicate and work with them effectively, there can be little hope of meaningful change.

It is unacceptable that only 15% of people with autism are in full-time paid work. It is unacceptable that right now, according to our survey, one third of people with autism are currently without a job or benefits. It is clear to me that if we are to see the step change that we need in the number of people with autism in work or accessing support from benefits, we need to see strong leadership from Government.

› In England, the Government is working to produce a landmark adult autism strategy, aimed at tackling the isolation and lack of services faced by thousands of adults with autism. The strategy is an important opportunity for departments across Government to come together to end the exclusion faced by so many. The strategy will be published in spring 2010, following which the Government has also committed to issuing statutory guidance that will underpin its delivery.

The NAS wants to see a bold and ambitious strategy that embodies the recommendations outlined in this report. Work and financial security are hugely important to everyone and people with autism are no different. A strategy that does not tackle these issues head on will necessarily be limited in its impact.

The NAS thinks that the delivery of the adult autism strategy will to a large extent rely on the establishment of specialist autism teams in every local area. Improving the employment prospects of people with autism must be integral to the remit of each of these teams. Working with local Autism Coordinators, these teams will improve the way learning disability, mental health and transition services meet the needs of people with autism who need support to find employment.

- In Wales there is an opportunity to provide strategic leadership on this issue. Although the Assembly Government's groundbreaking *Autism Spectrum Disorder strategic action plan*[18] does not contain targets on employment issues, the forthcoming Task and Finish Group report on adults with autism could provide a blueprint for change. NAS Cymru is calling on the Welsh Assembly Government to take heed of the Task and Finish Group's recommendations and to prioritise their delivery.

- The Scottish Government's 2003 report *Working for a Change?*[19] contained some helpful recommendations, but neglected to address fully the employment and support needs of people with autism. NAS Scotland is calling on the Scottish Government to revisit and update *Working for a Change?*, specifically to address the lack of co-ordination and focus across employment services, and to promote clear routes to work for people with autism.

- In Northern Ireland, the Assembly's widely welcomed 2009 *Autistic Spectrum Disorder Strategic Action Plan*[20] focuses on issues of health and social care, but does not contain actions to address the low employment rates that people with autism experience. NAS Northern Ireland believes that the Department for Employment and Learning should build on the Action Plan by producing an employment strategy for people with autism.

By taking clear and often simple steps, governments across the UK can deliver real change for people with autism.

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[18] Welsh Assembly Government. (2008). Autistic Spectrum Disorder (ASD) strategic action plan for Wales. Cardiff: WAG.

[19] The same as you? National Implementation Group. (2008). Working for a Change? Edinburgh: The Scottish Government.

[20] Department of Health, Social Services and Public Safety. (2009). Autism Spectrum Disorder (ASD) Strategic Action Plan. Belfast: DHSSPS.

ADULTS WITH AUTISM NEED

- a JOB WHEN THEY CAN WORK
- bENeFITS WHEN THEY CAN'T
- aND A GOVERNMENT THAT LEADS THE WAY

The experiences of the people you have met throughout this report show that much needs to be done to ensure that adults with autism are able to get a job when they can work and benefits when they can't.

- The Department for Work and Pensions (DWP) should run an accessible communications campaign for people with autism, their families and carers to ensure that everyone is aware of the support offered by ESA.
- It is crucial that people applying for benefits are asked at the start of their application whether they have a disability in order that the necessary adjustments can be made during their application process.
- It is important that everyone applying for ESA is informed of their right to have someone help them through the application process.
- Those who want an independent advocate must be supported to access one.
- There is no need for sick notes for ESA and the Government should scrap them.
- The DWP must ensure that all written communications that concern sanctions or meetings at Jobcentre Plus are automatically provided in easy-to-read and plain English formats.
- The DWP should introduce a written warning instead of a benefit cut the first time someone misses a Work Focused Interview.
- Those involved in delivering Jobcentre Plus services require training in autism.
- If the DWP is serious about its commitment that no one should be "written off" then it needs to ensure that its contracts for employment support work for everyone with autism. This means recognising that some people will cost more and take longer to support into work than others.
- A new network of Autism Coordinators should be established.
- **What is ultimately needed is clear government leadership to make sure that adults with autism are no longer written off.**
    - In England, through an Adult Autism Strategy that establishes Specialist Autism Teams in every local area
    - In Wales, through the Welsh Assembly Government Autism Spectrum Disorder Adult Task and Finish Group Report.
    - In Scotland, through an updated Scottish Government *Working for a Change?* strategy.
    - In Northern Ireland, through a new Northern Ireland Assembly employment strategy for people with autism.

Methodology

The research for *Don't Write Me Off* involved three main streams of work, as described below.

Survey

The National Autistic Society (NAS) designed a quantitative questionnaire to find out what experience adults with autism had of employment and benefits. This survey was sent by post and email to people who had previously filled out the *I Exist* survey in 2007 and who had agreed to be involved in follow-up research. They were sent a cover letter giving assurances about confidentiality and explaining the background, objectives and purposes of the research, and the terms used.

The survey was open for two months and closed on 7th May 2009. There was no incentive for respondents to participate in the survey.

Responses were entered into a survey analysis software package (MERLIN) and analysed on an anonymous basis to produce the aggregated tabulated results. Responses to open-ended questions were also coded for analysis.

Sample

Of the 1,787 people in the *I Exist* population, 600 people (34%) were identified as eligible for follow up, but 78 were no longer contactable. Therefore, only 522 were invited to participate; 311 questionnaires were sent by post and 211 people (those with email addresses) were sent email messages asking them to complete the survey online. After removing duplicate and incomplete responses, 323 responses were accepted for analysis (a response rate of 62% overall): 159 from postal returns (51% response rate) and 164 online (77% response rate). Our sample size yielded a 95% confidence interval (+/- 5%).

The people who responded to the follow-up survey were representative of the larger population the sample was drawn from and had the following composition.

Nation:	78%	England
	12%	Scotland
	9%	Wales
	1%	Northern Ireland
Gender:	74%	Male
	26%	Female
Age:	35%	18–24
	28%	25–39
	33%	40–64
	4%	65+
Diagnosis:	71%	AS/HFA[21]
	27%	Autism
	2%	Other

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[21] AS stands for Asperger syndrome and HFA stands for high-functioning autism.

In-depth interviews

Case study participants were recruited through the website of The National Autistic Society beginning in January 2009. Only adults with autism or Asperger syndrome (age 18 and over) applying for ESA, and/or their parents or carers, were eligible to take part in the research. Most individuals were recruited when they were going through the assessment phase for the benefit but a few were recruited once they received a decision on whether they would receive the benefit. One participant contacted us about involvement in the research before applying for ESA.

Interviews were scheduled to take place after participants had received a decision about the benefit. Ten people were ultimately recruited and interviewed about their experiences of applying for ESA:

- eight people had a diagnosis of Asperger syndrome
- two people had a diagnosis of autism and associated learning difficulties
- the age range was 19–48
- there were seven males and three females
- four individuals were interviewed alone
- three individuals were interviewed supported by parents
- three parents were interviewed on behalf of an individual.

Phone interviews

Structured phone interviews were conducted with a sub-sample of people who completed the follow-up survey. Those who reported having spoken to a Disability Employment Adviser and who gave permission to be contacted again were phoned in June and July 2009. Out of the 51 people who were identified as being eligible for a phone interview, 76% responded - a total of 39 people.

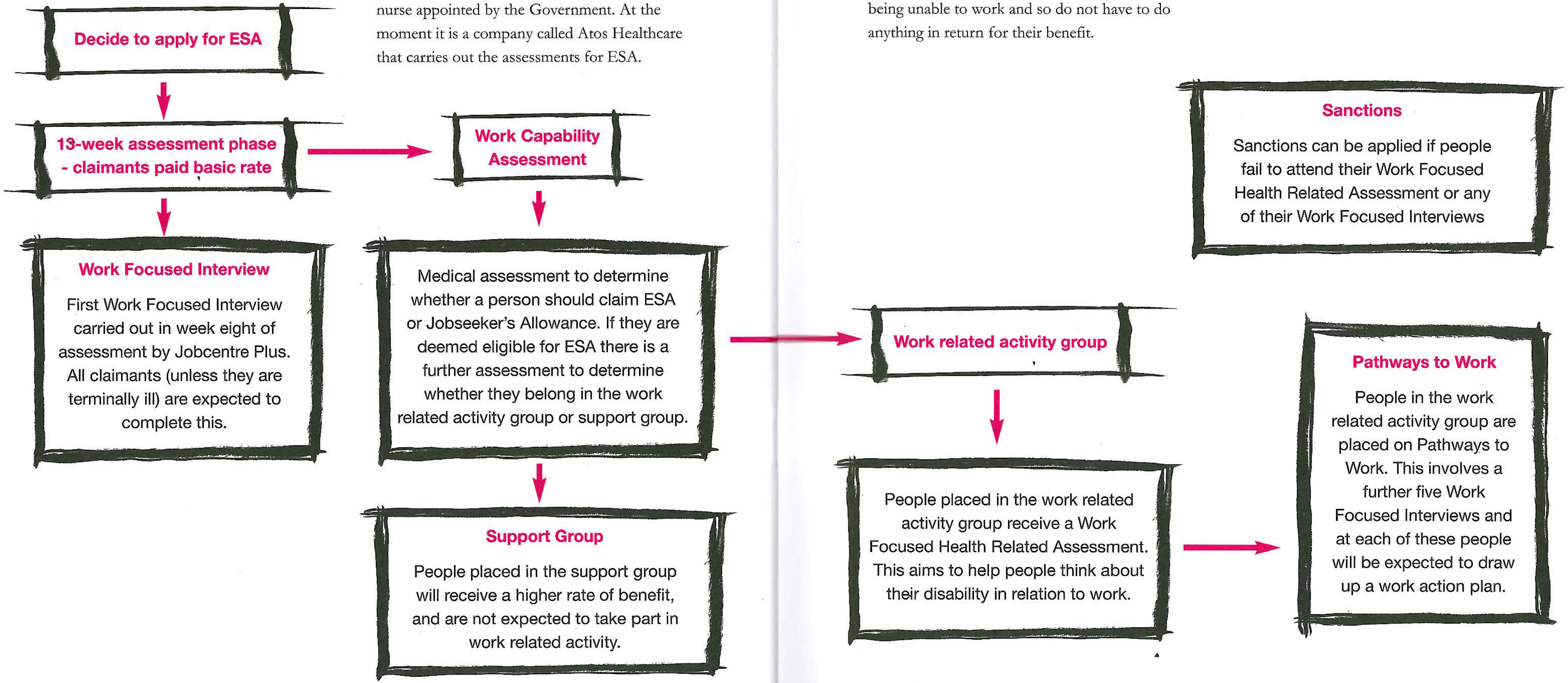
What is Employment and Support Allowance?

Employment and Support Allowance (ESA) is the new benefit for people who cannot work, or find it hard to work, because of their disability. It will replace Incapacity Benefit (the old benefit for people who cannot work because of their disability). At the moment, it is only people claiming benefits for the first time who apply for ESA but from 2010 onwards the Government intends to move everyone on Incapacity Benefit to ESA. Of our survey of adults with autism, 26% were receiving Incapacity Benefit and over the next few years will therefore be assessed for ESA, so it is vital that ESA works for people with autism.

Applying for ESA should take 13 weeks. During this time most people will have to go for an assessment called the Work Capability Assessment. This is split into a medical assessment and an assessment to look at how an individual's disability affects what work they can do (known as a Work Focused Health Related Assessment). These assessments are carried out by a doctor or nurse appointed by the Government. At the moment it is a company called Atos Healthcare that carries out the assessments for ESA.

The doctor will write a report that will be used to decide whether someone can get the benefit. People will also have to attend an interview at Jobcentre Plus where they will talk about what they can do to find work – this is called a Work Focused Interview. At the end of the application process people are told whether or not they will get the benefit. If they get ESA then they will go into one of two groups:

- **Support Group:** this group receives more money than the Work Related Activity Group and although people in this group can look for work if they want to, they have been assessed as being unable to work and so do not have to do anything in return for their benefit.
- **Work Related Activity Group:** people in this group are expected to get ready for work and if they do not do this their benefit could be cut. To help them prepare for work, people in this group are expected to attend interviews called Work Focused Interviews and these are part of what is known as Pathways to Work. In some areas these interviews will happen at Jobcentre Plus, in other places it is charities or businesses who carry out the interviews for the Government. If people fail to go to these interviews and cannot explain why they missed an interview then their benefit will be cut.



Work Focused Interview

First Work Focused Interview carried out in week eight of assessment by Jobcentre Plus. All claimants (unless they are terminally ill) are expected to complete this.

Medical assessment to determine whether a person should claim ESA or Jobseeker's Allowance. If they are deemed eligible for ESA there is a further assessment to determine whether they belong in the work related activity group or support group.

Support Group

People placed in the support group will receive a higher rate of benefit, and are not expected to take part in work related activity.

People placed in the work related activity group receive a Work Focused Health Related Assessment. This aims to help people think about their disability in relation to work.

Pathways to Work

People in the work related activity group are placed on Pathways to Work. This involves a further five Work Focused Interviews and at each of these people will be expected to draw up a work action plan.

Sanctions

Sanctions can be applied if people fail to attend their Work Focused Health Related Assessment or any of their Work Focused Interviews

Key people

When accessing Employment and Support Allowance (ESA), or seeking help to find work from Jobcentre Plus, there are three main professionals who people with autism can meet.

- **Atos doctors and nurses:** carry out medical assessments for people applying for ESA. They write a report of the assessment and send it to the Decision Maker at Jobcentre Plus who is the person that decides whether or not someone will get ESA.
- **Personal Advisers:** Jobcentre Plus staff who carry out Work Focused Interviews with people who are either applying for ESA or are in the Work Related Activity Group. People claiming Jobseeker's Allowance will also see a Personal Adviser.
- **Disability Employment Advisers (DEAs):** work at the Jobcentre Plus and support people with disabilities who are looking for work or who have a job but need some support at work. People do not need to claim benefits in order to speak to a DEA.

Glossary

Advocacy
Advocacy is having someone to help you present your case and an advocate is the person who helps you do this.

Atos
Atos Healthcare is the company paid by the Department for Work and Pensions to carry out medical assessments for ESA, Disability Living Allowance and Incapacity Benefit.

Benefit
A benefit is a payment of money by the Government to an individual. This may be to help someone because they do not have a job or need extra money because they have a disability.

Child Benefit
Child Benefit is the benefit paid to all families with children who are aged under 16, or under 20 if they are in full-time education or training (excluding university).

Decision Maker
This is the person at Jobcentre Plus who is responsible for looking at all the evidence involved in a claim and deciding if a person should receive the benefit.

Department for Work and Pensions
This is the Government department responsible for administering benefits and pensions. It is also responsible for Jobcentre Plus.

Disability Employment Adviser
This is the person at Jobcentre Plus who specialises in giving employment advice for disabled people.

Disability Living Allowance
This is a benefit to help with the extra costs of disability. There is child and adult DLA and it is paid in two parts:

- care – there are three rates for this, determined by care needs.
- mobility – there are two rates for this, determined by mobility needs.

Employment and Support Allowance
Employment and Support Allowance (ESA) is the new benefit for people who cannot work due to sickness or ill health.

Employment Support Services
The Jobcentre can provide people with or refer them to services that will provide them with extra help to find a job.

Incapacity Benefit
This is the old benefit for people who cannot work due to disability or ill health.

Income Support
This is a benefit for people with a low income.

Jobcentre Plus

Jobcentre Plus has two main roles.

- To administer Jobseeker's Allowance and ESA.
- To provide support to people looking for work through its network of jobcentres.

Jobseeker's Allowance

This is the benefit paid to people who do not have a job and are trying to find work.

Personal Adviser

This is the person at Jobcentre Plus who carries out Work Focused Interviews and carries out most interviews with jobseekers.

Welfare reform

Welfare reform is the name given to all the changes the Government is making to the benefits system.

Work Capability Assessment

This is part of the assessment for ESA. It is carried out by a doctor or nurse from Atos Healthcare. The first part of the assessment is a medical. This looks at whether an individual can work, and if they cannot work, whether they should go into the Support Group or the Work Related Activity Group. The second part of the Work Capability Assessment is called a Work Focused Health Related Assessment. This looks at how a person's disability might affect what work they can do. It does not affect whether or not an individual gets ESA.

Work Focused Interview

This is an interview in which people applying for ESA or receiving ESA talk to an adviser about what they are doing to find work and what they could do in the future.

Work Focused Health Related Assessment

This is an assessment that looks at how a person's disability could affect what work they can do. It is carried out by an Atos Healthcare doctor or nurse.